Chronic Kidney Disease: Patient Information Need, Preferences and Priorities

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Abbreviations

APD	Automated Peritoneal Dialysis
CKD	Chronic Kidney Disease
CKD-INQ	Chronic Kidney Disease – Information Needs Questionnaire
ESRF	End Stage Renal Failure
ESRD	End Stage Renal Disease
GFR	Glomerular Filtration Rate
HD	Haemodialysis
INQ	Information Needs Questionnaire
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NKF	National Kidney Federation
NSF	National Service Framework
PCT	Primary Care Trust
PD	Peritoneal Dialysis
PMP	Per Million Population
RA	Renal Association
RIXG	Renal Information Exchange Group
RRT	Renal Replacement Therapy
QOL	Quality of Life
UK	United Kingdom of Great Britain and Northern Ireland

Glossary of Terms

Anti-rejection drugs	Medicines to suppress the response of a transplant recipient's immune system, which recognises the transplanted organ as a foreign tissue and attempts to reject it
Arteriovenous fistula	Created by joining a vein to an artery, usually in the forearm, to increase the blood flow directly into a vein: this causes enlargement of the vein, into which a needle can be repeatedly inserted to allow regular access to the blood stream
Automated Peritoneal Dialysis	A form of peritoneal dialysis in which a machine is used to carry out the multiple fluid exchanges
Cardiovascular disease	Disease relating to the heart and blood vessels
Catheter	A hollow tube used to transport fluids into and out of the body (such as in peritoneal dialysis)
Chronic Kidney Disease	An abnormality of the structure and function of both kidneys, lasting more than three months often progressive
Co-morbidity	The coexistence of more than one illness or disease, such as chronic kidney disease and diabetes
Diabetes	A group of disorders in which normal insulin mechanism fails so that glucose in food cannot be metabolised, and builds up in the blood. Over time raised blood glucose causes damage to blood vessels, including those in the kidney, causing cardiovascular disease and loss of kidney function
Dialysis	A blood purifying treatment in which waste products and excess water are filtered out of a patient's blood artificially. It is used when the patient's kidneys no longer function sufficiently to maintain life (see haemodialysis and peritoneal dialysis)
Established Renal Failure	Also called End Stage Renal Failure (ESRF) and End Stage Renal Disease (ESRD) and is chronic kidney disease which has progressed so far that the patient's kidneys no longer function sufficiently to maintain life

End Stage Renal Disease	See Established Renal Failure
Fluid Exchange	In peritoneal dialysis, the process of draining out used dialysis fluid and replacing it with fresh
Glomerular Filtration Rate	The rate at which the glomeruli in the kidneys excrete waste products and excess fluid. It reflects the percentage of normal filtration functioning remaining. Formulae for calculating estimated *e*GFR take into account factors such as the patients age, body mass and ethnic origin
Glomerulonephritis	A kidney disease caused by the immune system, which results in inflammation and damage to the glomeruli
Haemodialysis	A blood purifying treatment in which the patient's blood is circulated through a machine drawing out waste products by diffusion and excess water through a filter. Normally performed for four hours, three times a week, usually at a hospital or satellite unit
Hypertension	Persistently high blood pressure
Incidence	The number of people in a population who develop a given condition
Morbidity	The state of being ill or diseased
Peritoneal Dialysis	A form of dialysis in which the dialysis fluid is introduced into the peritoneal cavity in the patient's abdomen, where it draws waste products and excess water out of the blood using the peritoneal membrane as a filter. The fluid may be exchanged four or five times per day, or a machine may be used to carry out the several fluid exchanges, usually overnight
Pre-emptive transplant	A transplant carried out before the patient has had to begin dialysis
Prevalence	The number of people in a population who have a given condition, for treatment the number of new and existing cases
Pruritis	Intensive chronic itching. In advanced kidney failure can be caused by excess phosphate normally be regulated by kidneys

Renal Replacement Therapy	Treatment to augment or replace the function of failing kidneys, by dialysis or transplantation
Satellite unit	A unit providing haemodialysis, and at times other services, linked to a main unit, which provides a full range of service. Usually it provides treatment for more stable patients, closer to where they live than the main unit
Transplantation (kidney)	A donated kidney is inserted into the recipient’s lower abdomen, and the blood vessels and ureter are connected to the recipient’s blood vessels and bladder. Anti-rejection medicines are given to prevent rejection of the organ.
Uraemia	The toxic condition caused by excess waste products of protein metabolism (urea etc) remaining in the blood
Vascular access	A fistula, catheter or graft allowing access to the bloodstream for haemodialysis

(Adapted from DH 2004a)

Abstract

Chronic Kidney Disease: Patient Information Need, Preferences and Priorities

This thesis seeks to explore, identify and describe the information needs and the preferences and priorities for information of chronic kidney disease (CKD) patients. The premise of the research being that CKD patients will have preferred key information needs, which are of a priority to them, at different times during the progression of their disease.

Attention will focus on three areas:

- The theory and methodology underpinning information need research in health and information science, exploring key concepts to establish working definitions
- What information patients' want and the contextual factors that influence the manifestation of an information need
- The development and testing of a CKD Information Needs Questionnaire (INQ) that profiles and prioritises information topics to facilitate, demographic and disease progression sub-group analysis

Chapters one and two, set the scene and focus of the study, identifying the context of CKD, aetiology, prevalence, current NHS policy and service provision building a clear study rationale. The national political agenda advocates the need to develop patient-led services alongside encouraging self-management skills for CKD patients to meet the future demands on renal services. For this to be achieved understanding the information needs of CKD patients is important.

Chapters three to six, consider the theory and methodology underpinning existing research in the field of information need, drawing on expertise from both Information Science and Health. The meaning of *information* and *information need* are explored and the contextual factors that influence the need for information extrapolated. Existing evidence on information topics important to CKD patients are drawn from a systematic literature review. The study adopts a mixed method approach combining qualitative in-depth semi-structured interviews and a paired comparison INQ to identify, understand and measure information need.

The study findings are presented sequentially in chapter's seven to nine. The first two chapters scrutinise the qualitative data to elicit core information needs and explore the context in which information needs arise. Information topics from the literature are compared and contrasted with data extracted from the in-depth interviews and nine core information needs identified. These include information on what is CKD and what to expect in the future; physical affect and symptoms of CKD; complications and side effects; different treatment options, practical aspects of treatment; self-management information regarding diet, fluids, medication and blood results; impact of CKD on daily life and social activities; information on how to cope and adapt with CKD and information from other patients about their experiences. Findings indicate that CKD patients have preferences for information that emerge to satisfy an underlying goal. Information needs are hierarchical in nature and influenced by the context of the individual, factors include the relevance of topic, personal circumstances, coping styles, current events and lifestyle.

The core information needs were used to ground the development of the INQ, followed by the testing of the tool and subsequent statistical analysis, in chapter nine. The information topics considered highest priority are concerned with information about self-management, complications and physical symptoms. Middle range items included information regarding practical aspects of RRT, how it affects daily life, the cause of CKD, treatment options. Information topics considered less important were how to cope and adapt to life with CKD and information from other patients about their experiences. Differences between information priorities were observed across demographic groups influenced by age, treatment modality and time since diagnosis.

Chapter ten draws together the evidence and discusses the findings in context with the wider literature highlighting the strengths and weaknesses of the research strategy. An innovative patient-led information strategy is proposed based on the construction of meaning and making sense of information, alongside practical changes to improve the quality of information provision to meet the needs of CKD patients.

Chapter eleven concludes the study and denotes recommendations for future information need research, information provision in practice and policy. These include the application of the nine core information needs (as a topic guide) in clinical practice to initiate patient discussion and draw out specific individual information need. The evidence base developed from this in-depth study will inform and support the current and future content of patient education programmes. Developing healthcare documentation that records the preferences and priorities for information of a CKD patient as they emerge and captures the patient's temporal goals of information, information purpose and the influencing contextual factors, is essential to effectively communicate patient information needs within the multi-professional team. Finally the introduction of a patient-led information service is recommended that would facilitate and encourage self-management skills and effective information provision in clinical practice. Such a proactive approach implemented from diagnosis throughout the disease trajectory would meet the continuous information needs of CKD patients.

Chapter One

Introduction

Current National Health Service (NHS) policy advocates the need to develop patient-led services and firmly places the patient at the centre of service design and delivery (DH 2000, DH 2005a). The Renal National Service Framework (NSF) (DH 2004b) has been developed with these goals in mind and recognises the need to optimise the role that people with chronic kidney disease (CKD) can take in the management of their care. This together with focusing services around the patient's needs and preferences (DH 2005a,b) so patients have choices and the information to help them make choices (DH 2004b), are key policy drivers.

When patients are encouraged to self-manage their long term chronic illness there are recognised benefits such as providing them with greater control, a feeling of well being and the ability to cope more effectively, reduced number of complications, unnecessary hospital admissions and a reduction in the sense of powerlessness (DH 2004c). Indeed patients receiving treatment for CKD indicated that two key components for living a long life on dialysis were actively seeking information and getting answers to questions (Schatell and Sacksteder 2002). To realise national strategic aims the NSF advocates meeting the information needs of the patient through the provision of high quality, tailored information and educational programmes as a marker of good practice (DH 2004b).

However, within the field of health, the term *information need* is used throughout policy documents (DH 2004b, DH 2007) without clear definition as to what this actually means, or how it can be achieved (Beaver 2004). To date there appears no explicit definition for information needs in health, usually it is inferred by the focus of an article (Timmins 2006, Lambert and Loiselle 2007). In health research information need is taken by some to mean what the patient needs to know and by others to encompass learning and education needs (Scott and Thompson 2003, Timmins 2006). This uncertainty raises questions then as to how health care professionals can provide information to address information needs without understanding what the term means. Evidence exists, predominantly in the field of cancer, to suggest that understanding what a patient needs to know and when during the course of their care is vital to ensuring the delivery of quality care (Scott and Thompson 2003, Rutten et al. 2005). Other fields such as CKD have been slow to respond, although descriptive evidence exists strong empirical evidence is lacking.

With the prevalence of CKD forecast to increase considerably over the next few years (Levey et al. 2003, Ansell et al. 2007, Zhang and Rothenbacher 2008), so will the demands on already stretched services limiting the time a health professional has available. It becomes increasingly important for clinicians when they interact with patients to use their time effectively. To achieve this professionals require a robust evidence base that informs practice to facilitate high quality information provision that addresses the patients own information priorities (DH 2004b). Consequently at this time, identifying and meeting the information needs of CKD patients has never been so high on national and political agendas.

Innovative studies to identify and explore the information needs of patients (in the fields of cancer and asthma) highlight that patients have priorities and preferences with regard to what information they need and when (Luker et al. 1995, Degner et al. 1998, Caress et al. 2002). The premise of this research is that CKD patients will share similar characteristics and have preferred key information topics that are of a priority to them at different times during the progression of their disease.

In response to the current gaps in evidence, the thesis aim is to explore, identify and describe the information needs of CKD patients and the context in which they manifest. This includes developing a CKD specific instrument to measure and examine information need priorities and the influence of demographic variables or changes in information need over time.

The four study objectives include:

- To identify, from the patients perspective, the key information needs of a group of CKD patients and to develop an understanding of the contextual factors that influence the manifestation of information need

- To develop and test the validity and reliability of a measuring scale that profiles and prioritises the information needs of CKD patients

- To investigate whether the type and need for information changes over time or as a result of demographic variables such as age, gender, education level, socio-economics, ethnicity, treatment modality

- To contribute to the theory of information needs, CKD patients' information needs, measurement of information needs and implications for clinical practice based on the user perspective

To achieve this aim the thesis begins in chapter two with CKD, its aetiology and prevalence. It goes on to describe pertinent NHS policy, service provision, and to highlight the different renal replacement treatment options. The chapter expands on and generates a rationale for the proposed research.

Chapter Three introduces the theoretical concepts surrounding the terms *information* and *information needs* to establish working definitions and increase understanding of the issues that need further contemplation. The approach adopted in this chapter, given that the research on information need in health is limited, is to examine information research within the domain of information science. This provides a wider, more comprehensive perspective from which to extend and build on current theory and knowledge. The purpose of the chapter then is three-fold: to clarify study terms and explicate meanings; generate an understanding of different information need theories and models and the relevance to health; and identify key components that influence the emergence and representation of information need.

Chapter Four shifts the focus to the information needs of CKD patients and presents the results of a systematic literature review of published research identifying the expressed needs for information pertinent to this patient group. The literature searched and evaluated spans a period of 12 years, and it was possible to draw out information themes and topics identified by patient patients, alongside their concerns and factors that influence their need for information. The evidence underpins and reinforces the theoretical constructs drawn from chapter three and provides some indication of the real life relevance of information and information provision to CKD patients.

Having explored the meaning of information need, the relevant theory and existing research in health and CKD research it was important to rigorously examine the methodology and research philosophies underpinning information need research. Chapter Five provides a critical analysis of how the information needs of patients, across different chronic conditions, have been investigated by way of discussing the advantages and disadvantages of different questionnaires, surveys and interviews. There is a particular focus on the design and effectiveness of information need questionnaires given that the study aims to develop a specific instrument for use with CKD patients. Informed by the evidence and critical examination of preceding work, Chapter Six outlines the research study central to the thesis, the aims and objectives, chosen methodology, data collection techniques and instruments, analytical frameworks and the operational aspects of the research.

The study findings are revealed and separated into three sequential chapters. The first Chapter Seven is engaged with identifying information need, Chapter Eight focuses on understanding information need, and Chapter Nine measuring information need preferences and priorities.

Chapter Seven combines the findings of qualitative data with the themes derived from existing literature to identify core information needs for CKD patients. This chapter presents the comprehensive analytical journey undertaken to generate reliable and valid information needs expressed by the patients involved. The core information needs form the basis for the study instrument developed to measure the information needs of the CKD patient cohort, the findings of which are presented in chapter nine.

The context of information need is explored within Chapter Eight, generating a comprehensive understanding of the factors that suppress or initiate the manifestation of an information need for CKD patients. This chapter presents the *real life* information needs of CKD patients, providing explanations for the purpose of information, information goals, the different characteristics between individuals and their context and how these manipulate and influence information need.

Chapter Nine presents the findings of the study instrument measuring the information need preferences and priorities of CKD patients. This provides the broader consensus view of what is important to CKD patients and through sub-group analysis reports the demographic and disease progressive characteristics that influence information need importance and preference. Patient preferences with respect to information provision different methods and the use of different information sources is described.

The final part of the thesis Chapter Ten brings together the key research findings and generates discussion in context with the wider existing literature. The patients core information needs, preferences and priorities are discussed and how information facilitates them to construct meaning within their context of *real life*. A definition of *information need* pertinent to the field of health is postulated. In addition the analysis suggests a change in the delivery of information to patients in clinical practice by developing, in-line with national priorities, patient-led information services in the future. The strengths and weaknesses of the study are highlighted including the uptake of the study findings into national guidelines. Recommendations for practice, policy and future research naturally emerge from the study findings and are presented in Chapter Eleven followed by concluding remarks.

Chapter Two

Background

Introduction

It will soon become evident that a recurrent and central theme in this thesis is one of context, particularly the context of adult CKD patients' need for information. Therefore it would seem somewhat paradoxical if the first chapter did not comprehensively describe and explain the context of CKD: what the disease is, how it manifests, indications of increased prevalence worldwide, disease treatment and management and service provision influenced by national initiatives and policy directives. In addition current CKD patient education and information provision are examined, identifying a lack of available evidence, which underpins the need and timeliness of this research.

Background

Kidney (renal) function is essential to life (DH 2004b), so that when a patient's kidney function is impaired and depending upon the severity, there is the potential that it could progress to be life threatening. Some diseases of the kidney can be treated successfully to prevent lasting damage whilst others can be progressive, slowly damaging the kidney and gradually reducing the function. Irreversible and progressive kidney disease is known as chronic kidney disease (CKD) (DH 2004b). With careful control of both diet and blood pressure to prevent further damage a patient diagnosed with a progressive kidney disease could remain in good health for the rest of their natural lives. However for less fortunate patients CKD causes damage to such a critical level that a more active treatment intervention is required.

Chronic Kidney Disease

When the critical level of kidney function has been reached a patient is known to have established renal failure (ERF). The level of kidney function is estimated by measuring the glomerular filtration rate (GFR), the rate at which the kidneys filter waste products, taking into account variables such as age, gender, race and body size (Levey et al. 1999). The estimated figure equates to the percentage of normal kidney function remaining, in CKD the critical level is reached when the GFR is less than 15mls/min, indicating only 15% kidney function remaining. Only as recently as 2002 have the five stages of chronic kidney disease been classified (Table 1) (Levey et al. 2003). A person, with no evidence of kidney damage or underlying disease, particularly someone elderly, may have a GFR within the range of stage two (60-89) but would not be considered to have CKD.

Table 1: Stages of Chronic Kidney Disease (*Levey et al. 2003, p139)*

Stages of Chronic Kidney Disease	***eGFR** ml/min/1.73m
Stage 1 - The eGFR shows normal kidney *function* but already known to have some kidney damage or disease	90 or more
Stage 2 - Mildly reduced kidney function AND already known to have some kidney damage or disease.	60 to 89
Stage 3 - Moderately reduced kidney function.	30 to 59
Stage 4 - Severely reduced kidney function.	15 to 29
Stage 5 - Very severely reduced kidney function.	Less than 15

[* e=estimated]

A patient with very severely reduced kidney function, at stage five, has end-stage renal failure (ESRF) or end-stage renal disease (ESRD), an irreversible, chronic condition, for which the only way to survive is to have renal replacement therapy (RRT). Recent recommendations in the United States (Levey et al. 2003) suggest RRT should be initiated at stage four, and for some patients in the UK where ureamic symptoms are severe this is the case (Ansell et al. 2007). As the kidney function reduces to around 15%, the build up of waste products in the body and the inability to remove excess water, increase the likeliness of a patient experiencing a range of physical symptoms, the most frequent being; a loss of appetite, nausea, vomiting, fatigue, tiredness and weakness, shortness of breath, oedema, pruritus and insomnia (Levy et al. 2001). In addition, psychologically they may feel less able to cope with normal life given the increased anxiety and stress of the physical symptoms (DH 2004b).

CKD can be diagnosed without first needing to establish the cause or underlying disease (Levey et al. 2003). Indeed, the most recent national registry audit (Ansell et al. 2007) identified that for 26% of new adult patients starting RRT in 2006 the primary renal disease was uncertain and the most common cause was diabetes (22%). Other causes included approximately 10% glomerulonephritis (inflammation of the kidney filters), 7% pyelonephritis, 7% vascular disease (narrowing of the blood vessels to the kidney), 7% polycystic kidneys and 5% hypertension (DH 2004b, Ansell et al. 2007). The major outcomes of CKD, regardless of cause, include progression to renal failure, complications caused by reduced kidney function and cardiovascular disease (CVD), some of which, if detected early, could be prevented and treated (Levey et al. 2003).

People who are more at risk of developing CKD have existing medical conditions for example diabetes and hypertension, or a family history of CKD. In addition, certain socio-economic factors increase susceptibility such as being aged over 65 years, or those from particular ethnic minority groups (South Asian, African and African Caribbean) (Levey et al. 2003, DH 2004b). Indeed, South Asian and African Caribbean people are three to five times more likely to suffer kidney failure requiring dialysis than white Caucasians (diabetes and hypertension being the biggest cause of renal failure within these communities) (Lightstone 2001).

Worldwide Incidence and Prevalence of ESRD

The United States Renal Data System (USRDS) has been compiling annual reports for over 19 years, collating data from different national registries to facilitate the comparison of both the incidence and prevalence of RRT worldwide. Similarly the UK Renal Registry (Ansell et al. 2007), which shares data with the US, has now produced ten annual reports to examine the activity of RRT and ESRD within the four home countries (Northern Ireland, Scotland, England and Wales). It is from both these data sources that comparative information has been drawn.

Year on year, the incidence of ESRD in the UK continues to rise steadily from 110 per million population (pmp) in 2005 to 113 pmp reported in 2006 (Ansell et al. 2007). A similar pattern can be observed in several European countries (Sweden, Norway, Denmark, Netherlands, Italy, and Spain). Australia and New Zealand show rates between 99-126 pmp of new patients starting treatment, in 2005. However, higher rates are reported elsewhere in Europe for example, Germany (203 pmp), Greece (193 pmp) and Czech Republic (175 pmp). Speculation suggests that early death as a result of cardiovascular disease in the UK could be a significant contributing factor to the difference in the rates observed (Ansell et al. 2007). The highest incidence of ESRD, reported in 2005 can be seen in South East Asian countries such as Taiwan (404 pmp) and Shanghai, China (275), as well as Jalisco (Mexico) (302) and the United States (351 pmp) (USRDS 2007). In contrast, lower rates are reported in Iceland (67 pmp), the Philippines (79 pmp), Russia (24 pmp) and Bangladesh (9 pmp) (USRDS 2007).

Those countries reporting higher incidence rates also treated a large number of diabetic patients for example 60% of new patients in Jalisco (Mexico) had a primary diagnosis of diabetes compared to only 19% UK, 11% Russia and 5% in Iceland (USRDS 2007, Ansell et al. 2007). Across continents the number of male patients with ESRD is greater than females and in the United States (where data is on the whole more reliable) racial disparity has been shown to exist across minority ethnic groups in the incidence of ESRD. Rates in 2005 demonstrated that African Americans (991 pmp) were 3.7 times more likely to develop ESRD; Native Americans (516 pmp) 1.9 times more likely; and Asians (355 pmp) 1.3 times more likely compared to white Caucasians (268 pmp) (USRDS 2007).

The total number of people receiving RRT has been taken as a proxy measure for the prevalence of ESRD. There are very high prevalence rates for RRT reported in Taiwan (1,830 pmp, dialysis patients only), United States (1,585 pmp) and Germany (1,057 pmp). The prevalence in the UK in 2006 was reported at 738 pmp. This is similar to rates observed in Italy, Netherlands, Norway, Denmark, Finland, New

Zealand and Australia. The lowest rates of just 115, 87 and 83 pmp again are reported in Russia, Philippines and Bangladesh respectively (USRDS 2007, Ansell et al. 2007). It is generally agreed, that in addition to the numbers identified there will be considerably more people in the general population that have not yet been diagnosed and need for RRT not yet recognised (DH 2004b).

As mentioned earlier, the stages of CKD have only recently (since 2002) been adopted for the classification and identification of patients with potential to progress to ESRD. It is therefore not possible at this time to accurately assess the prevalence of CKD worldwide or within the UK, although renal registries are developing ways to capture such data in the future. A recent systematic review of population based prevalence studies indicated that although the burden of CKD seems quite high less than 2% of CKD patients progressed to ESRD (Zhang and Rothenbacher 2008). Despite this, consensus agreement suggests CKD is already a considerable public health problem worldwide (Levey et al. 2003, Zhang and Rothenbacher 2008).

Treatment of End Stage Renal Disease

Forty years ago the diagnosis of ESRD left few options for treatment and often resulted in death. Since this time the significant advancement in the way the condition is treated has enabled people to live longer. Advances, particularly over the last 15 years, such as the rapid growth and availability of dialysis treatment, the development of kidney transplantation with new more effective anti-rejection drugs, combined with the treatment of older patients with co-morbid conditions has improved survival for this group of patients (DH 2004b).

There is evidence that since the introduction of RRT patients can survive the rigours of the treatment long-term, some for over 30 years but this is not common (DH 2004b). On average in the UK the mean survival rate for patients on RRT is 5.1 years, with transplanted patients surviving up to 10.2 years. However, for those receiving haemodialysis (HD) or peritoneal dialysis (PD) the picture is considerably more depressing with average survival being reported as 2.8 and 2.0 years respectively (Ansell et al. 2007). On the whole the dialysis population is usually older than transplanted patients and therefore a lower survival rate would be expected, but the stark reality of the difference in survival is significant. The crucial survival period of dialysis treatment is the first 90 days and over the last eight years there has been an annual improvement of 3% in survival rates in both HD and PD and in both the under and over 65 year age groups (Ansell et al. 2007). However, some patients progress to ESRD and choose not to have RRT requiring conservative management, supportive care and eventually end of life palliative care.

Two common forms of dialysis treatment are HD and PD. Within HD the patient’s blood is circulated through a machine, which filters out waste products and excess water. HD is normally four hours a day, three times a week and can be performed in a renal centre, satellite unit or by the patient themselves when fully trained in their own home. Despite guidance recommending that renal patients are clinically suitable should be offered home haemodialysis as an option, it is not well used throughout the UK as a treatment of choice (NICE 2002).

Both daily HD and nocturnal HD are receiving much international attention and both are now being considered as options in the UK (Greater Manchester Renal Strategy Group 2008). In these treatments patients have daily short regular bursts of HD or longer slower treatment overnight that is perceived to be much more effective at replacing kidney function (Lebner et al. 2007, Raymont and Bonner 2008).

HD requires the patient to have surgery to establish permanent long-term access to the blood supply. For patients whose veins and arteries are undamaged an arteriovenous fistula is usually the vascular access of choice, with the fewest complications, but even after being formed it can take over two months to develop. Once established, two needles are inserted into the fistula each dialysis treatment. Where permanent access has not or cannot be achieved temporary central venous catheters are used, often sited in a patient’s neck, bringing with it an increased risk of serious infection, morbidity and mortality (Ansell et al. 2005). From the hospital admissions of dialysis patients, 25% are a direct result of access problems or complications and a major cause of morbidity (Levy et al. 2001) and in 2005 only 31% of patients starting RRT had established vascular access (Ansell et al. 2005).

PD involves dialysis fluid being introduced into the peritoneal cavity in the patient's abdomen. Similar to HD, access is required for PD but not into the patients circulatory system. A catheter/tube is placed under local anaesthetic through the abdominal wall into the peritoneal cavity, where the peritoneal membrane acts like a filter drawing waste products and excess water out of the blood. PD is performed at home; it can be manual, where the fluid is exchanged (drained out then replaced) four to five times a day, or automated where fluid is exchanged more frequently, by a machine, usually performed daily throughout the night whilst the patient is sleeping. The different types of PD evolved to maximize the efficiency of the treatment and for the social convenience of patients, to free up more time during the day (Levy et al. 2001).

Kidney transplantation is considered the best form of RRT for approximately 40% of patients who are clinically stable (DH 2008a, Greater Manchester Renal Strategy Group 2005). The optimum transplant being pre-emptive, taking place before a person requires dialysis. Organs can be donated from a living or deceased donor, with living related donations commonly take place between related individuals. Recently, paired donation, where a family member is willing to give their kidney to an unknown individual in exchange for their own relative to benefit from a kidney donated by the other paired donor is being considered (DH 2008a).

In the UK in 2006, HD was the first treatment choice for 77% of patients, PD 21% and 3.4% of patients received a pre-emptive transplant (Ansell et al. 2007). The current Renal Association guidelines (2007a) recommend that patients be placed on the kidney transplant waiting list six months prior to their anticipated start of dialysis. Of the 43,901 adult patients receiving RRT at the end of 2006, 45% had a kidney transplant, 43% were on centre-based HD, 1% on home HD and 11% on PD (a figure which is falling) (Ansell et al. 2007). The type of RRT is age related, in the UK 57% of patients under 65 years had a functioning transplant and 43% on dialysis compared with older patients where 21% had a functioning transplant and 79% were on dialysis (Ansell et al. 2007).

There are considerable variations across countries with respect to the preference and use of different types of dialysis (Table 2). The highest worldwide rate for the use of PD was reported in Hong Kong in 2005, with 83% of dialysis patients receiving this treatment. Similarly high rates are reported in Mexico (71.7%) and Iceland (35.1%). HD is the most frequently used form of treatment in most parts of the world, particularly in Japan (96.3%) and Germany (93.9%) where PD patients form a very small percentage of the dialysis population. The UK has a similar dialysis treatment pattern to Denmark and Australia with 77% HD patients and 21% PD patients. New Zealand has an equal numbers of patients receiving HD and PD but reports a higher number of home HD patients (14.6%) than any other country, closely followed by Australia (9.4%). France, Spain, Denmark and the UK all report that home HD patients account for only 2.0-3.4% of the dialysis population (USRDS 2007, Ansell et al. 2007).

Table 2: Examples of Different Country Percentage Distribution of Dialysis Patients by Modality (USRDS 2007, Table 12.d, and Ansell et al. 2007)

Country	HD	Home HD	PD
*Japan	96.3	0	3.6
Germany	93.9	0.8	5.2
Austria	92.0	0.2	7.7
United States	91.8	0.6	7.6
Greece	91.1	0	8.9
Russia	91.5	0	8.5
Italy	87.0	0.7	12.3
Spain	87.8	3.4	8.8
France	86.1	2.4	11.5
United Kingdom	77.0	2.0	21.0
Denmark	72.3	2.9	24.8
Australia	69.4	9.4	21.2
Iceland	64.9	0	35.1
*New Zealand	43.5	14.6	41.9
Jalisco (Mexico)	28.3	0	71.7
Hong Kong	17.0	0	83.0

*(*2004 data, all other countries 2005 data, UK 2006 data)*

In 2005, the United States, France and Spain reported the highest number of kidney transplants performed per year at 57-67 pmp, more than double the rate of Northern Ireland (20 pmp), Scotland (22 pmp), Wales (28 pmp) and England (29 pmp) (USRDS 2007, Ansell et al. 2007). Within countries such as Turkey, Bangladesh, and Russia the transplants performed annually was less than five pmp. The difference noted in transplant rates reflects not only the variety of healthcare infrastructures but also wide cultural differences towards the practice of transplantation across the different countries (USRDS 2007). Recent challenging targets and recommendations in the UK, from the Department of Health and UK Transplant Authority, are anticipated to significantly impact on and increase the number of transplants performed in the future (DH 2008a).

Implications and Complications of ESRD

In addition to removing waste products the kidney is also responsible for the control of the body's acidity, salt balance, and production of haemoglobin, blood pressure and bone formation. Therefore, along with treatments such as HD or PD often a patient will be prescribed various fluid and diet restrictions and complex medication regimes to establish a careful internal balance. When there is an imbalance or the treatment is not working effectively patients are at risk of numerous complications such as anaemia, cardiovascular disease, hypertension, fluid overload, fluid depletion, hyperkalaemia, acidosis, renal osteodystrophy, and malnutrition (Levy et al. 2001).

Added to this list for adult patients are sexual and reproductive problems such as impotence and a reduced likelihood of conception and successful pregnancy, both of which are improved following successful transplantation (DH 2004b). Even with kidney transplantation, the complex medication regime brings with it the risk of developing a number of associated side effects. It is not surprising then that survival rates, particularly for dialysis patients are so poor, given the complexity of both the disease aetiology and the necessary treatment regime. For the patient to comprehend, adhere to and manage such restrictions and regimes, on top of a rigorous treatment schedule they require effective and appropriate information and education (DH 2004b).

The treatment of ESRD often has social and financial implications and lifestyle changes are often unavoidable. The time taken up by treatment schedules, for HD can be in excess of 18 hours a week, including travelling to and from a unit, which can have serious implications for those employed. Even those patients who choose PD and perform exchanges at work often have difficulty long-term. The financial burden of lost earnings and reduced income can affect the whole family. Both planning and affording holidays can be difficult with patients on HD needing a destination close to a renal unit where they will continue to have their treatment, and PD patients needing to organise fluid deliveries to holiday destinations. The physical, psychological and socio-economic problems, experienced by patients with long-term conditions can reduce their quality of life and sometimes lead to social exclusion (DH 2001).

UK Variations in ESRD/RRT Prevalence

The population prevalence in the UK from 2005 to 2006 raised from 694 pmp to 725 pmp a growth of 6.9% (Ansell et al. 2007). In the National Service Framework (NSF) for Renal Services (DH 2004b) figures quoted from 2001 indicated 27,000 people receiving RRT and this was predicted to rise to 45,000 over the next ten years. In just five years, this prediction has almost been realised as 2006 figures show a considerable rise to 43,901 adults receiving RRT (Ansell et al. 2007).

Table 3: Prevalence of RRT in the UK on 31.12.06 (Ansell et al. 2007, p52)

	UK	**England**	**Wales**	**Scotland**	**N Ireland**
All UK centres (n=72)	43901	36462	2151	3934	1354
Prevalence pmp HD	311	306	318	336	381
Prevalence pmp PD	78	76	107	81	65
Prevalence pmp dialysis	389	382	425	417	446
Prevalence pmp transplant	336	336	300	352	331
Total Prevalence pmp	725	718	725	769	777

Variations in the prevalence of RRT patients can be observed between the four home countries of Northern Ireland, Scotland, England and Wales (Table 3). There are 52 renal centres in the England, 5 in Wales, 6 in Northern Ireland and 10 in Scotland (data from the two centres in Glasgow were grouped together). Overall the treatment rates in England are lower compared to all three of the other countries in the UK.

To date not all, but the majority of renal centres participate in the renal registry audit although data return can be incomplete. For example, ethnicity data was incomplete from more than 60% of centres making figures unreliable. A cautious screen of ethnic minority groups within the UK RRT patient population can be identified based on partial figures from 67.6% of centres (Table 4) (Ansell et al. 2007). The importance of reporting accurate data is reinforced given the racial differences noted in the incidence of ESRD in the United States and the expected higher incidence of CKD within these particular patient groups.

Table 4: Patients in Different Ethnic Groups in the UK (Ansell et al. 2007, p28)

% of patients	**UK**	**England**	**Wales**	**Scotland**	**N Ireland**
White	81.7	79.9	97.4	100	100
Black	5.8	6.3	1.6		
South Asian	9.5	10.4	1.1		
Chinese	0.4	0.5			
Other	2.6	2.9			

The median age of patients starting RRT across the UK is 65 years, with minimal fluctuation noted over the past five years. Overall in the UK 50% of patients accepted for RRT were over 65 years, with greater proportions seen in Northern Ireland (58%) Wales (56%) and Scotland (51%) compared with only 49% in England (Ansell et al. 2007). As in previous years, 62% of all patients starting RRT were male. Across all age groups there was a higher number of male than female patients with relative proportions increasing in the 65-89 year age group (Ansell et al. 2007). This is higher than in other countries (USRDS 2007).

The number of patients accepted onto RRT varied considerably between different centres, as did the availability of services and treatment modalities. Forty-eight areas had exceptionally high acceptance rates, 30 in England (including 20 in London, East and West Midlands), 10 in Wales and 8 in Scotland (Ansell et al. 2007). At least half of the areas, predominantly in England, where high acceptance rates were reported had ethnic minority populations of more than 10%. The NSF (DH 2004b) predicted an increased demand on services given the ageing population in England, particularly in black and minority ethnic groups.

Provision of Services in the UK

Different treatment modalities were established and the understanding of the effectiveness of different RRT's refined during the 1970s and 1980s. It was at this time the UK, saw the introduction of home HD and active PD programmes. In the 1990s the focus shifted towards redesigning and organising services, models introduced in some areas included a 'hub and spoke' configuration where a central unit supported one or more satellite units bringing HD closer to patients' homes. More recently these models have been developed further into managed clinical networks, a recommendation within the NSF (DH 2004b) in order to develop renal services and bring together all the stakeholders within primary and secondary care including the patients and users of the service (DH 2004b).

Equity of access is an important goal for service provision (DH 2004b). However there is a wide variation in the prevalence of patients in each centre and the distribution of these patients across the different modality groups. Several reasons are thought to influence the prevalence and modality selection: geographical location, local population density, age distribution, ethnic composition, social deprivation, and preference of the consultant (Ansell et al. 2007). A key factor is also local organisation of services and what facilities are actually available to a patient. For example, a patient having to travel over 50 miles round trip to attend a local HD centre for treatment may choose PD to be able to spend more time at home, even if their first choice of treatment was HD. Alternatively given a local satellite unit close to home the patient's choice may be more straightforward. The purpose of re-organising renal services into clinical networks is to overcome the lack of equity and choice for patients that exist in different parts of the country with regard to the availability and access to treatment they prefer, and provide appropriate services that meet the demands of the local population (Roderick et al. 2005).

The projected increase in the number of people requiring RRT will place more pressure on the health economy, renal units and other health care resources as greater numbers of older people with co-existing illnesses begin treatment. The cost of RRT and treating patients with ESRD creates an intense demand on limited resources, with it estimated as consuming 1-2% of the total NHS budget yet targeting only 0.05% of the population (DH 2004b). For one person receiving HD the cost per year is approximately £23,177 (DH 2008a). A lack of resources and the increasing number of patients places considerable strain on the workforce. Even before, and since, the publication of the renal NSF activity has focused on examining and developing the multi-disciplinary workforce to effectively meet the current and future service demands (BRS 2002, Renal Association 2007b).

Renal service delivery requires a co-ordinated and integrated approach with a multi-professional team, comprising of a range of skills to manage patients throughout their journey of care (BRS 2002, DH 2005c).

Table 5: Renal Workforce Requirements in the Future (BRS 2002, p7)

Professional Group	**2001 Establishment**	**2010 Requirements**
Renal Physicians	290	803
Transplant Surgeons	87	130
Transplant Co-ordinators	87	144
Dieticians	180	738
Social Workers	73	555
Clinical Psychologists	7	168
Technicians	225	583
Pharmacists	97	669
Nurses	2330	4223

A major increase is forecasted in all professional staff groups by 2010 to ensure there is a sufficient workforce to meet the anticipated increased demand on the adult services (Table 5). Of course staff shortages are not just a problem for renal services but across the health service in general (Skills for Health 2003).

There is within the current establishment a shortage of both social workers and clinical psychologists and geographically patients have inequitable access to these important services that provide psychosocial support (DH 2005c). Within renal services nurses have over many years held a prominent role in the care of ESRD patients as experts and clinical specialists in the different forms of dialysis treatment offered to patients. Nurses' roles have advanced usually in response to developing service need, taking on the insertion of central venous catheters in some areas, co-ordinating living related donation, anaemia management and developing pre-dialysis education programmes for patients prior to starting RRT. More recently roles have been developed to streamline and co-ordinate aspects of the service for patients not yet starting RRT, such as establishing vascular access, and preventative clinics to control hypertension, alongside teams of nurses now monitoring and supporting those patients identified to be at the earlier stages two and three of CKD. Indeed, these roles are similar to that of the proposed community matrons in supporting patients with long-term conditions (DH 2007) and have been in existence in renal services for many years, with teams of both PD and HD community nurses (Morris et al. 1997), and more recently established CKD nursing teams.

Much of the development in renal nursing has been in response to local service needs and nationally a lack of consistency exists between titles, roles and responsibilities. Role developments across the renal team are becoming formalised, using skills escalators to advance the training of key individuals so appropriate care can be provided at an appropriate time by the best person with the necessary skills (DH 2005c). Competency frameworks are being introduced to achieve national standards for renal services, ensure uniformity and equity, with the vision to create flexible working throughout the renal team and develop new ways of working (Skills for Health 2003). The fundamental role of the renal nurse within new and existing roles has been and always will be to provide a high standard of care, support, education and information for CKD patients to facilitate and enhance their life with CKD.

Greater Manchester Managed Clinical Network

In the North West of England, in particular Greater Manchester, renal services are organised into a Managed Clinical Network, comprising of two sectors the East and West. Salford Royal Hospitals NHS Trust forms the renal in-patient centre for the West, and Manchester Royal Infirmary (MRI) for the East. Both centres link strategically to local Trusts in secondary and primary care. MRI also houses the sectors adult transplant unit, which serves the whole of Greater Manchester, Lancashire and parts of Cheshire and totals around 4.5 million people (Greater Manchester Renal Strategy Group 2005). The purpose of the clinical network is to develop renal services in response to local service needs, generating collaborative partnerships between primary and secondary care to improve referral and identification, provide preventable treatment, and appropriate long-term care of patients with CKD.

Table 6: Example Network PCT Population Statistics (Age, Ethnicity, Dialysis Prevalence) (*Greater Manchester Renal Strategy Group 2008, Tables 3&5)*

		Population	% *BME	% Over 60	Dialysis Prevalence (pmp)
West Sector	Ashton, Leigh and Wigan	305,500	2.4%	20%	326
	Bolton	262,400	12.2%	20%	373
	Bury	182,900	7.5%	20%	301
	Heywood, Middleton and Rochdale	206,500	12.8%	19%	342
	Oldham	219,600	15.0%	19%	368
	Salford	218,000	5.8%	21%	399
East Sector	Manchester	452,000	22.2%	16%	404
	Stockport	280,600	5.4%	22%	305
	Tameside and Glossop	246,500	4.9%	20%	282
	Trafford	211,800	9.6%	21%	296
	Total	**2,585,800**			

**BME: Black and Minority Ethnic population*

The Greater Manchester Renal Strategy Group has focused on developing more equitable services throughout the East and West sectors, as well as assessing the need for renal services by examining the demography of the local population, for which it serves (Table 6).

The demand for services within the clinical network is increasing, at the Manchester unit the waiting list for transplants is the largest in the UK. Indeed, it was recognised within the Greater Manchester clinical network that HD provision was and is sub-optimal (Greater Manchester Renal Strategy Group 2008), with patients still unable to access local HD, having to travel miles to receive hospital HD three times a week.

Table 7: Existing and Planned Expansion of HD Facilities (Greater Manchester Renal Strategy Group 2008, Table 6)

		Dialysis Stations	**Planned New HD Stations**	**Home HD Training Stations**
West Sector	Sub Total	**74**	**7**	**2**
Salford Royal Hospital (renal centre)		22	7	2
Bolton		18		
Wigan		18		
Rochdale		16		
East Sector	Sub Total	**83**	**6**	**4**
MRI (renal centre)		25		
Wythenshawe		18		4
Macclesfield		6	6	
Tameside		18		
North Manchester		10 (+6)*		
Prestwich (self care patients only)		6		
Overall Total		**157**	**13**	**6**

** 6 stations for isolation of patients with viral blood infections*

Services are being developed (Table 7), in response to standards identified in the NSF (DH 2004b). Over the last two years new satellite units have opened (Wigan and Tameside) to offer a local based HD service. In addition extensions are underway at existing renal units to expand the availability of number of HD spaces. More satellite facilities are proposed for the future, one based in Stockport to meet the needs of the ageing population and one in Oldham where there are high proportion of people from ethnic minority groups thus demand is expected to increase (Greater Manchester Renal Strategy Group 2008).

The fundamental purpose of expanding and developing services is to ensure patients have access to the form of RRT they choose and that is clinically appropriate. This will include future expansion of PD, home HD and self-care HD programmes according to the needs of the local population (Greater Manchester Renal Strategy Group 2008). With a shortage of HD provision patients whose first choice may be to receive HD close to their home, end up with a *managed choice* often directed to PD (NHS Institute for Innovation and Improvement 2008). Although changes and initiatives have been developed in response to national policy and the renal NSF (DH 2004b) it takes both time and adequate resources to achieve changes in practice.

National Policy for CKD/ESRD

Given that the prevalence of CKD in the UK is set to increase dramatically, key national developments have been introduced (DH 2003, The Information Centre, Prescribing and Support Unit 2007) to increase awareness and identify more patients at risk or in the early stages of CKD and to prevent disease progression. Recent initiatives include '*Putting Prevention First*' (DH 2008b), an approach introduced this year to identify and predict those patients who are vulnerable to vascular disease. The initiative is expected to detect at least 25,000 more people a year with diabetes and kidney disease. Managing the disease at such an early stage can greatly increase the chance of slowing or stopping the progression to established renal disease, which for many patients means they may never be referred to a specialised renal centre and in turn will go someway to reduce the burden of future demand.

Current NHS policy advocates the need to develop patient-led services (DH 2000 NHS plan; DH 2005a, DH 2007, DH 2008d) placing the patient at the centre of service design and delivery. The Renal NSF (DH 2004b) embraces this idea and actively promotes the goals of the NHS plan to improve within the next 10 years, the range, quality and choice of renal services and the user experience. There is evidence that patient-led services are being operated at a local level with the changes introduced and expansion of services within Greater Manchester, in response to the needs of the local population. Another proposition to increase patient involvement within the renal service is to optimise the role that people with CKD can take in the management of their care. Indeed the NSF (DH 2004b) emphasizes:

> *'…adults with chronic kidney disease are to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision making, with an agreed care plan that supports them in managing their condition to achieve the best quality of life'* (DH 2004b, p3).

When patients are encouraged to self-manage their long term chronic illness there are recognised benefits such as; providing them with greater control, a feeling of well being and the ability to cope more effectively, decreases in the number of complications, unnecessary hospital admissions, and a reduction in the sense of powerless (DH 2004c). For many chronic conditions patients are self-caring and may only interact with a health professional for a few hours a year (DH 2004c). This is not the case for many CKD patients where contact with a professional particularly for HD patients is a minimum of three times a week. This is much less for PD and home HD patients who are regularly visited or are seen in an outpatient clinic. However, as the prevalence of CKD increases so does the demand on already stretched services limiting the time a clinician has available. Therefore it becomes increasingly important for clinicians when they interact with patients to use their time effectively. This includes providing information to the patient that is meaningful and relevant to their needs to promote the development of self-management skills.

To achieve self-care, high quality and comprehensive information and educational programmes tailored to meet the information needs of the patient are viewed as a marker of good practice (DH 2004b). Education and information are key to supporting people with long-term conditions and encouraging them to be actively involved in planning their own care (DH 2005b). Together with focusing services around the patient's needs and preferences (DH 2005a,b), so patients have choices and the information to help them make choices (DH 2004b). To achieve this NHS organisations are asked to become:

> *'…better at understanding patients and their needs, use new and different methodologies to do so and have better and more regular sources of information about preferences and satisfaction'* (DH 2005a, p5).

A patient-led service values the experience of the patient for knowing and understanding their own illness and how it impacts upon their lives (DH 2005a). After extensive research involving patients, the public and NHS staff, a definition of the *patient experience* was derived indicating the importance of meeting emotional as well as physical needs, through (DH 2005d, p7):

- *'Getting good treatment in a comfortable, caring safe environment, delivered in a safe way'*
- *'Having information to make choices, to feel confident and to feel in control'*
- *'Being talked to and listened to as an equal; being treated with honesty and dignity'*

With this in mind the focus on identifying and meeting the information needs of CKD patients has never been so high on national and political agendas. The central concepts are tailoring education to the needs of the patient and understanding their preferences and priorities for information within the context of their own lives. Indeed, supporting patients with long term conditions involves not just treating the condition but delivering personal, responsive care based on *how* people want to live their lives (DH 2007). National policy advocates that patients' '*lives can be transformed by being given support that's right for them'* (DH 2007, p5). This is much more than just giving patients' information about their condition but achieving better outcomes because the patient feels empowered and proactive about their health.

It is evident throughout many policies that self-care, education and information provision are integral to the success of achieving patient led-services. However, an inherent problem in implementing and indeed achieving the desired outcomes, particularly within CKD, is the lack of evidence upon which to develop practice. For example the term *information need* is used throughout policy documents (DH 2004b, DH 2007) but without providing a clear definition as to what this actually means, or how it can be achieved (Beaver 2004). The evidence base identifying what information patients' need, why they need that information and for what purpose for many chronic conditions particularly CKD is seriously lacking.

National Initiatives for Education and Information Provision

Five examples have been selected to demonstrate the variety of national initiatives, projects and campaigns introduced with the aim to improve the education and information provision for CKD patients.

The Renal Services Information Strategy (DH 2005e) was compiled to complement the NSF for renal services. It creates a plan for radically improving the use of information technology throughout renal services encompassing primary care to promote the sharing of clinical, diagnostic information to streamline patient management and early referral and current evidence to increase knowledge. As part of this programme the Department of Health for the NSF and for Renal Services provides links to; the National electronic Library for Health (NeLH) which acts as a repository for information about all aspects of CKD; agencies such as NICE for professionals to access clinical guidance; NHS Direct and more recently NHS Choices for patients, families and carers to access information; as well as professional, voluntary and charitable organisations (such as the British Renal Society; Renal Association; National Kidney Federation; Kidney Alliance; Kidney Research UK) (DH 2005c).

The Renal Information Exchange Group (RIXG) involving key representatives from throughout the renal community has developed an innovative initiative *Renal PatientView* (RIXG 2005). The initiative has developed an electronic system by which patients can access their health records, diagnosis and treatment information alongside blood results, which are particularly important to renal patients. Initially, it was tested in three pilot sites but since 2007 it has been established in at least 29 units involving 3330 patients throughout the UK. In 2006 the project was awarded an accolade from NHS Connecting for Health for being at the forefront in developing patient-led services.

The White Paper in 2006, '*Our health, our care, our say*' (DH 2006) made a commitment to improving the accessibility of information for patients with long-term conditions by providing *Information Prescriptions*. The subsequent initiative involves partnership working between public libraries and health and social care professionals to develop relevant lists, signposts and links to reliable information sources that patients can access in their own time to locate information to satisfy their individual information need (DH 2008c). It combines the expertise of information scientists to seek out appropriate information alongside the clinicians' experience and knowledge of the medical condition. This type of initiative can only complement and improve the effectiveness of information provision in practice by stimulating and targeting questions between the patient and the clinician based on information sought. It is however dependent upon the patient and whether they choose to seek out additional information.

Good practice initiatives have been introduced to target and improve education and information to ethnic minority groups. The A Better Life Through Education and Empowerment (ABLE) campaign (Kidney Research UK 2001) was introduced to develop peer educators, lay members of the community specially trained to reach out to many people in diverse religious and language groups, particularly South Asian and African Caribbean populations. Subsequent initiatives include; attitudes to organ donation, health screening facilities, health promotion regarding diet, salt intake, exercise, education materials, public relations campaigns to increase awareness of not just CKD but diabetes, hypertension and cardiovascular disease, bringing together primary and secondary care professionals.

Kidney Research UK in collaboration with key organisations, and with financial assistance from the Big Lottery Fund, has recently developed and produced two promotional DVD's *'Living with Kidney Disease: What you should know.'* These were developed by renal patients, for renal patients with the help of professionals to explain CKD and the medical condition. Real patients present their perspective of the different treatment options, describing how it affects their life, advice on holidays, employment, blood tests, and practical tips ranging from eating well to waste disposal. There are links provided for patients to explore and obtain additional information.

It was the inception of this idea, before the project began, that highlighted the need for this PhD study; the lack of evidence identifying the information needs of CKD patients. The need for empirical research in this area to ensure information provision is based on what patients want to know not what professionals consider to be important. Previous patient education materials used throughout the 1980s and 90s, as renal services developed, were sponsored by manufacturers and often presented a positive spin on their particular treatment. This initiative however, was derived from patient experiences; patients were involved as partners in developing and identifying the content of the DVDs, which provides a degree of content validity and reliability reflective of a patient-led service. Even though the DVDs are powerful tools there is still a gap a need to develop a rigorous evidence base upon which to direct information provision in the future.

CKD Patient Education and Information

Educating a CKD patient is integral to practice throughout the UK, the responsibility of all the multi-professional team, but often co-ordinated by the nurse. To be able to successfully manage CKD, patients need to understand and take responsibility for many aspects of their own treatment (Curtin and Mapes 2001). Early education of patients within the pre-dialysis stage (prior to receiving RRT) has been shown to be effective in increasing knowledge levels (Klang et al. 1999, Devins et al. 2000). For the last 15 years it has been established practice within most UK renal units to provide pre-dialysis patient education programmes, usually 6-12 months prior to a patient starting RRT (Kidney Alliance 2001), although nationally these vary in structure, content and quality (NHS Institute for Innovation and Improvement 2008). The sharing of good practice through prolific publications of programme frameworks and education evaluations, both within the UK and Worldwide, highlight accepted approaches (Lowry 1995, Hunter et al. 1996, King 1997, O’Donnell and Tucker 1997, Karley et al. 1998, Klang et al. 1999, Piccoli et al. 2000, Iles-Smith 2005, Goovaerts et al. 2005).

The purpose of pre-dialysis education is twofold; firstly to enable patients to make an informed choice of available treatments and secondly to actively prepare and socialise patients towards taking on a collaborative role in the self-care and management of the ESRD (Devins et al. 2005). Education programmes may take on different forms; taking place during individual home visits, group training sessions (Karley et al. 1998, Klang et al. 1999, Goovaerts et al. 2005), weekly/monthly sessions and workshops (King 1997, O'Donnell and Tucker 1999), using books, leaflets, DVD's, videos, formal presentations, and visits to the unit to observe different dialysis taking place (Piccoli et al. 2000, Goovaerts et al. 2005). Patients are encouraged to talk about their experiences during planned sessions or on an individual basis (O'Donnell and Tucker 1999, Goovaets et al. 2005). More formalised programmes developing patients as educators themselves include 'Patients Educating Patients' (PEP) in the United States (Hartwell 2003) and the Expert Patient Programme established in the UK (DH 2001). Patients have identified that they value the opportunity to talk to other patients within the education process (NHS Institute for Innovation and Improvement 2008). Often the pre-dialysis education approach is multi-disciplinary, particularly involving the dietician, nurse and social worker (King 1997, Karley et al. 1998, O'Donnell and Tucker 1999, Klang et al. 1999, Piccoli et al. 2000, Goovaets et al. 2005), some have dedicated renal patient educators (Morris et al. 1997, Campbell 1999). The general education content approach includes presenting information about normal kidney functions, diseases of the kidney, the different forms of dialysis and their advantages and disadvantages, nutrition, medication, self-management and lifestyle. Indeed, targeted education on self-care has been shown to increase the number of patients who go on to choose PD, home HD or self-care dialysis to remain independent (Piccoli et al. 2000, Manns et al. 2005). Methods have been introduced specifically to coach patients towards self-care (Teschan 2002). A good education programme, with appropriate education materials in a variety of formats (translated in areas of high ethnicity) is seen as fundamental to the ideal pre-dialysis patient pathway (NHS Institute for Innovation and Improvement 2008). This year two action learning sets have been introduced with in the UK, with a patient focus to understand what patients need in the year prior to staring RRT (DH 2008d).

Most educational intervention studies have been conducted with patients who have advanced CKD prior to the initiation of RRT and often evaluate satisfaction with pre-dialysis education programmes, content and preparation (O'Donnell and Tucker 1997, Piccoli et al. 2000, Goovaets et al. 2005, Manns et al. 2005). Not surprisingly patients report satisfaction with the programmes they have attended. Effective education is typically measured by one test immediately after a programme to indicate a knowledge gain (Falvo 1995), but often programmes fail to measure whether the patient has understood what they have been taught. There is little evidence to suggest that such programmes are based on the information needs of the patients themselves, or whether they are initiated at a time that is appropriate for the patient. Lowry (1995) over 10 years ago identified that there was no means prior to an education programme of establishing what information a patient considered to be important, and still today there is little evidence to suggest this has changed.

Once starting RRT targeted patient education and training continues. It is usually delivered or facilitated by nurses who are responsible for teaching the selected RRT and promoting self-care. Specially designed programmes focusing on the RRT (Cook 1995) with protocols on what to teach (Kollee and Pearson 2000) and structured tools to direct teaching (Brundage and Swearengen 1994) help patients understand diet and medication, to help control symptoms, and facilitate psychosocial adjustment (Mathers 1998). Long-term education appears to focus on behavioural approaches to increase adherence; using individual teaching sessions and handouts (Morgan 2000), tailored dietetic programmes (Leon et al. 2001) explaining why compliance is important (Waldron 2004) and even incentive based programmes (Berg et al. 2004) to reduce fluid weight gain between dialysis treatments. Piccoli et al. (2000) stress the need to reiterate information long-term not just at one point in time. PD patients in one unit are periodically retrained to remind them of important factors related to their treatment (Zuccherato et al. 2003).

Information acquired through such education programmes can be retained for very long periods (Devins et al. 2000), but even though some patients hold this information they choose to ignore it. Increasingly researchers are finding that whether a patient chooses to adhere to their treatment plan or not, it is not related to their level of knowledge (Shaw-Stuart and Stuart 2000). Neither is it related to whether they have had targeted education, counselling or have experienced certain symptoms like itching manifesting because of a poor diet (Thedford 2004). There are other attributes such as coping skills and self-efficacy that will influence their ability to self-manage their illness more than just acquiring the knowledge (Favlo 1995, Oscar 1996). Indeed CKD patients who perceive a loss of control over their treatment attempt to regain control through negative behaviour and non-adherence to diet and fluid restrictions (Christensen 2000).

There is no doubt that education and information is crucial to CKD patients' survival and self-management of the disease. Indeed it has been demonstrated that providing information and support can enable patients to maintain employment (Rasgon et al. 1993) and ward off depressive symptoms that sometimes arise when people are undergoing long-term dialysis (Korniewicz and O'Brien 1994, Rasgon et al. 1998, Klang et al. 1998). But education and information is most effective when tailored to the cultural needs of the individual and take account of other influences such as age and disability (DH 2004b). There is no clear evidence from the different education programmes that patients' information needs are identified or used as the focus of education, but that is not to say that this does not happen. It would appear ineffective to provide an education programme that teaches aspects of CKD management that is considered meaningful to the patient and pertinent to their lives without knowing what they consider important, and of a priority to them. Theories of adult education consistently state that adults will devote energy to learn something in proportion to how they perceive it will help them perform tasks or deal with problems they are currently confronting (Wingard 2005, Jarvis et al. 2003). To achieve desired outcomes professionals need to ensure education goals are geared to the patients' information needs (Wingard 2005), to do this clinicians need to know what the information needs are.

Rationale for Study of Information Need

It is clear from the evidence presented in this chapter that the focus on identifying and meeting the information needs of CKD patients is high on both national and political agendas and it is viewed to be central to the development of patient-led services (DH 2004b, DH 2005a, DH 2007). For practice to progress and be developed upon this premise then a research evidence base that identifies CKD patient' information needs, their priorities and preferences for information, is essential. Indeed the term *information need* requires further explanation with respect to its meaning and use within the field of health.

Renal patients are provided with information throughout their life on RRT, although much of it is presented in the pre-dialysis phase when the decisions over which treatment modality to select are made. Pre-dialysis education programmes often receive positive evaluations, but there is little evidence, from the patients' perspective, to suggest whether the type, amount and timing of information are appropriate and indeed whether it addresses their needs. Because CKD is a long-term condition it is imperative to understand how information needs change as patients' progress through the stages of CKD and whether needs differ the longer patients have experienced RRT. It would be prudent to examine the priority of their information needs over time. This would inform the development of education programmes and prevent overloading individuals with information.

Without robust evidence both education and information provision will continue to be based on inferred rather than actual patient information needs (Jenkins et al. 2001). Research over ten years ago identified that cancer patients have priorities regarding their information needs (Luker et al. 1995). This being the case it would not be unrealistic to assume that CKD patients would also have information priorities that are pertinent to them. If these priorities could be identified and described then information provision can be targeted to ensure needs are satisfied. Clinicians have been found to underestimate the amount of information patients want (Degner et al. 1997), the only way to avoid this is to have a clear understanding of patients' preferences, what information they want, when and how much.

Information provision may not be effective if it is not considered relevant to the patient at that point in time. Bekker et al. (1999) within a systematic review of informed decision-making highlighted that the context of the individual will influence whether even good quality information is taken on board or used, particularly if the information is not perceived important enough to the actual person. There is little understanding regarding the context in which a CKD patient's need for information arises, what may influence that need, and whether patient characteristics such as age, gender or ethnicity influence the type of information a person requires.

Until empirical evidence is available to guide clinicians, information provision to patients will be unsystematic and disorganised and is unlikely to meet their needs. This study explores, describes and investigates the information needs of a group of CKD patients providing a much needed evidence base to inform the development of renal services. The potential impact of such evidence would be to:

- Facilitate targeted information provision to respond to the information needs of the patient
- Generate an understanding of a patient's preferences and priorities for information
- Enable effective patient participation, self-care and informed decision-making as a result of effective and appropriate information provision
- Create a greater understanding of how a patient's individual context, personal circumstances and demographic characteristics influence their information needs
- Ensure effective use of both the patient's and clinician's time
- Create a more knowledgeable and informed workforce
- Provide a clear evidence base on which to ground education programmes and develop patient led-services for information and education provision

Schatell and Sacksteder (2002) analysed data from a group of dialysis patients who had received treatment for at least 15 years and found that *getting answers to questions* and *active information seeking* were two key components for living a long life on dialysis.

Aims and Objectives

Given the overwhelming evidence, this study is both justified and timely. The aim of the study was to explore, identify and describe the information needs of CKD patients and the context in which they manifest. This includes developing a CKD specific instrument to measure and examine information need priorities and the influence of demographic variables or changes in information need over time.

The four study objectives were:

- To identify, from the patients perspective, the key information needs of a group of CKD patients and to develop an understanding of the contextual factors that influence the manifestation of information need

- To develop and test the validity and reliability of a measuring scale that profiles and prioritises the information needs of CKD patients

- To investigate whether the type and need for information changes over time or as a result of demographic variables such as age, gender, education level, socio-economics, ethnicity, treatment modality

- To contribute to the theory of information needs, CKD patients' information needs, measurement of information needs and implications for clinical practice based on the user perspective

Summary

The rationale for the study is powerful it makes explicit the need for such a focused research study, and the extensive benefits that can be gained by extending and generating a robust evidence base available to health professionals. The increased prevalence of CKD and increased demand on current services requires that health professionals' work more effectively. Understanding what information patients' need, why and when and targeting information at the most appropriate time will give rise to effective care that meets the needs of the patient.

The study could not have been designed without a thorough exploration and understanding of existing theory behind the concept of information need and what it means. Given that it features so strongly within national policies and central to the provision of high quality patient care, it is important to examine the term definition, where and how it had been used and indeed in what situations measured or observed. To this end, and reflecting this extensive journey of discovery, the next two chapters three and four, explore the theoretical underpinnings upon which the study is based and examine existing knowledge regarding information need with respect to its use and application in the field of health, in particular with CKD patients.

Chapter Three

Theory of Information and Information Need

Introduction

The Renal NSF is focused on achieving patient-led services (DH 2005a), empowering patients to develop skills that enable them to self-manage and direct their care, through effective and appropriate information provision (DH 2004b). If these fundamental goals of the current NHS are to be realised, then the information needs of patients and their preferences for information need to be exposed and understood (Sowden et al. 2001).

Information need provides the focus for this chapter. An information need perceived and recognised by the user instigates information seeking (Wilson 2006). Without a clear understanding of what the term means, how information needs emerge and the influencing factors, healthcare professionals cannot begin to provide information to address them (Timmins 2006). Patients identify that they want more information, requiring different kinds of information at different times for different purposes (Scott and Thompson 2003). What then are these different information needs, when are they important and for what purpose do patients need information? Research evidence predominantly in the field of cancer suggests that understanding what a patient needs to know and when during the course of their care is vital to ensuring the delivery of quality care (Scott and Thompson 2003, Rutten et al. 2005). However other fields such as CKD have been slow to respond and empirical evidence of patient information need is lacking.

Many scientific fields share common interests for research and education, yet often these fields do not communicate with each other and are unaware of existing work (Dervin 2003, Zhang and Benjamin 2007). This chapter draws on the experiences from information science where considerable research exists related to information needs. The rationale for such an approach lies in the lack of empirical evidence available within the health arena. To date there appears no explicit definition for information needs in health usually it is inferred by the focus of an article (Timmins

2006, Lambert and Loiselle 2007). A deeper understanding of the phenomena can be achieved by exploring information research and perspectives wider than healthcare.

This chapter introduces and explores the theories surrounding information, information needs and the factors that influence how a need is perceived, represented and portrayed. The central concept being the information need, not the subsequent process of information seeking that may take place in response to a need. The strength in this demarcation is that it allows a profound focus on the phenomena in question rather than distracting attention to seeking information, which is not the focus of the proposed study. Nonetheless to demonstrate how and where, in the overall process of information seeking, an information need is conceptualised, appropriate models and metaphorical frameworks are exploited.

Searching for a Definition of Information

Information Definitions

From the Oxford English Dictionary (OED), the earliest use of the word *information* dates back to the 1380's and working definitions refer to it as the act of; [1] '*informing, or giving form or shape to the mind, as in education, instruction, or training';* [2] *'communication of the knowledge or 'news' of some fact or occurrence; the action of telling or fact of being told of something'* (Oxford English Dictionary 1989). Despite the word proliferating the English language for the last 600 years there is today little consensus between scholars regarding its '*absolute*' meaning (Case 2002 p40). More recently, over the last fifty years, the explication of the term *information* has confirmed that it is a polymorphic phenomenon and a polysemantic concept (Wilson 1981, Buckland 1991, Hayes 1993, Dervin 1999, Losee 1997, Case 2002, Bates 2005, Floridi 2005, Zhang and Benjamin 2007). The different forms of information are visible within the two opening definitions where information can be viewed as physical phenomenon ('*giving form or shape to the mind'*); a message (*'news' of some fact'*); a process (act of '*education, instruction, or training'*); and a channel of communication ('*informing*'). In addition, depending upon the originating theory or discipline in which it is used, application of the term to real life suggests numerous, merging concepts (Losee 1997). Case (2002, p43) highlights a number of diverse examples where information has been used to refer to aspects of problem solving, decision making, human thinking and learning, sensory stimulation, states of mind, communication processes, information needs, knowledge and objects that carry information such as documents.

The majority of work defining the term *information* has, understandably, been derived from the discipline of Information Science. Information was for many years conceptualised objectively within a hierarchical structure alongside other concepts such as data (at the bottom) and knowledge (at the top) (Case 2002). Data usually refers to something that makes a difference; information a collection of one or more data, which are meaningful and well formed; and knowledge a true belief based on evidence (Floridi 2005). However, it is the overlapping similarities of these concepts that have generated much debate, confusion and disagreement. Some definitions blur the boundaries and propose that information is knowledge (Encarta® 2007). Others differentiate between the characteristics of information and knowledge in that: information, by being told, is acquired whereas knowledge is information which has been given meaning and understanding through thinking (Bates 2005); new knowledge can be acquired without taking on new information (Case 2002); knowledge can change as soon as new information is discovered causing people to change their thinking; and out-dated knowledge becomes information (Jarvis et al. 2003).

Hayes (1993), whilst exploring the measurement of information, proposed a sequential schema to represent the relationships between the different concepts (Diagram 1). He perceived a two-staged process consisting of both external and internal components for the recipient. Facts are defined as statements of which the truth can be tested. Data are described as not facts, the specific meaning elusive but infinite possibilities such as *recorded symbols, printed characters*, *spoken words, visual images* are inferred. Information is viewed as both a process of *being informed* and the *state of being so.* These are considered to be external to the recipient in contrast to understanding, knowledge and decisions, which are internal processes. In particular, he differentiates knowledge as a cognitive *state* generated internally not received externally like information.

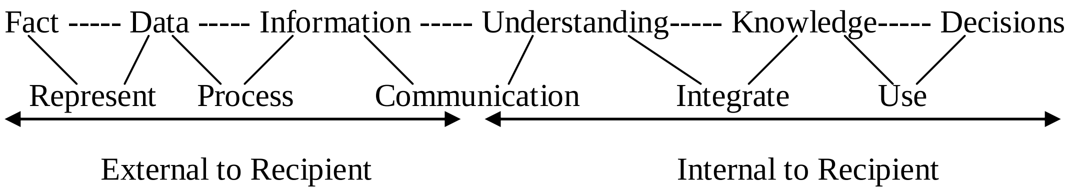

Diagram 1: Schema of Terms (Hayes 1993, p2)

This diagrammatical representation appears more logical, particularly the demarcation between internal and external processes, rather than a hierarchical conception. It also pictorially reinforces the perceptions of others who suggest that distinct differences exist between such concepts as data, information and knowledge. This illustration provides a glimpse of both the processes involving the user and the use of information.

Use of Information

Studying how information is used generates a number of different interpretations regarding the function and application of information. Although the majority of studies originate within the library setting there appear central analogous characteristics, which provide some clarity on how the term information may be translated to other settings. Wilson (1981) distinguishes between three central uses for the term information, a physical entity, a channel of communication, or factual data. Similarly, Buckland (1991) grouped the meanings associated with information into three principal uses: *information-as-process* the act of informing; *information-as-knowledge* the actual knowledge communicated which could be in the form of news, some fact, or event and/or that which reduces uncertainty; and *information-as-thing* objects such as data and documents that are informative and can impart knowledge. Later a review by McCreadie and Rice (1999), attempted to refine previous postulations. In it information is reorganised and conceptualised as four representations. Information as a resource/commodity, data in the environment, a representation of knowledge and part of the communication process. The isolation and association of key dimensions existing within the different interpretations of information use and the nominal Oxford English Dictionary definitions provide visible, albeit tenuous, links across perspectives (Table 8).

Table 8. Links Across Information Definitions and Use Perspectives

Definitions of Information (OED 1989)	**Information Use Dimensions**
'informing' *'communication of'* *'the action of telling or fact of being told of something'*	*channel of communication* (Wilson 1981) *information-as-process* (Buckland 1991) *being informed* (Hayes 1993) *part of the communication process* (McCreadie and Rice 1999)
'giving form or shape to the mind, as in education, instruction or training'	*physical entity* (Wilson 1981) *information-as-knowledge* (Buckland 1991) *state of being so* (*informed*) (Hayes 1993)
'news' *'some fact or occurrence'*	*factual data* (Wilson 1981) *information-as-thing* (Buckland 1991) *resource/commodity* (McCreadie and Rice 1999) *data in the environment* (McCreadie and Rice 1999) *representation of knowledge* (McCreadie and Rice 1999)

Case (2002) stresses, however, that although these explanations seem to suggest similar groupings the underlying meanings of terms used by the different authors, for example, *resource* and *thing* are distinctly different. A continuum of objectivity through to subjectivity exists and scholars attach their definitions at different points reflecting their underlying beliefs (Bates 2006, Hjørland 2007). Wilson (1981, 2006) three decades ago and still today contends that one single definition for the term information is not necessary but distinguishing between how the term is used, is paramount to ensure clarity of the focal concept being studied.

Users of Information

A fast emerging field both within information science and other disciplines is the study of the *user* of information, encompassing the purpose and relevance of information to the individual, in their environment, alongside the process of how information is used. This approach reveals further semantic dimensions associated to the concept of information and perhaps offers a more grounded and real life perspective towards understanding the multifaceted way in which information can be perceived. One such pioneer of this approach, Dervin (1992, 1997, 1998, 1999) differentiated between the notions of external and internal processes and applied these concepts to describe different types of information. External information or *objective* information is that which attempts to describe reality. Whereas internal information represents the person's own picture of reality and is *subjective*. The third type of information proposed, *sense-making* information, concerned the processes and behaviours used to understand and act on the internal and external information. From the basis of this typology and extensive studies of the *person in context,* particularly with respect to sense making, the study of information exploded to encompass the role that emotions and feelings play when making sense of situations, the process of being informed (Dervin 1992, 1998). Dervin advocates a generalised approach to understanding how humans (users) derive their own individual meaning from information and makes no attempt to distinguish between concepts such as data, information and knowledge. In actual fact Dervin's (1977) construct of information is that of a '*tool that is valuable and useful to people in their attempts to cope with their lives' (p18)*.

Along similar lines, focusing on the user and from a holistic perspective of information, Krikelas (1983, p7) defines information as *'any stimulus that affects one's certainty.*' This definition rests on the belief that the individual user, in an attempt to reduce their individual uncertainty, defines what information is by combining memories, individual impressions, observations and interpersonal communication. It is important to note the possibility within this definition that information can increase uncertainty as well as reduce it (Dervin and Nilan 1986). A concept concerned with reducing uncertainty ironically continues to be used in different ways with multiple and ambiguous meaning (Buckland 1991). Indeed, it is anticipated that the problem with definitions will be exacerbated as the term information is used even more widely as a central concept to physical and biological sciences, such as in health (Bawden 2006).

Study Definitions

It is the approach to studying information from the perspective of the individual that aligns itself to the primary focus of this study, the user of information, the patient diagnosed with CKD. For the purpose of this thesis it is not necessary to explicate the term *information* any further, or generate a new definition of the term, which given the variety of meanings postulated would not be feasible. Case (2002) indicates that the differences amongst academics with respect to defining information are too many to resolve and it is more useful to accept the idea of different concepts. A working definition needs to be exposed that will embrace the individual with CKD and allow information to be viewed from their perspective. One such broad definition by Brasher and colleagues provides a starting point, information being:

> *'...stimuli from a person's environment that contribute to his or her knowledge beliefs'* (Brashers et al. 2002, p259).

Another, posed by Case (2002) incorporates the external and internal processes/types of information identified separately by Hayes (1993) and Dervin (1992), stating that information is:

> '*…any difference you perceive, in your environment (external) or within yourself (internal), it is any aspect that you notice in the pattern of reality'* (Case 2002, p5).

Both these definitions provide a platform from which to study the user of information without imposing predetermined notions of what information is, but allowing the user the freedom to determine them. Krikelas's (1983) definition of a '*stimulus that affects one's certainty'* (p7) would also be fitting, given the uncertainty that patients find themselves in once presented with the diagnosis of CKD.

It becomes possible to comprehend the meaning of information if one accepts that it has different forms and meanings: a difference perceived either within a person's internal and/or external environment or situation, that influences their perception of reality (Case 2002), knowledge or beliefs (Hayes 1993, Brashers et al. 2002); a thing, stimulus, motivation, fact, experience, observation or event that affects their certainty (or uncertainty) (Buckland 1991, Krikelas 1983). The concepts central to this enquiry would be the purpose and relevance of information to the user in their real life. What information do CKD patients need?

Information Needs

Historically, within healthcare *information need* has been used as a primitive term resulting in little definition and understanding of how it behaves, what it is and what it is not. A policy report by the Consumers' Association (2003) that explored patient information suggests that information need is often treated as '*self evident or intuitive'* (p15) within the healthcare setting. This could almost certainly explain the lack of appropriate operational definitions available within health research regarding the information needs of patients (Scott and Thompson 2003, Browall et al. 2004, Rutten et al. 2005, Ransom et al. 2005, Ankem 2006).

It is not just within health where definitions have been elusive. In the field of Library and Information Science, where copious research has taken place on user information needs, there lacks common understanding of the term, although explanations demonstrate some shared elements (Shenton and Dixon 2004). Theorists from Information Science such as Wilson (1981, 1999), Dervin (1992, 1999) and Savolainen (1993, 1995) have much to offer health researchers towards generating an understanding of the characteristics of information needs emerging within health.

It is not within the confines of this thesis to determine a definitive meaning for the concept of information need, particularly given the multiplicity of meanings just for term information. The purpose is to explore the ideas and postulations of others and identify a working definition for the proposed study.

Basic Need

Again, to go back to the Oxford English Dictionary (2007), need is defined as: [1] a '*necessity, requirement,'* [2] or to have a need '*to require or be under a necessity to do something,'* [3] (*Psychol.*) '*a motivational state resulting from such a feeling, a* *drive.'* Green (1990) draws together four philosophies from social science to identify the perceived characteristics about the concept of need. The first two to some degree concur with the OED definition and wider consensus opinion; that needs are '*instrumental*' (action focused) referring to a '*means towards an end'* and that needs are related to the concept of necessity. The third proposes that needs are '*contestable*' thus differing from wants. The fourth challenges the psychological definition from OED and suggests that it is '*not necessarily a state of mind'* as a person may be unaware of their *'true*' needs (Green 1990, p65-67). Psychologists would argue that given that needs change as a result of the information encountered they are synonymous with an individual's current psychological state (Harter 1992).

These definitions refer to need with respect to basic (primary) or human needs such as health, food, shelter, safety, survival, communication. The World Health Organisation has since 1946 defined health as *'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'* (WHO 1946). Therefore health needs incorporate the wider social and environmental factors influencing health such as deprivation, housing, diet, education and employment. Need in healthcare (healthcare encompassing health education, disease prevention, diagnosis, treatment, rehabilitation, and terminal care) is commonly defined as *'those that can benefit from healthcare'* (Wright et al. 1998, p1310).

Human needs form the premise for the majority of information seeking literature with the need for information predominantly being perceived by information scientists as secondary to more primary basic needs (Wilson 1981, Case 2002, Spink and Cole 2006). In contrast, psychologists advocate that intrinsic to a basic need is the need to know, a fundamental right (Maslow 1987). At whatever level information is conceived to be positioned in the hierarchy of needs, it is clear that information needs are integral to the fundamental concepts of health and survival and wider concepts physical, psychological and social well being. To be able to understand health and how to survive illness, particularly a chronic illness such as CKD, a person needs to have information about it.

Given the range of definitions associated with the term information and lack of consensus opinion surrounding its meaning there is no surprise to find that when coupled with need, a further contentious concept, there continues to be a lack of clarity.

Definition of Information Need

Information needs arising from basic human needs could be considered to have cognitive, physiological and psychological/emotional qualities (Wilson 1981). Many authors agree fundamentally that information needs arise as a result of some '*dissatisfaction with their existing situation'* (Shenton and Dixon 2004, p297). One of the early perspectives of information needs was that they emerge as a result of '*a vague sort of dissatisfaction'* leading to seeking answers and forming questions (Taylor 1968, p76). This '*vague dissatisfaction'* was conceived differently by Belkin (2005), who described a deficiency in a person's knowledge to find a solution for a particular problem, as an '*anomalous state of knowledge'* (ASK) (p44). A further conceptual representation includes '*uncertainty*' as a cognitive motivator for seeking information, a perspective advocated by a number of different scholars (Krikelas 1983, Kuhlthau 1991, Nahl 2005). Krikelas (1983) elucidates that information need is defined and recognised by the individual as a state of uncertainty influenced by their real world environment. Dervin's (1992) ideas regarding information needs, although she does not use this term, overlap and build on those of Belkin and Taylor. She describes the motivation towards searching for information arising as a result of a '*gap*' in life's experience, also described as a '*gap*' in knowledge.

Timmins (2006) recently explored the concept of information need within the context of health literature and identified, in most articles that '*expressed in its simplest term* (an information need) *could be interpreted as what the client needs to know'* (p379). In the wider context it is perceived to represent a gap or knowledge deficit that could be rectified by information and/or education (Scott and Thompson 2003, Timmins 2006). The phrasing of *what the client needs to know* is ambiguous suggesting that they may not always be determined by the client/individual, but biased by professionals who consider it to be appropriate (Coulter et al. 1999, Leydon et al. 2000, Timmins 2006) which continues to be the case within some healthcare settings (Scott and Thompson 2003, Shenton and Dixon 2004). Timmins (2006) acknowledges this tension and highlights that the client’s own expressed needs are central to this particular definition.

Nursing has developed over the years based on, amongst many others, theories of adult learning (Knowles 1989) and self-care (Orem 2001), promoting the need to identify and understand the learning/education needs of individual patients. Nurses are compelled to provide information that improves patient knowledge and subsequently health outcomes. However, information provided in this fashion that has an educational aim often represents information needs identified by staff (Timmins 2006). Indeed, Hyland et al. (2006) suggest that if a clinician identifies that a patient’s knowledge compromises their self-management it indicates the patient has information needs, or could this be education need? Timmins (2006) differentiates between the concepts by highlighting that learning and education needs imply a knowledge deficit, objectively measured and resolved through education and learning. Consequently, in health, the definition of information need remains blurred with the synonymous use of concepts such as learning needs and education needs to explore what information individuals want (Scott and Thompson 2003). Although the confusion is understandable given the earlier definitions presented regarding the term information, perceived as an act of informing which occurs when education takes place and information can in itself be educational.

A perplexing definition is offered within a Consumers’ Association (2003) Policy Report that discusses patient information, they define information need (for the purpose of the report) as an ‘*individual’s capacity to benefit from information’ (p15).* It is derived from an earlier definition for healthcare needs the premise of which is the *‘capacity to benefit’* (Wright et al. 1998, p1310). To apply this same concept to define information needs is not only misleading it is highly inappropriate, given that much has been written to suggest that information can just as easily increase uncertainty as decrease it, and not necessarily be beneficial (Krikelas 1983, Dervin and Nilan 1986). To use the term being defined within its own definition continues to perpetuate a lack of clarity, not to mention the fact that it fails to take into account the multiple meanings associated with each concept. Although the authors progress and identify that information need can refer both to an individual’s need for knowledge and to the resources that might satisfy this need (information), the definition alone adds little to the debate.

Case (2002) after reviewing numerous scholarly perspectives and explicating the term *information need* proposes a more comprehensive yet practical working definition that:

> ‘*information need is a recognition that your knowledge is inadequate to satisfy a goal that you have’* (Case 2002, p5).

This definition adds the dimension of a purpose (Derr 1983) acknowledging that the knowledge deficit is recognised because of an underlying goal that cannot be reached without it (Wilson 1999, Case 2002, Wildemuth and Hughes 2005, Lambert and Loiselle 2007). Moreover this definition is pertinent and transferable across both information science and health disciplines.

Types of Need

Definitions of information need, particularly in information science, are based on the assumption that individuals are aware of their information needs (Case 2002, Wilson 2006). These have been conceived in two ways. Firstly through *‘expressed needs’* (Shenton and Dixon 2004, p299) or ‘*immediate needs’* (Krikelas 1983, p8) verbalised to another party and acted on by seeking information. Within health research patient information needs, identified by the type of questions posed to healthcare professionals, are considered to be expressed needs (Timmins 2006). Secondly, ‘*unexpressed need’* (Shenton and Dixon 2004, p299) or ‘*deferred needs’* (Krikelas 1983, p8) where the individual recognises them but chooses to ignore them thus insinuating that a trait of an information need is that it can be prioritised and some hold greater importance over others.

It is however, much more complex than these two simplified distinctions infer. A number of authors suggest another type of need, one that exists but which individuals are unaware of (Derr 1983, Green 1990, Dervin 1992). These are conceived as ‘*dormant*’, ‘*unrecognised*’ (Nicholas 2000, p22-23) or ‘*unconscious needs’* (Krikelas

1983, p8). They are thought to exist when an individual has an information deficit of which they are not aware and if not rectified may result in negative consequences. One example, suggests that some patients at risk of a disease without realising it may not be aware of their information needs (Consumers' Association 2003). Having a lack of information does not necessarily mean that you subsequently have a need for that information (Derr 1983). The tension, with the concept that unrecognised needs exist, lies in the fact that they must be judged and determined by someone other than the individual and based solely on external factors. Alternatively individuals sometimes coincidentally acquire useful information that they were not aware they needed whilst monitoring their world (Williamson 1998).

Needs, Wants or Desires

A further contentious issue that warrants discussion is the relationship between need, wants and desires. Green (1990) distinguishes between a need and a want by suggesting an individual's need could be judged and contested by others but if they indicate they want something it cannot be disputed. In many health studies the terms want and need with regard to information are used interchangeably (Leydon et al. 2000, Hepworth 2004, Timmins 2005), also in the Oxford English Dictionary (2007) definition.

Derr (1983) highlights differences between needs and wants, including the fact that information may be needed without being desired. There is overwhelming evidence in health studies suggesting that some patients, to be able to cope effectively, want an abridged description about their condition rather than comprehensive information (Luker et al. 1995, Degner et al. 1997a, Leydon et al. 2000, Rees and Bath 2001). This reinforces the need for healthcare professionals to recognise and respect someone's desire not to want information (Consumers' Association 2003). However, it is also possible that an individual might *want* some information for a purpose or to fulfil a need. It could also be argued that it is not necessary to differentiate between the two concepts because this is the language and terminology familiar to patients and to adopt the stance that the user defines what information they need and/or wants.

Information Topic

Although the focus of this thesis remains the information needs of CKD patients. It is important at this point to clarify an additional term that is an integral element of an information need. The term topic represents *aboutness* and users articulations of information need rely heavily on topic (Yoon and Nilan 1999). An information topic cannot fully explain the underlying information need of an individual but can indicate what is important, the focal point upon which two people can easily agree. From descriptions of an information topic it is possible to identify the content of an information need (Yoon and Nilan 1999). Studies that attempt to identify the information needs of patients frequently refer to pertinent information topics (Hepworth and Harrison 2004, Timmins 2005, Rutten et al. 2005).

Factors Influencing Information Needs

Goal/ Purpose of Information Needs

There is strong opinion that information needs emerge because of an underlying purpose, to meet a goal or activity (Derr 1983, Allen 1996, Wilson 1999, Case 2002, Watters and Duffy 2005, Lambert and Loiselle 2007). Wilson (2006) identified that one of the problems with studies of users of information is the failure to ask the user why they decided to seek information and what purpose it will serve.

Allen (1996) suggests that *'information needs happen to individuals embedded in a range of social situations'* (p88), thus a person's information need is situated in the context of some other purpose or task. He proposed a *person-in context* approach, to understanding information needs. A simple example in information science could be a person whose overarching *task* is to complete an assignment for which they have information need but could be seeking information regarding a specific topic within the domain of the assignment (*embedded task*). Within health this is a useful approach to adopt when attempting to understand the different motivations behind the stratified goals in which information needs arise.

Evidence suggests that information needs in health arise as a result of different underlying tasks or goals such as coping with a health-threatening situation, having to participate or be involved in making a medical decision, or the need for a behaviour change to prevent further problems (van der Molen 1999, Rees and Bath 2001, Timmins 2006, Lambert and Loiselle 2007). Like many chronic conditions an individual with CKD could be managing all three of these underlying goals simultaneously (Timmins 2006, Lambert and Loiselle 2007).

Goals/tasks appear to be hierarchical in nature with fundamental goals for patients such as survival and coping with illness broken down into manageable more focused goals, embedded tasks generating information needs to address specific issues, some more important than others. For example, cardiac patients have been observed to prioritise information that is pertinent to survival (task) such as symptom management, cardiac anatomy and physiology, medications and physical activity (embedded tasks) (Scott and Thompson 2003, Timmins 2005). In other studies, predominantly cancer, to develop an understanding of the illness (to facilitate coping and reduce uncertainty) specific information about the possibility of a cure, prognosis, spread of disease, treatment, side effects and medication were needed particularly when first diagnosed (Luker et al. 1995, Browall et al. 2004, Rutten et al. 2005, Mayer et al. 2007, Parker et al. 2007). Patients within both these different disease groups indicated that additional embedded tasks related to broader lifestyle goals such as exercising, diet control, or psychosocial issues were important but less of a priority (Scott and Thompson 2003, Browall et al. 2004, Beaver 2004, Timmins 2005). A long-term overarching goal identified by multiple sclerosis patients was for information that would enable them to live with their condition (Hepworth and Harrison 2004). At the diagnosis stage however, similar to other disease groups, managing drugs, the course of the disease and physical symptoms were more of a priority (Hepworth and Harrison 2004). Indeed the patient care pathway for many chronic conditions involves:

> *'the experience of a series of challenges each of which defines a new set of purposes and so information needs'* (Consumers' Association Report 2003, p23).

Seeking out information is a method commonly used to try and cope with stressful situations (Timmins 2006). One major factor that helps a person determine what information is needed to achieve a goal or task is previous knowledge and experience (Vakkari 1999).

A frequently cited study within health is that by Coulter et al. (1999) who derived a broad generic framework for patient information needs primarily in terms of the purposes for which information is used (Box 1).

Box 1: Framework for Patient Information Needs (Coulter et al. 1999, p319)

- Understand what is wrong
- Gain a realistic idea of prognosis
- Make the most of consultations
- Understand the processes and likely outcomes of possible tests and treatments
- Assist in self-care
- Learn about available services and sources of help
- Provide reassurance and help to cope
- Help others understand
- Legitimise seeking help and their concerns
- Learn how to prevent further illness
- Identify further information and self help groups
- Identify the ‘best’ healthcare providers

This framework is advocated by the Consumers’ Association (2003) to be used by both professionals and patients to address their needs.

> *‘If we know why people need the information, the question of what should be much more transparent’* (Consumers’ Association 2003, p18).

The framework simply identifies a number of embedded tasks for which information might be sought to achieve a specific goal, described by others as information intentions, both drivers and effects of cognitive information utilisation (Todd 2005). A recent theory posed within information science by Todd (2005, p199-200) describes five information intents, purposes of why information is needed: *to get a complete picture* (expand ideas and add specific detail), *changed picture* (change existing ideas), *clearer picture* (greater understanding and clarity), *verified picture* (verify existing ideas), *and get a position in a picture* (opinion or viewpoint). This theory is based on the assumption that information enables people to move forward making new pictures that represent new understanding, but this cannot be separated from the context of the individual's personal experience, existing knowledge and current stage in life. Although the framework by Coulter et al. (1999) appears useful, it provides little information as to whether tasks are: prioritised, temporal or continuous, related to a specific event, situation or context and relevant to specific individuals and/or groups of patients.

Overwhelming evidence suggests that the priority placed on goals and in turn information needs is directly dependent upon the context and situation in which an individual is located (Savolainen 1995, Allen 1996, Dervin 1999, Wilson 1999). Indeed, what a patient wants to know from the healthcare professional is information that will enable them to cope effectively with their current situation (Timmins 2005). CKD patients, striving to achieve possible overarching goals identified earlier, could also be experiencing a loss of control, coping with stress, psychological and emotional distress, and challenges for long-term changes in behaviour (Christensen and Ehlers 2002). It therefore becomes impossible to consider goals and information needs without understanding the context and situation in which they transpire.

Context

Given that *'information needs do not arise in a vacuum but rather owe their existence to some history, purpose and influence'* (Case 2002, p226) it is not surprising that the context and situation of the individual are key concepts for information behaviour research. As in healthcare where the individual is viewed holistically based on physical, psychological and social dimensions the recent drive to view the real world of the user of information has taken over information science. Part of this originates from the Sense-Making[1] work of Dervin (1992, 1997, 1999) who advocates that the

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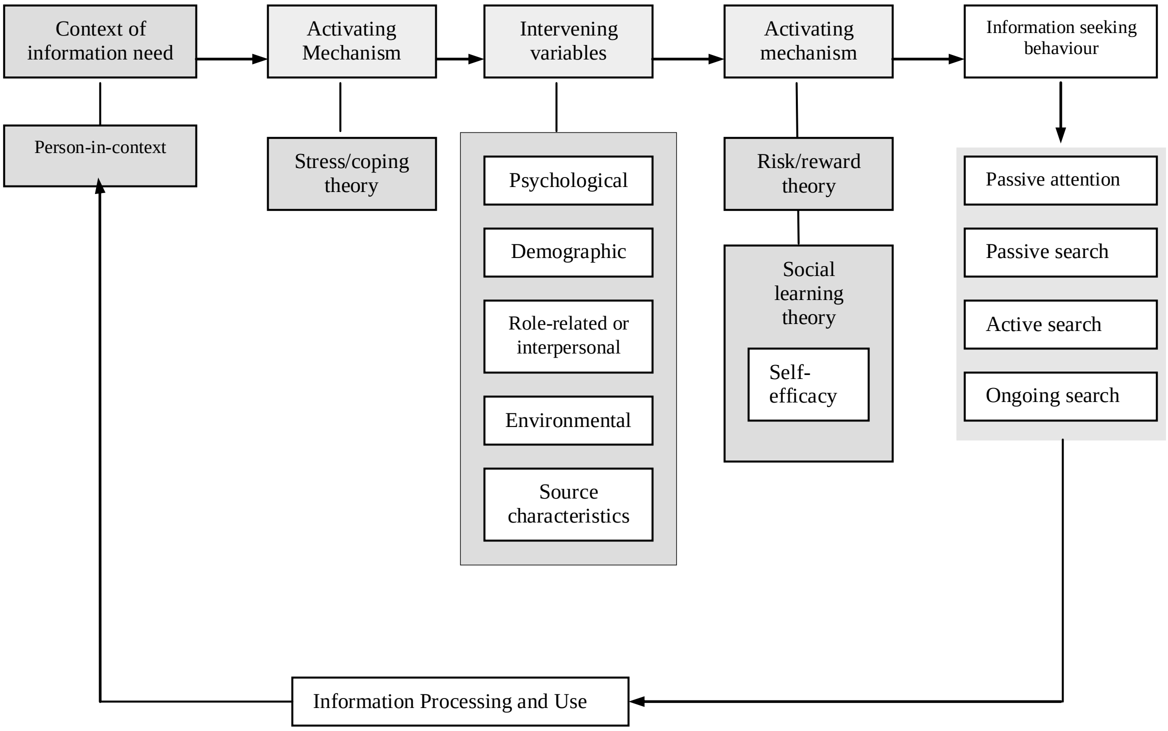
[1] *Sense-Making (capitalized) refers to the methodology; sense-making (not capitalized) refers to the phenomena of making and unmaking of sense (Sense-Making Methodology Site - ongoing).*

study of a person's reality and the 'gaps' in that reality for which people need information has to take place in context. Others reinforce the importance of context although the term takes on a variety of meanings (Savolainen 1995, Wilson 1999, Case 2002, Johnson 2003, Wikgren 2004, Ankem 2006, Zhang and Benjamin 2007). Studies of information user contexts and information needs have focused on a specific or combination of features, for example; occupation (Chatman 1991, Pettigrew 1999, Neidźweidzka 2003), roles (McKenzie 2002, Agosto and Hughes-Hassell 2006), demographics (such as age, gender, income, education) (Harrison et al. 1999, Leydon et al. 2000, Arora et al. 2002), disease group (Luker et al. 1995, Degner et al. 1997a, Christensen 2000, Caress et al. 2002, Hepworth and Harrison 2004, Timmins 2005, Burkell et al. 2006, Mayer et al. 2007,) psychological state (Miller 1987, 1995 Christensen 2000), self-efficacy (Savolainen 1993, Christensen 2000, Arora et al. 2002) and everyday life (Savolainen 1995, Spink and Cole 2001).

Without getting into an unnecessary debate over meanings, a broadened view of *person-in-context* is used to describe the components that come into play and to generate a deeper understanding of it (Baker and Pettigrew 1999). Within information science many models exist that portray the process of information seeking-behaviour (Case 2002), which is not the focus of this study. However, Wilson's 1996 Model (Wilson and Walsh 1996, Wilson 1999), which incorporates earlier research perspectives, provides one of the most comprehensive overviews of the contextual influencing factors of an information need (Neidźweidzka 2003) (Diagram 2).

For the purpose of this discussion the contextual influences have been organised from the key concepts drawn from the Wilson model: psychological, stress, self-efficacy, demographics, role-related and environmental. Although, Wilson (1999) separates the occurrence of need with what he terms 'activating mechanisms' and 'intervening variables', described as barriers to information seeking. He identifies that the barriers that impede the search of information will arise from the same context in which the information need occurs (Wilson 1999). It is from this perspective that these concepts have been used here to understand the influence such factors have on the generation of the information need in the first instance (Neidźweidzka 2003).

Diagram 2: Wilson's 1996 Model of Information Behaviour (Wilson 1999, p257)



Psychological

With respect to the generation of information needs a number of cognitive and affective psychological variables can interplay whilst trying to find sense in the world (Dervin 1997, Wilson 1999, Case 2002, Neidźweidzka 2003). For example an individual's existing knowledge, their outlook on life, stereotypes, prejudices, preferences, self-perception, emotions, interests, memories, intuitions, attitudes, feelings, experiences, motivations and personality influence how information needs are conceived and represented (Wilson 1981, Kuhlthau 1991, Dervin 1992, Solomon 1997, Case 2002, Hepworth 2004, Ankem 2006). Psychological states of anxiety, presence of depression, and feelings of control may affect information needs (Ankem 2006). An individual could experience cognitive uncertainty manifesting as anxiety (Kuhlthau 1991) resulting from their judgment of the knowledge required to overcome challenges or problems (Heinström 2003). In addition, they may experience affective uncertainty related to feelings of insecurity and pessimism (Wilson et al. 2002, Nahl 2005). A person who perceives that they have sufficient knowledge to overcome a problem or make a decision will not identify an information need (Wilson

1981). Personal characteristics influence the choice, hierarchy and strength of information needs (Neidźweidzka 2003).

Stress and Coping

Context can be perceived on a cognitive level. The more an individual's central life goals, for which they may require information to achieve, are threatened by illness, the more stress the individual experiences influencing their coping abilities (Youngkill and McCormick 2002). Two recent systematic reviews of patient information needs in healthcare settings (Rutten et al. 2005, Timmins 2006) identified that managing stress and coping were the underlying focus/goals of information needs within the majority of studies. There is particular reference to Lazerus and Folkman's work on stress and coping (Folkman and Lazerus 1980, Folkman et al. 1986). The premise of this work lies in the perception that an individual has a combined relationship with their environment. When faced with a stressful encounter an individual first appraises the situation with respect to what is at stake, what coping resources are required, and what options are available. The cognitive behaviour used to master, endure or reduce external and internal demands and conflicts is known as coping. This could be by way of two approaches, problem-focused coping by managing their relationship with their environment, or emotion-focused coping regulating stressful emotions (Folkman and Lazerus 1980). These fundamental ideas, that underpin the concept of coping, are closely associated with the sense-making process (Dervin 1992, Savolainen 1993). Making sense of what is happening, identifying and satisfying information needs plays an important part in helping patients cope with the demands of their illness (van der Molen 1999, Leake et al. 1999, Rees and Bath 2001, Christensen and Ehlers 2002, Rutten et al. 2005).

There is evidence that differences exist between people, those who find their situation challenging and are persistent and proactive in looking for answers (monitors) and others who do not (blunters) (Miller 1987, 1995, Baker and Pettigrew 1999, Nicholas 2000, Hepworth 2004). There are a variety of behavioural responses to stress and coping that influence how an individual perceives the depth of a gap in knowledge and the need for information (Savolainen 1993). Some may use avoidance if they have information overload or the '*gap seems too big'* (Godbold 2006, p6) resulting in too many information needs and questions to possibly satisfy in the time available.

Having too much information can be perceived to increase their fear of uncertainty and anxiety (Case 2002). They may not understand the problem sufficiently to be able to articulate or recognise their information needs, or it may not be personally relevant (Case et al. 2005, Longo 2005). Coping with this can manifest in the form of *blunting* or avoidance (Miller 1987, 1995) or fatalism (Chatman 1991).

Closely linked to coping styles is personality (Folkman and Lazerus 1980). An information need that appears insurmountable to a pessimist might be no obstacle to an optimist (Savolainen 1993). In a recent study by Kidachi et al. (2007) four personality types of CKD patients receiving haemodialysis treatment were identified, agreeable, submissive, sensitive and balanced. Personality characteristics influence how individuals identify, prioritise and satisfy information needs (Nicholas 2000, Heinström 2003). Among CKD patients a high degree of agreeableness has been associated with reduced depressive symptoms (Hoth et al. 2007) suggesting better coping styles. Reduced survival rates have been associated with less positive health practices, such as non-adherence to treatment, of high neuroticism personality traits (Christensen et al. 2002). However, personality traits may vary in visibility depending upon the situation, a major life event, age, or as a result of a physical factor such as tiredness, which could influence uncharacteristic behaviour and in turn motivation (Heinstörm 2003). Self-motivation can be seen to increase when an information need is personal, identified internally rather than imposed externally (Julien and Michels 2004).

Self-efficacy, Beliefs and Control

Similar interrelated concepts to consider alongside motivation and personality are self-efficacy and locus of control with respect to information behaviour, the recognition and generation of information needs (Savolainen 1995, Wilson 1999). Self-efficacy beliefs determine how people think, motivate themselves and behave (Bandura 1994, 2004, Eccles and Wigfield 2002). Perceived self-efficacy is defined as an individual's self-belief in their own capabilities to be able to influence events that affect their lives (Bandura 1994). Individuals with strong self-efficacy set higher goals and demonstrate a greater commitment and motivation to achieve them. Particularly for CKD patients a feeling of self-efficacy enhances self-management skills (Thomas-Hawkins and Zazworsky 2005). Individuals who believe they have the coping skills to control threats or challenges are less vulnerable to anxiety, stress and depression (Bandura 1994). Newly diagnosed patients identifying a need for information who experienced barriers accessing health information were found to have less confidence to deal with health-related issues (Arora et al. 2002). Wilson's model of information behaviour adopts self-efficacy as part of the activating mechanisms to explain why some information needs are not pursued. Similarly a lack of self-belief could in turn inhibit the recognition of an information need, as could a feeling of lack of control over the disease, their treatment and decisions.

A further comparable theory, Sense of Coherence (Antonovsky 1993, 1996) is the ability to create meaning or sense of stressors in the presence of illness. When faced with a stressor an individual with a strong sense of coherence will be motivated to cope, believe that they understand the challenge ahead and have the available resources to cope (Antonovsky 1996, Youngkill and McCormick 2002). Savolainen (1995) suggests that for a person to have mastery of life skills (an ability to keep things in order), they must have a sense of coherence. There is also a need to consider an individual's health beliefs, their perceived severity and susceptibility to a health outcome and its consequences are closely associated with the motivation to act (Goldring et al. 2002, Bankhead et al. 2003, Cvengros et al. 2005). A patient's apprehension about their condition, particularly terminally ill patients, can generate a conflict between wanting to know and fearing bad news which impacts upon the level of information they feel they need (Parker et al. 2007).

Types of information needs identified and characterised by an individual with a strong self-efficacy, locus of control and sense of coherence will inevitably be very different from someone experiencing less confidence, lack of control and threatened by the severity of and susceptibility to illness. CKD patients with an active style of coping who perceive a loss of control over their provider led dialysis attempt to regain control through negative behaviour and non-adherence to diet and fluid restrictions (Christensen 2000), as a result possibly resisting and ignoring emerging information needs or considering them less of a priority.

Demographic

Demographic variables such as age, gender, social and economic status, level of education, ethnicity, health status, diagnosis and stage of disease determine information needs (Luker et al. 1995, Degner et al. 1997a, Wilson 1999, Case 2002, Longo 2005, Rutten et al. 2005, Ankem 2006, Parker et al. 2007, Mayer et al. 2007). Most research looks at demographic variables and discusses differences in demographics with regard to the need for, and seeking information.

Younger patients have been shown to need more information than older patients, maybe a result of different coping styles or life expectancy (Ankem 2006, Parker et al. 2007). Older patients rely more on information from the doctor whereas younger patients access a wider range of information sources to satisfy their information needs (Rutten et al. 2005). The non-participatory role adopted by men and older patients in the management of their illness was seen to be a factor in their reduced need for information (Leydon et al. 2000). Women were found to seek more information than men (Rutten et al. 2005), in particular females with higher incomes required more information (Mayer et al. 2007). Income and education were shown to be positively associated (Mayer et al. 2007) and higher education levels correlated with the need for high levels of information (Rutten et al. 2005). In contrast other studies suggest that gender, education level, time since diagnosis and their stage of illness, particularly for cancer patients may not be related to information needs (Browall et al. 2004, Ankem 2006). Studying the everyday information behaviour of teenagers highlighted similarities in information needs across socio-economic, ethnic, cultural and geographic boundaries (Agosto and Hughes-Hassell 2006).

Although there are comparable findings, there remains a lack of consensus across studies as to whether particular characteristics with respect to information need, can be consistently associated with a specific demographic group. Talja (1997) laments that making sweeping statements regarding the information needs of individuals or groups is problematic in that it fails to consider the individual’s roles, tasks and identities in society. Case (2002), although partially in agreement, draws attention to the value gained from the generalisations about individuals and groups, emphasizing the importance of also considering the context in which the individuals are situated.

Role-related

Information needs are personal, idiosyncratic and shaped by personal circumstances and values (Case 2002). Hepworth (2004, p696) groups concepts such as role, social norms and tasks as '*environmental data'*. Wilson (1999) in his model separates role-related factors from environmental but they are implicitly linked.

Individuals can play many social roles within the family, in society, related to their occupation and as a patient. Certain roles indicate specific information needs (Neidźweidzka 2003). Lecturers determine to some degree the information needs of their students (Nicholas 2000). The needs of a medical doctor differ from those of a nurse, and in turn a patient. Indeed the needs of individuals within the same groups are dependent upon changes in the environment (Neidźweidzka 2003). Work-related or occupational roles, the type of work, the social norms guiding the work, values regulations and limitations, an individual's position, level of responsibility, experience and knowledge will shape and stimulate different information needs (Chatman 1991, Savolainen 1995, Pettigrew 1999, Neidźweidzka 2003, Leckie 2005).

Environmental

Contextual factors such as culture, social norms and values, politics, economics and technology may influence by either hindering or stimulating an individual's information needs (Savolainen 1995, Dervin 1997, Neidźweidzka 2003). These contextual factors not only influence the occurrence and determine the kind of need but also affect the perception of information barriers, and the ways in which needs are satisfied (Wilson 1981, Case 2002, Neidźweidzka 2003). Chatman (1991) identified this in her study of female janitors who she described as existing in a small world sharing a common cultural, social and occupational perspective. Social networks influence the way in which information is perceived and used (McCreadie and Rice 1999).

Context can be construed as the information environment in which a person exists (Cool and Spink 2002). Johnson et al. (2006) describe this as *information fields* in which people are embedded that determine their level of awareness and knowledge of particular issues. An information field consists of interpersonal contacts, networks of friends and/or family, communication channels such as newspapers, television and the

Internet, that influence the nature of the information to which an individual is exposed. Those individuals who are diagnosed with an illness are more likely to shape their information field to include health-related information sources to obtain information to meet information needs and answer concerns (Johnson et al. 2001, Johnson 2003, Johnson et al. 2006).

Within healthcare, to gather a complete understanding of the context in which information needs originate, it is important to consider variables such as the healthcare structure, delivery of care and information environment (Longo 2005). In any setting the local core values, norms, constraints and opportunities need to be considered (Savolainen 2006a, Zhang and Benjamin 2007) to understand how information needs are formed and influenced by such contextual factors (Attfield et al. 2006).

Relevance and Salience

The salience or personal significance of specific information to an individual is determined by their risk/reward assessment as to whether it is beneficial or harmful to know (Johnson et al. 2001). This is particularly important for a patient diagnosed with a chronic disease who may decide that understanding the disease is paramount or secondary to financial stability or sustaining employment. The relevance of certain information, a basic notion in information science (Saracevic 2007), is usually interlinked with its salience. Johnson and colleagues (Johnson et al. 2001) suggest that demographics, experience, salience and beliefs are key concepts within information seeking. The timing and situation in which a patient is located, their personality, psychological state, alongside the stage of the disease will all contribute to the decisions of information need significance. Some information needs will be more relevant and salient at different stages in the sense-making process (Ford 2004).

Situation

A term closely related to context is situation, usually used with a narrower meaning (Case 2002), defined as a particular set of circumstances in which people find themselves that creates an awareness of an information need (McCreadie and Rice 1999, Julien and Michels 2004, Ankem 2006).

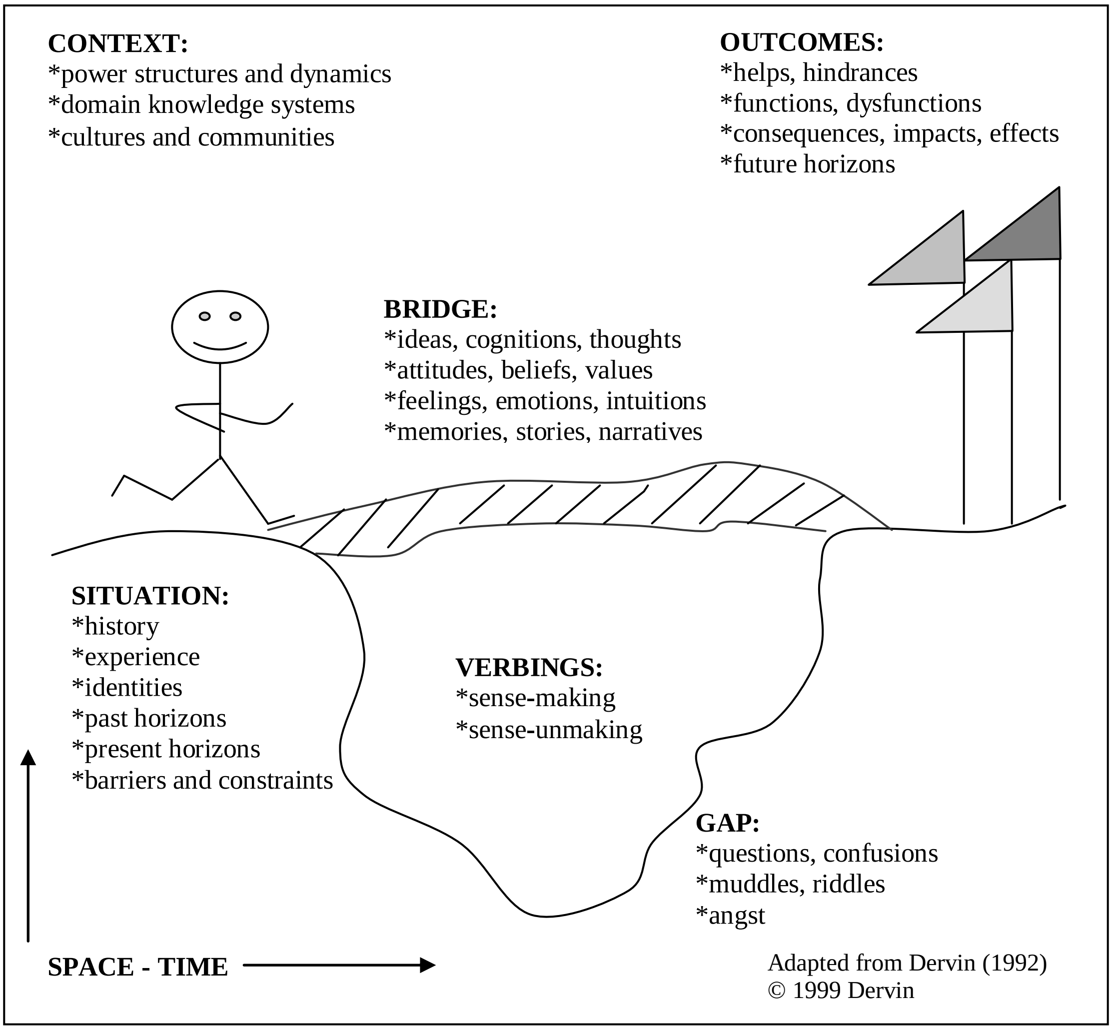
To understand where situation fits within context it is important to look at the pioneering Sense-Making work of Dervin, who was influential in shifting the focus of research in information science from documents and sources to consider the situation and context of the user (Dervin 1977, 1992, 1997, 1998, 1999, 2005). The *person-in-context* in Wilson's model (1999) is based on Dervin's work. Sense-Making is based on a metaphorical framework:

> *'of human beings travelling through time-space, coming out of situations with history and partial instruction, arriving at new situations, facing gaps, building bridges across those gaps, evaluating outcomes and moving on'* (Dervin 1998, p39).

Information is communicated and interpreted alongside opinions, intuitions, questions, evaluations and effective responses to make sense of discontinuities, knowledge gaps and solve problems arising in the real world. It has often been referred to as a methodology and/or meta-theory and was developed as both a philosophical and practical project with the ultimate aim of finding out what users '*really think, feel, want and dream'* (Dervin 1998, p39). The foundation being the intrinsic connection between how an individual views a situation or experience and what sense they construct from it (Dervin 1992) (Diagram 3).

Within this metaphorical framework the term situation refers to the time-space context in which the sense is constructed, the gap comprises of the barriers to movement, questions posed and information needs identified (Savolainen 1993). Situations could be an event, critical incident, encounter, experience or activity that occurs at a moment in time located within the wider environmental and personal context of the individual. Information is interpreted with respect to the past, present and future, drawing on previous experiences of situations and existing knowledge, comparing this with the current situation and the goals for the future (Dervin 1999). An individual could be an expert in some situations (work related) but a novice at others (health problems) (McCreadie and Rice 1999).

Diagram 3: Dervin's (1992) Sense-Making Metaphorical Framework



Within health, studies identify that situations arise as a reaction to a stimulus such as life changes, perceived threats or life-threatening and incapacitating illness (Timmins 2006), and/or stress and anxiety (van der Molen 1999, Rees and Bath 2001). Limiting the definition to situations of threats is too rigid as this could be one of several reasons/situations where individuals seek information (Lambert and Loiselle 2007). Indeed a situation could be as simple as a clinic appointment (Attfield et al. 2006) or a specific event, such as decision-making, planning and obtaining instructions (Julien and Michels 2004). In response to changing situations information needs and preferences for information inevitably change (Harrison et al. 1999, Attfield et al. 2006). An individual's information behaviour across different situations could be influenced by factors such as the nature of the activity (work related or personal life), time, motivation, location and the purpose for which the information is required (Julien and Michels 2004).

Time

Time and *'temporal issues are inexplicably linked with the questions of how to define the concepts of situation and context'* (Savolainen 2006b, p113). Dervin (1992) stresses that situations occur in context at a specific moment in time and space.

Along the disease continuum, particularly for patients with a chronic condition it is no surprise that their information needs change over time related to a series of challenges, critical and/or social events (Attfield et al. 2006). The complexity of the concept of time and the importance of temporal characteristics is demonstrated through the myriad information needs associated with a patient consultation that change over a short time period (Table 9) (Attfield et al. 2006).

Time issues are inherent, it is possible that some information needs will be satisfied during the consultation others will remain ongoing. In reality, individuals have *'more than one gap at a time'* and *'ongoing gaps'* (Godbold 2006, p12). Information needs, can be deferred, like goals placed on one side whilst a person focuses on other issues. One gap might lead to the discovery of other gaps, which need navigating first or ignoring till a later date (Case 2002). This is observed in patient studies where their preferences and priorities highlight which gap they consider relevant to their current situation, at that point in time (Beaver 2004, Timmins 2005) influenced by both personal and environmental factors. Julien and Michels (2004, p552) identified, by observing one individual, that their information needs were influenced by time pressures and coded *'crisis'* - needed today, *'short term'* - within a few days, *'long-term'* - within a few weeks, *'undetermined'* - no set time. Lack of time often prevents individuals meeting their information needs even when they are highly motivated to do so (Nicholas 2000).

Table 9: Patient Information Needs Surrounding a Consultation (Attfield et al. 2006, p167-177)

Point in Time	**Information Need**
Prior to consultation	• Assessing whether need a consultation • To gather a basic understanding to reduce the amount of explaining a practitioner may have to do during a consultation
During a consultation	• Find an explanation for the symptoms they were experiencing • Identifying specialists who could provide the best treatment • Understanding their condition or potential condition • Understanding their treatment options and how these might relate to their own specific circumstances • Clearer understanding of what symptoms they are experiencing in relation to providing effective information to the practitioner to be able to make and effective diagnosis • Desire to identify the best solution for their particular circumstances, unconstrained by perceived limitations in knowledge, judgement and priorities of the practitioner
After a consultation	• To ratify a diagnosis • Ensure the proposed treatment was appropriate • To know more about how to manage their treatment

Patients across studies have been shown to fluctuate between the desire for more and the avoidance of information at different times during their illness (Leydon et al. 2000, Rees and Bath 2001). For some patients, when first being diagnosed with an illness, too much information can be distressing and hard to comprehend whilst other patients prefer limiting the amount of information to match their personal coping style (Leydon et al. 2000, Parker et al. 2007). The amount of information patients need is seen by some to be constant throughout the disease trajectory rather than decreasing as the familiarity with and knowledge of the disease increases over time, different needs continually emerge (Ankem 2006). Others note that less information is needed as the disease progresses (Parker et al. 2007).

Evidence does suggest that patients, both within and across different disease groups, have similar types of information needs corresponding to a point in time/event along the disease trajectory (Echlin and Rees 2002, Hepworth and Harrison 2004, Parker et al. 2007). Diagnosis specific information needs are different to those emerging over the long-term (Beaver 2004, Timmins 2005). However, Harrison et al. (1999) found little or no change over time in the type of information needs identified by women with breast cancer over a first course of radiation therapy. Reasons for this could have been that the short observation period (4 weeks follow up) was not sufficient to detect change or that information needs were not being adequately addressed and thus remaining a priority.

Without disregarding personal and environmental factors that clearly influence an individual's information need it would at the same time appear possible to tease out common information needs. Evidence suggests this is achievable at particular points in time or within expected situations (such as at diagnosis, consultation) or simply because commonalities exist within groups of patients following similar disease pathways. The value of such information enables the professional, particularly in healthcare where time is limited to improve identification and target resources to meet the information needs of patients.

Satisfied Information Needs

Giving patients what they want to know, increasing their knowledge and meeting their information needs has been shown to: improve functional adjustment (Ankem 2006) reduce stress and facilitate coping (Rutten et al. 2005, Timmins 2006, Ankem 2006, Lambert and Loiselle 2007); improve well-being and personal control (Hepworth and Harrision 2004, Lambert and Loiselle 2007); create more knowledgeable and competent patients (Larson et al. 1996, Lambert and Loiselle 2007); increased self-management, self-care and compliance with treatment (Larson et al. 1996, McIver 1998, Harrison et al. 1999, Lambert and Loiselle 2007); and reduce dependency on health services (Hepworth and Harrision 2004).

When information provision matches the information needs of patients the outcomes are generally reported positively. However, for some, negative outcomes are experienced revealing feelings of being overwhelmed and increased anxiety (Lambert and Loiselle 2007) because the information increased uncertainty. For those unable to satisfy information needs feelings of dissatisfaction, increased stress and difficulty coping have been reported (Timmins 2006).

Information Provision and Source Characteristics

An inherent problem in healthcare is that professionals often take on the role of being *'needs determinants'* (Shenton and Dixon 2004, p299) giving greater importance to a particular information deficit (associated to treatment, symptoms, medication) without taking on board the individual's own priorities or need for information (Case et al. 2005, Timmins 2006). An individual needs to recognise their ignorant and missing information for a need to arise (Case et al. 2005). Although some prefer to be ignorant, particularly in health matters (Rees and Bath 2000), ignorance may occur because the information is not considered to be personally relevant (Case et al. 2005, Haider and Bawden 2007). The paternalistic role professionals adopt towards patients occasionally is: to underestimate a patient's desire for and ability to cope with information; to filter what and how much to tell a patient; and to decide which treatment is best without offering all the choices (Coulter et al. 1999, Leydon et al. 2000).

Despite the shortcomings of healthcare professionals people have a strong preference for information that comes from other people (Johnson 1997). Doctors are typically cited as the most frequently used health professional for information (Scott and Thompson 2003, Rutten et al. 2005, Browall et al. 2004). The qualities patients look for in information providers are knowledge, trust, empathy, honesty and balanced compassion with hope; someone who allows questions and monitors understanding (Parker et al. 2007). Evidence indicates that a considerable amount of information provision coincides with a stressful event where recall and retention of information for the patient is limited (Beaver 2004); or that opportunities are taken during a clinic consultation where time is limited to offer full explanations (Coulter et al. 1999).

Without empirical knowledge of what and when patients want information patient education and information will continue to be given in an unsystematic manner (Harrison et al. 1999). Ideally information should be provided as and when it is needed over the entire disease trajectory (Beaver 2004).

Patients often reinforce, supplement or even substitute information provided face-to-face by healthcare professionals by accessing additional information sources, such as written information, newsletters, magazines, the Internet, books and peers in similar situations (Hepworth and Harrison 2004, Timmins 2006, Mayer et al. 2007). Health professionals have historically influenced the content of patient information materials focusing on technical/clinical treatment effectiveness with little consideration of what information is needed by the patient to cope with the realities of everyday life (Coulter et al. 1999, Consumers' Association 2003). Usually these require a trained professional to guide and explain the meaning of the material to some degree (Timmins 2006). Patients require information that is digestible, in a language that is understandable and repeated on different occasions as necessary (Leydon et al. 2000, Parker et al. 2007).

The Internet is growing in popularity as a source of information (Skeleton 2001, Mayer et al. 2007). A recent survey of health information consumers identified that 90% would prefer healthcare providers to recommend appropriate Internet sites (Health On the Net Foundation 2005) where information is reliable and balanced (Beaver 2004). To make sense of information that is available patients need to be equipped with appropriate critical appraisal skills (Consumers' Association 2003).

Gradually the shift in information provision is moving to include increased patient involvement. It is recognised that patients cannot express informed preferences about their care, or whether and how they want to participate in care decisions, unless they are given appropriate and sufficient information (Coulter et al. 1999, Sowden et al. 2001). In turn to effectively provide such information healthcare professionals need to understand what information is important to patients, why and at what point in time.

Conclusion

Chapter Three has identified that the term information has multiple meanings and forms and the available literature provides no definitive answer. Drawing on work performed in information science, it exposes three perspectives that represent information in such a way that provides greater clarity. The objective stance portrays information as external to the user represented in the form of data, a fact or a thing, the subjective as internal information representing the person's own picture of reality. The sense-making information standpoint combines internal and external perceptions of information and the behaviours of making sense. All three perspectives to some degree at varying times/situations would appear plausible within the healthcare environment. Although the construct of information proposed by Dervin (1977), that it is a '*tool that is valuable and useful to people in their attempts to cope with their lives'* (p18), epitomizes the role information plays within a patient-centred health service. Is there then a need, or is it ever possible, to define such a polymorphic concept? For the purpose of this study it is sufficient to understand the relevant semantics and continue to observe how they operate within the healthcare arena.

More significant, is the definition of the term information need. Within health this term has been over used and apportioned ambiguous meanings with little or no definition. In many studies it is taken in its rudimentary form to mean what the patient needs to know and by others to encompass learning and education needs. A practical working definition derived within information science but transferable to healthcare was that '*information need is a recognition that your knowledge is inadequate to satisfy a goal that you have'* (Case 2002, p5). This would be a good place to start for health researchers to define what information needs mean for patients. This definition encompasses the notion of gaps in knowledge, recognised by the individual (patient) not an external source (such as a healthcare professional) and related to their own personal goals.

The overview of current research demonstrates that the context of an individual, situation and time play a major role in the type of information needs, how they are internally perceived and externally represented. This wider view of a *person-in-context* in information science is not new to healthcare but integral to every component of patient care, particularly nursing. The study of patient information needs has predominantly taken place within cancer. Professionals in other disease areas have been slow to respond and much work remains. Evidence suggests there are similarities between patients experiencing other chronic or life-threatening conditions, particularly surrounding specific events such as diagnosis. Evidence is less conclusive regarding differences in patient information needs over time, whether they remain the same, change or are reduced as a patient becomes more familiar with their medical condition. Although there is a strong emphasis that information needs can only be fully understood on an individual level the value of discovering common or similar needs within a group of individuals allows a healthcare professional to target or narrow the focus of information provision.

Godbold (2006) suggests that future research is needed with respect to the gap itself, what gaps exist and how people navigate that gap. Within information science the focus has been predominantly on information seeking processes and the gap or information need is usually implicitly or only partially explored. From this chapter there are key elements of information need that can be gleaned and taken forward within this study (Box 2).

Box 2: Information Need Key Research Elements

- The term information is both polymorphic and polysemantic and as a result there lacks consensus agreement regarding its definition
- An '*information need is a recognition that your knowledge is inadequate to satisfy a goal that you have'* (Case 2002, p5), encompassing the notion of gaps in knowledge recognised by the individual related to their own personal goals
- The context in which a person is located influences on three different levels the type of information need that emerges and how it is perceived:
  - Personal characteristics such as psychological, stress/coping style, personality, self-efficacy and demographic differences
  - Role-related characteristics such as role in the family, at work, in the local community and wider society
  - Environmental characteristics such as cultural and social norms, values,

information fields, healthcare structure and information environment and delivery of care

- Situation is a particular set of circumstances in which individuals find themselves that creates an awareness of an information need, this could range from a life-threatening or chronic illness, perceived health threat, stress or anxiety, an event (diagnosis or clinic consultation) to an experience or encounter
- Time is integral to the study of information needs as situations and the context of the individual are all represented at a moment in time and continually change in response to changing circumstances
- Overwhelming evidence reinforces the benefits of identifying and satisfying the information needs of patients and directly contributes towards achieving the goal of NHS policy in developing informed and self-managing patients (DH 2004b)
- Provision of information to patients could be improved through increased patient involvement in identifying their priorities of what, when and how information is preferred
- There is a need for more empirical evidence within the health arena and to learn from other disciplines such as information science where the majority of work regarding information needs originates

To take this forward chapter four focuses on research performed in CKD to evaluate the rigour of the work so far and isolate the gaps and information topics that patients identify as important. Chapter five examines the different methods used across disciplines to identify and measure information need.

Chapter Four

CKD Patients' Information Need - Review of Current Evidence

Introduction

In the previous chapter evidence suggests a lack of consensus regarding a definition of information need, both within the disciplines of information science and health. Much of the work performed in health to explore the information needs of patients has focused on cancer patients. This chapter presents the findings of a systematic review pinpointing studies where the information needs of CKD patients have been exposed.

The purpose of the literature review was threefold:

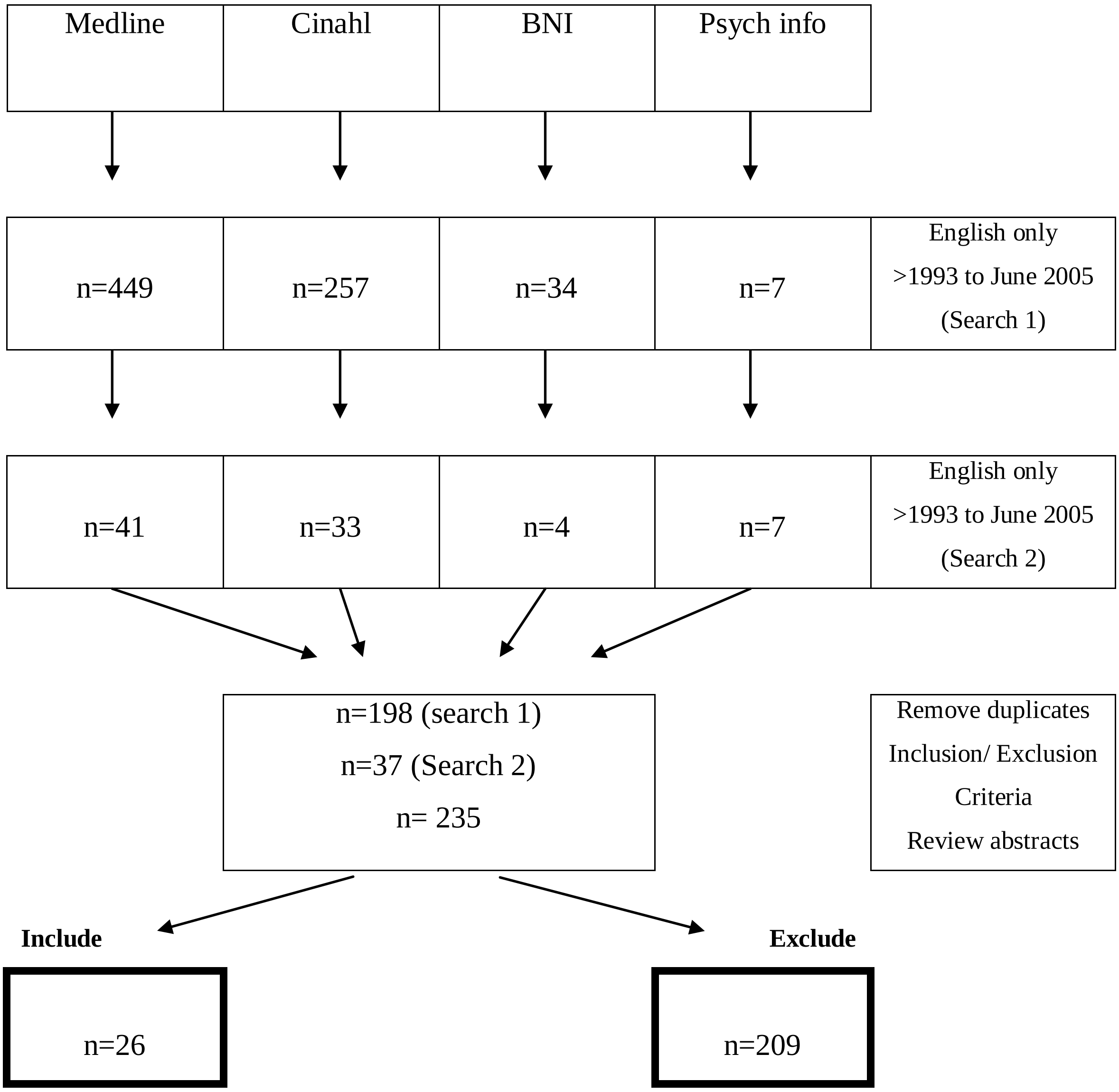
1. To identify and describe information topic areas that are important to CKD patients
2. To examine whether CKD patients have priorities and preferences for information topics
3. To determine the factors that influence the information needs of CKD patients

To achieve the aims of the review a comprehensive search of current literature was undertaken. The search strategy employed is described alongside the critical appraisal methods adopted to determine the quality and relevance of included studies. The findings provide an overview of the information topics pertinent to CKD patients but reveal a lack of pragmatic evidence determining patients' priorities for information. Factors that influence the depiction of information needs for CKD patients draw parallels with those observed within other patient groups and reinforce the importance of key theoretical concepts highlighted earlier.

Search Strategy

The review combined two search strategies and was completed in June 2005. The two strategies were similar in that they contained the same search terms (appropriate to individual database key search terms) (Appendix 1) but different in application and use of Boolean operators. Search (1) consecutively combined all the possible terms with respect to three topic areas: patient education and knowledge; information needs; and CKD. In contrast, search (2) separated the three topic areas and combined all three together at the end of the search. Search (1) was the most productive method but search (2) did identify 37 additional papers and as such it was prudent to include both approaches. Each search was limited by date (1993 - June 2005) and language (English only), the early 1990s signifying the time at which renal services were re-organised and the growth and availability of RRT (Diagram 4).

Diagram 4: Combined Searches 1 and 2



The combined search of four databases via Ovid host (Cinahl, Medline, BNI, and PsycoInfo) retrieved 832 articles, health databases were selected to target patients with CKD. From these the review of abstracts, in the first instance, highlighted 235 of interest. On closer scrutiny using an iterative two-staged approach and structured inclusion/exclusion criteria (Appendix 2), 209 articles were excluded. A number of which (71) described the method and content of patient education programs, many derived from the professional's perception rather than that of the patient. Only 26 articles directly reported the information needs/topic areas important to CKD patients from the patient's perspective, and these were included in the review.

Updated Search

The original literature search performed in June 2005 identified information topics that informed the development of the study instrument described in subsequent chapters. It was necessary, however, to update the search to ensure the wider literature review discussion presented in this chapter was based on current evidence.

The combined search strategy approach was rerun from June 2005 – February 2008. The search yielded 156 unique references after adjusting for duplicate items across the four databases. The titles and abstracts of all 156 references were screened using the same inclusion/exclusion criteria. One article was identified as relevant and the full paper retrieved.

The article retrieved, by Fine et al. (2007), was a short report of a replica study to one already in the original review by the same authors (Fine et al. 2005). The difference in the later study was the sample, patients recruited at a later stage of CKD prior to RRT. The methodology was identical and had been critically appraised. Indeed the authors provide limited detail in this short report but make reference throughout to the earlier article. Consequently it was decided that the initial review would be sufficient to highlight the information topics pertinent to CKD patients and this particular paper would add little to the overall findings and discussion. As such the remainder of this chapter presents the findings of the review from the original search.

Results

Overview

A total of 26 papers, published between 1993 and June 2005 were identified and critically appraised, 23 of which were research papers. One study is described in two parts across two papers, one focusing on the methodology the other the findings. Both papers have been combined and reviewed as one study (Schatell et al. 2003a, 2003b). For one paper the research strategy was unclear, the others used a predominantly qualitative approach (13), and/or both qualitative and quantitative methods (9). Eleven were exploratory studies; three used grounded theory; and one was descriptive in nature. Seven studies used patient satisfaction and survey designs and one measured an educational intervention. Of the three papers that were not research studies, one was a literature review and two personal accounts from individual patients describing their experience of CKD. Twelve studies were carried out in the United States; seven United Kingdom; four Canada; two Sweden and the literature review authors originated from Finland. Eight papers report the time taken to perform the study, four took between two and four months and the remainder were greater than 12 months in duration, the maximum being 2 years.

Study Aims

Studies combined various aims to investigate a particular research question. Across the 26 studies aims overlapped and seven central themes could be drawn out which captured their focus. There was a clear aim to elicit the patients’ perceptions of managing and experiencing end-stage renal disease (ESRD) and RRT in the majority of studies (23). Thirteen studies explored the information CKD patients require; six focus on dialysis patients, identifying gaps in knowledge and information seeking behaviour; the remaining seven examined pre-dialysis patient experiences, their information needs and satisfaction with education and information provision. Eight studies investigated decision-making, seven of which were interested in how CKD patients choose a particular RRT, the other explored the end of life decisions taken by elderly dialysis patients. Five papers (two personal accounts from patients themselves) reported the effect dialysis has on patients; the psychological impact, their quality of life and the strategies patients adopt to survive long-term.

Information Needs, Topics, Preferences

With respect to the topic area of CKD patient information needs, 21 studies directly or indirectly reported information topics/needs from the perspective of the CKD patient. Six out of the 21 studies also highlighted the health care professional perspective of the type of information patients need. In addition studies identified factors that impact on the information needs of patients (23), describe patient concerns that potentially could influence a patient’s need for different types of information (17), and report patient preferences for information (14). Six involved the evaluation of an educational intervention, predominantly pre-dialysis education programmes.

Patient Modality

All 26 studies involve patients with CKD these included transplanted, haemodialysis (HD) and peritoneal dialysis (PD) patients, and pre-dialysis patients who had not yet commenced RRT. HD patients were the most prevalent group recruited in all but five of the studies, closely followed by PD patients. However 62% of studies (16) targeted more than one patient modality group although in different combinations. Six of these combined studies also included the perspective of the health care professionals and/or the family members of CKD patients.

Sample and Sampling Method

The number of patients recruited within the 23 research studies varied from six (Wilkinson 1998) to 197 (Orsino et al. 2003). Fifteen studies recruited a sample of less than 50 patients (range 6-43), and eight more than 50 (range 56-197). Twelve studies chose to recruit patients from more than one centre or study site, eleven were concerned with patients from a single site.

On the whole reporting of sample selection and recruitment was mixed within the 23 research studies. Nine studies performed random sampling selecting patients from a pre-determined list. Three adopted an opportunistic sampling approach to study patients available on a certain dialysis day or within a specific clinic, and one a consecutive sampling approach of patients referred to a service. Others used self-selection by patients (2) or targeted the whole sample population (4). Non-random sampling was used by five studies, four of which used a theoretical approach whilst the other uses a purposive approach to target patients who would provide alternative perspectives. For two studies the sample selection method was unclear and required further clarification (Breckenridge 1997, Klang et al. 1999).

Ethical Approval

Eleven studies report having obtained ethical approval for their study from a recognised authority (University, Hospital or Local Research Ethics Committee), for eleven it was unclear whether ethical approval was obtained and four studies did not require formal approval. The process of obtaining informed consent from participants prior to recruiting them into the research study was described in fifteen studies, but in six it was not discussed. Consent was presumed on return of posted questionnaires in two studies and for the remaining three it was not applicable.

Data Collection

The most popular fieldwork method was face-to-face interviews. Nine studies used a semi-structured approach and four used structured instruments to direct the interview discussion. Two studies performed telephone interviews and one used focus groups to elicit both patient and health care professionals' perceptions. Questionnaires, surveys and validated instruments were adopted by six studies. One study (Groome et al. 1994) used a mixed method approach utilising first face-to-face interviews that then informed the development of a survey. Another study combined questionnaires with the length of in-patient hospital stay (O'Donnell and Tucker 1999).

Researcher Bias

The researchers were external to the renal field or separate research assistants/nurses were employed to perform the study fieldwork in the majority of research studies (16). However, in four studies the potential for researcher bias was present. With the researcher being the person responsible for the educational intervention under investigation, and/or a health care professional working within the renal setting with prior knowledge and potentially preconceived ideas of the patient population (Coupe 1998, Wilkinson 1998, O'Donnell and Tucker 1999, Andrew 2001). In the remaining three research studies insufficient detail prevented the assessment of possible bias.

Analysis

Fifteen of the 23 research studies provided an adequate or comprehensive description of the approach used for data analysis. For the remaining eight studies the descriptions were limited, for example, using the constant comparative method but providing no explanation as to how this approach was applied (Breckenridge 1997). From the descriptions provided the majority of research studies (12) used content or thematic analysis or a combination of the two approaches to examine the qualitative data. Of the eight studies that utilised questionnaires/tools as a method of data collection, seven analysed the data using appropriate statistical tests. One study posted a questionnaire to participants but offered no description of how the returned data was analysed (Coupe 1998). Two studies used a qualitative computer package to organise the data but provided no explanation as to how data was manipulated within the programme to generate pertinent themes (Breckenridge 1997, Andrew 2001).

Quality Review of the Evidence

All studies were subjected to the same critical appraisal to determine the quality and rigor of the reported findings. The critical appraisal framework was adapted from an existing appraisal tool (HCPRDU 2001) (Appendix 3) and uses a quality coding framework in line with NICE (2007) methodology checklists. The issues drawn out for subsequent discussion regarding quality focus on the following three key components:

- Sample
- Method
- Analysis

For a comprehensive overview of critique for each study within the review, see Appendix 4 (Table 10) and Appendix 5 (Table 11).

Sample

Study samples were drawn from dialysis, transplant and/or pre-dialysis patient populations, staff groups related to the care of dialysis patients, and/or patients' families; these were all considered to be appropriate to the respective studies and the different phenomena under investigation. However, the small sample sizes (<40 participants) in 56% of the studies raised concerns over how representative the sample recruited was to the wider target population (Wilkinson 1998, Andrew 2001, Bath et al. 2003, Harwood et al. 2005, Tweed and Ceaser 2005, Iles-Smith 2005). Equally the sampling methods adopted in some larger studies also raised questions over reliability (Klang et al. 1999, Curtin and Mapes 2001).

Wilkinson (1998) evaluating pre-dialysis education divided patients up into two groups those patients experiencing the education programme and those who did not. Three patients were drawn at random (although there are no details of the randomisation process) from each of the groups and interviewed regarding their pre-dialysis educational experience. Similarly, Harwood et al. (2005) make generalisations based on a sample of eleven patients, nine of whom were men and the majority over 61 years of age. Both these studies lacked explicit descriptions of the wider target population to determine whether the samples were representative. In some studies with limited samples, the findings were found to reflect larger studies (Wuerth et al. 2002) or details of how the sample represented the wider population were offered which increased the validity of the sample (Whittaker and Albee 1996). Despite this drawing on a larger study sample would have increased the reliability of a number of studies (Whittaker and Albee 1996, Breckenridge 1997, Bass et al. 1999).

When studying the CKD population there are a number of different variables to consider such as age, gender, length of time on dialysis and ethnicity. At least five different studies claim to have stratified sampling frames to adjust for two or more of these variables. Bath et al. (2003) report a stratified random sample to represent time on dialysis, age and gender but this would seem less than feasible given that only ten patients were recruited. Moreover the small sample size in a number of studies probably accounts for the lack of evidence in the findings that these variables were considered when analysing the data (Groome et al. 1994, Bass et al. 2001, Wuerth et al. 2002, Bath et al. 2003). One exception is Fine et al. (2005) who recruited a sample of 100 patients. Whilst they clearly identified the participant characteristics they failed to provide sub-group analysis within the findings. Orsino et al. (2003) recruited 197 CKD patients and presented evidence to suggest that differences do indeed exist and should be considered with respect to age and gender when investigating the information needs of this patient group.

The selection of patients begins with a target population in most studies originating from the health care professionals records. From this list of patients different random and non-random methods were applied to generate an appropriate sample. Random selection included picking names from a hat (Harwood et al. 2005) or use of a table of random numbers (Murray et al. 1999). Specific dates and time frames were also used to focus the patient selection (O’Donnell and Tucker 1999) as well as targeting all patients who had participated in a specific education programme (Coupe 1998, Klang et al. 1999). Groome et al. (1994) chose a non-random sampling method allowing the medical staff to identify patients who could contribute to the wide range of treatment experiences. This method complemented the aim of the study that was to identify information topic areas that patients perceive important to know prior to making a decision about a specific treatment. An element of bias may have been introduced if medical staff selected educated, compliant patients who had positive experiences of different therapies. Similarly an opportunistic sample referred by a CKD educator had the potential to be manipulated to include only those patients with high knowledge levels to ensure the education programme received a favourable evaluation (Schatell et al. 2003a).

Other random sampling methods included use of opportunistic and consecutive samples of patients being treated at a specific unit or clinic, and/or on a specific day (Hines et al. 1997a, Hines et al. 1997b, Orsino et al. 2003, Iles-Smith 2005, Fine et al. 2005). Self-selection was apparent in one study where the sample was patients who had contacted the organisation for more information (Juhnke and Curtin 2000). Tweed and Ceaser (2005) wrote to all pre-dialysis patients who had made a decision regarding treatment and asked those interested in the study to opt-in. For this study only nine patients were recruited but the total number who opted in was not disclosed, making it difficult to assess the effectiveness of the method.

Non-random sampling methods involved theoretical sampling frames based on criteria centred on the aims of the study (Whittaker and Albee 1996, Breckenridge 1997, Curtin and Mapes 2001). One such study utilised a modified ‘snow-ball’ sampling method where initially patients surviving long-term dialysis were identified and then asked to identify others who they knew had also survived dialysis for a similar length of time (Curtin and Mapes 2001). The non-random sampling methods reflected the qualitative nature of the studies and in turn impacted on the size of the sample achieved.

Methods

A range of methodological designs and approaches were evident. The underlying approach utilised by the majority of studies (15) was semi-structured and structured interviews. In addition ten studies developed specific self-report research instruments/surveys three of which were administered within a structured interview (Hines et al. 1997a, Hines et al. 1997b, Murray et al. 1999). One study, employed focus groups to elicit both the patients’ and health care professionals’ perceptions (Bass et al. 1999). For an overview of the comprehensive method critique see Appendix 5.

Three studies focused directly on the information needs of patients developed research instruments, two based on current literature (Orsino et al. 2003, Fine et al. 2005) the other grounded on interview data from patients and health care professionals (Groome et al. 1994). Both methods of generating and validating the initial content of the tools appeared rigorous and tools were pilot tested prior to administration. The purpose of the initial interviews by Groome et al. (1994) was to identify a comprehensive list of information topic areas that informed the development of a 65-item tool. They used an innovative approach to facilitate the prioritisation of the different information topics by encouraging patients and healthcare professionals to imagine themselves in the place of a new CKD patient about to require treatment, what would they want to know to be fully informed or to be able to make an informed choice? This method appeared effective in identifying the perceived priorities of new patients based on the knowledge of experienced dialysis patients.

Orsino et al. (2003) explored medical decision-making, preferences and information needs of patients receiving dialysis. The questionnaire was developed from existing instruments used with cancer patients by Cassileth et al. (1980) and Fallowfield et al. (1995). The self-report survey was 19 pages long with 69 questions (the content of which was not described in detail) that asked patients to describe their role in making the decision to receive their current treatment. In addition patients were asked to provide socio-demographic characteristics, medical information, demonstrate knowledge of illness, treatments and information preferences. By capturing this type of data within a cross-section of patients disparity could be isolated for variables such as age, gender and education level. The length of time on treatment was recorded but findings did not extrapolate whether time on dialysis and/or progression of the disease had an impact upon the information needs of patients.

The third instrument developed by Fine et al. (2005), like Orsino et al. (2003), was also adapted from a validated questionnaire used with cancer patients (Cassileth et al. 1980) to assess the type of information desired by these patients and their preferred degree of participation in their medical care. At the time the authors identified no comparable questionnaire for renal patients. The questionnaire was prefaced by a description of survival on dialysis being varied between patients, depending upon age, co-morbid conditions and identifying that without dialysis a patient would die. The 15-item questionnaire focused on the type of information (6 items), preferred information for decision making (5 items), and a further 4 items explored reasons why patients wanted more information about life expectancy. The six types of information items were concerned with possible side effects of dialysis; limitations of quality of life; actual life expectancy on dialysis; what dialysis does to the body; effectiveness of dialysis; and what will dialysis accomplish. Patients were asked to rate items using a three-point Likert scale (don’t want to know, would like to know, and absolutely need to know). The majority of the questions used identical phrasing to the instrument developed by Cassileth et al. (1980) although the wording of one question included '*likelihood of cure*' and was changed to '*life-expectancy'*. The other nine items were rated using a five-point Likert scale (1=strongly agree to 5=strongly disagree). The drawback of this questionnaire is that the items that patients rated were pre-determined by professionals. Even a patient with no conception or desire for information may be persuaded by the salience of categories presented on a list for them to rank thus distorting their real concerns and priorities.

Measuring the knowledge level of patients with respect to their disease and treatment was integral to many studies. This was either to measure the impact of an educational intervention (Klang et al. 1999) or to develop a greater understanding of patients' knowledge levels to assess whether they were adequately informed to provide consent or make decisions (Hines et al. 1997a, Hines et al. 1997b, Murray et al. 1999, Schatell et al. 2003a). Three studies utilised Likert scales attached to disease specific questions as a measure of knowledge (Hines et al. 1997a, Hines et al. 1997b, Klang et al. 1999). Murray et al. (1999) combined multiple choice and true or false questions to determine the patient's knowledge of a kidney transplant. Schatell et al. (2003a) used open questions and asked patients to list symptoms of CKD, laboratory tests and treatments. Their knowledge was assessed alongside the number of prompts required to recollect information. Klang et al. (1999) also included questions which explored the patients' impression of the amount of information received with respect to: diet restrictions; progression of the renal failure; medication; kidney disease in general; dialysis treatment; kidney transplantation and other patient experiences. Orsino et al. (2003) reflects that a limitation of their study was that patients were asked to record their perceived level of knowledge without this being verified by a specific knowledge test. Problems exist with the interpretation of the results obtained by measuring the patient's perceived level of knowledge in that you cannot be certain that a high score reflects that the patient has increased knowledge or whether they don't understand, what they don't know.

Knowledge tests seem valuable when assessing the effectiveness of a specific educational intervention or measuring how informed patients are. For example Murray et al. (1999) highlighted that patients lacked accurate knowledge regarding the success rate of kidney transplants. However, this type of knowledge test does not identify whether a particular aspect of knowledge/information perceived to be important by a health care professional has the same importance to the patient. For example, a patient informed of the meaning of different blood results may choose not to retain such information if this is something they perceive more appropriate for a professional to know. In an attempt to overcome this Klang et al. (1999) use open questions to enable patients the freedom to identify issues that were important to them before and after starting dialysis and their reasons for choosing the specific modality. Those studies that utilise a satisfaction audit tool to measure the effectiveness of a pre-dialysis education programme (Coupe 1998, O'Donnell and Tucker 1999) only measured the patient's perspective of the information they had received not the comprehension and recall of the information. A combined approach, to assess the level of knowledge and elicit the patient's perception of what information/knowledge is important to them, would appear more appropriate.

Additional validated tools used to complement the main study instruments included the Sense of Coherence Scale (SOC) (Klang et al. 1999) and the O'Connor Decision Self Efficacy tool (Orsino et al. 2003). The SOC measures the comprehensibility, manageability and meaningfulness of life stressor situations. The O'Connor Decision Self Efficacy tool measures patient confidence in medical decision-making. Although these tools appeared relevant to the aims of the particular studies, examining factors that could influence information need, they were not directly concerned with identifying a patient's specific need for information.

Interviews were demonstrated to be a valuable method to draw out the perceptions and experiences of CKD patients with respect to treatment, decision-making and the provision/need for information. However, the lack of detail provided by some studies impeded the quality assessment of the interview approach (Wilkinson 1998, Andrew 2001). Bass et al. (1999) provide a comprehensive description of operating a group interview to elicit the domains with respect to quality of life (QOL) affected by ESRD and suggests that this group method is more efficient than a one-one interview when assessing patient preferences and QOL. They compare the differences found between the health care professionals' and patients' perceptions of QOL issues and note a greater difference than was found in other studies such as Groome et al. (1994).

The majority of individual interviews took place face-to-face with the exception of two studies that chose telephone interviewing (Juhnke and Curtin 2000, Schatell et al. 2003a) to facilitate the recruitment of patients across wide geographical areas. Approaches to interviews were influenced by the research aims. Two studies adopted a less structured approach enabling patients the freedom to tell their stories and experiences of life with CKD and then clarified relevant aspects within each story (Whittaker and Albee 1996, Curtin and Mapes 2001). Others demonstrated rigor and content validity by developing interview guides based on current literature (Murray et al. 1999, Bath et al. 2003) or previously tested patient interviewing techniques (Wuerth et al. 2002). Breckenridge (1997) derived a simple Patient Perception Interview Guide and refined the content validity and reliability by first asking nurse managers from dialysis units to rate the clarity of the open ended questions. They then pilot-tested the guide on eight patients before a final schedule was generated.

One of the most comprehensive methods applied to ensure completeness of data was based on three criteria; saturation, redundancy and the search for disconfirming evidence, until such a time that all these criteria were achieved interviewing continued (Curtin and Mapes 2001). In comparison, Harwood et al. (2005) investigated stressors that patients experience when approaching dialysis and claimed data saturation after interviewing what could be perceived to be a small unrepresentative sample (11 patients with a mean age of 72.7 years, 82% male, four of which reported experiencing no stressors). Reporting findings supported by one individual raises questions regarding the reliability of data saturation unless the theme is unlikely to be elaborated on or clarified by gathering more data.

Five studies indicate that HD patients were recruited and asked to complete study instruments or undergo an interview whilst receiving haemodialysis therapy (Hines et al. 1997a, Hines et al. 1997b, Breckenridge 1997, Orsino et al. 2003, Harwood et al. 2005). However, there is evidence to suggest that during dialysis patients experience reduced cognitive functioning as a result of chemical imbalance (Niccum and Pérez 2000). This could raise questions regarding the reliability of data retrieved whilst patients are receiving dialysis particularly when measuring knowledge levels, exploring decision-making or expecting patients to recollect experiences. Hines et al. (1997a, 1997b) used a mini-state mental exam to measure cognitive capacity during the interview. Although they found that greater cognitive capacity was associated with a better understanding they did not determine whether cognitive capacity would have been improved if the patients had not been receiving the dialysis.

Analysis

Quantitative data were analysed using different statistical tests, for those studies where variables within the sample were compared, such as age, race and modality; the method of choice for three out of five studies was Students t-test (Groome et al. 1994, Klang et al. 1999, Orsino et al. 2003). Pearson's correlation test was found to be useful when comparing the importance of mean scores, particularly when assessing the priorities of patients towards specific information topics (Groome et al. 1994). Other tests included Chi Square, regression analyses and other inferential statistics (Hines et al. 1997a, Hines et al. 1997b, Fine et al. 2005) and Fishers exact test (Groome et al. 1994).

For qualitative data the most popular method was content and thematic analysis (Bass et al. 1999, Klang et al. 1999, Curtin and Mapes 2001, Wuerth et al. 2002, Iles-Smith 2005). Based on a similar premise others used Interpretative Phenomenological analysis and/or the constant comparative method to verify and compare themes between individuals (Whittaker and Albee 1996, Breckenridge 1997, Wilkinson 1998, Tweed and Ceaser 2005). Inside of these approaches the use of independent verification of emerging themes minimised bias within most studies. Verification was undertaken by: different members of the research team (Bass et al. 1999, Harwood et al. 2005, Tweed and Ceaser 2005); external professionals (Murray et al. 1999, Whittaker and Albee 1996, Breckenridge 1997, Wilkinson 1998, Wuerth et al. 2002); and/or patients (Curtin and Mapes 2001). Insufficient information resulted in the inability to assess the quality of the analytical approach adopted by some studies (Coupe 1998, Juhnke and Curtin 2000, Niccum and Pérez 2000). Two studies utilised qualitative computer packages to organise data, Ethnograph and Nudist (Breckenridge 1997, Andrew 2001). Overall the qualitative analysis approaches appeared successful in extracting and identifying the information needs, concerns and preferences of the individual patient and different groups.

Summary of Quality

The overall quality of the studies was high. Critical appraisal facilitated the classification of both the quality and rigor of a study, using three categories – low (-), medium (+) or high quality (++). From the 26 studies, twelve were judged to be of a high quality, six medium and eight low, Table 12 provides a summary of the quality ratings (Appendix 6).

Of the six studies assessed to be of low quality, three were excluded from methodological scrutiny, two were not applicable because they presented the opinion of one person (Hedman 1998, DeCuir 1998) and the other was a literature review (Leino-Kilpi et al. 1993). However, all three articles, particularly those reporting patient opinion raised issues and highlighted information needs that corroborated with the other studies.

Studies adopting a single methodological approach such as qualitative interviews or quantitative instruments were effective in extracting the information needs of patients with respect to CKD, RRT and decision-making, although studies combining these approaches strengthened the rigor of the research data (Groome et al. 1994). The research tool used by Groome et al. (1994) clearly exposed the proposed information needs of new CKD patients. Likewise the instruments developed by Orsino et al. (2003) and Fine et al. (2005) were particularly effective in identifying the information needs of patients inside of decision-making processes. There was no specific tool that identified the information needs and priorities of a particular individual or that captured variables such as length of time on a particular treatment or the progression of the disease. Although the information needs of individuals and their preferences could be isolated within qualitative in-depth interviews (Murray et al. 1999, Wuerth et al. 2002) this time consuming method restricted the size of the sample and in turn the quality of the findings (Iles-Smith 2005, Tweed and Ceaser 2005).

Many of the studies could not be generalised further than the single site where the study took place because of the relevance of the findings to a specific education programme (Coupe 1998, Klang et al. 1999, Schatell et al. 2003a) or wider because of a lack of information to assess whether a sample was representative of the wider population (Breckenridge 1997, Wilkinson 1998, Andrew 2001, Iles-Smith 2005, Tweed and Ceaser 2005). When the details of a specific education programme were transparent then findings could be translated to those study sites where similar education interventions were performed (O'Donnell and Tucker 1999). For those studies where sufficient quality and rigor existed the findings on the whole could be generalised, to the wider CKD population (Groome et al. 1994, Hines et al. 1997a, Hines et al. 1997b, Orsino et al. 2003, Fine et al. 2005). Despite a small sample size the findings of studies were considered more reliable when they substantiated or corroborated the findings from larger, more rigorous studies (Bath et al. 2003).

Twenty-one studies described information needs and/or information topics that were considered important for CKD patients, from the perspective of the patient and ten also reported the perspective of the health care professional. The majority of studies illuminated the information needs of patients, as well as describing the factors (23), concerns (17) and preferences (14), which influence the need and type of information patients require. A number of different information topic areas were identified within, and reinforced across, the variety of studies in the review.

Theoretical Constructs

The combined findings from the reviewed studies elucidate and corroborate the theoretical assumptions associated with information need and patient information priorities. A number of factors, similar to those discussed in the previous chapter, shaped the information needs of CKD patients. Factors such as age, gender and education level, preferred levels of autonomy, type and experience of RRT, the psychological impact of starting and sustaining dialysis, social circumstances and how to maintain a normal life and other patients' experiences, exerted a degree of influence on the type of information needed by patients. Intrinsically linked to factors that influence a patient's information needs are patient concerns and preferences towards their treatment, their lifestyle and family. In addition the content, style and timing of information was found to be an important factor as was the information seeking behaviour of the patients themselves.

Definition of Information Need

Leino-Kilpi et al. (1993) draw attention to a lack of research on the information needs of dialysis patients, the reason being that in 1993 the dialysis technique was relatively new and patients were just starting to be involved in their treatment. Although the treatment and nursing care has radically advanced since this time there is still today a dearth of studies focusing on the information needs of CKD patients, compared to the prolific research that exists for other chronic disease groups.

The primary focus of papers included in the review relate to decision-making, education, concerns and perceived knowledge levels with patient information needs embedded within the findings. Thus a clear definition of the meaning of an information need was not to be found. Indeed the term information need was used synonymously with concepts such as education needs and goals (O'Donnell and Tucker 1999, Niccum and Pérez 2000, Schatell et al. 2003b); subject knowledge (Wilkinson 1998, Murray et al. 1999, Klang et al. 1999); and/or to identify what a patient needs and/or wants to know (Orsino et al. 2003, Fine et al. 2005). One study uses the term 'topic' as a descriptor for a subject area about which the patient wants to learn more and have information (Juhnke and Curtin 2000). It suggests that information topic is a meaningful signifier of both the subject and content of the underlying need.

The review by Leino-Kilpi et al. (1993) does present an interesting overview, albeit it dated, of the literature surrounding the meaning of information to the patient. They suggest two functions of information, one ideological and the other practical. Ideologically patients want to know and have a right to know health information indeed information plays an important role for patients influencing their autonomy, dignity and self-respect. Consequently information assists patients to become active participants in their own care dispelling uncertainty and increasing patient awareness of different treatments, alternatives and consequences. The second function from the practical perspective is to ensure patients have the necessary self-care skills to prevent complications, and increased understanding to facilitate compliance, all of which is considered essential to the success of nursing (Leino-Kilpi et al. 1993). Two possible purposes of information were highlighted but no definition.

Demographics

Age and Gender

Both age and gender were shown within two studies (Klang et al. 1999, Orsino et al. 2003) to influence and impact upon the information needs of CKD patients. Women and men were found to require different gender specific types of information. Women showed a greater concern towards the fear of side effects, relief of symptoms, feeling sad or blue and religious/cultural beliefs compared with men and the decision to go on the transplant list (Orsino et al. 2003). Influential factors for women in the choice of treatment included fear of dialysis procedure, fear of side effects of dialysis and transportation considerations (Orsino et al. 2003). In a study by Klang et al. (1999), men achieved higher knowledge scores than women on topic areas including general kidney disease, medication and diet restriction after starting dialysis. Overall men perceived that they had received a greater amount of information than women (Klang et al. 1999).

Similarly, younger people were discovered to have contrasting information needs compared with older patients particularly with respect to receiving information about strategies on how to survive dialysis and withdrawing from treatment (Orsino et al. 2003). Younger patients perceived themselves as having more knowledge than older patients (Klang et al. 1999) particularly regarding types of dialysis, reasons for requiring a transplant and the risks/benefits of transplantation (Orsino et al. 2003). This could be expected given that an older patient would be more likely to be considered unsuitable for transplantation and therefore the option and information topic not discussed. Klang et al. (1999) reported a negative correlation between age and knowledge about dietary restrictions, progression of renal failure and kidney transplantation.

Knowledge and Education Level

Variations were shown to exist between patients in knowledge and education levels. With respect to preferred levels of knowledge some patients indicated low levels of knowledge regarding their CKD treatment and disease and were content to remain uninformed (Bath et al. 2003). Hines et al. (1997a) identified that elderly patients lacked a basic understanding of the cause of their CKD and were not aware of the advantages or disadvantages of different treatments. They argue that without such a basic knowledge then it is impossible for a patient to make informed treatment choices or decisions. Whether patients preferred to have this type of information was not examined. Neither is the meaning of *basic*, what this should include and from whose perspective. Some evidence suggests that each patient, as an individual, has different information needs (DeCuir 1998, Andrew 2001), and that age and gender both impact upon the type of information a patient may require (Orsino et al. 2003). If this were the case then the preferred knowledge levels would vary for each patient. The value of assessing knowledge levels was demonstrated when determining whether patients held inaccurate information with regard to certain topic areas (Murray et al. 1999).

The education level of a patient was shown to influence the depth of information they can comprehend and in turn impact upon the level of information that can be presented (Hines et al. 1997a, Hines et al. 1997b). Older people in particular were found to need more time to acquire and internalise knowledge and change patterns of behaviour (Klang et al. 1999).

Psychological Affects and Coping

The psychological impact of dialysis has a direct influence on the information needs of the patient. The fear of the unknown influences what information patients need, '*kidney failure is scary if you do not know what is happening to your body'* (DeCuir 1998 p252). Patient concerns include having to confront new situations with regard to their treatment, feelings of uncertainty about the future, the impact on their mental attitude and potential changes in their personality (Bass et al. 1999, Bath et al. 2003). Wilkinson (1998) recommends that more time be allocated to discussing the patients' concerns regarding facing a future on dialysis.

CKD and dialysis treatment diminishes cognitive functioning (Hines et al. 1997a) and can affect the patient's ability to perceive process and organise information (Niccum and Pérez 2000). Consequently patients may find it difficult to verbalise their information needs and/or comprehend the information provided requiring persistent repetitive information.

How a patient learns to cope with the psychosocial demands of RRT and the strategies they adapt to cope shapes their individual need for different types of information (Klang et al. 1999). Some patients compare themselves against others and perceive others to be worse off; some are reluctant towards change whilst others are positive to make efforts to survive (Bath et al. 2003, Tweed and Ceaser 2005). Others require information regarding what else can be done to improve their chance of staying around a little longer (Schatell et al. 2003b). Andrew (2001) suggests that there is a need to consider patient behaviour changes, possible grief and coping mechanisms that will impact on the patient's preference for information at a particular time along the continuum of acceptance. Similarly, evidence suggests that seeking information is a common coping strategy but equally patients can use denial as a defence mechanism that prevents them from seeking the advice they need (Klang et al. 1999).

Self- efficacy and Control

Studies highlight differences that exist between patients and their preferred level of autonomy with respect to their treatment and control over their disease (Breckenridge 1997, Orsino et al. 2003). Some patients have a preference for knowledge and others are ill informed and content to remain so (Bath et al. 2003). This is influenced by the patient's level of concern and fear towards becoming an invalid and the desire not to adopt the sick role (Whittaker and Albee 1996).

Findings imply that patients with CKD may feel reduced independence (Klang et al. 1999, Niccum and Pérez 2000) and become more reliant on the health care professional to make decisions (Breckenridge 1997). Being dependent on others becomes harder to accept the longer it persists (Hedman 1998, Bass et al. 1999). Bath et al. (2003) suggest that dependency directly influences a patient's involvement in their own care and this impacts on their information needs, or reflects the need for more information to increase independence. Older patients often failed to take an active role in obtaining sufficient information to be able to provide informed consent

(Hines et al. 1997a). However, the older patients were more likely to seek out information from others when doctors provided advanced warning of their need for dialysis (Hines et al. 1997a). Younger patients demonstrated increased self-efficacy and confidence in seeking information (Orsino et al. 2003).

Being empowered means that patients have learnt enough about their disease and health to evaluate the cost and benefits of adopting a wide variety of health care activities (Curtin and Mapes 2001). In a study by Whitaker and Albee (1996) the majority of patients identified three areas that they valued, maintaining pre-dialysis lifestyle, maintaining autonomy and maintaining a self-care perspective. The need to be autonomous and keep a level of control was seen as important to some patients (Coupe 1998, Wuerth et al. 2002). Indeed patients who had long-term experience of dialysis advocated the need to seek out information, to be informed and develop self-management strategies (Curtin and Mapes 2001). Therefore it could be deducted that a patient wishing to be autonomous and in control of their own treatment would have different information needs than a patient who is happy to take on a more dependent role. However the desire to be more independent cannot be considered in isolation as other factors such as the lack of social support and physician preferences were cited as contextual factors that blocked autonomous decision-making (Whittaker and Albee 1996).

Context and Situations

The wider social context in which the patient is located directly impacts on and influences their information needs. The needs of their families, work situations and financial income, alongside sustaining social activities, influence the information patients need in particular when choosing a RRT to complement their existing lifestyle (Breckenridge 1997, Coupe 1998). Information that enables a patient to maintain a sense of normality, maintain factors of value and minimise disruption to their day-to-day lives is important (Whittaker and Albee 1996, Fine et al. 2005). Patients want information that has current importance to the situation in which they find themselves (Leino-Kilpi et al. 1993), and need to protect their family from the impact of the disease and not become a burden (Bath et al. 2003).

Maintaining normality is not just restricted to the patient’s life but influenced by the perceptions of significant others as to what treatment best suits the whole family (Whittaker and Albee 1996, Wuerth et al. 2001). Certainly the opinions of families had great influence on the type of dialysis chosen by older people (Orsino et al. 2003). Harwood et al. (2005) identified that having spouses learn about renal failure and be provided with information to enhance their understanding was both helpful and supportive to the patient. However, the need to protect a loved one from the fate of dialysis influenced a patient’s decision not to obtain further information about or even discuss living related donation, preferring to consider cadaver donation (Murray et al. 1999). DeCuir (1998) suggests the importance lies in understanding both the patient and their normal life before offering advice and information.

Treatment specific situations, such as the availability, flexibility and type of treatment that a patient prefers and receives (Breckenridge 1997, Wuerth et al. 2001) will influence the need for different types of information (Bass et al. 1999). Similarly patients will need tailored information to overcome concerns regarding different aspects of the therapy, such as their fear of needles and the risk of infection (Whittaker and Albee 1996, Bath et al. 2003) or specific problems maintaining fluid and diet restrictions (DeCuir 1998). Physical events arising from the experience of treatment side effects will engender information needs, whether it is being prepared about what to expect or how to cope and minimise the physical effects (Fine et al. 2005). Some patients feel unprepared for the physical effects of the different treatments (Coupe 1998) and information needs raised reflected concerns regarding perceived altered body image and disfigurement (Bass et al. 1999, Whittaker and Albee 1996).

Events such as undergoing dialysis access surgery will influence the decision to start HD rather than having to go through further surgery for a PD tube, irrespective of the information provided to the patient (Whittaker and Albee 1996). Similarly patient experiences of acute haemodialysis or a different modality or what they have witnessed during a stay in hospital (Coupe 1998, Whittaker and Albee 1996) will impact upon their need for information and treatment choices. It is suggested that the longer the patient survives dialysis the more well informed they become and knowledgeable about their disease and its treatment (Curtin and Mapes 2001).

Timing

The timing of providing specific information was stressed to be important (Juhnke and Curtin 2000, Orsino et al. 2003). Too much information at one time was problematic for some patients (Schatell et al. 2003b) whilst adequate time to digest information was found to increase a patient's participation in their care (Andrew 2001). Patients identified the need for time to absorb information and adjust to approaching dialysis (Harwood et al. 2005). Evidence suggested that information should be provided earlier, before requiring dialysis (O'Donnell and Tucker 1999). Presenting at clinic with a problem and thus requiring dialysis reduced the amount of preparation a patient had and decreased their ability to make an informed choice regarding their treatment (Coupe 1998). However, the most appropriate time to be told about the need for dialysis and different therapy options is unclear. Some patients prefer to be informed when they are first told that they have a kidney problem, others suggest that it would have been frightening to get too much information at this time (O'Donnell and Tucker 1999). Information given too early or at the wrong time may find patients unreceptive or they may lack the understanding required to comprehend the importance and implications of the information.

No study explored whether the information needs of patients change over time or identified the best time for providing specific information, with the exception of the content of information that should be addressed with new CKD patients (Groome et al. 1994). Although, Leino-Kilpi et al. (1993) in their literature review indicate that dialysis patients need information that is relevant to them in different phases of their nursing process, thus suggesting information needs change over time. Schatell et al. (2003b) recommend that future studies should include clinical information to understand patients' needs as the disease progresses.

Information Seeking

The comments from patients with CKD indicated that information increased their compliance with treatment (Hedman 1998, DeCuir 1998). Indeed long-term survivors of RRT (over 15 years) reinforced that being knowledgeable about the disease and overseeing aspects of therapy facilitated their survival (Curtin and Mapes 2001).

However this is not to say that just by increasing information patients will survive longer but increased information was found to contribute to the development of self-management strategies that enhance survival.

Patients suggest that information is available but the onus is on each patient to search out pertinent information (Bath et al. 2003) although some patients didn't know how to find it (Iles-Simth 2005). Klang et al. (1999) demonstrated that chronically ill patients faced with treatment modifications found additional information. In their study the control group, after starting dialysis, had similar knowledge scores to those who had received an education intervention, indicating that they had located the information from other sources. Some patients suggested that there can never be enough information and that education is a continuous process (Juhnke and Curtin 2000). Schatell et al. (2003b, p17) take this further suggesting that within the CKD patient group individuals can be defined as either '*active information seekers*' or '*passive information recipients*'.

Source Characteristics – Information Provision

Whether the right information is delivered at the right time and in the right format is dependent upon the individual's needs at that specific time. Substantial cultural and personal variability exists in preferences for medical information (Hines et al. 1997a). Patient concerns included not being fully informed, needing to know more and being involved. One patient suggested that the problems they experienced were a result of not being involved, not knowing what to do and what questions to ask (Schatell et al. 2003b). Another found the written information too much to absorb because their lack of formal education restricted their level of understanding (Harwood et al. 2005). In a different study informants reported a wide variation in the amount of information given, some suggesting that information provision was dependent upon the doctors and their preference for the patient (Whittaker and Albee 1996).

Some patients felt there was an element of bias in the presentation of some of the educational material, with particular types of treatment being favoured against others. Patients prefer information to be unbiased and presented equally so they can make up their own minds and not be influenced by external preferences or service demands

(O’Donnell and Tucker 1999). Rather than providing the minimum amount of information or too much doctors should ask patients what they want to know, in how much detail and when they wish to be told and the types of treatment options patients prefer to be informed about (Hines et al. 1997a). DeCuir (1998) suggested that patients simply prefer to be kept informed about what is happening. However, the purpose of the information (the underlying goal) is equally important, whether it is to help a patient make decisions, to reduce fear of the unknown, advice to enable them to live longer or to learn about their kidney problem (Schatell et al. 2003b, Fine et al. 2005).

There was limited evidence to identify patient preferences with respect to the optimum method of information provision. Orsino et al. (2003) identified that although the medical consultant was the primary person consulted prior to making a decision about which treatment to choose, younger patients also sought the opinions of the nurse and other renal patients. In one study, patients described using information gleaned from a variety of sources including verbal information from the physician, structured education programmes, written information, using the internet, the opinion of a spouse or significant other, and information from other patients (Wuerth et al. 2002). There was a general preference towards the presentation of written education material. However, Orsino et al. (2003) report that gender differences exist with women showing a preference for information books and men preferring the information binder produced specifically by a Kidney Foundation.

Some patients identified that visiting the dialysis unit and having the opportunity to talk to other patients regarding the reality of RRT provided useful information and insight (Coupe 1998, Harwood et al. 2005). Information received from other patients subsequently influenced their choices to change or select a particular therapy (Breckenridge 1997). Having a relative or friend on a specific modality influenced the bias of information patients’ received and their decision to select a particular therapy (Whittaker and Albee 1996).

Patient Information Needs/Topics

Information needs/topic areas perceived to be important by CKD patients were identified from the review of the literature. The topic areas that emerged addressed different aspects of the therapy, disease and the impact upon a person's lifestyle and can be grouped into nine distinct but interrelated themes.

- Progression and medical impact of CKD
- Future survival
- Issues surrounding RRT
- Issues specific to transplantation
- Symptoms, risks and complications of treatment
- Diet, medication and fluid regimes
- Social life, family and work
- Self Care - Independence versus Dependence
- Psychological impact

These broad topic headings were used to inform discussion, combining available evidence to systematically describe and discuss the information needs of established CKD patients receiving RRT and new patients developing an understanding of CKD.

Progression and Medical Impact of CKD

Patients suggested information would be useful about how the kidneys work and what actually happens when they fail (O'Donnell and Tucker 1999). General information about kidney disease (Juhnke and Curtin 2000, Schatell et al. 2003b) would help them understand what was happening to their bodies (DeCuir 1998) and prepare for dialysis (Harwood et al. 2005). Finding the balance of information can sometimes be difficult, as what suits one patient may not always suit another. For example, one pre-dialysis patient identified that for them it was too dramatic to hear that CKD was a fatal disease (Klang et al. 1999). Orsino et al. (2003) found that both men and women wanted a similar amount of information about kidney disease. Elderly haemodialysis patients were found to be lacking in their knowledge and understanding about the cause of their medical condition (Hines et al. 1997a).

Pre-dialysis patients aware of the impending therapy suggested that information on how to protect the remaining kidney function considering options such as new clinical trials, drugs, new surgical procedures or new treatments would be useful (Schatell et al. 2003b). Similarly dialysis patients advocate the provision of information on the efficiency of the different treatments for reversing and minimising co-morbid disease such as hypertension, heart disease and bone/joint disease (Groome et al. 1994). Trying to understand how to delay the progression of the disease is important to some patients prior to starting dialysis and minimising the effects of the disease and therapy important to others patients receiving dialysis. However, Iles-Smith (2005) found that pre-dialysis patients rarely spoke about the medical consequences of the disease. A reason for this could be a lack of this type of information and/or an inability to ask the right questions to extract the information they require (Juhnke and Curtin 2000).

Future Survival

Issues surrounding the expected future and survival whether receiving or having refused dialysis were topics of information that were important to patients (Groome et al. 1994, Orsino et al. 2003, Iles-Smith 2005, Fine et al. 2005). Patients needed to know right from the start what they could expect in the future particularly their life expectancy (Juhnke and Curtin 2000, Fine et al. 2005). Many considered it important to know whether refusing dialysis would affect their future medical care, although older patients were found to need more information about the possibility of death resulting from dialysis refusal (Orsino et al. 2003). Hines et al. (1997a) suggests, with respect to elderly patients, that a willingness to discuss death and plan for the future could contribute to a better understanding of their medical condition. Indeed a similar study regarding end of life decisions found that information about death, complications of treatment and being able to withdraw from treatment were fundamental information topics (Hines et al. 1997b). Realistic information about what to expect in the future could ensure that patients make best use of their time prior to needing dialysis to fulfil existing lifestyle goals (Harwood et al. 2005, Fine et al. 2005). Patients in the early stages of CKD (who may never require dialysis) indicated that doctors should voluntarily disclose prognosis information to patients to facilitate coping in the future (Fine et al. 2005).

Issues Surrounding RRT

Understanding the initiation of dialysis, how the different and specific treatments work, what will happen and what they involve was important to patients (Groome et al. 1994, Breckenridge 1997, Hedman 1998, Coupe 1998, DeCuir 1998, Juhnke and Curtin 2000, Schatell et al. 2003b, Orsino et al. 2003). Without this type of information it is difficult for the patient to make an informed choice between the different treatment options (Breckenridge 1997). A lack of information regarding dialysis was found to be stressful for patients (Harwood et al. 2005). However, being provided with information about the medical effectiveness of renal replacement therapies did not seem to be a priority, so long as there was an awareness of some advantages and disadvantages of the treatments (Tweed and Ceaser 2005). Although in one study, 97 out of 100 pre-dialysis patients indicated that information regarding how effective dialysis treatment has been on patients of similar age and comorbidity was important (Fine et al. 2005).

More detailed information was requested by patients to be able to fully understand the impact the treatment has upon their lifestyle (Fine et al. 2005). Information such as the flexibility of the treatment schedule, travelling to the hospital for treatment compared with having the treatment at home, the amount of time each treatment takes and whether it can be performed independently (Groome et al. 1994, Bass et al. 1999, Orsino et al. 2003, Iles-Smith 2005). Experienced dialysis patients suggested more practical information was needed (O’Donnell and Tucker 1999) concerning the needling procedure in HD (Bass et al. 1999), the effects of having a catheter on the ability to swim or shower, or being restricted during treatment but having the ability to do other activities to pass the time (Groome et al. 1994, Juhnke and Curtin 2000).

Patients identified that it was good to learn about the dialysis options, to understand the effects and side effects of the both HD and PD, to visit the dialysis wards, and hear the perspectives of the different health professionals (Klang et al. 1999). Iles-Smith (2005) found that pre-dialysis patients gained insight into dialysis from information provided by other patients’ experiences. This was reinforced by experienced dialysis patients who were interested in the experiences of others, particularly success stories, but not as a source of medical information (Juhnke and

Curtin 2000). Patients compare themselves with others as a means of providing reassurance and reducing feelings of isolation (Tweed and Ceaser 2005). In a personal account an experienced renal patient reinforced the value of information about different patient organisations (Hedman 1998) in as much as it gave patients the opportunity to contact and receive independent information regarding CKD and available treatment.

The majority of studies looked at the CKD patient group as a whole although two studies identified differences based on age. Orsino et al. (2003) found younger patients wanted more information about the flexibility of a treatment schedule than older patients, possibly to understand which treatment would complement their existing lifestyle. Elderly patients were found to lack even a basic awareness of comparative burdens and benefits of HD and PD (Hines et al. 1997a). It was suggested that there was a need to reinforce information clearly and repetitively to elderly patients regarding the cause of their renal failure, that it was permanent and that they had a choice of treatment (Hines et al. 1997a).

Two additional topic areas revealed in Groome et al. (1994) related to the importance of information about availability and quality of nursing and physician care and, to a lesser degree, the availability of facilities if the patient experienced problems with HD. These did not emerge in other studies possibly indicating relevance only to Canadian medical care provision.

Issues Specific to Transplantation

Patients with CKD required more accurate information about the true success rate of kidney transplantation (Murray et al. 1999). This included detailed information concerning the risks of infection, risks related to the surgery, the possible risk of rejection of the transplanted kidney (Groome et al. 1994) and the importance of immunosuppressive therapy (Hedman 1998). Those patients not suitable for a transplant should receive adequate information to understand why this option is not available (Hedman 1998). Murray et al. (1999) found that patients and their families needed information which dispelled *the myths and fears* of going on the transplant list and promoted family participation in the decision process.

Symptoms, Risks and Complications of Treatment

Patients report experiencing a variety of different symptoms related to both the progression and management of the disease and/or complications from specific treatments. Symptoms included: swelling; changes in urination; weight loss; nausea; vomiting; itching or skin rash; fatigue; feeling cold; anaemia; pain in the joints, legs/and or back; gout; shortness of breath; chest pain; headaches; fainting and dizziness; changes in taste; ammonia breath; forgetfulness; and trouble concentrating (Bass et al. 1999, Schatell et al. 2003b). Patients who had survived dialysis for over 15 years identified the importance of having the information and knowledge to be able to identify and report their own symptoms (Curtin and Mapes 2001). In this study patients placed the responsibility of gaining such information with the patients themselves, but recognised that this knowledge comes with experience, that there is no formal training, they had learnt over time what symptoms to report, when and to whom.

It was considered important to have specific information about the complications that could be anticipated with the different forms of treatment (O'Donnell and Tucker 1999, Fine et al. 2005). Complications included; hypotension, catheter migration (Coupe 1998), temporary/permanent loss of dialysis access, and the risk of infections related to the specific therapy (Groome et al. 1994). Patients need not only information about what to expect but also information about how to manage the consequences of complications/symptoms, such as how to get rid of itchy skin or how to sleep better (Niccum and Perez 2000).

The impact of CKD and different treatments on the patients' physical appearance and subsequently their body image can be devastating and experienced dialysis patients indicated the need to provide this type of information (Groome et al. 1994, Coupe 1998, Bass et al. 1999). Patients' decisions regarding which form of treatment to choose was influenced by their own self-concept and body image and weighing up which form of disfigurement (type of access) was most acceptable (Tweed and Ceaser 2005). Orsino et al. (2003) identified that younger patients wanted more information about physical appearance. A further important area that required appropriate information was the effects on and ability to have sexual intercourse (Groome et al.

1994, Bass et al. 1999). One study showed that men desired more information than women on the effect of dialysis on sexuality and younger patients wanted more information effect of dialysis on sexual activity (Orsino et al. 2003).

Diet, Medication and Fluid Regimes

Diet and fluid restrictions are a necessary part of the therapy for treating CKD but impact considerably on the quality of life of patients (Bass et al. 1999). When reflecting on their dialysis experience patients suggested information about the management of diet and fluids to be important (Juhnke and Curtin 2000). Similarly, a number of studies report that patients require adequate information on nutrition, diet and fluid regimes to minimise the effects of the impaired renal function and complement dialysis therapy (Groome et al. 1994, Wilkinson 1998, Coupe 1998, Niccum and Perez 2000, Schatell et al. 2003a, Harwood et al. 2005).

Patients also suggested that information about medication regimes and the side effects of the prescribed drugs are important (Coupe 1998, Groome et al. 1994). Leino-Kilpi et al. (1993) in a review of different clients information needs, highlighted that dialysis patients lacked knowledge and information on medication, in particular the indications, effectiveness, duration and what action to take if medication had been missed.

Social Life, Family and Work

CKD and its subsequent treatment infiltrates and impacts directly on the social life, family and career of the patient. Pre-dialysis patients wanted to know what impact dialysis will have on their lives (Iles-Smith 2005) and those inadequately informed expressed regret once having started dialysis that they would have done things differently in their personal lives had they received accurate information (Harwood et al. 2005). For example taking the time to travel more or changing their eating habits to stay off dialysis longer. Once on dialysis patients still required information about their ability to travel and organise holidays (Groome et al. 1994, Wilkinson 1998) particularly older patients who plan to travel when retired (Whittaker and Albee 1996).

The ability to maintain a normal lifestyle and information on how this could be achieved is important to patients of all ages (Groome et al. 1994, Orsino et al. 2003, Tweed and Ceaser 2005). The impact of dialysis is not felt just by the patient but by the whole family, particularly when dialysis is performed at home (PD or home HD) (Groome et al. 1994). CKD can impact on the patients' role and function within the family (Bass et al. 1999). Younger patients were found to require more information about the ability to continue working whilst receiving dialysis (Orsino et al. 2003, Whitaker and Albee 1996). For those where work was impossible there are financial implications (Harwood et al. 2005) and information was needed on how to adapt their financial situation and what, if any, additional support may be available. Patients felt that these topic areas are not adequately addressed (Juhnke and Curtin 2000).

Patients require advice and information about maintaining and sustaining social relationships, networks, activities and commitments (Groome et al. 1994, Whitaker and Albee 1996, Wilkinson 1998, Bass et al. 1999). In particular, younger patients requested information on the effect of dialysis on social activities (Orsino et al. 2003). There were questions about leisure activities, hobbies such as water sports, swimming, and exercise and whether these can continue once dialysis has commenced (Whittaker and Albee 1996, Juhnke and Curtin 2000, Schatell et al. 2003b).

Self-Care and Tests

Four studies raised issues of independence. In Bass et al. (1999) patients described how CKD impacted upon their freedom, inhibited their independence and challenged their ability to be in control. It was important to maintain normality, autonomy and not be dependent upon anyone (Tweed and Ceaser 2005). To achieve this, patients required clear information to understand the degree of control and responsibility they would have over their own treatment (Groome et al. 1994). Patients of all ages considered it important to know about the effect dialysis would have on their ability to care for themselves (Orsino et al. 2003). In two studies patients highlighted insufficient information on the different tests and investigations performed (Coupe 1998), how to interpret results (laboratory markers for CKD such a serum creatinine) and their relationship to different symptoms (Schatell et al. 2003a). Information to achieve self-care included adequate information on different tests and blood results to enable patients to understand the cause of problems or symptoms manifested and modify behaviour where appropriate.

Psychological Impact

There was little evidence to suggest patients directly ask for information to understand the psychological impact of CKD such as experiencing problems like forgetfulness or difficulty concentrating. More common issues raised that required information involved adapting and coping to dialysis in everyday life (Coupe 1998, O'Donnell and Tucker 1999, Bass et al. 1999); the need for information to make the decision between the different treatments and then information to cope once the decision was made (Groome et al. 1994, Juhnke and Curtin 2000). Additional aspects uncovered in Groome et al. (1994) focussed on the psychological issues of uncertainty and the wait for a transplant, or the consequences of a failed transplant on the patients' life and sense of well-being.

The impact of CKD on a patients' mental attitude and the increased anxiety experienced is well documented (Bass et al. 1999). Therefore it is difficult to comprehend, within the studies reviewed, why patients do not ask for more information to help overcome or deal with these types of problems. It may be patients are information deficient in the first place for them to understand and recognise when a psychological problem manifests. On the other hand information regarding psychological issues may not be seen as a priority by the patient group as a whole.

Conclusion

The review included 26 papers and from these there was clear evidence to suggest that a number of broad information themes (and many sub-themes) exist that are important to CKD patients. Twelve information topics were extrapolated (Box 3):

Box 3: Twelve Information Topics Drawn from the Literature Review

- CKD information and the future
- RRT and transplant information
- Physical symptoms / body image
- Complications of both disease and treatment
- Family and social life
- Work and finance
- Diet and fluid restrictions
- Medication
- Tests
- Psychological impact
- Experiences of other patients
- Patient organisations/Associations (independent information providers)

The review findings suggest that many different variables impact upon the information an individual patient may require, such as age, gender, education level, choice of treatment, preferred level of autonomy and control, cognitive functioning, adaptation to chronic illness, the degree of information seeking behaviour, and the opinions of family members or other patients. How these variables influence each other and impact upon the priorities and preferences of patients with regard to information is ambiguous. In light of this confounding evidence is it realistic to assume that identifying broad information topic areas could possibly overcome the diversity within the CKD population? Further research is needed to examine whether commonalities exist between groups of similar patients and their priorities and preferences for specific information topics. Undoubtedly if generic information topic areas can be confirmed, by focusing the discussion between patients and their health care providers (particularly for patients having difficulty articulating their information needs) the provision of information can be enhanced.

For many years professionals have determined the content of CKD patient education programmes. If core information topics can be identified for particular patients or patient groups at pertinent times education can be targeted and be more effective based on the needs of patients. However, concepts such as basic, perceived and actual knowledge levels require deeper appreciation and clarification. A basic level of understanding was advocated to enable patients to make informed decisions (Hines et al. 1997a). No explanation was offered to indicate the meaning of the word *basic level* or whether this level can be standardised from one patient to another. It could be that the depth of knowledge on a particular information topic is dependent upon the individual patient characteristics, preferences and priorities for information in relation to their circumstances and existing knowledge level. Contention exists in establishing and measuring such knowledge levels and as to who is best placed to determine whether a knowledge level is deficient (be it the patient or professional). It would appear that a combined approach might be the most effective approach, determining what a patient knows and what is important for them to know, alongside repetitive measures to determine the extent of information recall. Further research is required to define and understand patient knowledge levels and whether a minimum level of knowledge can be explicated and applied to the patient group.

Groome et al. (1994) based on the experience of established dialysis patients, identified that new CKD patients have different priorities and preferences for the provision of information. However, little work has been undertaken to determine the priorities of established dialysis patients themselves, and measure how these priorities change over time, during the progression of the disease, as a result of co-morbidity and/or the treatment trajectory. Back in 1993, Leino-Kilpi et al. (1993) suggested that CKD patients require information that is relevant to them in different phases of the care pathway, although little evidence has emerged since which measures and describes this notion of changing information needs.

The review touches on information seeking behaviour demonstrated by some CKD patients, particularly long-term survivors. The evidence does not indicate whether the information needs of active patients seeking information differ from those patients who do not seek out information, the information priorities between the two groups remains unclear. It could be hypothesised that all patients have common information topic areas but the depth of information required on a specific topic at a specific time varies amongst patients. Those who consider an information topic to be pertinent to their current circumstance will seek out additional information (either because they want to know more or do not understand). Whilst others may be content with a low level of information and refrain from seeking further information because the particular topic area is less important to them at the present time.

The review was valuable in identifying and describing the information topic areas that CKD patients consider important and highlighting the factors that influence the information needs of CKD patients. However, the lack of pragmatic evidence determining patients' priorities and preferences for information, particularly with respect to changes over time along the continuum of the chronic disease, draws attention to the need for further research on this topic area. There was limited evidence to suggest that contextual factors influenced the need for information of CKD patients, for example striving to maintain a normal life, coping with the physical affects of CKD, events that occurred, and along the disease pathway, and work. These findings lack clarity and thorough understanding, generally emerging anecdotally from studies. Both the context and purpose of information underpinning and influencing information needs requires deeper exploration.

Chapter Five

Approaches to Measuring and Identifying Information Need

Introduction

In chapter three the theory of information and the related concepts were explored drawing on the extensive research experience in information science and the available evidence in health research. Understanding the multiple meanings and different forms of information is fundamental to developing a study identifying and measuring CKD patients' information need.

The systematic review of the available evidence within the field of CKD indicated a lack of empirical evidence grounded from the patients' perspective, particularly within the UK (chapter four). However, the review proved valuable enabling the identification of potential core information need themes important to patients. The methods used to measure or identify information needs employed within CKD were limited creating the need to look wider than this speciality and draw on the work of others with greater expertise in this field of research. This broader position provided the opportunity to examine the strengths and weaknesses of available methods and facilitated the selection of an appropriate methodology for this study based on an informed choice.

The choice of methodology is not taken in isolation, indeed the underpinning philosophical paradigm, thoughts and perspective of the researcher forms a critical component to any decision. The study idea originated from a passion to address the gap in research knowledge that identifies the need and purpose of information from the perspective of the CKD patient rather than what information the professional thinks they ought to know. Fundamental to this study is the value and respect shown to the perspective of the CKD patient, to generate a deeper understanding of what information *they* consider important and essential to manage *their* life with long-term kidney disease.

This chapter was compiled with the aim to make visible the perspective of the researcher, to provide an overview and examples of the different approaches used to measure and identify information need, and clarify the motives behind the choice of study methodology (described in chapter six).

Philosophical Perspective of the Researcher

To understand the epistemology guiding this particular research study of information need it is necessary to briefly revisit the theory of information presented in chapter three. The tenets of whether information is objective (external) or subjective (internal) appear divided.

Dervin's (1992) meta-theories underpinning sense-making suggest that information is created through interactions and by making sense of reality that occurs as a result of encounters with problems and discontinuities in knowledge. This, although Dervin does not describe it as such, is synonymous with constructivism (Dewey, 1960, Case 2002) and infers that what we know is determined by our ideas and that reality is constructed in our heads and invented by us, that information is subjective and internal. Within the realms of naturalistic and constructivist enquiry, the methods advocated by Dervin such as the sense-making interview places the meta-theory towards one end of the epistemological spectrum. The constructivist perspective has been useful in the health care professions, particularly psychology, to focus on the individual client, what they believe and what is real for the person whose health is compromised. Indeed believing that a person constructs his or her own meaning underpins this study but believing that one person's meaning is the absolute truth and that reality has no relevance to what we know, is not. Constructivism fails to acknowledge those:

> *'structural and institutional features of society which are in some respects independent of the individuals' reasoning and desires'* (Pawson and Tilley 1997, p23).

Reality is central to the enquiry and realism espouses that an external world exists independently of our representations of it (Speed 1991, Cromby and Nightingale 1999). Information can be objective and external to the individual, CKD information exists, it is known, whether that person is diagnosed or not, that is the reality. The information a person who is diagnosed with CKD needs to be able to understand what is happening to them, to construct meaning, to make sense of their real life with a chronic illness, and help them cope is the centre of the research attention. Reflecting on the study definitions posed in chapter three, Case (2002) combines the opposing opinions of Hayes (1993) and Dervin (1992) that information is *'any difference you perceive, in your environment (external) or within yourself (internal), it is any aspect that you notice in the pattern of reality'* (p5). To study both types of information the epistemology of constructionism is compatible with realism in ontology. Constructionism, different to constructivism, in that it takes the objective seriously, is open to the world and brings both the objective and subjective positions together (Crotty 2003), such as a person constructing meaning as they engage with and interpret the world. It is not to be confused here with the narrow focus of social constructionism that believes all meaningful reality is socially constructed (Berger and Luckman 1967). Although, the research philosophy acknowledges the importance of both social and cultural mechanisms governing behaviour, and how they may influence the way meaning is constructed by a person, it is not seen in isolation. Taken in the broadest sense constructionism widens the focus from an individual mind making meaning to the '*collective generation [and transmission] of meaning*' (Crotty 2003, p58). We know differences exist between people and their need for information and constructionism allows and encourages those differences to be compared to generate collective meaning. Patients themselves use peer comparison, comparing their experience of CKD against the experiences of others, constructing new meaning to help them understand and cope with their illness (Bath et al. 2003, Tweed and Ceaser 2005).

The philosophical perspective underpinning this study reflects an embedded theory of learning and education that will extend further than the research in question and seek to inform and guide the provision of information in clinical practice. This notion of constructionism is based on the theory of learning developed by the educationalist Seymour Papert (1980), *learning-by-making*. It conceives learning as a self-directed, iterative process by which learners construct *'knowledge structures'*, learn by making meaning, by internalising their actions, through experience, whether it worked and using tools and mediation that best supports them (Papert and Harel 1991, p1). It focuses on the needs of the learner, the context and situation in which they find themselves, their motivation, curiosity, willingness to engage, social activity, experiences and time. Central to the theory are the dynamics of adaptation and change and comparing how different people think when faced with alternative views, adjusting and expanding their current view of the world. This is particularly pertinent to patients faced with the diagnosis of CKD whose world view is changing, they are learning-by-making sense of what is happening to them and having the appropriate tools such as information at the right time is fundamental to enable them to effectively cope and adapt to their illness.

This digression focusing on learning theory was not to distract the focus from epistemology but to strengthen the constructionist stance adopted and make clear the long-term view for taking such a position. Similarities can be drawn between the Sense-Making theories of Dervin (1992) and that of Papert's (1980) constructionist learning theory both of which have been instrumental in developing the fundamental views of the researcher. Information that meets the need of the CKD patient is an integral component in the patients' learning journey and cannot be considered separately to theories of how patients make sense and construct meaning from it. Valuable evidence that informs healthcare professionals regarding what, why and when, patients need information will improve and enhance the quality of care patients receive.

Research Approaches to Measure and Identify Information Need

The philosophical origins of this study are therefore based on the assumptions that an information need is subjective, bound by the context of the individual, whilst at the same time acknowledging that the type and content of information need can also be measured objectively. Methodologies focusing on the information need of a *person-in-context*, favour more in-depth, inductive, subjective and unstructured qualitative approaches, adopting methods such as interviews, observation and diaries to tease out aspects of the phenomena. Whereas deductive methods broaden the research from the specific to the general using more structured, quantitative methodology such as surveys and questionnaires. Information needs in health are usually assessed by asking patients what information they prefer to receive from a health care professional, achieved either using a single or combined methodological approach (Pinquart and Duberstein 2004). The following examples of both qualitative and quantitative methods provide an impression of the diversity of approaches that exist including nomothetic describing *what* information need and idiographic methods exploring *why* information needs arise.

Qualitative Methods

Interpretative or naturalistic approaches are often embraced to draw out the information need of a *person-in-context* and elicit the perspectives of individual’s. This means that considerable emphasis is on the collection of qualitative data using methods such as individual in-depth interviews, focus groups and diaries. These types of methods appear effective at drawing out what information needs patients have as well as providing more in-depth data as to the purpose of information and the individual’s reasons as to why they are important to them.

Interviews

Interviews have been commonly used across different health settings to explore in-depth the information needs of patients, the popularity of which is clearly evident from the review of CKD studies in the previous chapter. Studies have included disease specific groups such as cancer, asthma and polycystic ovarian syndrome (PCOS) (Leydon et al. 2000, Caress et al. 2002, McCaughan and McKenna 2006, Avery and Braunack-Mayer 2007). Others have focused on a specified group for example adolescents or pregnant drug-addicted women (Cardillo 1999, Dervin et al. 1999); whilst some have taken a more generic approach exploring, for example, the information needs of patients before and after a consultation with a health care professional (Attfield et al. 2006); or the everyday life information needs of an individual (Julien and Michels 2004).

Interview Techniques

Interviews in the studies highlighted above were semi-structured (Attfield et al. 2006, Mccaughan and Mckenna 2006, Avery and Braunack 2007). Whilst some use a conversational style (Caress et al. 2002, Julien and Michels 2004), others describe their in-depth interview technique as '*listening*' to patients (Leydon et al. 2000, p1). Typically interview schedules are generated to guide, prompt and to explore similar issues across interviews, taking care not to restrict or influence an individual's subjective perspective. Whilst schedules may be piloted prior to use (Dervin et al. 1999, Avery and Braunack-Mayer 2007) interview questions can develop iteratively as interviews progress (Caress et al. 2002, McCaughan and McKenna 2006). Key interview questions include; what information was wanted, what information was received, whether it was helpful, how it was helpful with particular reference to their health problem, diagnosis, disease or condition (Leydon et al. 2000, Caress et al. 2002, McCaughan and McKenna 2006, Avery and Braunack-Mayer 2007), or examined information needs surrounding a particular situation or event (Attfield et al. 2006, Julien and Michels 2004).

Specific interview techniques, developed as part of the Sense-Making Methodology by Dervin have been used widely to understand how information assists sense-making and sense-unmaking for individuals within the context of their lives (exemplars of which can be found on the dedicated Sense-Making Methodology website). Two examples are described here to illustrate the interview techniques employed. In Dervin et al.'s study of the information needs of pregnant drug addicted women (1999) the first stage of the interview is initiated by asking the participant to think back to a time in her pregnancy when she felt worry or concern related to herself or the baby. The participant was then asked to recall everything that happened to her in the situation she was remembering. Each step was catalogued on white index cards and numbered to correspond to gaps, questions or confusions that occurred at the same time (written in pink index cards). Once this stage was complete all index cards were set out and reviewed by the participant and further thoughts, questions or events added. The participant was then asked to choose four thoughts and four questions which stood out in their mind regarding the particular situation. The interviewer then, using 36 open-ended questions, explored in greater depth the thoughts and questions chosen by the participant and the uses of answers they constructed to questions. Cardillo (1999) used a similar interview technique in her study with adolescents. In this study the context on which the research was to focus, issues of power, control and autonomy of adolescents experiences with health care providers and caregivers was determined at the outset, and the participant asked to reflect on a worst experience.

This particular interview lasted four hours, which may reflect the researcher's inexperience of the particular technique given that similar interviews took less than 90 minutes to execute (Dervin et al. 1999).

The technique used in both Sense-Making studies involves a painstaking '*circling and re-circling'* (Cardillo 1999, p6), probing and exploring the situation (event when information need arose), gaps (questions and information deficit/need) and uses (sense made of information). The fundamental difference therefore, between the Sense-Making interview and the exploratory semi-structured approaches adopted by other researchers appears to be the amount of depth to which one element within an interview is exposed and examined in minute detail, not necessarily the systematic questioning technique per se. The added dimension of the Sense-Making method is the ability to draw out and understand how the participant feels and how information is used in context, as well as identifying what information needs and why they are important.

Concept of Time in Interviews

One of the important aspects to note regarding some interview techniques is the dimension of time. Integral to the Sense-Making Methodology is the concept of time and space, and micro-moment time-line interview technique explores a particular situation, experience or event and the sense made from them at a specific point in time or over a span of time (Dervin 1992). Similarly in other exploratory studies information need is investigated at a specific time during disease progression such as the time diagnosed (Leydon et al. 2000, McCaughan and McKenna 2006); and the time of a specific event such as clinical consultation (Attfield et al. 2006). The benefit of using a time dimension within an interview framework would appear two-fold, to capture the changes in information need with respect to a specific event over time, as well as to focus and guide the interview ensuring the information gained from individuals is meaningful to time and context. Time has also been used within the analytical approach adopted by Julien and Michels (2004) who prioritised information need, by coding the time within which information were perceived to be needed; today (crisis); in a few days (short-term); few weeks (long-term); and undetermined, no time limit within which the information was needed.

Interview Analysis

Different inductive techniques were used to analyse interview transcripts and identify emerging themes, ranging from thematic analysis (Leydon et al. 2000, Julien and Michels 2004), content analysis (Caress et al. 2002, Avery and Braunack-Mayer 2007) and grounded theory using the constant comparative analytical method (Attfield et al. 2006, McCaughan and McKenna 2006) based on the work of Straus and Corbin (1998). Dervin et al. (1999) report the application of similar analytical techniques within Sense-Making, such as recognising patterns regarding the key concepts (situations, gaps, uses) and using content analysis to draw out key concerns. The process is systematic and reflects the underlying assumptions of the Sense-Making theory, that participant concerns and their efforts to construct useful answers are embedded within social and cultural interactions alongside perceptions and feelings bound by the context in which they arose (Dervin et al. 1999).

Simultaneous reflection is often used throughout the interview process to clarify and verify aspects of the discussion back to participants (Julien and Michels 2004, McCaughan and McKenna 2006) and through the generation of index cards to focus and re-visit the same issue (Dervin et al. 1999, Cardillo 1999). The reliability and validity of emerging themes can be increased by data analysis performed by more than one person and/or participant verification of theme accuracy (Leydon et al. 2000, Caress et al. 2002, McCaughan and McKenna 2006).

Diaries

Diaries have been used effectively in information science research to record information seeking alongside information needs, for example the use of archives by historians (Wildemuth 2002). Williamson (1998) used telephone diaries to capture the everyday incidental information acquisition of older adults. Participants recorded through the diary the purpose and topic of incoming and outgoing telephone calls, over a two-week period. Although participants were provided with a list of fixed categories (such as appointments and gathering information) to attribute their calls the researcher reports difficulties with ambiguity and subsequent coding of the complex unstructured data. This method identified the need for deeper information regarding different topic areas, and follow up interviews were later performed to explore the purpose of information.

Hepworth and Harrison (2004), in their study that employed a mixed method approach, describe an audio-recorded diary to explore the day-to day experience of a person with multiple sclerosis. Each person was instructed to record events; situations in their daily life where they needed to know something wanted to find out something or had a problem to solve. The purpose of using such a method was simply to explore the kind of information that could be generated by such a tool not to influence or inform the subsequent survey that was developed. The diary captured the range of symptoms people experienced over a short time period and indicated the perceived importance of taking an active role in life, well-being and quality of life. To capture the every day information needs of one individual, over a ten-week period, a similar diary method, combined with weekly interviews, was used by Julien and Michels (2004). The participant was asked to reflect and document his thoughts regarding particular information seeking situations, which formed the focus of the subsequent weekly interviews to explore an individual’s in-depth information behaviour.

Advantages and Disadvantages of Qualitative Methods

The primary advantage of using qualitative methods such as interviews or diaries within the context of exploring information need, is not just that information needs can be identified but also the opportunity to develop an greater understanding of why such needs arise, the purpose and meaning to an individual in the context of their lives, values and personal perspectives (Julien and Michels 2004). This understanding can be used in a variety of ways; whether it is with the intention to develop or extend theories (Leydon et al. 2000, McCaughan and McKenna 2006); generate a grounded theoretical and reliable platform upon which to develop quantitative instruments (Caress et al. 2002, Hepworth and Harrison 2004); or make sense of individual experiences within context (Dervin et al. 1999, Cardillo 1999, Attfield et al. 2006). Hepworth and Harrison (2004) suggest that the diary method is more effective, in providing valuable detailed data on the type of situations people are confronted with and their thoughts about the purpose of the information they need than questionnaires and surveys. A further benefit of using diaries being that participants thoughts regarding information need are concurrently recorded rather than considered retrospectively (Wildemuth 2002).

The main drawback and disadvantage of such investigative profundity is that qualitative methods often dictate small samples given labour intensity and time required to appropriately execute such techniques not only by the researchers themselves but also the expected time burden for the participant. For example, Hepworth and Harrison (2004) only managed to recruit five people with multiple sclerosis to use the diary method compared with over 2000 people who responded to subsequent questionnaire. Similarly interview recruitment is often poor (Caress et al. 2002) and personal interviews could skew the sample towards the perspectives of those who find it easier to talk (Leydon et al. 2000). Small qualitative studies have a high internal but low external validity and hence limited generalisability, although confirmation of similar findings through triangulation of methods or from other studies increases confidence (Leydon et al. 2000, Caress et al. 2002, Avery and Braunack-Mayer 2007).

Despite the limitations of qualitative methods the depth of exploration and value of such techniques cannot be overrated, given that the majority of quantitative instruments derive content face-validity primarily through individual or group interviews.

Quantitative - Measurement Scales

There are a number of quantitative scaling methods available for measuring the information need of patients, some of which have been in existence for nearly 30 years. The main objective of scaling is to obtain accurate, representative findings, with minimal cost and the least amount of measurement error (Degner et al. 1998). Two types of measurement scales, summated and differential, have been used to measure information need, both measures use different answering categories and focus on different information topics (Mesters et al. 2001). However it not so easy to distinguish between which types of measure has been used within a particular study as collectively they are often referred to as *Information Needs Questionnaires* or abbreviated to INQ.

Summated Scales

Summative scales, the most common being Likert scales, are easy to develop and use a subject-centred approach to scale individuals at different points along a continuum (Degner et al. 1998). They achieve this by presenting a list of statements about a single topic and asking respondents to identify their level of agreement or disagreement with each statement, rather than only those with which they agree. Each response is assigned a numerical value. The total scores for individuals are obtained by adding together the response scores of constituent items (McIver and Carmines, 1981) and this determines the position of the subject with respect to the measured dimension(s) (Degner et al. 1998).

One of the first, the Information Needs Styles Questionnaire (Cassileth et al. 1980) was generated for cancer patients in the UK, and has since been modified and used by others within the same field (Fallowfield et al. 1995, Meredith et al. 1996). Orsino et al. (2003) developed a questionnaire for measuring the information needs of CKD, the content of which was drawn from existing tools based on the work of Cassileth et al. (1980) and Fallowfield et al. (1995). However, there is insufficient evidence of the questionnaire or adequate descriptions within the published work which makes it difficult to evaluate in any depth. This type of information needs questionnaire was used by Kumar et al. (2004) to measure the information needs of Asian cancer patients, which appears to be one of its kind performed with patients from ethnic minority groups.

More recently Fine et al. (2005) in Canada, adapted the Cassileth et al. (1980) questionnaire for use with nephrology patients (patients who do not yet require or in some cases may never require dialysis), to assess patients’ expectations of what information the doctor should provide if dialysis became necessary. As described earlier (chapter four) the 15-item questionnaire focused on the type of information (6 items), preferred information for decision making (5 items), and a further 4 items explored reasons why patients wanted more information about life expectancy. The six types of information items were concerned with possible side effects of dialysis; limitations of quality of life; actual life expectancy on dialysis; what dialysis does to the body; effectiveness of dialysis; and what dialysis will accomplish. Patients were asked to rate items using a three-point Likert scale (don’t want to know, would like to know, and absolutely need to know). The majority of the questions used identical phrasing to the instrument developed by Cassileth et al. (1980) although the wording of one question included '*likelihood of cure*' and was changed to '*life-expectancy'*. The other nine items were rated using a five-point Likert scale (1=strongly agree to 5=strongly disagree). A significant flaw within the study was that patients were recruited who were not destined for dialysis and asked to respond to a theoretical rather than a real life situation, this was later rectified in a replica study performed with patients at CKD stage 4 (Fine et al. 2007).

Although the items within all the developed Information Need Style questionnaires (Cassileth et al. 1980, Fallowfield et al. 1995, Meredith at al 1996, Fine et al. 2005) have face-validity, criterion-related validity has not been tested and internal consistency scales are not provided making it difficult to assess the reliability of the instruments (Pinquart and Duberstein 2004).

Other summated instruments that adopt a similar Likert scale ranking method include; the Toronto Informational Needs Questionnaire (TINQ-BC) used with breast cancer patients in Canada (Galloway et al. 1997, Harrison et al. 1999); and the Patient Information Need Questionnaire (PINQ) used with breast cancer and Hodgkin disease patients in the Netherlands (Mesters et al. 2001). The TINQ-BC initially designed with 51 items was modified and a two further items added when used by Harrison et al. (1997). Each item begins with the stem '*it is important for me to know',* and items are collated under five topic domains (disease, tests, treatment, physical and psychosocial), measured on a 5-point Likert scale (ranging from 1=not important to 5=extremely important). Internal consistency appeared satisfactory with Cronbach's alpha higher than 0.75 for the sub-scales and 0.97 for the questionnaire as whole. A similar tool the PINQ was considered more relevant for use with cancer patients when compared to other instruments, because of the practicality of a reduced number of items and the inclusion of psychosocial concepts (Mesters et al. 2001). Within the 17 items; five were associated with information regarding the disease; four the treatment; two the best way to talk to friends, family or the physician about problems; and one item each relating to the patient's current social situation (work, hobbies, food and drink), exercise, where to find help if experiencing problems, wanting more educational material about illness or prosthesis, and orientation to the hospital setting.

Items were rated on a 4-point scale ranging from no need, some need, moderate need, to great need. The tool was tested within different groups of cancer patients and the internal consistency was indicated to be repeatedly satisfactory, although not stated.

Within a different cohort of patients, Hepworth and Harrison (2004) surveyed the information needs at the time of diagnosis of people with multiple sclerosis (PWMS) alongside information provision, and the importance of and difficulty in obtaining for specific information topics. Information topic importance was measured using 24 items that covered a whole range of topics from disease, physical, social and psychological problems through to employment, financial, transportation, practical resources and aids. Each item was rated using a 4-point Likert scale (ranging from 1=unimportant to 4=very important). The measurement of the difficulty in obtaining information was assessed using the same set of 24 items with 4-point Likert scale (1=very difficult to 4=not at all difficult) and participants were also offered the category of ‘not needed’ if they had indicated in the previous question that the specific item was not important. Again although items had face-validity, there is no report of criterion-validity or internal consistency.

More recently Hyland et al. (2006) developed the Lung Information Needs Questionnaire (LINQ) for Chronic Obstructive Pulmonary Disease patients. Although this questionnaire claims within the title to measure information need it appears misleading when the content of the tool is placed under closer scrutiny. The majority of the 17 questions posed asked patients ‘*what do you know…*’ or ‘*have you been told…*’ rather than ‘*do you prefer to know’* (p1811-1813), a distinct difference when compared to other tools. There is no attempt to identify the information needs of patients but more to establish what they already know, based on the assumption that everyone should know specific items, have a basic understanding. The recommendations of the study restrict its use to a pre-interview knowledge assessment tool, but even used in this way it does not accommodate individual preference for information.

Differential Scales

The differential type of scale takes an alternative approach, concerned with measuring the subjective meaning of a concept to a respondent, instead of how much they believe in a particular concept (Robson 1993). One such differential scale, and the most common used within health settings, adopts the Thurstone (1974) paired comparisons approach. Thurstone (1974) identified that a set of items (stimuli) possess some attribute in varying degrees and an individual would make a preference judgement regarding the importance of an item when compared with another. It is not assumed that each item will evoke the same response from different individuals or that the same individual will make the same judgement at different times (McIver and Carmines 1981). Therefore amongst subjects it is assumed that a preference will exist that for each item the preference will be normally distributed around the items most frequent response (Maranell 1974). Any two items may differ in scale values, and can be ordered in priority along a continuum representing status, from most to least. The preferred proportions for an item are translated into standard normal scores referred to as Z scores and the larger the value the more preferred was that item (Degner et al. 1998).

The first to develop this type of information need scaling approach was Degner and colleagues (the underpinning theory and developmental work is detailed in Degner et al. 1998). The scaling method was piloted in the UK and Canada with breast cancer patients (Luker et al. 1995, Luker et al. 1996, Bilodeau and Degner 1996, Degner et al. 1997a and 1998).

The method developed by Degner et al. (1998) involved identifying nine core information needs by way of an extensive literature review. The information topics identified included chances of cure, spread of disease, treatment options, family risk, adverse effects, home self-care, impact on family, social activity and sexuality. Once the core needs were identified they were ordered into 36 pairs, with one item compared against another and respondents asked to decide which was considered most important. The pairs were presented in such a way to avoid presentational bias (Ross 1974). Since the development of this scaling method a number of researchers have adopted the approach across different health settings but predominantly to measure the information needs of patients with breast cancer, ovarian/gynaecological cancer, and colorectal cancer (Luker et al. 1995, Luker et al. 1996, Bolideau and Degner 1996, Degner et al. 1997a, Beaver et al. 1999, Wallberg et al. 2000, Browall et al. 2004, Beaver and Booth 2007). Within all studies authors report internal consistency using Kendall’s coefficient of agreement demonstrating consistency between respondents’ comparative judgements (Edwards 1974).

Advantages and Disadvantages of Measurement Techniques

Both scaling methods have advantages and disadvantages when applied in practice to measure information need. Likert scales are easy to construct, can contain many different items and are practical in terms of cost (Robson 1993). Although it is easy to introduce bias in the way items are positively/negatively worded requiring item analysis and rigorous testing over time. Paired comparison scales require a time-consuming selection processes in the preliminary stages of a study to ensure optimum items are included the in the instrument (Degner et al. 1998). However there is always the possibility that items important to only a small number of individuals may be eliminated during this process. The paired comparison method forces an individual to articulate a preference for one item over another, but does not accommodate responses that may sit between either agreeing/disagreeing with an item (Degner et al. 1998). Likert scales provide total scores for each item, allowing individuals the opportunity to assess the degree to which they agree or disagree, but when these scores are the same for items there is no way to determine whether one item is considered more important than another.

Indeed, one of the inherent disadvantages of the summated scale is the possibility of the results indicating a *ceiling effect*, for example all respondents could identify that they find information *extremely important* for all the topics listed. For clinicians whose time is limited, identifying that an individual needs as much information on every topic impedes targeted information provision, whereas methods that identify information priorities could be considered more useful. Degner et al. (1998) identified such a problem, in their early work using Likert scales, where participants indicated high levels of desire to know a *fair bit* or *almost everything* about all information topics presented. It was this that motivated the researchers to look towards the alternative paired comparison approach. This approach unlike the Likert scale has the ability to not only rank items and create a preference/priority order but also to measure the distance between items giving a greater idea of how much more important one item is over another.

One of the clear advantages of using questionnaires and survey methods is the ability obtain breadth to the research and target a large sample (McDowell 2006). Within the studies mentioned above, sample sizes ranged from 53 patients (Beaver and Booth 2007) to a maximum of 498 (Mesters et al. 2001). The majority of researchers chose to administer the questionnaires within a face-to-face structured interview, to facilitate the clarification and understanding of the concepts being investigated (Bolideau and Degner 1996, Luker et al. 1995, Degner et al. 1997a, Meredith et al. 1996, Harrison et al. 1999, Wallberg et al. 2000, Mesters et al. 2001, Browall et al. 2004, Fine et al. 2005). Hepworth and Harrison (2004) on the other hand used a postal questionnaire and recruited 2030 PWMS.

The advantage of targeting large numbers of patients provides an opportunity to identify the information needs for distinct groups within a sample, to understand and explore how demographic characteristics (for example age, gender, marital status, employment, education level, stage of disease) can influence both the need and type of information (Luker et al. 1995, Degner et al. 1997a, Wallberg et al. 2000, Browall et al. 2004, Kumar et al. 2004). For example, both Harrison et al. (1999) and Meredith et al. (1997) explore differences by demographics and differences with respect to type of surgery and treatment received. Hyland et al. (2007) were able to demonstrate differences between the information need of patients who had contact with a healthcare professional and those who did not. Hepworth and Harrison (2004), despite recruiting such a large sample from the population with multiple sclerosis, fail to report any demographic differences or similarities within the sample group with the exception of changes in information need since the diagnosis. Apart from the study by Kumar et al. (2004) a review by Watts et al. (2004) highlighted a dearth of research regarding the breast cancer information needs of women of ethnic minority groups. Although the findings by Kumar et al. (2004) indicated that ethnicity did not influence the need for information and most patients wanted as much information as a possible. This may account for the fact that in other healthcare settings differences in ethnicity seems to have been overlooked as a feasible demographic variable, although difficulties in recruiting appropriate samples is more than likely to be the reason. One of the disadvantages of broadening the research across a large sample is the inability to understand the reasons why an information need is more of a priority to a group of individuals. Unlike interviews instruments are not sensitive enough to capture the deeper contextual and situational issues influencing an individual's information need, or allow postulations as to why some individuals prefer more information than others (Hepworth and Harrison 2004).

Instrument Face-Validity

As previously mentioned the importance of using qualitative measures for identifying information needs cannot be underestimated given that the majority of surveys and questionnaires were derived from such origins. The face-validity of many questionnaires was determined using preliminary patient interviews or focus groups to agree and confirm the instrument content (Cassileth et al. 1980, Degner et al. 1997a, Mesters et al. 2001, Hepworth and Harrison 2004, Fine et al. 2005, Hyland et al. 2007). Failure to involve patients at the outset in instrument design draws doubt on whether the tool can successfully address the needs of the patient and again goes back to patients' information preferences being determined by professionals and not grounded in what patients themselves consider important (Scott and Thompson 2003).

Cross-sectional and Longitudinal

The majority of studies highlighted above use a cross-sectional or retrospective design (Cassileth et al. 1980, Meredith et al. 1996, Degner et al. 1997a, Harrison et al. 1999, Fine et al. 2005). The dimension of time has been measured within cross-sectional studies by comparing different lengths of time individuals have been diagnosed with a specific illness. Hepworth and Harrison (2004) compiled a distinct set of information needs for patients first diagnosed and different long-term information needs. Longitudinal measures by Luker et al. (1995) (at diagnosis then 21 months later) suggest that information need changes as the disease progresses, although later research by Harrison et al. (1999) using a different tool did not confirm these findings. Mesters et al. (2001), in a prospective longitudinal study measuring information needs at different time periods (6, 13 and 52 weeks), report that the need for information on disease and treatment reduces as time progresses and is replaced by information needs about access to help find solutions to problems. Evidence suggests that adding a time dimension either through longitudinal or cross-sectional measures is useful in determining differences that may exist between the needs of newly diagnosed patients and those patients experiencing a long-term chronic illness.

Analytical Methods

Quantitative analysis typically includes both descriptive and inferential statistics. For example, studies using Likert scale methods chose to present the frequencies of aggregated data, total percentage (% like and not liked) scores for responses to specific items using descriptive statistics (Hepworth and Harrison 2004, Hyland et al. 2007). In addition, Meredith et al. (1996) used cross tabulation mean scores to compare across demographic variables. Mesters et al. (2001) and Hyland et al. (2007) used t-tests to compare domain scores between different groups of patients, measuring dimensions such as changes over time and educational contact from different professionals respectively. Whereas Harrison et al. (1999) performed more sophisticated analysis using mean percentage scores of the sub-scales; chi square tests proportions to look for significant difference across demographic variables, independent t-tests to assess changes in individual scores over time, as well as one-way analysis of variance (ANOVA) and Pearson's Product Moment Correlation to explore repeated measures at each time interval.

Analysis performed within the paired comparison is more complex requiring bespoke analytical software, designed by Sloan et al. (1994) for the subsequent application in the work by Degner et al. (1998). Sloan et al. (1994) developed a comprehensive manual outlining the mathematical and statistical analytical procedures for the thorough analysis of the Thurstone Scaling approach. Valuable resources for researchers adopting this approach were the analyses packages available free to download from the University of Manitoba. Authors using the paired comparisons approach identify accessing these analytical packages (Luker et al. 1995, Bolideau and Degner 1996, Degner et al. 1997a, Wallberg et al. 2000, Browall et al. 2004 Beaver and Booth 2007).

The analytical program used in the paired comparison approach produces a matrix to reflect the number times each item is preferred over every other item. The preferred proportions are then translated into standard normal scores and reflect the patients' weightings of the items. The larger the value the more preferred an item; a scale score of 0 indicates that 50% of the respondent preferred the item, and a negative score indicates that less than 50% preferred the item (Sloan et al. 1994). Similar to Likert scale analysis, independent t-tests, analysis of variance and chi square tests all have a role to play in Thurstone Scaling data analysis, to compare scale scores alongside demographic characteristics. Reliability is determined using Kendall’s coefficient of consistency measuring the consistency of an individual in their comparative judgments and Kendall’s coefficient of agreement measuring consistency between respondent choices (Edwards 1974). From the computer manual developed by Sloan et al. (1994) the Mosteller chi-square test of internal consistency with a non-significant p-value indicates whether the scale values fits the observed data. The majority of the studies using this approach however chose not to report these results. Profiles of information needs across sub-groups are compared using a test for quality of proportions using a Bonferroni correction. One problem identified, particularly within using this type of instrument in longitudinal studies, is that the statistical package to measure change over time between information needs has not been developed within the manual (Browall et al. 2004) restricting analysis to comparing differences in scale values across time intervals.

Additional Concepts

Various concepts have been studied alongside information need to understand and identify factors that may influence an individual’s need for information. These include information sources, preferences for information, decision-making preferences, control preferences, self-efficacy, anxiety, depression and psychological symptoms.

Information sources (who should provide information and in what format) and the participants’ preferences regarding the perceived usefulness of different sources to satisfy their information need are generally explored in two ways. Within more structured studies participants are asked to indicate and then rate an information source and its perceived usefulness, usually from a pre-determined list using a Likert scale (Luker et al. 1996, Meredith et al. 1996, Orsino et al. 2003, Hepworth and Harrison 2004). Alternatively information sources are discussed with individuals within exploratory interviews (Julien and Michels 2004, McCaughan and McKenna 2006, Avery and Braunack-Mayer 2007). Both methods appear effective at highlighting the preferred information sources either by an individual or a particular patient group. However, more structured Likert scale instruments used within larger samples provide the opportunity to compare and contrast patient preferences alongside demographic characteristics (Luker et al. 1996). Differences in information source preferences have been identified between different age groups (Orsino et al. 2003).

Using the seven-item information sub-scale from the Health Opinion Survey Harrison et al. (1999) identified no significant difference between an individuals preference for information compared with their desire to be informed about health decisions. The early information needs questionnaire by Cassileth et al. (1980) and subsequent modified versions such as Fine et al. (2005) included questions regarding information provision related to decision making, the majority of patients preferred information which promoted self-care and enabled them to participate in decisions about their care, whether that information was good or bad news. Similarly, decision-making preferences using the Control Preferences Scale, by means of a card sort method developed by Degner et al. (1997b), was used alongside information need instruments to compare and contrast patient preferences (Wallberg et al. 2000, Beaver and Booth 2007). The importance of measuring such factors is to identify whether a patient's perceived control over their illness and treatment decisions influences the depth and type of information they require. Comparative results across studies show that patients may indicate a strong preference for disease related information but not necessarily want an active role in their treatment decision (Luker et al. 1996, Degner et al. 1997b, Wallberg et al. 2000).

Orsino et al. (2003) in their study of CKD patients used the O'Connor Decision Self Efficacy (DSES) questionnaire to measure the level of confidence in medical decision-making. Patients were asked four simple and focused questions regarding the preferred level of participation in treatment decisions. Questions were posed to allow patients to select an appropriate statement, such as '*prefer to make treatment decisions alone'*; *'want equal responsibility with healthcare team for decision-making'*; and *'prefer the health care team to mostly make the final decision'* (Orsino et al. 2003, p5). The preferred and actual participation experienced by the patient was measured using the same responses, with findings indicating a significant difference between what was preferred and what was actually occurring in practice. Older patients indicated a more passive role reliant more on the healthcare professional to make ultimate decisions. Higher decisional self-efficacy (DSES) scores represented greater self-efficacy in engaging in treatment decisions, younger patients scored higher but no significant difference was noted between genders. Three concepts were compared by Klang et al. (1999) with CKD patients; sense of coherence (their perceived ability to understand and effectively manage stressful life situations); their knowledge after receiving an education intervention; and their perceptions regarding the amount of information received. However, no significant correlation was found between the scores of the three items.

Mesters et al. (2001) in the Netherlands used Spielburger State-Anxiety Inventory and the Rotterdam Psychological Symptom checklist to explore whether unmet information needs increase other indicators of emotional distress such as psychosocial complaints and depression. The findings indicated that a higher level of depression corresponded to a greater need for information and also greater information need related to higher psychological complaints. This study highlights the need to be aware of the potential psychological effects a lack of information can produce and reinforces the importance of identifying and meeting the information needs of patients.

Summary/Choice of Methodology

The methodological overview illustrates the existence of a number of pertinent approaches that identify and measure information needs within health care settings. They explore and describe contextual aspects to understand how information needs emerge and analyse demographic characteristics of patient groups to observe patterns of information behaviour. Rutten et al. (2004) indicate an increase in publications since the year 2000, particularly within the field of cancer care, suggesting a renewed and growing interest in such a topic, more than likely instigated by policy directives. To date however, the existing evidence has not yet established the best way to measure the type and amount of information a patient may wish to have. One explanation for this could be that philosophical perspectives force researchers to differentiate and choose between qualitative versus quantitative methods. What is clear from the evidence is the potential benefit that could be gained from harmonising both approaches to establish a deeper understanding of information need in context alongside obtaining a broader appreciation of the interaction of variables in a complex environment, across larger patient groups.

Indeed, researchers adopting a qualitative strategy advocate the subsequent development of quantitative measures to test further their findings with a more representative sample (Leydon et al. 2000, Caress et al. 2002, Avery and Braunack-Mayer 2007). Those using quantitative instruments describe the greatest drawback as being the lack of contextual evidence within which to explain findings (Scott and Thompson 2003, Hepworth and Harrison 2004). A more combined exploratory and analytical approach is one way forward, building upon research experience gleaned from both perspectives (Miles and Huberman 1994). This is not a new approach as mixed methods have been fundamental in the construction of many of the quantitative instruments developed, the content of which is derived primarily from qualitative methods (Cassileth et al. 1980, Degner et al. 1997a, Mesters et al. 2001, Hepworth and Harrison 2004, Fine et al. 2005, Hyland et al. 2007). However, the problem with such studies is the lack of adequate reporting of the qualitative evidence alongside the presentation of quantitative data, to explore the macro and micro levels simultaneously and add depth and explanation to the research findings.

There is overwhelming evidence to suggest that in-depth interviewing is an effective method of identifying information need and capturing contextual issues that help to explain the purpose of information needed by an individual. Although Sense-Making interview techniques are thorough they also appear complex and for a researcher unfamiliar with such methods, possibly time consuming. Degner et al. (1998) highlight the benefits of using a differential scale as opposed to a summated measuring scale, particularly in avoiding the *ceiling effect* where patients identify wanting to know everything. An additional advantage of the paired comparisons approach is the ability of the scale to not only rank information items according to importance but also to measure the distance between items giving a clearer idea of the significance of certain information needs over others. This type of knowledge along with understanding the purpose of an information need and how this information is to be used is invaluable to the clinician with limited time to provide patient information. Effective tools that clearly identify the information need of a patient will enable focused and appropriate information provision corresponding to an individual’s needs.

The evidence from information needs research with CKD patients is lacking particularly empirical research performed in the UK. Studies with cancer patients highlight that they have priorities and preferences with regard to what information they need and when (Luker et al. 1995). The premise of this study is that CKD patients will share similar traits and have preferred key information needs, which are of a priority to them, at different times during progression of their disease. In order for this to be determined a methodology that combines both an inductive and deductive approach, such as mixed methods is considered most appropriate (Johnson and Onwuegbuzie 2004).

Chapter Six
CKD Information Need Research Study

Introduction

The constructionist foundations of this study are based on the assumptions that an information need is subjective, bound by the context of the individual, with the type and content of information need being measurable objectively. The research focus lies on the CKD patients' perspective of reality and the information needed to be able to understand what is happening to them, to construct meaning, to make sense of their real life with a chronic illness, and help them cope.

The research study has multiple and ambitious aims. It seeks to explore, identify and describe the information needs of CKD patients and the context in which they manifest. This includes developing a CKD specific instrument to measure and examine information need priorities and the influence of demographic variables or changes in information need over time. The study aims were defined within four study objectives:

- To identify, from the patient's perspective, the key information needs of a group of CKD patients and develop an understanding of the contextual factors that influence the manifestation of information need.

- To develop and test the validity and reliability of a measuring scale that profiles and prioritises the information needs of CKD patients.

- To investigate whether the type and need for information changes over time or as a result of demographic variables such as age, gender, education level, socio-economics, ethnicity, treatment modality.

- To contribute to the theory of information needs, CKD patients' information needs, measurement of information needs and implications for clinical practice based on the user perspective.

This chapter presents the research study approach, the methods and techniques selected, and the subsequent application to achieve the study aims and objectives. The study draws extensively upon the knowledge and expertise of differential scaling methods, first developed in health research by Degner and colleagues (1998). The pragmatic motivation behind the study being the inherent lack of user-focused empirical and descriptive evidence of the information needs of CKD patients upon which to base clinical practice.

Study Methods

To realise the study objectives a mixed methods approach was adopted using an exploratory, descriptive and analytical design conducted in two distinct phases. Phase one applied in-depth exploratory qualitative methods to meet the first study objective. To identify and describe the information needs of CKD patients alongside the purpose and context in which information need manifested. The core information needs identified in phase one was then used to develop the structure and content of the CKD specific information need questionnaire (CKD-INQ). Phase two addressed the second and third study objectives. A cross-sectional survey design was used to test the validity and reliability of the CKD-INQ in profiling and prioritising information need. Sub-group analysis of information need priorities investigated the influence of demographic characteristics and information need changes over time. The findings of both phases were combined to inform information need theory in health and generate recommendations for practice and future research.

Phase One

The aim of phase one was two-fold; to identify key information needs that could be used to develop the content of a measurement tool, the CKD-INQ; and to explore and understand the *person-in-context*, how information needs arise and the factors that influence information need importance. Data was obtained to achieve both aims using semi-structured patient interviews.

Patient Interviews

Interviews were semi-structured and, to maintain focus, guided by a list of information need topic areas drawn from the existing literature (Appendix 7). A key question included in the interview to elicit information was *what information should a new CKD patient, be given*; similar to an approach used previously (Groome et al. 1994). An event ordering technique (Deacon 2000, Martyn and Belli 2002) was used. This is similar to the micro-moment time-line interviewing method described by Dervin et al. (1999) that focuses rather than directs the interview discussion. Throughout each interview patients were asked to think about their own situation and consider what information *they* needed and *why* at progressive stages of CKD. These stages included first being diagnosed, choosing which treatment and starting dialysis to becoming established on treatment. The prompt list of information topics was used to clarify and discuss whether certain topics were at all relevant or more pertinent at different moments or events in time.

Additional demographic data items such as: age, gender, time on dialysis; experience of different treatments; and date of diagnosis were collected prior to each interview. Current perceived knowledge levels regarding CKD were assessed using a 5-point Likert self-rating scale (1=know nothing about CKD, 5=know everything). The purpose of this question was to understand how an individual perceives their current level of knowledge not to examine whether patients hold accurate knowledge on particular CKD topics determined by clinicians. A low score of perceived knowledge could indicate an individual’s preference for not knowing rather than indicating a knowledge deficit (Bath et al. 2003). The response to this question therefore needs to be analysed in context alongside preferences for information. At the end of each interview to explore preferred methods of information provision patients were asked how (medium) and where (setting) they would prefer to receive information.

Interviews were expected to last no more than 2 hours, were tape-recorded and transcribed. Data collection continued until data saturation was achieved (Straus and Corbin 1998) in as much as patients were continually selected purposively from the sampling frame and interviewed until no new information need topics were uncovered. Core information needs and data identified in phase one was used to populate the CKD-INQ (the phase two study instrument).

Phase Two

The purpose of phase two was to test the validity and reliability of a CKD-INQ and confirm findings from the first phase with a larger CKD patient sample. The CKD-INQ measurement scale was designed to identify the information priorities of patients and the preference of particular information topics over others. The basis of the study was not to determine whether this was the most appropriate method for measuring information needs, or indeed compare and contrast results with studies performed with other patient groups, but to investigate whether this particular method was reliable when replicated in a population of CKD patients. Phase two data was collected using face-to-face structured interviews, the main component of which was the study instrument.

Study Instrument (CKD-INQ)

The complete and comprehensive study instrument (Appendix 8) comprised of four sections capturing data on priorities and preferences of information need, information provision, information sources, information seeking and health beliefs. The content was informed by the findings of the literature review and theoretical concepts (described in chapters three and four) and the interviews carried out in phase one. The four sections are described below.

Section 1. History of CKD

The patient was first asked questions to establish an accurate history of their CKD. These included date of diagnosis, cause of CKD, underlying conditions (co-morbidity), date started current treatment, current treatment modality and previous experience of different treatments (where applicable). An open question was used to establish the cause of CKD in order not to impose upon the patient’s own knowledge and descriptions of their disease. The free text responses were classified retrospectively using the European Renal Association/ European Dialysis and

Transplant Association Primary Renal Disease Group, coding system (ERA-EDTA 2004). Underlying co-morbid conditions were again recorded using free text, to determine whether patients who experienced medical problems additional to CKD had different information needs. Co-morbid conditions were grouped using a classification based on the Kidney Disease Outcomes Quality Initiative (K/DOQI) guidelines (National Kidney Foundation 2002). Diabetes and hypertension were not classed as a co-morbid condition if it was known to be the primary cause of CKD.

Within this first section patients were also asked to rate, their perceived knowledge level when first diagnosed with CKD and current perceived knowledge level, using 5-point scale (1=know nothing about CKD, 5=know everything). The purpose of which was to compare and contrast perceived knowledge levels with other influencing factors, such as their overall preference for information.

Section 2. Information Need and Provision

The core information need items were first listed and each one explained in turn to clarify understanding. Patients were asked to identify their current top-priority information need item and rate using a 5-point scale (1=very dissatisfied, 5=very satisfied) their level of satisfaction with the information they have regarding this particular item. Similarly they were asked to select from the same list what they considered to be the most important information need item for a newly diagnosed patient and asked to reflect on whether they received sufficient information about this item when they themselves were first diagnosed.

The innovative part of the CKD-INQ was developed based on the paired comparisons approach first described by Degner et al. (1998) (outlined in chapter five). With the type of differential scaling that the Thurstone approach permits, it is possible to measure the *distance* between scale items as well as the rank order (Thurstone 1974; McIver and Carmines 1981; Steiner and Norman 2003). The core information need items, identified from the patient interviews, were ordered in pairs using Ross's matrix (1974), this calculates the optimal way of pairing the items to prevent presentational bias. The number of pairs of items was determined by the formula [n(n-1)/2] (where n=number of core items) (Degner et al. 1998). Patients were asked if they could have information on only one of the two items which item would be chosen. For each pair of items to be considered separately additional pairs on the same page were hidden using a sheet of paper to prevent distraction and focus selection. On completion of the paired comparisons each patient was asked to consider if the information needs identified were relevant and whether other important information needs had been omitted.

Information provision and information sources are integral to many information need questionnaires (Luker et al. 1996, Meredith et al. 1996, Orsino et al. 2003, Hepworth and Harrison 2004) and as such it was considered important to explore these concepts with CKD patients. Patients were asked to rank from a pre-determined list of possible methods of information provision (ranging from verbal face-to-face to using an audiotape) their preference of how they would like information presented (1=most preferred, 7=least preferred). Questions also explored whom they liked to get information from (such as doctors or nurses), whether they actually got information from the sources that they identified and rate using a 5-point scale whether they were happy with who provided the information (1=very happy, 5=very unhappy). In addition, the use and usefulness of information sources was investigated using a pre-determined list, gleaned from previous research studies and modified to include renal specific information sources (such as specific nurse roles in both hospital and the community). Patients were asked to first identify sources they had experienced using and then rate the usefulness of each source using a 5-point Likert scale (1=not useful, 5=very useful).

Section 3. Information Seeking Behaviour and Health Beliefs

It was not the focus of this study to examine in-depth information seeking but it was considered important to capture the overall need for information and extent to which an individual seeks information to be able to fully understand the wider analysis. Therefore, two key questions were included drawn from previous instruments (Meredith et al. 1996, Fine et al. 2005). The need for information was recorded using five statements and a patient was asked to indicate which response best described them. Four statements ranged from needing to know as much as possible to not wanting to know anything. The fifth statement was left open to allow patients the option of using their own words, if none of the other statements were considered appropriate. The extent to which a patient seeks out and locates information was explored using three statements and a patient was asked to indicate which response best described them. Statements ranged from always seeking out additional information to never asking or seeking out additional information.

The degree to which a person considers their disease to be serious could impact on their motivation to seek out additional information (Case 2002). Similarly the control a person perceives they have over their disease and treatment decisions could result from their information seeking behaviour (Cvengros et al. 2005). Therefore, **s**elf-efficacy and sense of coherence, with respect to treatment decision-making (Degner et al. 1997b, Klang et al. 1999, Orsino et al. 2003) and health beliefs (whether a person considers their condition is under control or they feel susceptible to developing complications particularly for CKD patients) (Cvengros et al. 2005) were considered pertinent concepts to explore. Building on previous research, four questions were constructed to capture the primary focus of such concepts. Patients were asked to select between two statements exploring whether they perceived themselves to be vulnerable as a result of CKD and the risk of developing complications or whether their disease was under control. The degree to which a patient perceived their CKD to be serious was investigated using four response statements. Patients were asked to indicate which response best described their perception (ranging from not too serious, serious, up to life threatening). Two further questions adopted a similar approach using response statements to elicit the perceptions of patients. The degree to which a patient perceived they had control over treatment decisions asked patients to select a response ranging from full control, equal control with health professionals, wanting more control, to preferring professionals to take control. A further question explored the degree to which a patient perceived they could control their CKD and influence their future, with responses ranging from full control and being able to influence the future, to having no control and unable to influence the future influence.

The rationale for not including validated instruments (such as the Control Preference Scale used by Degner et al. 1997b, or the O'Connor Decision Self-Efficacy Scale used by Orsino et al. 2003) to measure these additional concepts separately was taken based on minimising the length of the study instrument to ensure it was manageable, within a given time frame and patient fatigue.

Section 4. Demographic Information

Demographic data was collated in relation to age, gender, educational level, ethnicity (as stated by the patient), modality (Pre-dialysis, HD, PD) and duration on dialysis (where applicable). A patient's ethnicity was described using free text then coded by means of the UK Renal Registry coding taxonomy (UK Renal Registry 2007) routinely used nationally in clinical practice. Current occupations were first identified in free text by the patient then classified to facilitate comparative analysis using the Standard Occupation Classification (SOC 2000). Those patients not working were classified using their previous occupation.

Pilot Test

A consecutive sample of the first ten patients recruited for phase two was used as the pilot study group to test out the administration and applicability of the main study instrument prior to wider implementation. The administration method and style, length of time taken to complete and patient understanding of the purpose and content of the instrument was investigated during and after each individual structured interview. Field notes captured patients' comments. It was not the purpose of the pilot to test out the analytical process as this had previously been tested and found to be reliable and valid within earlier studies (Sloan et al. 1994, Degner et al. 1998).

Research Team and Expertise

From the outset collaboration with clinicians and patients in the design and subsequent analysis of the study findings was paramount to the both the relevance and meaning of the study to clinical practice. To this end a research team was convened comprising of; two expert clinicians from study site nephrology service, a lead nurse and consultant; an experienced researcher familiar with the application of the paired comparisons approach to measure information needs; and a CKD patient who was at that time a patient advocate active in the National Kidney Patients Federation. The role of the clinicians was to coordinate identification and access to the patient group; the experienced researcher guided the use of the paired comparison approach; the patient focused on the wording and content of the instrument and core themes; all the team advised on the development of the research study and were actively involved throughout in the sequential analysis and dissemination of study findings.

Sampling Method and Sample Selection

Study Site

Patients were identified from renal services comprising the West sector of the Greater Manchester Managed Clinical Network in the North West of England (described in chapter two), which encompassed: hospital based HD; home HD; PD; transplanted and a pre-dialysis (PRE) patient population. The rationale for using one specific site, indeed a specific sector within a network, rather than comparative sites in different regions was to enable depth to the study within the time and resources available.

Inclusion/Exclusion Criteria

Experienced clinicians, within the research team, identified that the information needs of some patient groups were likely to be different particularly for; home HD patients, transplanted patients, patients with acute renal failure, and those pre-dialysis patients who had opted for conservative management (no RRT). Therefore, after discussion it was agreed that the focus of the study would be pre-dialysis, hospital based haemodialysis and peritoneal dialysis patients. In addition it was considered both unethical and inappropriate to approach those patients cared for in a nursing home, unwell or inpatients at the time of recruitment. As a result a comprehensive inclusion and exclusion criteria guided patient selection throughout the study (Box 4 and 5).

Box 4: Inclusion Criteria

- Aged 18 years or over
- CKD patients receiving HD or PD
- Pre-dialysis patients at stage 5 (Glomerular Filtration Rate of <15ml/dl recorded at the study site)
- Patients who could provide written informed consent

Box 5: Exclusion Criteria

- Patients with a functioning kidney transplant
- Patients performing HD at home
- Pre-dialysis patients at stage five who opted for conservative management
- Patients at pre-dialysis stage five but not yet visited by the CKD nursing team
- Patients who are considered unwell and not fit to participate (determined by the clinician)
- Patients who are in-patients at the time of recruitment
- Patients cared for in a nursing home
- Patients with difficulties communicating (a physical problem not associated to language barrier)
- Patients receiving HD but for acute renal failure
- Visiting patients from other units

Problems Identifying and Maintaining Sample Structure

Identification of the different sample groups was problematic. Databases at the study centre were in the process of being updated therefore it was necessary for some patients to be identified from hand searching nursing documentation generating an independent study list. This was time-consuming and took three months longer than anticipated. It was not possible from the clinical databases or hand searching notes to confirm the ethnicity or cause of CKD for all the target population, which limited subsequent determination of whether the study sample was homogeneous. As a result both these variables were confirmed with the patient during an interview.

Indeed although an initial target population could be identified for phase one it took time to confirm and establish the status of patients and whether they were eligible for the study. This was further impacted by the constant changing of the sample profile in terms of patients changing modality, being transplanted, and admitted to the ward as an in-patient and unfortunately dying. To ensure that an accurate list of patients was maintained throughout both phases a senior nurse from each modality checked and re-checked the patients' status prior to posting recruitment letters. Although this added security check was very useful and sensitive in identifying many changes, unfortunately one patient died just after the recruitment letter had been posted.

Phase One Target Population

Within the target population for phase one 470 CKD patients were identified, 61.7% male and 38.3% female. The mean age of the patients was 58.90 years (median 61.00, range 18–94), with over 50% of patients older than 60 years. There was no significant difference found between age and gender (t-test, p=0.356). Patients were drawn from three different modality groups: 37.9% (178) PRE stage five; 36.4% (171) HD; and 25.7% (121) PD. In each modality group there was a higher ratio of males to females and a high proportion of patients were aged 60 years or over (Table 13).

Table 13: Gender/Age /Modality - Phase One Target Population

Type of Modality	Gender n=		*Total*	Age (yrs) n=		
	Male	Female		18<40	40<60	>60
PRE	110	68	*178*	17	60	101
HD	111	60	*171*	26	57	88
PD	69	52	*121*	20	45	56
Total	290	180	*470*	63	162	245

There was a significant difference between the ages of patients within the three groups (ANOVA, p=0.009), with a higher mean age of patients (61.50 years) within the PRE group compared with patients in the other treatment groups (HD and PD). Within the two renal replacement groups (HD and PD), the majority of patients (55.8%, 163) had been receiving treatment for between 1-5 years, 29.1% (85) had started treatment in the last 12 months and 15.1% (44) for over five years.

From the phase one target population of 470 patients, 23 (5%) were excluded from the sample prior to recruitment as a result of eligibility checks, 14 male and 9 female. The five reasons for patient exclusion were: unwell at the time of recruitment 21% (5), an inpatient 48% (11), being cared for in a nursing home 21% (5), had since passed away 4% (1) and one further patient was excluded because their health status was unconfirmed (4%). Therefore, the actual target population for phase one included 447 patients across different modality/treatment groups.

Sample Recruitment

All eligible patients (n=447) within the target population were invited to take part in study phases one and two. Each patient was recruited by post using an invitation letter and information sheet (Appendix 9 and 10) sent by the researcher using the names and addresses of patients generated at the Trust. The first wave of recruitment took place at the end of April/beginning of May 2006. Those who were happy to take part in the research study returned a reply slip in the pre-paid envelope, providing their contact details. All were given 30 days to reply before a follow-up letter and information sheet was re-sent. If after 14 days there was still no reply it was assumed they were not interested in participating and no further contact was made.

Phase One Stratified Sampling Selection

It was important from the outset to recruit a sample that reflected the key demographic characteristics on which the study was to focus such as age, gender, treatment modality and the length of time on established treatment. As such a stratified sampling method was developed, that was thought to be sufficiently sensitive to identify a patient’s demographic characteristics and to facilitate unbiased recruitment for the study. The sampling frame was stratified by; modality group (HD, PD, PRE); time on dialysis (not applicable to pre-dialysis patients); age and gender (Table 14).

Table 14: Stratified Sampling Frame

1. Modality	**2. Time on dialysis**	**3. Age**	**4. Gender**
Haemodialysis (HD)	<1yr	18 to <40yrs	Female
Peritoneal Dialysis (PD)	1 yr to <5yrs	40 to < 60yrs	Male
Pre-dialysis (PRE)	> 5yrs	>60yrs	

Patients were selected using a purposive random sampling method from the different strata to ensure maximum diversity within the sample. For example, reply slips from female patients who had been on HD for less than one year and were aged between 18-40 years were placed into a box and one patient picked out at random. For each of the different stratified groups this process was repeated although alternate male and female patients were selected to represent the different age groups, ensuring an equal number were recruited, progressively. It was anticipated that no more than 30 patients would be recruited for phase one based on previous studies (Caress et al. 2002). Sample size was determined using data saturation where patients were continually selected from the sampling frame and interviewed until no new information need topics were uncovered (Straus and Corbin 1998).

Phase Two Target Population

Four months elapsed between phase one and phase two data collection therefore the eligibility of all patients was checked by the senior nurses in each modality including those patients who had already agreed to be involved in the study at the initial recruitment drive in phase one. This checking process took a further three months to complete. As a result there was a change to the profile of the target population, but the overall characteristics of the sample were comparable to phase one. An increase in the number of patients who had just started treatment (HD or PD) over the past 12 months being the only difference noted.

For phase two 541 CKD patients were identified, representing an increase of 71 patients when compared with the first phase. Similar to phase one, 61.4% were male and 38.6% female patients. The mean age of the patients was 58.96 years (median 61.00, range 18–94), the majority (53%) aged greater than 60 years. No significant difference was found between age and gender (t-test, p=0.089). Patients were drawn from three different modality groups: 35% (188) PRE-dialysis stage five; 40% (219) HD; and 25% (134) PD. Again, comparable to phase one, in each group there was a higher ratio of males to females and a high number of patients were aged over 60 years (Table 15).

Table 15: Gender/Age /Modality - Phase Two Target Population

Type of Modality	Gender			Age (yrs)		
	Male	Female	*Total*	18<40	40<60	>60
PRE	114	74	*188*	20	61	107
HD	141	78	*219*	32	68	119
PD	77	57	*134*	23	49	62
Total	332	209	*541*	75	178	288

There was a significant difference between the ages of patients within the three groups (ANOVA, p=0.012), with a higher mean age of patients (61.14 years) within the PRE group compared with patients in the other treatment groups (HD and PD). Within the two renal replacement groups (HD and PD), the majority of patients (46.5%, 164) had been receiving treatment between 1-5 years compared with 12.5% (44) for over five years. The primary difference in the phase two target population was the increase in patients who had just started treatment in the last 12 months, 41% (145) in phase two compared with 29.1% (85) in phase one.

Despite the perceived increase in phase two target population on closer scrutiny by senior nurses checking the patient status and eligibility, 155 (29%) were excluded, 110 male and 45 female, the majority (61%) over 60 years. A higher proportion (50%) of those patients excluded were from the PRE compared with only 22% in phase one. The majority (90%) of patients excluded from the HD and PD groups had less than five years experience of the treatment modality.

The rise in the number of patients excluded in phase two compared with phase one was influenced by 42 pre-dialysis patients starting RRT, thus being excluded from the pre-dialysis list. However, these patients were not lost to the sample as they were picked up as new patients in the RRT groups, 29 moved onto HD and 13 to PD. Other reasons for being excluded included patients being unwell (27); in-patients (18), the patient had died (24) or had been transplanted (13). For 15 patients status could not be confirmed during the recruitment phase. Taking into account the excluded patients there was a potential target population of 386 patients, 61 patients less than were identified in phase one (447).

Phase Two Sample Selection and Recruitment

The purpose of phase two was to recruit a larger sample within which to test the study instrument. It was anticipated that at least 50% (approximately 200 patients) would be recruited for this phase of the study using the same stratified sampling approach as phase one to ensure a representative cross-sectional sample was selected. Using Cohen (1988), for a power of 0.80 and $\alpha=0.05$ a sample size of 32 was needed to show a medium effect.

From the 386 patients identified in the phase two target population, those patients who had not been contacted previously in phase one were sent a letter and information sheet inviting them to take part. The researcher sent these using the patient names and addresses generated at the Trust. This second wave of recruitment took place at the end of September/beginning of October 2006. Following the same recruitment process as in phase one all were given 30 days to reply before a follow-up letter and information sheet was re-sent. If after 14 days there was still no reply it was assumed they were not interested in participating and no further contact was made. Those patients who had agreed to be involved in the study at the first recruitment drive and were still eligible to take part were contacted by telephone to organise a convenient time and place to conduct the structured interview.

Ethical Issues

Ethical approval for the study was provided on three levels: by the Local Research Ethics Committee (LREC), the University of Salford Research Ethics Committee, and the Trust Research and Development Committee. As part of the approval process the PhD student was required to hold an honorary research contract with the participating Trust, which required a police check prior to being able to access, contact or recruit the patient group.

Informed Consent

Each patient was recruited by post using an invitation letter and information sheet. The patients who agreed to take part returned a reply slip in the pre-paid envelope, providing their contact details. The researcher contacted patients by telephone at which point the purpose of the study was reiterated, further explained and any questions answered. A convenient time and place for the interview was arranged. Prior to any interview, in both phases of the study, written consent was obtained from each patient by the researcher.

Non–English Speaking Patients

For those patients within the target population who could not speak English or for whom English was their second language a translation service was available. Clinical experience (within the research team) indicated that many patients had family members who translate letters written in English and would be able to explain the study information in the first instance to the patient. The invitation letter and information sheet sent as the first contact stated that bi-lingual workers were available to translate information in the following languages (Urdu, Punjabi, Gujarati and Bangla). These languages were identified by clinicians as predominantly the languages of those patients who were not fluent in English. The letter provided a direct telephone number to contact to speak to a bi-lingual worker of the same language in order to answer any questions regarding participation in the study. In addition bi-lingual workers would be available at interview to overcome communication barriers. To ensure the collaborating translation service was able to answer the questions regarding the study if contacted by a patient, copies of all the study information were distributed to key telephone personnel.

Data Handling and Storage

All databases, both at the Trust and the University, were password protected, within the Hospital patients were anonymous using patient numbers, in the University research codes. The main database, which contained the names and addresses of participants and their subsequent research code, were stored in the clinical area on a password-protected computer accessed only by the research team. All paper based copies of completed questionnaires and field notes were research coded and stored in a locked filing cabinet, in a locked office, the key accessible only by a member of the research team. All data will be stored for a period of 5-10 years after publication of the results to enable verification of data if challenged. This data is anonymous and stored securely until a time when it can be shredded and disposed of appropriately. Tapes from the interviews in phase one will be destroyed on completion of the study as the data available is transcribed on both paper and electronic copy.

Data Analysis

Qualitative Analysis - Identifying Information Need Topics

The analytical process used in phase one to identify the information need topics to form the basis of the study instrument was methodical and sequential, involving three distinct stages (the process is described in more detail in chapter seven alongside emerging findings).

- Stage 1: Identification
- Stage 2: Confirming and Merging
- Stage 3: Verification and Validation

In stage one, a combination of content and thematic analysis techniques (Miles and Huberman 1994) were used to elicit the core information items identified by the patients. A thematic framework grounded from the data was applied to all interviews. A sample of five interviews were independently analysed using the framework by the experienced researcher within the research team and no new themes identified. Stage two involved comparing and contrasting information need themes with those identified from the systematic literature review (reported in chapter four). The condensing and merging of themes was performed and agreed by all members of the expert research team through discussion. The core information need themes identified were summarised and sent to all phase one patients for verification and validation, in stage three. Patients were asked to comment regarding whether the core themes were considered relevant and whether the wording was easy to understand and made sense. Based on patient comments and with the assistance of the patient on the research team core themes were re-worded then final core information needs were prepared for the study instrument.

Qualitative Analysis - Contextual Factors

Secondary exploratory content analysis was performed on all the qualitative interview data, this time scrutinizing contextual explanations as to:

- Why is information needed
- When information needs occur
- What influences information need occurrence

The purpose of this analysis was to add depth and contextual understanding to CKD patients' need for information. Contextual analysis was guided by key theoretical factors including complex relationships between factors, such as goals, situations, coping styles, time, relevance and salience of information topics, self-efficacy and control. The unit of analysis throughout was the individual patient and their information need. Both the *manifest* (visible and obvious components of the text) and *latent* content (relationships that require interpretation of the underlying meaning of the text) were extracted and coded, using phrases, words and statements that related in meaning to a particular contextual concept surrounding an information need (Graneheim and Lundman 2004, p3). Interlinked groups of contextual concepts and the interpretation of meaning was confirmed, agreed and verified by an independent researcher through discussion with the researcher.

Quantitative Analysis - CKD-INQ

In phase two data was coded and entered into an SPSS statistical package to undertake the Thurstone paired comparison analysis. An SAS computer program developed in Canada by Sloan et al. (1994) was used to produce profiles of information needs based on Thurstone's Law of Comparative Judgment (Thurstone 1974).

Sloan et al. (1994) with the statistical computer package actually provides three methods of complex data analysis, for the paired comparison approach, two based on case V and III of Thurstone’s Law of Comparative Judgment. The difference between the two cases being that; case V stringently assumes that there is no correlation among different rankings an individual gives, whereas the more lenient case III allows for and estimates differences among individual item variability. The basic underlying assumption the of Law of Comparative Judgment is that when two stimuli are presented together they could be ranked in terms of some attribute, the attribute in this study being perceived importance (McIver and Carmines, 1981). Each item will vary in terms of the attribute when investigated, although an individual may vary in their judgment of an item from one instance to the next, but overall there will be a frequent occurring response (Luker et al. 1995). The frequent occurring response is referred to as its modal discriminal process on the psychological continuum. This simply means an individual makes a discrimination involving a judgment as to the relative importance of an item (McIver and Carmines, 1981).

The computer program generates a frequency matrix of the number of times that each item is preferred over every other item. The preferred proportions are then translated into standard normal scores and reflect the patients’ weightings of the items which can then be rank ordered along a continuum. The larger the value the more preferred an item, a scale score of 0 indicates that 50% of the respondent preferred the item, and a negative score indicates that less than 50% preferred the item (Sloan et al. 1994).

The level of agreement between patients’ in terms of the judgments, particularly what items of information were important and in what order, was measured using Kendall’s coefficient of agreement (Edwards 1974) for paired comparisons. Kendall’s coefficient of consistency measured how consistent and logical each patient was in their judgment. Logical comparisons of items were determined when an individual preferred item A over item B, then item B over item C, and then logically chose item A over item C. When item C was selected over item A then an inconsistent comparison had been made, referred to as a circular triad (a mismatch of the comparative judgement between items) (Edwards 1974). Sloan et al. (1994) indicates that an individual is allowed a maximum of 30 circular triads before they are considered to be inconsistent in their ratings. By combining these tests it was possible to assess if each patient in the study was consistent in their choices of information need and that consistency existed between patients, rather than choosing items at random.

Sloan et al. (1994) used the Mosteller Chi-square test of internal consistency, a goodness of fit test, was used to determine how well the data fit the underlying assumptions of the Thurstone scaling case V and/or case III statistical model. A non-significant p-value indicates the scale values fit the observed data. A further test included the Gulliksen and Tukey's (R^2) measure of reliability that calculated the *scalability* of the data, the extent to which the Thurstone scale scores account for the variability of the individuals' responses. The higher the R^2 score the more scalable the data (Sloan et al. 1994).

Descriptive statistics were used in the analysis of rank ordering of items and satisfaction with information giving. Independent-samples t-tests and one-way analysis of variance (ANOVA) were used to compare the mean Thurstone scale scores for the core items by subgroups on each of the demographic variables in turn. This analytical approach has been tested in previous studies and found to be valid and reliable (Luker et al. 1995, Degner et al. 1998, Wallberg et al. 2000, Browall et al. 2004, Beaver and Booth 2007). Statistical significance, unless otherwise stated, was set at $p<0.05$.

A third, simpler, and more modern method of analysis applied by Sloan et al. (1994) uses the Averaged Preferred Proportions (APP) for each item rather than the Thurstone score value. The purpose of using the technique is to make the scale scores more appealing and easy to interpret by clinicians, values are presented as a percentage number who preferred one item more than another. The APP is calculated for each item and the inferences that can be drawn from the results are the same as from the Thurstone scale scores. This analytical method is used to directly compare different groups and their comparative judgements, when significant differences are identified between the APP values of items it indicates that the groups selected items differently and had contrasting preferences. The Bonferroni correction (Sloan et al. 1994) was used to protect against a Type I error. In this case nine items are compared against each other therefore case alpha (0.05) is divided by 'K=9.' If any of the p-values are less than ‘test’ (p=0.0055) then the APP for each item is found to be not the same for each group, and significant differences have been observed between items.

Summary

The all-embracing mixed method approach enabled an intense examination of the phenomena in the individual context and widespread comparative analysis of the phenomena across different patients. Exploring the patient experiences in real life through in-depth patient interviews was the principal method, the data from which in turn informed and shaped the content and development of the study instrument.

Throughout the study, from the choice of methods to the analytical techniques imposed upon the data, the approach focused on three embedded spheres of information need research:

- ***Identifying*** what information needs
- ***Understanding*** the context of why, when and how information needs arise
- ***Measuring*** which information needs are a priority for who and when

Data generated within the spheres is fundamentally linked, although within the majority of research studies these are areas of interest that are generally explored separately. To identify what information needs exist without understanding the purpose and the information deficit that caused it to occur has limited meaning.

The data generated in this study leant itself to be divided in a similar way resulting in the formation of three discrete findings chapters (seven to nine), each focusing on a specific sphere. The strength of this study, however, lies in the eventual amalgamation of evidence from the three spheres to facilitate a deeper knowledge and understanding of CKD patients’ information need.

Chapter Seven

Identifying Information Need Topics

Introduction

Identifying information need topics was central to the aims of the research study. The topics form the basis of the study instrument used to measure patient preferences and priorities for information. For this purpose it was essential that the topics generated were grounded on what the patient needed to know and not influenced by the professional perspective. Key information that a patient wants with respect to CKD was identified through semi-structured patient interviews then compared and contrasted against existing research evidence.

The purpose of this chapter is to present the findings of the patient interviews carried out in phase one. The analytical framework adopted for this part of the study was progressive in nature and consisted of three distinct stages. As such the identification of information need topics and the confirmation and verification of information themes are presented in a staged format to mirror the sequential analytical process. The outcome of which, the core information need themes, was used to develop the INQ.

Characteristics of Phase One Sample

Twenty interviews were carried out with patients of different ages, gender and represented different treatment groups and experiences, up to the point that data were considered saturated and no new themes emerged from progressive interviews. It was initially anticipated that a patient would be recruited to represent each age group across the three treatment groups. Within the data collection time frame for the interviews however, neither a male or female patient was recruited from the pre-dialysis group within the age group of 18 to <40 years. Nevertheless, the goal of the purposive sampling frame was achieved since the sample represented a wide range of perspectives (Table 16).

Table 16: Overview of Phase One Sample Characteristics

<table>
<tr><th colspan="2">Gender</th><th colspan="2">Age (yrs)</th><th colspan="2">Age Groups</th></tr>
<tr><td>Male</td><td>n=11</td><td>Mean</td><td>52.55</td><td>18 <40</td><td>n=4</td></tr>
<tr><td>Female</td><td>n=9</td><td>Median</td><td>48.50</td><td>40 <60</td><td>n=9</td></tr>
<tr><td></td><td></td><td>Range</td><td>29 - 81</td><td>>60</td><td>n=7</td></tr>
<tr><th colspan="2">Modality Group</th><th colspan="2">Time on RRT</th><th>Ethnic Group</th><th>(N)</th></tr>
<tr><td>PRE</td><td>n=5</td><td><1yr</td><td>n=6</td><td>White</td><td>20</td></tr>
<tr><td>HD</td><td>n=8</td><td>>1yr <5 yrs</td><td>n=6</td><td></td><td></td></tr>
<tr><td>PD</td><td>n=7</td><td>>5yrs</td><td>n=3</td><td></td><td></td></tr>
<tr><td></td><td></td><td>No experience RRT</td><td>n=5</td><td></td><td></td></tr>
<tr><th colspan="2">Cause of CKD</th><th>(N)</th><th colspan="2">Socio Economic Group</th><th>(N)</th></tr>
<tr><td colspan="2">Glomerulonephritis/Sclerosis (I)</td><td>3</td><td colspan="2">Professional</td><td>8</td></tr>
<tr><td colspan="2">Pyelonephritis (II)</td><td>4</td><td colspan="2">Associate Professional and Technical</td><td>2</td></tr>
<tr><td colspan="2">Polycystic Kidneys (adult) (III)</td><td>2</td><td colspan="2">Administrative and Secretarial</td><td>4</td></tr>
<tr><td colspan="2">Diabetes (VI)</td><td>3</td><td colspan="2">Skilled Trade</td><td>2</td></tr>
<tr><td colspan="2">Miscellaneous (VII)</td><td>7</td><td colspan="2">Process, Plant and Machine Operatives</td><td>2</td></tr>
<tr><td colspan="2">Unknown (VIII)</td><td>1</td><td colspan="2">Elementary Occupations</td><td>1</td></tr>
<tr><td colspan="2"></td><td></td><td colspan="2">Unclassified (education/ never worked)</td><td>1</td></tr>
</table>

Overview of Staged Analytical Framework

The identification of information need topics from the interview data was achieved using a methodical analytical approach, comprising of three distinct stages.

- Stage 1: Identification
- Stage 2: Confirming and Merging
- Stage 3: Verification and Validation

In stage one the interview data was subjected to a comprehensive analysis, guided by information need theoretical concepts, to extract all relevant data and isolate topics on which patients wanted or needed information. Stage two compared and contrasted information need topics derived from both the patient interviews and the existing research literature. Topics were merged, re-built and confirmed by a panel of experts to pin point the focus of key information needs. Stage three involved reflecting back to the patient cohort core information themes for verification of content, relevance and clarity. Combined, the rigorous analytical approach was reliable and effective in identifying confirming and corroborating information need topics for CKD patients.

Stage One: Identifying Information Need Topics

Each interview was transcribed verbatim then checked for accuracy against the audio recording. To identify key themes from the interview data the analytical framework was grounded on the data itself. Starting with a blank piece of paper each interview was read and themes noted, and coded. After 16 interviews 31 broad themes had been identified, a further four interviews added depth and confirmed existing themes but generated no new themes, at this point data collection was considered saturated (Strauss and Corbin 1998).

The full 31-theme analytical framework (Appendix 11) was applied again to each individual transcript. Data in the form of phrases, sentences, or complete paragraphs was coded and extracted using a matrix design to organise data under broad theme headings (Miles and Huberman 1994). Phrases that contained multiple meanings were replicated and grouped under each pertinent theme. The thematic framework extracted data relevant to specific information topics as well as information provision, information seeking and information preferences. For the purpose of this chapter findings are presented that focus on specific information need topics. Additional findings concerned with information provision are presented in chapter nine.

Clarification of the Analytical Concepts

As the thematic analysis progressed clarity was required in understanding the concepts emerging in the data and the difficulty in isolating patient information need. Discussions between the researcher and external researcher with experience of this type of data analysis helped to clarify emerging issues. Informed by theoretical concepts (Williamson 1998, Nicolas 2000, Shenton and Dixon 2004) described in chapter three, a set of distinct rules was generated to ensure data was extracted and coded consistently and methodically. Four fundamental analytical concepts, *direct* (expressed need), *indirect* (unexpressed need), *coincidental* and *information deficit* underpinned the identification and extraction of information needs clarified by descriptor statements (Table 17, 18, 19, 20). Where there was ambiguity, phrases were signposted and included for wider research team discussion.

Table 17: Examples of Direct Information Need

Type of need	*Descriptor*
Direct Information Need *(Expressed need)*	**Directly states that they want to know or need information about a particular topic or issue**
‘I just want to know when they’ll stick me on that transplant list’ (3) *‘I needed to be told that there’s a possibility that I wouldn’t be able to work’ (7)* *‘What should I feel like with Vasculitis?’ (9)* *‘How long I can keep working for you know, how many other people are working, what do they do?’ (10)* *‘I want to know about the Cause* (of kidney disease*) they haven’t really told me’ (17)*	

Table 18: Examples of Indirect Need

Indirect Information Need *(Unexpressed need)*	**Aware of an information need but choose to ignore it**
‘I would like to know what was going to happen… the sane side of my brain the analytical side says that would be good information to possess but the other more sensible side says oh you know live for today don’t worry about tomorrow as long as your doing the things you need to do to keep healthy… too much information can become too big a weight to carry you know’ (1) *‘No no one has actually said, no one has actually put a name to my condition…I don’t know why my kidneys are failing, I know they are failing, I don’t know why they are failing I don’t need to know why because I know they are failing and there is nothing they can do about it.’ (2)* *‘We’ll deal with it when it happens* (when you need dialysis will you have questions?) *I would yes basically I would yes* (don’t want to know before then)*… Well there’s too much involved in it for me to and I don’t understand it you know what I mean and I’d have to start really studying and reading to understand it’ (4)*	

Table 19: Examples of Coincidental Information Need

Coincidental Information Need	**Acquires useful information that they were not aware they needed**
'They tend to tell you all the kind of things that can happen and you'll only see some of those… some of the problems they tell you you'll never experience, I think it's good to know so you don't worry' (8)	
'I thought I might try APD but I thought it was a couple of hours overnight but it turned out to involve ten hours, well I'm not in for ten hours in an evening so that was useful information without knowing that I think I would have chosen APD which wouldn't have suited my lifestyle at all' (8)	
'Wrote out a sheet explaining exactly what Vasculitis was and what the implications were, that it's incurable and that I will be on treatment for the rest of my life but it might go into remission which it did do… the initial amount of information given to me when they diagnosed the Vasculitis it was quite good' (9)	
'When I first started on CAPD she (the nurse) *did bring it up* (not being able to achieve an erection) *and she said this is one of the things that can happen…* (need to know) ... *something that somebody needs to bring up maybe once that's but you know it's quite an important issue you do need to know about it' (15)*	

Table 20: Examples of Information Deficit

Information Deficit *(Unconscious need)*	**Lack of information on a topic that if not rectified may result in negative consequences**
'I wish I had met other patients on dialysis who could tell me the ways that they had learned to cope before. I feel as if I've had to find my own way' (10)	
'I would have liked I think information when I was diagnosed, written information when I was diagnosed as to what could happen to you and I know I've had 20 years where I've been fine, not fine but you know what I mean it's been there but it's not had a huge impact and I think I would have liked to have known what could have happened, that I could reach dialysis stage' (13)	
'I didn't know how long I'd be on dialysis and after I'd been going it was about four weeks I naively said how long will I have to be on dialysis and the nurse the male nurse he says has nobody told you I said why why what is it and he said you're on it for life' (16)	

Problematic Information Topics

Identifying information needs with respect to psychological care, how to cope and feeling depressed was problematic. Interview data was found to be complex with semantic ambiguity requiring profound discussions with the research reference group, particularly the patient advocate, to clarify issues. An example of the dilemmas that required clarification included a patient feeling '*fed up'* and/or '*at times depressed'* but not identifying that they required information or support to help them with this problem. Unlike other themes the simplicity of a patient stating that they *needed to know what help was available to assist them in dealing with their depression* was an unrealistic concept although retrospectively some patients implied this. Often integral to the manifestation of a psychological problem such as depression, severe anxiety, or the use of a negative coping style such as denial is the inability to recognise the problem and/or acknowledge the need for help. This hinders the patient's ability to verbalise the need for information regarding psychological issues. Consensus decisions were taken within the research team to include tenuous phrases that implied the patient had an indirect need or an information deficit (Table 21).

Table 21: Examples of Types of Information Needs for Psychological Issues

Theme: **Psychological Issues, Coping, Feeling down and Fed up**
<u>Direct Information Needs</u> *'Maybe it might be well it could warn them or something* (should people be told that they might feel depressed) *I think it should be warned cause like I say I've been through it few times… I didn't take my anti rejection drugs cause I was so down… but I didn't get no (information)… now I can (recognise the symptoms) because like I say I've been to the psychiatrist …but at first I didn't and it could have went on for weeks and months and this time around I was lucky I caught it early enough' (14)* (information about how to recognise psychological symptoms can cope better) *'I do get upset about it all the time It's just managing it really isn't it… they don't talk to you about your emotions.' (10)* (lack of psychological care needed to talk to someone) *'I think in retrospect they could have prepared me more it was a real shock to me' (6)* (more information to prepare psychologically for the shock of needing dialysis and how to cope)

Indirect Information Need

'The worst things is the liquid restriction I'm restricted to 750 mls a day …the thought that this may go on for the rest of your life is actually quite depressing…. at times you get so fed up with the whole thing' (9) (information on how to cope)

'Some of my feelings remain the same as in you know absolute hatred of being constrained of being on dialysis' (10) (after five years remains hateful of the restrictions it places on her life)

'Nurse was fantastic she was really good she sat down she was very empathetic she very understanding about what I was going through and it wasn't just you know there is a shoulder to cry on, she came up with some very constructive things as well so she did start to sort of say well you might start feeling like this as well, yeah it was good I would say that side was very good'. (15)

Information Deficit

'I think its because it was shock and I just couldn't deal with it I really couldn't deal with it at all and I didn't feel…I looked very well so and also I had no symptoms I couldn't feel any symptoms so I didn't want to deal with it at that time' (10) (needed information on how to cope)

'I don't take it (EPO) but I should take it, it's another issue of compliance… I don't like injections it's also hard work it has to be ordered at the chemist its really hard work to do.' (10) (does not take medication, maybe lack of understanding as to why it's important)

'I felt very isolated I couldn't talk to my family or friends about it they had no idea' (10) (needed information on who to talk to)

Information Need Topics

A random selection of five interviews was sent to the external researcher for confirmation of thematic analysis. No additional thematic topics were identified. The initial 31-theme framework was merged into twelve core themes with 45 sub-themes (Table 22).

Table 22: Stage One- Information Need Themes and Sub-themes

Theme 1: CKD, progression of the disease, what why when not working, what to expect in the future

- *Not too much information – too soon*
- *Cause of kidney disease*
- *What the kidneys actually do?*
- *What to expect - what will happen?*
- *Prognosis / future*

Theme 2: Physical symptoms as a result of RRT and disease, what to expect and information, altered body image/ sexual health

- *Physical symptoms – side effects from RRT /disease– what to expect*
- *What to do if experiencing symptoms*
- *Sexual health*
- *Altered body image*

Theme 3: RRT (options, advantages and disadvantages of different treatments, practicalities, access, shifts, transplantation issues)

- *Different treatment options for dialysis*
- *What does the treatment involve – how effective?*
- *When will I start?*
- *Transplant options*

Theme 4: Practical aspects of RRT

- *Practicalities of having RRT*
- *How to do it?*
- *Amount of stock*
- *Transport issues (HD)*
- *Access for dialysis (Fistula/Tenchkoff)*
- *Changes in treatment regime*
- Dialysis long-term
- *Listed and waiting for a transplant*

Theme 5: Complications and side effects of RRT and disease, what to expect and information

- *Don't want to know possible complications*
- *What to do if experiencing complication/ how to recognise a complication/ what to expect?*
- *How to avoid complications?*
- *Chance of getting a complication*

Theme 6: Medication information and possible side effects

- *Side effects of medication*
- *Why am I on this medication – what is it for?*

Theme 7: Family and lifestyle issues and information

- *Impact of RRT and CKD on your lifestyle*
- *Fitting dialysis round your life*
- *Holidays and travel*

Theme 8: Work and financial related issues and information

- Able to continue working
- Fitting dialysis round work
- *Impact on ability to work, career progression and self-esteem*
- *Financial implications*

Theme 9: Diet and fluid restrictions, what and why

- *Diet and fluid restriction information for different RRT*
- *Fitting the diet restrictions alongside your lifestyle*

Theme 10: Tests, investigations and blood results

- *What should my blood results be – what can I do about it?*

Theme 11: Psychological issues, coping, feeling down and fed up

- *How to cope, normality, staying positive*
- *Peer comparison*
- *Adapting to the shock of needing dialysis*
- *Threat to survival*
- *Denial – deal with it when it happens*
- *Feeling depressed –discussing emotions*

Theme 12: Other patient experiences – Talking to other patients

- Other patients experiences
- Opportunity to talk to other patients

The complete thematic analysis of the information need topics from the interview data is presented in Table 23 (Appendix 12).

Stage Two: Confirming and Merging Themes

The range of experience within the research team was drawn upon to establish consensus agreement when comparing, merging and contrasting the information need topics with existing research literature. Thematic data was sent to each member of the research team, prior to a planned full-day research team meeting. The purpose of which was to enhance their understanding of the themes; to facilitate discussion as to theme content and meaning; to determine whether themes could be condensed and merged; and construct an appropriate label for each theme.

During the meeting problematic themes were discussed, alongside the ambiguity of particular phrases and consensus agreement achieved regarding conceptual analysis. The twelve core themes confirmed from the interview data were compared and contrasted with the categories derived from the existing literature (chapter four). To ensure accuracy key descriptors derived from both the existing literature categories and the interview data themes were used so as not to lose sight of the central questions and theme meaning (Table 24, Appendix 13). After lengthy discussion, it was agreed that themes 5 and 6, *Complications and side effects from the treatment and the disease* and *Medication and possible side effects* shared meanings and could be merged, with medication being integral to RRT. In addition, themes 7 and 8 involving family issues, maintaining a normal life, continuing to work and finances, were interlinked and consequently joined into one overarching theme.

There was discussion surrounding the meaning of themes 9 and 10, underpinning each theme was the need for information to be able to self-manage and influence the CKD treatment and condition. This was demonstrated through interview phrases concerning information to understand and manage diet and fluid restrictions effectively or being aware of blood levels that could indicate the need to alter or amend dietary intake. The shared purpose and goal of the two information topics influenced the decision to merge these themes and create a more pertinent theme label.

All but one of the categories (information about patient organisations) derived from the literature was confirmed within the interview data. Although one patient indicated considering contacting a specific patient association, demonstrating an awareness of its existence, there was no supporting evidence to suggest whether such information was needed or perceived to be useful.

'I've got information about the Vasculitus Society and I was thinking of joining I was a bit wary cause I don't want to join a group of people who are always talking about being ill' (9)

Theme 11 concerning psychological issues was reviewed in detail and research team discussions focused on the tentative clarification of phrases and the dilemmas of whether they indicated an indirect need for information or demonstrated the need for a support mechanism. After careful deliberation the consensus agreement was to take this theme forward to the next phase of the research and test its relevance with a larger patient sample.

Themes were broken down then rebuilt based on the interview excerpts and identifying exactly the purpose of the patients need for information. Nine core information need themes emerged. New theme labels were created and agreed by the group to ensure the language used and the meaning of the theme remained transparent.

Stage Three - Verifying and Validating Information Need Topics

The final stage of the sequential analytical process was to verify the relevance, wording and meaning of the nine core information need topics with the patient group from which they had been derived. Each patient who had agreed to take part in an interview (20 participants) was sent a list of the core information need topics and asked to evaluate whether the theme was appropriate and relevant to a CKD patient, whether the wording was easy to understand and whether it made sense. A further question explored their perception of whether any theme or topic was missing. Sixteen completed evaluations were returned and the results are shown in Appendix 14.

The overall response indicated the majority of patients considered that all nine themes were appropriate although some comments highlighted that the wording could be improved. One patient identified that an important topic missing was *information about benefits/allowances available and how to help claim them.* Although this topic was integral to an existing theme (7) it was not visible within the theme label. The abbreviations of different treatments used in the label of theme 3 (such as HD, PD and APD) were not understood by a pre-dialysis patient and therefore needed full explanation.

The additional comments were extremely useful to gauge whether a patient had actually understood the theme and drew attention to the need to explain each theme clearly using the descriptors derived from the data. As a result of the patient feedback, the wording of each theme was reviewed. For this the advice and experience of the patient from within the research team was crucial in changing the words of a theme without altering the meaning (Table 25).

Table 25: Re-wording of Information Need Topics

Information Need Topics Verified by Patients	**Final Information Need Topics**
Information about what is chronic kidney disease, what is the cause, how will it progress, what is the future	Information about what is **chronic (long-term)** kidney disease, what is the cause, how will it progress, what is the future
Information about how the disease will affect my body, how to recognise symptoms and what to expect	Information about how the kidney disease **may affect me, physically or in other ways,** how to recognise symptoms and what to expect
Information about the different treatment options, the advantages and disadvantages of each treatment (HD, CAPD, Transplant, APD) what the different treatments look like (machines etc)	Information about the different treatment options, the advantages and disadvantages of each treatment, what the different treatments look like (such as machines etc) **(Haemodialysis, Peritoneal dialysis, Transplant, Automated Peritoneal dialysis)**

Information about the practicalities and facts about what happens when I start, or change a particular treatment, up to date information on treatment changes (access, shifts, schedules, fluid restrictions, base weight, ordering stock, adjusting regimes)	Information about the **practical issues of starting or changing treatment, what will happen to me and what can I expect (such as having a fistula, or peritoneal catheter, the frequency and length of time of treatment sessions or exchanges, fluid restrictions, base weight, ordering stock, using different strength bags, to up to date information on treatment changes)**
Information about what complications or side effects I can expect as a result of the treatment or medication I'm taking	Information about what complications or side effects may occur as a result of the treatment or medication I'm taking
Information about things I can do something about diet, medication, how to keep my blood tests stable or make them better	Information about ways in **which I can manage and influence my own condition** such **as food** restrictions, medication, how to keep my blood tests/results stable or improve them
Information about the impact chronic kidney disease and the treatment will have on my daily life, social activities and work opportunities	Information about **the ways in which the kidney disease and the treatment may affect my** daily life, social activities, work opportunities and financial situation (benefits and allowances available)
Information from other CKD patients, what is it really like living with CKD and receiving treatment, practical tips on what I can do to make things easier (what are other peoples experiences)	Information from other patients about what it can be like living with chronic **kidney disease** and receiving regular treatment (such as practical tips on what I can do)
Information about where I can get additional support if I'm feeling fed up or depressed and need someone to talk to	Information about **how to cope with and adjust to chronic (long–term) kidney disease and who can provide support if I need it**

Key: Bold Text highlights word changes

Once the wider research team had agreed the final wording of each theme, a list of nine core information need topics was generated to form the basis of the Information Needs Questionnaire (Box 6).

Box 6: Final Nine Core Information Needs Topics

1. Information about what is chronic (long-term) kidney disease, what is the cause, how will it progress, what is the future
2. Information about how the kidney disease may affect me, physically or in other ways, how to recognise symptoms and what to expect
3. Information about the different treatment options, the advantages and disadvantages of each treatment, what the different treatments look like (such as machines etc) (Haemodialysis, Peritoneal dialysis, Transplant, Automated Peritoneal dialysis)
4. Information about the practical issues of starting or changing treatment, what will happen to me and what can I expect (such as having a fistula, or peritoneal catheter, the frequency and length of time of treatment sessions or exchanges, fluid restrictions, base weight, ordering stock, using different strength bags, to up to date information on treatment changes)
5. Information about what complications or side effects may occur as a result of the treatment or medication I'm taking
6. Information about ways in which I can manage and influence my own condition such as food restrictions, medication, how to keep my blood tests/results stable or improve them
7. Information about the ways in which the kidney disease and the treatment may affect my daily life, social activities, work opportunities and financial situation (benefits and allowances available)
8. Information from other patients about what it can be like living with chronic kidney disease and receiving regular treatment (such as practical tips on what I can do)
9. Information about how to cope with and adjust to chronic kidney disease and who can provide support if I need it

Summary

The robust analytical procedure applied to the patient interview data enabled nine core information need themes to be identified, that reflected the patient's own perspective not that of the researcher, or members of the research team. The data was *allowed to speak for itself* right from the outset without imposing a pre-determined structure. The analytical framework was grounded on the interview text. Ascertaining that the themes that emerged were both valid and reliable was vital to the three-staged process. Clarification within discussions was extensive and the patient involved in the research team was crucial at this stage. Indeed, the value of verifying the themes with the patient group was demonstrated with some words shown to be unclear and the meaning ambiguous, enabling important changes to be made.

This pragmatic approach created a reliable and valid foundation for the subsequent analysis of information need in context addressed in chapter eight. In addition the nine core information need themes (Box 6) were taken forward as the content for the paired comparison component (section 2) of the CKD-INQ, the findings of which are described in chapter nine.

Chapter Eight

Information Need in Context

Introduction

Having identified key information needs for CKD patients in chapter seven it was necessary to examine the data to understand:

- Why is information needed
- When information needs occur
- What influences information need occurrence

This chapter focuses on the study of context, the temporal conditions, circumstances and factors that affect and influence the perception and interpretation of the need for information. Key contextual factors are exposed and the contributory, complex relationships between factors, such as goals, situations, coping styles, time, relevance and salience of information topics, self-efficacy and control are explored.

Why is Information Needed?

Whilst the information needs were grouped thematically in the previous chapter further analysis of the interview data revealed *why* that information was needed; the purpose(s) that information would serve.

Information (or the information need identified) typically served multiple purposes, those purposes themselves often being iterative. For example, whilst information may initially facilitate understanding of the disease and the feasible treatment options, that understanding in turn may reduce uncertainty and provide reassurance. The phrasing of information topics identified in the previous chapter reflect this in that multiple goals were used to express the purpose of the information drawn directly from the content of the patient information need. The complexity of information purpose is augmented with embedded tasks, narrowing the purpose from the broad to a more specific aspect of the same information topic.

The purpose of the information needed by CKD patients in this study has been classified into a general typology of 10 purposes or goals (Box 7) drawn from Table 23 (Appendix 11).

Box 7: Classification of Information Need Purpose

- Understand about the disease and whether/how I can be treated
- Be prepared for what to expect, now and in the future
- Make decisions and influence what happens to me
- Recognise and understand what physical symptoms/complications/side effects may occur, what to expect, what they mean, how to prevent them and what to report
- Reduce uncertainty
- Gain reassurance regarding concerns
- Reduce anxiety and help me adjust and cope
- Feel in control or have more control over my illness, my treatment and my life
- Help me care for myself and influence/manage my illness and treatment to some degree
- Help me live (a normal life) despite my CKD and the restrictions imposed by the disease and treatment

An important finding was that at least half of the reasons identified behind the underlying purpose of an information need were based on an embedded psychological need for information.

Making Decisions, Understanding About the Disease, What to Expect

Being diagnosed with CKD generates a need for information for all patients the primary purpose of which is to understand what it actually means. For some patients the goal of understanding CKD and the treatment options can be achieved with a basic level of information. Indeed the goal for four out of the five pre-dialysis patients included not having too much information at an early stage, deferring the goal of enhancing their understanding until a more appropriate time.

> *'If it happens it happens if it takes a long time to happen all the better but if happens sooner well we'll deal with it when it happens...Well there's too much involved in it for me to and I don't understand it you know what I mean and I'd have to start really studying and reading to understand it' (4)*
> *'I just feel she came in and she gave me too much too soon I just feel it was I didn't need to know all that at that stage' (11)*

Alternatively, attending the renal out patient clinic for a long period of time without being prepared in advance of what to expect in the future, the potential need for dialysis, leads to feelings of disbelief and shock when later informed.

> *'I would have liked I think information when I was diagnosed, written information when I was diagnosed as to what could happen to you and I know I've had 20 years where I've been fine ... I think I would have liked to have known what could have happened, that I could reach dialysis stage' (13)*

Stemming from being presented with a diagnosis of CKD are information goals to find out the cause of kidney failure, available treatment options and what to expect, leading to making a decision of which treatment they prefer. For some this involved seeking out additional information to that provided by the health care professionals.

> *'I would like to know what was going to happen' (1)*
> *'I read about glomerulonephritis after that...at work there was a medical library' (6)*
> *'I now needed dialysis... I went on the Internet so that I was primed, and so that I knew...that gave me an awful lot of information so I just read up on all the different things. So at least I knew before she came and I'd have a good idea of what I wanted anyway' (13)*

Satisfying embedded tasks to find out the meaning of a specific word.

> *'I'm also not quite clear ... when they say a disease is in remission I assume that means it is still there you've still got in but its not active now I'm told that it's in*

> *remission at the moment and does that mean technically that you've still got Vasculitis?' (9)*

There was evidence to suggest that some patients, years after being diagnosed with CKD and receiving treatment, had unmet information needs regarding the cause and understanding why they developed CKD. However, their salience in seeking information to satisfy this goal was not obvious, or whether the intensity of the information need had reduced overtime or remained continuous but of less importance to other information needs.

> *'I would like somebody to talk to me …and explain everything how you've got your how they think you've got the disease or whatever it is… why it's deteriorated, why your kidneys are going' (7)*
>
> *'I want to know about the cause (*of *CKD) they haven't really told me' (17)*

Information is needed to be able to make the decision regarding which treatment option *best* suits their lifestyle, but also information to understand what that treatment involves.

> *'When somebody first goes onto dialysis they should have what CAPD means, what Haemodialysis means relative advantages and disadvantages…but that information came out in bits and pieces' (9)*
>
> *'It would have been useful if you could have sat down in another room or sat down talking to someone who was on dialysis and saying well what does it involve?' (12)*
>
> *'Make sure that this dialysis is right for them… that other lady I was talking to was on a smaller one, better freedom of life… if I'd have known… I would have said well can I not get on that smaller one but I didn't know they just put me on this' (5)*

Being prepared for what to expect in the future encompasses numerous goals and embedded tasks pertinent to the practicalities of the treatment selected. For example, needing access for dialysis and what this will look like, having to have needles inserted each dialysis session, waiting for transport to and from the unit and the amount of stock required for PD at home.

> *'When you get there you could have hours to wait and they don't tell you that you can have hours or a while to wait at the end for your transport home… So that is quite a shock really' (18)*
>
> *'I thought that the graft would end up with something that the machines were attached to, I didn't realise that then you would then have to put needles in' (18)*
>
> *'I got one visit, they didn't tell me what the fistula was going to entail apart from an artery and a vein was going to a u-turn and that was it… I never got told it would come like this' (12)*
>
> *'I have the backyard full of dialysis boxes because you have nowhere to put them' (6)*

Knowing what to expect included realistic information about what happens long-term if you start to run out of vascular access options or how long will it take to get a transplant and realistically how long a transplant would be expected to survive.

> *'If my access keeps giving in or the line gives in and then the only option is a kidney, she said and then you would have to be put on the emergency list' (19)*
>
> 'So I'm hoping if I get a transplant…it's the luck of the draw I sometimes wonder whether there's an age bias people may say the guy's 74 you know they say not' (9)
>
> *'Nobody said to me and it was only then when me kidney was failing that I found out about the success rate' (7)*

Recognise and Understand Physical Symptoms/Complications, What to Expect

Patients want information that enables them to identify when their kidney function is deteriorating or understand why they are experiencing certain physical symptoms. Not knowing what is happening when experiencing physical symptoms, as a result of the disease or a complication, increases uncertainty.

> *'If I'd have known what the onset of the symptoms were that would have been useful… I didn't realise it was gonna manifest itself in the way that it did… with your kidneys you think if affects the way you go to the loo you don't think it's*

> *gonna give you weight loss you don't think its gonna make you being sick all the time' (15)*
> *'I'd been on dialysis for so long without any infection I didn't know what it was but I kind of guessed…it was not what I expected it was a really sharp pain' (10)*
> *'Nobody told me that when I had this thing in me neck it was dangerous to do anything and I, anything involving dust and all… got septicaemia didn't I…I didn't know when your shaking and all that that there's problems you know I thought …I can't get warm I'm freezing cold, I was freezing cold and my temperature was sky high you know' (7)*

When there is a possibility of severe side effects, such as with transplant anti-rejection therapy, then knowing beforehand for some patients outweighs the fear and anxiety of later experiencing side effects and being unaware that they are drug induced.

> *'The medication with my transplant about the problems with that nobody mentioned at the time …they send me to Christies for cancer…I went back in and had a little talk and we think you've got it from the medication from your transplant and I know they never said anything about that to me…they didn't say anything about the cataracts' (7)*

Reducing Uncertainty and Gain Reassurance

Feelings of uncertainty are expressed within information needs through phrases relating to '*not knowing'* or the state of being unsure linked to being uncertain of what something means (doubt), what the outcome might be (unpredictability), or why am I feeling like this (questioning)? Information is either sought directly for the purpose of allaying fears of uncertainty or whilst finding answers to other questions uncertainty is reduced.

> *'What you would like to know is when and nobody can tell you that can they… Nobody can tell you that… ten years ago when I first went they said it would be in the next five years or so but here I am ten years on and I'm still no nearer' (4)*
> *'I think people should know the consequences… If somebody said to me, you've got cancer, well I'd want to know how long before it kills me' (12)*

To realise the goal and reduce the uncertainty of whether CKD can be treated can in turn lead to further uncertainty regarding how long a person can survive once established on a treatment.

> *'I pushed and I pushed and I kept saying I'd like to know what you know I said you can't obviously keep sticking these needles in me arm… I said so how long can that go on for?' (7)*

Information that enables individuals to recognise physical symptoms and understand that what they are experiencing is expected or *normal* is to some degree reassuring, reducing feelings of uncertainty. Further reassurance can be gained from information explaining when to report such symptoms and when to seek advice or medical assistance. Not knowing for some patients creates questions that remain unanswered.

> *'Presumably the hangover feeling I've got is due to dialysis the toxicity in my body?' (9)*
> *'Lets say I pick up a symptom or have a problem I would not wait for the next clinic appointment I would ring them up for advice' (8)*

Reduce Anxiety, Adjust and Cope

Information is needed to reduce the fears and anxiety associated with a chronic illness to help patients cope and adjust. Being able to effectively manage the psychological affects, such as feeling depressed and angry, from being restricted by both the disease and the treatment over a long period underpins the purpose of many emerging information needs. Receiving information from other patients on how they cope could be valuable.

> *'I do get upset about it all the time it's just managing it really isn't it… they don't talk to you about your emotions…. I hate it, I hate being connected to a machine really but it's something that you've just got to face and get over' (10)*
> *'The thought that this may go on for the rest of your life is actually quite depressing…. at times you get so fed up with the whole thing' (9)*

> *'I wish I had met other patients on dialysis who could tell me the ways that they had learned to cope before. I feel as if I've had to find my own way' (10)*

Feel in Control/Have More Control Over My Illness and Care for Myself

The purpose of some information is to enable a person to take control of their disease and treatment and feel confident enough to change their regime to suit their lifestyle. This can be achieved through increasing their understanding and knowledge so they can self-manage their care.

> *'At the hospital they said it's got to be every four hours on the dot well I would like to tell someone that it doesn't have to be every four hours… you have to fit it round your life that suits you rather than this you know regimented kind of system that they have me believe' (10)*
>
> *'As soon as I came home I changed my regime. I don't do three days a week I do alternate days so one week it's three times one week it's four… I explained what I was gonna do before I did it and I talked it through with the sisters and the nurses on the training unit and also with the doctor as well and they were fine with that as a regime' (15)*

To be able to self-manage information is needed about physical symptoms, diet and fluid restrictions and associated blood levels to be able to monitor their progress.

> *'It would be good if they send you something with these are your blood results and maybe a target and this is what you need to do' (6)*
>
> *'I think don't worry about the diet just worry about your what your blood results look like and if everything's fine just carry on… I quite like the clinic letters because I do understand what my creatinine and urea are' (8)*
>
> *'Know your own body, bare it in mind these are the symptoms that your gonna feel and if you come up with those you've just got to be aware of it and certainly in the early stages going through and having regular blood tests and checks to make sure that you are you know you're controlling things' (15)*

Help Me Live a Normal Life

Patients identify the need for information to help them understand how to achieve the right balance between the restrictions imposed by their disease and treatment and living a *normal life*. How people use this information or the importance or salience placed on this goal differs between individuals.

> *'I had an inkling of what would happen that my life would have to revolve around the dialysis, but right at the very beginning I did not know that my life would go bang, stop… dialysis takes priority' (12)*
> *'I don't think any renal patients follow it (diet) if they'd be honest… Well I just limited myself…if I have chocolate I won't say I'll have chips or crisps on the same day but I won't stick to a renal diet' (14)*
> *'I think they have been clear that it doesn't have to rule you life and I guess it's whether you take that on board or not. I certainly did and it was both an active work life and an active social life and I wasn't prepared to loose either' (8)*

For some the overriding goal in the first instance is having the information that enables them to continue working, even if it means selecting a form of dialysis that gives them the freedom to work, only to find later it's not suitable. Realistic information that helps them understand that continuing working may be unrealistic, particularly continuing manual work.

> *'Yes but it wasn't suitable for me (PD) I should have gone through to haemodialysis really but like I said I wanted to carry on working' (3)*
> *'At the start you need, well I did, I needed to be told that there's a possibility that I wouldn't be able to work which was never told to me' (7)*

When Information Needs Occur?

Similar to determining the purpose or goal of information the interview data was further scrutinised to explicate when and in what particular circumstances a need for information originates. An analytical framework was grounded from the CKD information need data, with themes grouped according to three naturally occurring categories; whether needs arose as a result of an event, experience or encounter. The conceptual proximity between these categories required that operational definitions be generated and applied to ensure reliable and consistent data coding. The Oxford English Dictionary (OED) definitions were used to clarify meaning.

- Event – *'anything that happens, or contemplated as happening, an incident, occurrence'* (OED, 1989)
- Encounter – '*the fact of meeting with a person or thing'* (OED 1989)
- Experience– '*being consciously the subject of a state or condition'* (OED 1989)

Distinctions could easily be made between an encounter and experience, although either could be classified as an event given the definition of *'anything that happens.'*

Therefore, for the purpose of this study an event was considered to be more objective, an incident, often identifiable to a stage in the progressive disease (such as diagnosis) or an aspect of the patient's treatment regime, or an activity in life, different to an encounter or experience. Examples to clarify the characteristics of the analytical concepts are shown in Table 26.

Table 26: Conceptual Clarity

Example Statement	**Conceptual Coding**
Having a biopsy	Event
Patient attending a clinic visit and an information arises as a result of information provided	Encounter
Patient experiencing physical symptoms and not knowing the cause	Experience
Patient having investigations but uncertain, not knowing why, what is wrong	Event, Experience
Patient experiencing physical symptoms and not knowing the cause, nurse visits and discusses symptoms	Experience, Encounter
Kidney function deteriorating, experiencing physical symptoms, and doctor indicates the need to start dialysis	Event, Experience, Encounter

Events, Encounters and Experiences

A myriad of events, experiences and encounters, influenced and spawned questions that shaped the patients desire for information. Often a combination of more than one of the three core concepts formed the context within which an information need emerged. Events were separated into two groups, those relating to the disease and/or treatment pathway and those occurring in the patient's home life. Experiences emerged that were physical and/or psychological in nature. Encounters were seen to be planned or unplanned.

- Disease and treatment pathway events
- Life events
- Planned encounters
- Unplanned encounters
- Physical experiences
- Psychological experiences

Disease and Treatment Pathway Events

Not surprisingly the majority of information needs correlated to events that transpired from, or were as a result of, the treatment trajectory and the care pathway in which CKD patients found themselves. Key chronological events could be identified within the pre-dialysis phase, early stages of starting treatment, through to being established on dialysis long-term (Table 27), as points in time where information needs arose.

Simultaneous, to the key events identified linked to treatment progression, a further sub-set of events were occurring due to the restrictions imposed by the treatment, different medication and the ritual of measuring blood levels to monitor progress.

- Diet restrictions – Day to day decisions whether to eat something or not
- Bloods tests - Monthly blood levels taken
- Medication – Taking different medication and not knowing what and why

These three events however, rarely existed in isolation but in conjunction with a physical or psychological experience or as a result of an encounter with a health professional, other patient or social occasion.

Table 27: Events Occurring as a Result of the Disease/Treatment Pathway

Event	**Example Descriptor**
Investigation prior to diagnosis	• Having a biopsy and not knowing why • Attending clinic but not knowing what the problem is
Diagnosed with CKD	• Being told the cause but not understanding what it means • After being diagnosed wondering what will happen
Deteriorating kidney function requiring treatment	• Attending out-patient clinic for 20 years never realised would need dialysis in the future • Being told need dialysis • Drug therapy not working and being told that needs dialysis
Making a decision and choosing a treatment option	• Making a decision about which treatment to select • Questions arising from having to make a choice and wanting more information • Which treatment suits lifestyle
Having access created for dialysis (vascular or PD catheter)	• Understanding access options • Having permanent access created for haemodialysis • Temporary line inserted for HD
Starting dialysis treatment – practical issues	• Starting treatment - knowing what the treatment involves how it works • Understanding the practical aspects of actually having HD • Learning the procedure for PD, what is important and why
Established dialysis treatment	• What the base weight means • What a wash back means • Having problems during dialysis and knowing what to do about it (dislodged needle, unable to drain) • Understanding the glucose content of PD bags and how this can be used to draw off extra fluid
Transplantation	• Being assessed for a transplant and visiting transplant hospital • Going on the transplant list • Waiting for a transplant • Being transplanted • Failed transplant
Changing dialysis treatments – failed treatment	• Failed dialysis treatment and needing to change to a different treatment option • Treatment choice not effective and need to change treatment to HD • Only option to stay alive if access cannot be established is to be placed on the emergency transplant list

Life Events

A number of key life events were identified from the data that were directly influenced by the CKD treatment regime and created information needs for patients (Box 8).

Box 8: Life Events

- To keep control of your life and fit dialysis in rather than change
- Social engagement/activity
- Going on holidays and travelling
- Planning a future holiday
- Needing to work
- Fitting dialysis round working day
- Remaining independent
- Threat to financial stability
- Relying on social security benefits to live
- Being unable to continue working
- Having a reduced quality of life

For all patients, when planning to start or receiving dialysis, the constant event of balancing life and social activities alongside the need for treatment was evident. Different information was required for different events such as being able to change a haemodialysis shift to attend a social function or missing a PD exchange to accommodate work. One of the most prevalent and far reaching life events described by patients centred on the need to continue working, to remain independent, maintain normality and financial stability. Initially information was needed to understand whether it was possible to combine necessary treatment with work commitments. If, for whatever reason, this was not possible the consequential events of being out of work, threats to financial stability and reduced quality of life produced additional information needs. Understandably these types of life events initiated a psychological response linked to coping with a chronic condition and treatment constraints.

Encounters

Encounters were key opportunities for information exchange and information needs arose as a result of an encounter often closely linked to an event. For instance being presented with the diagnosis of CKD at a clinic visit with the doctor or discussing treatment options to facilitate a decision at a home visit by the nurse. In some cases encounters provided an opportunity to seek information to satisfy existing information needs originating from a physical/psychological experience or life event.

Encounters could be classified as planned or unplanned (Table 28), with planned encounters occurring at formal scheduled clinic appointments, home visits by nurses or during haemodialysis treatment sessions on the renal unit. These frequently involved health care professionals although some meetings between patients were planned in advance. Unplanned encounters were less informal, spontaneous meetings frequently with other patients in communal waiting areas, whilst sharing transportation to treatment sessions or clinic appointments or observing the treatment of other patients in the dialysis unit. Patients commonly used these impromptu encounters to satisfy existing information needs, gaining reassurance from another patient’s realistic perspective, but naturally the result of an encounter, for some, stimulated new information needs.

Table 28: Planned and Unplanned Encounters

Planned
• Discussing dialysis options with the family • Reporting physical and psychological experiences/problems to professionals • Talking with the doctor (clinic appointment) • Talking with the renal unit nurse (during dialysis treatment) • Talking with the GP (scheduled appointment) • Visited by community nurse • Talking to the CKD nurse (scheduled appointment) • Talking to other patients about their treatment to gain realistic perspective (visit to dialysis unit) • Talking to someone and asking for help (scheduled visit or telephone call)

Unplanned

- Watching someone with a temporary line attached to dialysis and not requiring needles, looks a better option than a fistula (during dialysis)
- Comparing what medication you are taking with other people (waiting room, in-patient on ward)
- Talking to other patients and finding they have what looks like a better treatment (in transport from clinic)
- Seeing what other patients' fistulas actually look like (whilst on the renal unit)
- A patient showing what their PD catheter looks like (waiting room)
- Talking in the waiting room

Physical Experiences

Physical experiences initiated the need for information because of the patient's underlying uncertainty of what was happening to their body. Experiencing physical symptoms as a result of: a treatment complication such as an infection (pain, fever); a side effect of a prescribed drug (constipation, fainting); the dialysis treatment (headaches, cramps); fluid and diet imbalance (ankle swelling, breathlessness, itching); and deteriorating kidney function (tiredness, vomiting, sexual dysfunction); created a situation where patients wanted information to increase reassurance, understanding and knowledge (Box 9). Some physical experiences (pain, fever) act as indicators of an impending event (infection), either as a predisposing factor or a warning to take action to prevent a more serious incident (septicaemia) occurring.

Box 9: Physical Experiences

- Numerous painful attempts to establish permanent access and worry about what will happen if you run out of options
- Kidney function deteriorating showing physical symptoms
- Being admitted to hospital suffering with dehydration
- Physical symptoms as a result of the disease or form of treatment, such as muscular pain, headaches after and during dialysis
- Sexual dysfunction as result of disease and treatment regime

- Long-term problems (bone disease) and understanding why
- Potential threat of not being able to have children due to stopped periods, sterility from drugs
- Symptoms because of raised blood levels - finding out why and what you should avoid in your diet
- Knowing how to recognise an infection, what to do and who to report it to
- Painful symptoms of a complication and knowing what it is
- Finding that the PD tube is positioned on the side that you sleep on or too high to fit with your type of clothes
- Side effects from medication and not knowing what caused them

Psychological Experiences

Typically psychological experiences occurred simultaneously alongside or as a result of an event, encounter and/or physical experience. Psychological experiences involved feelings of uncertainty, perceived threats to survival, altered body image, depression, lack of control and denial. Information needs that emerged from psychological experiences centred on coping with the chronic illness and adapting to life with long-term treatment (Box 10).

Box 10: Psychological Experiences

- Too much information prior to needing dialysis increasing anxiety levels
- The shock of realising how much the treatment and CKD takes over your life
- Learning to cope and adjust your lifestyle to accommodate dialysis
- To not be prepared for what a fistula would look like or how noisy it maybe
- Worry about what will happen if you run out of access options
- Finding out the treatment is not what you expected and not the right choice
- Hate being restricted by dialysis machine
- Feeling fed up
- Feeling depressed/ future depressing
- Having good and bad days
- Being unable to cope emotionally

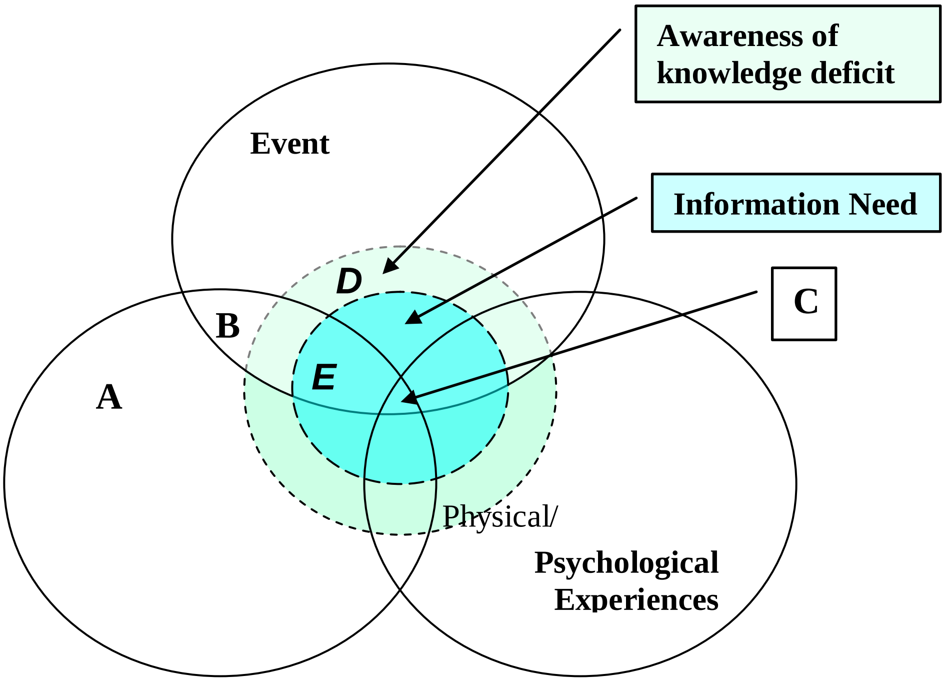
- Not adhering to treatment regime – choosing to not take prescribed medication
- Needing someone to talk to – feeling alone
- Altered body image with PD tube dislikes the look of it
- Recognising when dialysis and work is too much to cope with
- Needing to remain independent and continue working
- Initial problems stabilising on treatment affecting ability to work
- Giving up career aspirations - too tired to achieve them, too much time off sick
- Not able to concentrate as much at work which is affecting my performance
- Having a reduced quality of life because of reduced income from not working
- The worry of how to pay the bills and what to do now can't work
- Looking towards the future and wondering whether pension funds sufficient
- Fear when only option to stay alive is to be listed for an emergency transplant

Relationships between Context and Information Need Occurrence

Information needs have been shown to occur as result of an event, encounter or experience. However, overwhelming data suggests that considerable overlap exists between the related three concepts. The findings demonstrate that an information need is formed from different sets of circumstance involving one or more of these concepts. Diagram 5 represents the relationships between the overlapping concepts and superimposes the patient's potential awareness of a knowledge deficit and information need occurrence.

There was evidence to suggest that one or two, of the three concepts (events, encounters and physical/psychological experiences), may occur simultaneously without an awareness of information deficit or information need arising or being expressed (point A and B, Diagram 5). However, from the patient interviews it appeared that an information need always arose within situations where all three concepts featured (point C, Diagram 5). It is essential to note that the diagram is not to scale, thus the circle size does not represent the importance of one concept over another.

Diagram 5: Information Need Occurrence



The findings indicated that for some patients when experiencing physical symptoms, events or encounters they displayed no evidence of either a knowledge deficit or a need for information. This being the case these patients would be situated in the outer circle of the respective concept in the diagram (for example at point A, Diagram 5). If an information need arises because of a knowledge deficit then it is reasonable to deduct that for those patients who possess the appropriate knowledge an information need would be superfluous.

> '*I'm experiencing similar problems to what I had first time round so you know if you get something more than once you can tend to relate it to your end stage renal failure' (8)*

Others maybe unaware of their knowledge deficit at this time and have unrecognised information needs.

> *'Nobody told me how much time it (*haemodialysis) *would take up' (6)*

Other patients in the same situation may become aware that they have a lack of knowledge regarding what or why something was happening. Those who choose not to act on an information deficit may prefer to remain ignorant or could be suppressing an information need until a more appropriate time (deferred information need). This group of patients would be situated within the shaded, awareness of a lack of knowledge segment of the diagram, within the relevant concept circle or overlapping section (for example at point D, Diagram 5).

> *'Whenever the evil day* (need for dialysis) *when it happens then I'll do something about it* (is this the stage at which you will want information?) *Right… Yes. That's it, that's exactly it' (2)*
> '*For me that's something in the future (*transplant information*)…* I just wanted to get the dialysis bit sorted and get some benefit of feeling better' (13)

For those who take action to satisfy their knowledge gap, information needs are expressed and they would be located in the centre of the diagram within the relevant event, encounter, experience circle or overlapping segment (for example at point E, Diagram 5).

Events, encounters and experiences influence the initiation and expression of information needs. However, there was evidence to suggest that other differences exist between patients (such as knowledge levels) that when placed in the same situation some express information needs and others do not. Further exploration was needed to expose additional key contextual factors that exist and understand if and how they may influence the occurrence of an information need.

Intervening Factors

The emergence of information needs in context for CKD patients is multi-dimensional, with complex relationships existing between intervening factors or variables. Evidence drawn from the interview data suggests that different coping styles, self-efficacy, preferred levels of control, salience of information topics and/or the timing of a particular event or goal influences the initiation and expression of an information need, or the recognition of information deficit. Six examples were drawn to compare and contrast both the potential and actual interplay that existed between variables.

- Accepting (ignoring) and/or questioning coping style
- Coping style and/or goals
- Relevance/salience and/or managing more than one gap
- Timing and events and/or information overload
- Life event and/or role related
- Self-efficacy, self-management and control

Accepting (Ignoring) and/or Questioning Coping Style

The findings pointed to the existence of both *blunting* (ignoring/accepting) and *monitoring* (questioning) coping styles. Some patients chose to ignore (blunt) information, exhibiting a fatalistic philosophy of *what will be, will be*, pessimistic that what they had no control over was not worth knowing. These patients could be seen to be accepting of the information provided by professionals, rather than questioning. This style of coping decreased their information seeking behaviour and in turn reduced the initiation and expression of information needs.

> *'I don't want the information. It's a case of you know I'm very much a glass half full person rather than half empty you know so it's and like I say, a need to know basis if I don't need to know' (1)*
> *'I'm one of life's fatalists what will be will be and if they say I need dialysis I need dialysis so I'll have dialysis' (4)*
> *'I'm a firm believer in what I don't know doesn't harm me you know that's the way I've always worked unless its something that I've got to learn then I'll learn it then' (20)*

Other patients adopted a more questioning style of behaviour needing to know everything, which increased both the generation and expression of information needs, and encouraged information seeking behaviour.

> *'I like to know what I'm getting myself involved in. I know what I'm talking about and that helps me you know find the information' (14)*
> *'I do like to know everything and I try to understand what's going on around me and what's going wrong with me so I don't think you can ever have too much information' (15)*
> *'I'm one of those people that needs to know everything really and a lot, you've got to judge I suppose by looking by talking to somebody they're capable of taking the information' (7)*

Coping Style and/or Goals

There was evidence to suggest that the level of importance placed on a goal was associated with either an accepting or questioning coping style. However, it was unclear from the evidence whether the coping style of an individual influenced the level of goals set or whether the goal determined the coping style. For example, a blunter would have different goals, which were more than likely to be less challenging and easier to achieve than a monitor who would need to seek information to achieve more exigent goals (Table 29).

Table 29: Goals and Coping Styles

Patient Comments	**Goal**	**Coping Style**
'I just want to know that I'm stable as long as they tell me I'm stable the ins and outs of it I'll leave it to them to worry about' (1)	To know I'm stable	Blunter
'I'm on loads of medication… That's enough, no I don't know what each one does' (2)	To know I'm on medication	Blunter
'In the Library I used to sit there and go through all the medicines that I was on and…see the side effects of everything' (7)	To know what medication I'm taking, what they are for and what side effects they may cause	Monitor

'It doesn't have to rule your life and I guess it's whether you take that on board or not I certainly did and it was both an active work life and an active social life and I wasn't prepared to lose either' (8)	To be able to continue to live an active work and social life without being restricted by the disease or treatment	Monitor

Monitors seek information to satisfy needs, driven by inherent goals to increase understanding and find out more, rather than just accepting the information provided.

> *'I found out I had IGA I went and found the girl and asked her what she knew about the disease' (8)*
> *'Yes I'll get that from reading that book'* (what CKD does to your body) *(9)*

Goals of high importance to the individual influenced directly the type and amount of information needed, such as waiting for a transplant where the goal to live a *'normal'* life again was uppermost. Information needs surrounding such a goal periodically emerged and re-emerged as the wait became longer and the goal became increasingly important.

> *'I was always fairly optimistic that I would get a kidney fairly quickly …after a couple of years of being on the list, I mean I'm the most common blood group, and I was a little surprised… I hadn't even been called up… I was speaking at one of the regular check ups… one of the doctors there and they wrote to the transplant people just to find out exactly what the problem was… I've got certain genes, which I didn't know beforehand, and as a consequence that makes the match a little bit more difficult… they also give… a minimum length of wait and a maximum length of wait and I'm way outside of that* now (8 years later)… *again I've been talking to people…' (15)*

Relevance/Salience and/or Managing More Than One Gap

Although a patient's underlying coping style could sometimes be aligned to characteristics such as generally being accepting/ignoring of the information provided or taking a more questioning stance, this did not appear to be the most significant factor that determined whether an information need originated. The same patient could be seen to ignore (blunt) some information topics and generate information needs regarding other topics, suggesting a transient coping style, dependent upon the personal significance of the information topic to the individual at a specific point in time. Indeed, the relevance of the information topic could be more significant and influence which coping style to adopt.

An example being one patient close to needing dialysis searched for information to increase her knowledge about dialysis treatment options prior to being visited by the CKD nurse. Her goal was to have a clear understanding of what treatments were available to make the right decision. This information was a high priority to her at this particular stage in the treatment pathway or event and her monitoring style of coping was to ask questions and seek information.

> *'I needed to know the information of what was likely to be … which is why I went on the internet…I know the doctor had said there were three different types so I thought well I'd have a look at least get it into my head my own head beforehand. I think it would have been worse if I didn't know anything and then have been asked which one do you want. At least I knew' (13)*

At the same time the depth of information was important and she preferred only to have a simple explanation at this time rather than detailed information on each treatment option.

> *'I don't think I would like to know the ins and outs of every minute detail, I was quite happy to know... simply…what were explained to me' (13)*

She also deferred other information needs, although aware of her deficit in knowledge on transplantation she chose to ignore her information need until a time when she could cope with the information. This indicates the necessity to prioritise information needs to be able to manage more than one gap in knowledge, suggesting limits on how much information can be processed at any one time. Whether information is relevant either to the individual, event or current situation influences priorities.

> *'For me that's something in the future I just wanted to get the dialysis bit sorted … I'm gonna know what I'm doing (with HD) and then…as and when a transplant appears, because I haven't got a lot of information on the transplant. There is an information pack but I haven't asked for it yet cause, they hadn't got any left, so I thought oh it would only probably scare me' (13)*

Patients who exhibited blunting responses to many information topics occasionally expressed needs towards topics that were of personal interest or considered more relevant. In contrast, those who generally ask questions and seek information chose to ignore information needs on topics that were not considered relevant, particularly information about possible complications that increased anxiety.

> *'I don't think you need to know all the bad things that can go wrong… you don't want to make people more nervous because they are nervous enough' (8)*
>
> *'Yeah I don't think I'd want to know (all the complications)… Cause I'm quite happy knowing what I know' (3)*
>
> *'I wouldn't want to know about the complications I wouldn't want to know that and I would only be able to deal with them on the here and now, if it happens because if your informed about the complications you can start worrying' (11)*

Information needs left unsatisfied or unanswered but personally significant continued to re-emerge, even 16 years after first being diagnosed with CKD.

> *'Yeah I want to know about the cause* (of CKD) *they haven't really told me' (17)*

Timing of Events and/or Information Overload

Four out of the five pre-dialysis patients strongly indicated that they only required a minimum level of information about dialysis treatment and the future, at that particular stage of their CKD. They considered it to be more pertinent to have such information when they were closer to needing dialysis. Despite being aware of their deficit in knowledge regarding the topic of dialysis treatment the patients preferred to defer or ignore information needs to a later time when they were prepared to cope differently. The timing of information need was linked closely to an event, a stage in their treatment pathway.

> *'No I'm on a need to know basis. No I don't want to know. If I wanted to know I guess I could find out' (1)*
> *'Whenever the evil day, when it happens, then I'll do something about it' (2)*
> *'I should suppose now I know it's getting lower* (kidney function) *that I should re visit the different dialysis and what you know the EPO injections and transplant work probably should revisit that now …if I haven't been told all this information five years ago maybe now I would be more accepting of discussing it'* (11)

The lack of relevance of the information topic created a blunting response. Alternatively, a reason could be feeling overwhelmed by the information presented, overloaded, the gap in knowledge with respect to CKD was too big to cope with resulting in the avoidance of information and blocking of information needs. Too much information increased uncertainty on how they or their family may cope and fear of the future.

> *'Well there's too much involved in it for me to and I don't understand it you know what I mean and I'd have to start really studying and reading to understand it' (4)*
> *'She gave me too much too soon I just feel it was I didn't need to know all that at that stage… just a broad spectrum but not gone into the depth… not give you the full…give it to them on a need to know basis…I was concerned that how they gonna cope without me you know, because as far as I was concerned I was gonna finish up hooked up to a machine 3, 4 times a week. I just felt the level was too much too soon to be honest' (11)*

Between being diagnosed with CKD and starting dialysis, coping focused on taking every day as it comes, and the need for information to provide reassurance of disease stability between clinic visits, which appeared sufficient at this stage.

> *'I just want to know that I'm stable as long as they tell me I'm stable the ins and outs of it I'll leave it to them to worry about'* (1)

> *'I think I'm sort of going along taking it day by day enjoying what there is and not worrying too much about the future knowing that eventually I'm going to have to face up to something' (2)*

Life Events and/or Role Related

Information needs can be initiated by a life event that can take priority over other events occurring simultaneously within the treatment pathway. This was observed surrounding the need to make a decision as to which treatment to choose, where the need to continue working was the main concern and goal and reflected in the focus of information need. However, the influence behind continuing to work included the need to remain independent, financially stable and was very much related to role with the individual being the breadwinner for the family. Such a key role influenced the priorities of information needs. Not surprisingly this group of patients also demonstrated monitoring/questioning coping styles.

> *'That was the most important thing for me was to carry on working' (7)*
> *'They know I need to work. I have to work. I can't go on part time or anything. I have to be full time' (13)*
> *'I wanted to continue working and do the job I was doing I was travelling up and down the country…and it would have been impossible to carry on working doing the job that I was doing when I had to go back into hospital three times a week where as CAPD would give me that additional mobility and I was able to fit my working life around CAPD a lot better' (15)*
> *'I'm fortunate I feel quite strong but I wish that for me I was always gonna work always going to work to be independent I didn't like the idea of being dependant on my family… I want to be working and independent' (10)*

The patients who struggled to achieve the goal of continuing working had a manual occupation where the physical work was impossible to sustain alongside treatment. For this group earlier information at a time when there was an opportunity to change career prior to starting treatment was an identified retrospective information need, at the time an unrecognised information need, as they were led to believe it would be possible.

> '*It didn't dawn on me that I couldn't go, that it was impossible for me to go back to work, if somebody had said …right at the start you need well I did I need to be told that there's a possibility that I wouldn't be able to work, which was never told to me…then the next thing was no money…there was a lot of expense going out and not knowing whether we could meet these expenses or not' (7)*

Self-efficacy, Self-management and Control

When a patient had high self-efficacy they believed in their own ability to influence and control events and treatment, they also demonstrated a questioning and monitoring coping style which in turn increased their need for information. These patients seek information to enable them to self-manage, adapt and control their treatment to suit their lifestyle. Their information needs are considered relevant and/or of personal significance.

> *'When I was actually going on haemodialysis I was reading about a study that they were doing over in the States of daily dialysis whereby you'd go on for about two or three hours and you do it every day… it seemed like a good idea… I was thinking well perhaps that would be better for cause if I go on and it is only two hours a day that would be great… I started doing the alternate days and that's been fine for me' (15)*
>
> *'When the Dr prescribes something I will always ask what's it for and what does it do, in case I don't think it is necessary, I do know what my pills are doing… I can find out from other people and don't just rely on the consultant or nurse for that information' (8)*
>
> *'I tried getting Haemodiafiltration (HDF)…I've got all the pros and cons I gave him the letter and that and he was looking into it… well I've looked on the Internet and me friend…he does it so he told me all the benefits' (14)*
>
> *'I like to be in control of what's going on. I know it can't always happen but I'd rather know what's going on and make my own decision about what's happening' (13)*

There were other patients who felt they had no control over what was happening to them. They accepted information, didn't ask questions and preferred to leave the responsibility with the health care professionals. The majority of these patients were in the pre-dialysis stage (but not exclusively), choosing to ignore their information deficit at that time and defer information needs.

> '*You tell me what to do and I'll do it and don't second guess I don't see the point that's what they get paid to do (*professionals*)' (1)*
> *'I don't need to know why because I know they are failing and there is nothing they can do about it' (2)*
> *'I don't see the point in saying well I don't think so because I know nothing about it and he does so I've always been one to accept' (4)*
> *'I don't like having facts figures and what this and what that in my head you know I'd sooner just live day by day, have done with it' (20)*

Following or changing diets and taking different medication were within a patient's control. Some exerted their control by not adhering to the recommended diet and not taking the medication despite having the information and the knowledge as to the problems this could cause.

> *'I don't take it* (EPO) *but I should take it, it's another issue of compliance' (10)*
> *'I don't think any renal patients follow it if they'd be honest…Well I just limit myself…if I have chocolate I won't say have chips or crisps on the same day but I won't stick to a renal diet' (14)*

To have more control one significant information need was to understand blood results; what was wrong; if they were abnormal; and what they could do about it. Those equipped with this information monitored their blood levels, avoided problems and self-managed their fluid and diet restrictions accordingly.

> *'It would be good if they send you something with these are your blood results and maybe a target and this is what you need to do' (6)*
> *'I itch occasionally and I know that's because of high potassium…I need to cut down on things like chocolate and if you don't know that then you carry on quite*

> *happily doing whatever you do or if you're overloaded you start feeling fuzzy and you feel like your skins too tight for your body so you cut down on drinks'* (15)

Summary

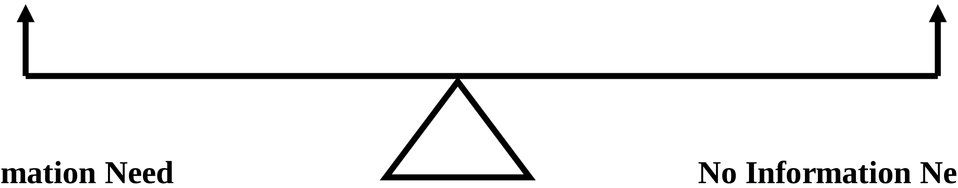
The purpose of this chapter was to generate a deeper understanding of the context surrounding the initiation and expression of information needs for CKD patients. It was feasible from the interview data to provide evidence that highlighted and described key contextual factors and demonstrated how these influenced or inhibited the formation of information needs. However, it was impossible to determine whether one factor or variable was dominant, or more influential than another. What appeared to exist was a fine balance between information need and no information need, where variables influenced either independently or collectively whether an information need emerged or not (Diagram 6).

For example, one variable such as the information topic being personally significant to an individual could swing the balance towards the expression of an information need. Alternatively, for another patient a topic may also be significant but the blunting coping style exerts a greater influence at the time, suppressing the information need. The potential variables characterised by the data were considered influential to information needs but without further exploration cannot be considered exhaustive. Diagram 6 attempts to provide order, to facilitate understanding, of what could be considered a chaotic and intricate contextual maze.

The findings were drawn from the interview data of twenty patients. Although this was a small cohort the plethora of information extracted was valuable and edifying. It clearly demonstrated that preferences and priorities exist for patients with respect to information need and provided an insight into key characteristics that influence these priorities. There were indications that differences exist between the information need priorities and preferences of established dialysis patients when compared with pre-dialysis patients. However, further evidence drawn from a larger sample was required to explore whether similarities and differences exist between the collective priorities of groups differentiated by gender, age, education level, socio-economic, ethnicity as well as treatment modality.

Diagram 6: Information Need Contextual Factors

Relevant information topic	Topic not relevant
Relevant to event	Not relevant to event
Personally significant	Not personally significant
Relevant goal	Not relevant to goal
Questioning/monitoring coping style	Accepting/ignoring, blunting coping style
High self-efficacy	Low self-efficacy
Want to be independent	Dependent on others
Desire to be in control	No desire to be in control
Want to self-manage disease/treatment	Want others to manage disease/treatment
Not enough information	Information overloaded
Important to role	Not important to role
Appropriate time	Inappropriate time



Information Need **No Information Need**

Chapter Nine
CKD Information Need Questionnaire

Introduction

The overarching aim of the research study was to explore the information need of CKD patients from multiple dimensions to generate a robust evidence base upon which to develop practice. The findings presented in chapter seven confirmed core information needs exist for CKD patients and chapter eight highlighted the contextual factors that influence individual patient preferences and priorities for information. A further dimension of the study, phase two, was to develop the CKD specific Information Needs Questionnaire (CKD-INQ) based on the core information needs to investigate whether:

- Preferences and priorities for information need topics exist within a larger CKD patient sample
- The priority of information changes over time or as a result of differences in demographic characteristics
- The CKD-INQ tool is a reliable and valid measure of information need
- CKD patients' have preferences regarding information provision

Chapter nine presents the results of the CKD-INQ. Analysis examines whether differences in demographic characteristics influence patient preferences and priorities for information as a result of gender, age, ethnicity, modality group, educational qualification, and employment status.

The INQ findings indicate that differences do indeed exist between demographic groups and identify further components, alongside contextual factors, to consider when understanding the information needs of CKD patients. Information provision preferences, an added dimension to the INQ, provide evidence to inform subsequent recommendations for practice.

Characteristics Phase Two Sample

The target population for phase two was 386 patients (see earlier chapter 6) all of whom were invited to take part in the study. Of these 91 participated in a phase two interview, a response rate of 23.6%, less than was first anticipated. Two interviews were terminated soon after starting when it became apparent, since agreeing to take part in the study; two pre-dialysis patients had selected conservative management rather than active treatment. Their information needs were considered to be very different therefore, in line with the exclusion criteria and with the agreement of the participants, the researcher sensitively withdrew and data was excluded.

As a result 89 participants were recruited to the second phase. Table 30 presents the sample characteristics. Comparisons made between the sample and the target population found it to be representative of the wider population. There were no significant differences found between age (t-test, p=0.131), modality (t-test, p=0.502), and time on RRT (t-test, p=0.885). The proportions of male (59.6%) and female (40.4%) patients were comparable to the population (male 57.5% and female 42.5%).

The sample was relatively homogenous with respect to ethnicity (83 white), which was thought to reflect the wider population although this was not possible to confirm, as the information was not available from the Trust databases at the time of sample identification. The recruitment of participants from ethnic minority groups was poor and subsequently constrained sub-group analysis. There were sufficient numbers to successfully stratify the sample according to gender, modality, time and experience on treatment and since diagnosis, current situation with respect to work, educational qualification (using upper and lower groupings), co-morbidity and to perform appropriate sub-group analysis to realise the aims of the study.

Table 30: Phase Two Sample Characteristics

Gender		**Age (yrs)**		**Age Groups**	
Male	n=53 (59.6%)	Mean	56.67	18 <40	n=10 (11.2%)
Female	n=36 (40.4%)	Median	59.00	40 <60	n=39 (43.8%)
		Range	25 - 83	>60	n=40 (44.9%)
Modality Group		**Time on RRT**		**Time Since Diagnosis**	
PRE	n=23 (25.8%)	<1yr	16	<2 yrs	21
HD	n=38 (42.7%)	>1yr <2 yrs	19	>2 yrs <10 yrs	27
PD	n=28 (31.5%)	>2yrs <5yrs	17	>10 yrs <20 yrs	28
		>5yrs	14	>20 yrs	13
		No experience RRT	23		

Ethnic Group	**(N)**	**Co-morbid Conditions**	**(N)**
White	83	No	45
Black Caribbean	1	Yes	44
Pakistani	2	**Groups:**	
Indian	1	1 – Diseases causing CKD	11
Chinese	1	2 – Diseases unrelated to CKD	14
Not disclosed	1	3 - Cardiovascular disease	24
Current Situation	**(N)**	**Cause of CKD**	**(N)**
Full-time employment	14	Glomerulonephritis/Sclerosis (I)	8
Part-time employment	8	Pyelonephritis (II)	11
Unable to work due to ill health	27	Polycystic Kidneys (adult) (III)	9
Unemployed	4	Hypertension (IV)	9
Full-time education	1	Renal Vascular Disease (V)	0
Retired	35	- Diabetes (VI)	14
		- Miscellaneous (VII)	20
		- Unknown (VIII)	18
Education Qualification (N)		**Socio Economic Group**	**(N)**
No formal qualifications	18	Managers and Senior Official	10
CSE/O level/GCSE equivalent	10	Professional	18
A level/ONC/OND	11	Associate Professional and Technical	15
HND/HNC/BTEC	7	Administrative and Secretarial	15
GNVQ	2	Skilled Trade	11
College/University first Degree	6	Personal Service	2
Higher Degree	6	Sales and Customer Service Operators	1
Professional Qualification (RGN/City Guilds)	24	Process, Plant and Machine Operatives	9
		Elementary Occupations	4
Other	5	Unclassified (education/ never worked)	4

Pilot Test

A pilot test was required to ensure the paired comparisons approach was acceptable and the instrument easy to understand and administer. Even though the wording of the themes had been checked and re-checked in the previous phase, it was necessary to test whether other patients, who had not seen the themes before also knew what they meant and that there was no ambiguity.

A consecutive sample of the first ten patients recruited for phase two was used as the pilot study group. Feedback following administration of the questionnaire indicated that the information need themes were found to be clear, relevant and easy to understand, as such no revisions were made to the instrument. However a prompt sheet was developed for the interviewer using the key descriptors identified in phase one to ensure theme descriptions were consistent and identical for each participant. The final version of the INQ can be found in Appendix 14.

Administration of the INQ

The face-to-face interview administration of the INQ was effective in clarifying both the meaning and understanding of instrument items with each individual patient, albeit time consuming. The majority of interviews took place in the patients' homes at their request, although some preferred to meet at the hospital, their workplace and during haemodialysis treatment (Table 31).

Table 31: Location of Interview

Location of Interview	Patients (N)
Home	77
Hospital	5
Work	2
Haemodialysis unit	2
In-patient ward	1
Posted questionnaire	2
Total	**89**

One patient agreed to be involved, was then admitted to hospital, but insisted the interview took place on the hospital ward. Prior to interview the researcher confirmed with the staff on the ward that the patient was fit enough to take part. Two other participants, unable to meet for an interview, completed and returned the questionnaire by post, in a stamped pre-addressed envelope.

In most cases the researcher completed the tool with the participant, reading out the items, although a small group of participants found it easier and preferred to complete it themselves. The advantage of having a researcher present when completing the instrument was that no items were missed. Only one questionnaire had a missed item and that was returned by post. All nine core information needs items appeared comprehensible and the tool easy to complete, the majority taking between 45-60 minutes (the quickest being 30 minutes and the longest 2 hours).

Overview of Data Analysis

The questionnaire data was coded and entered into an SPSS statistical package to undertake the Thurstone Paired Comparison Analysis (Sloan et al. 1994) (described in chapter six). Agreement between respondents' ratings of the core information items was measured using Kendall's coefficient of agreement for paired comparisons.

The Mosteller Chi-square test of internal consistency, a goodness of fit test, was used to determine how well the data fit the underlying assumptions of the Thurstone scaling Case V and Case III statistical model. A further test included the Gulliksen and Tukeys measure of reliability that calculated the *scalability* of the data, the extent to which the Thurstone Scale Scores account for the variability of the individuals' responses. Descriptive statistics were used in the analysis of rank ordering of items and satisfaction with information giving. Independent-samples t-tests and one-way ANOVA were used to compare the mean scale scores for the core items by subgroups on each of the demographic variables in turn. Statistical significance, unless otherwise stated, was set at $p<0.05$.

In addition to analysing the differences in rank and Thurstone scale values from the Case V results the Averaged Preferred Proportions test was used to directly compare different groups and their comparative judgements. This test examines the average preferred proportion for each item. When significant differences are identified between the average proportion scale values of items it indicates that the groups selected items differently and had contrasting preferences. The Bonferroni correction was used to protect against a Type I error. In this case nine items are compared against each other therefore case alpha (0.05) is divided by ‘K=9.’ If any of the p-values is less than ‘test’ (p=0.0055) then the average preferred proportion for each item is found to be not the same for each group, and significant differences have been observed between items.

Instrument Items

Participants were asked to comment on the relevance of the core information need items underpinning the INQ. The majority of participants, 63 (70.79%) participants agreed all nine items were relevant. Indeed, all 89 participants considered item 6 (information about how to manage own condition) and item 9 (information about how to cope and adjust) relevant. Of the remaining 26 participants 13 identified one or more of the core items (1, 2, 3, 4, 5 and 7) as not relevant or items for which they had sufficient information to meet their needs. Item 8 (other patients experiences of CKD) generated the most comments with 17 out of the 26 participants considering the item as ‘*not useful’* or a topic in which they were ‘*not interested.’* Consequently this was considered to be the least relevant theme. One explanation suggested that:

> *‘Patients’ experience is more relevant to PD patients as they see no-one, HD patients see people all the time’*

Participants were asked to indicate any additional information needs that were not captured by the core information need items described in the INQ. The majority of participants, 67 (75.28%) indicated no additional information need topics. From the remaining participants 16 (17.97%) provided additional comments of ‘*missing*’ items, all of which could be classified within the existing items. For example:

> *‘What blood results mean – what’s happening in relation to normal levels?’*
> *‘More information on different options PD, HD and APD’*
> *‘What happens if you miss a night dialysis or manual exchange?’*

Field notes highlighted that the majority of additional comments were concerned with the patient reiterating the importance to a particular information need rather than describing an omission within the core items. However, six participants (6.74%) provided similar comments to suggest the need for information and clarity regarding aspects of service provision and delivery, particularly the need to see a Consultant regularly.

> *'Who is the consultant, what clinics, where to go if there is a problem, advice?'*
> *'Who's in charge of the care - no information about the service for a new patient?'*
> *'Would like access to doctors and more information about the service and how it is delivered'*
>
> *'Access to expert advice and services'*

Findings

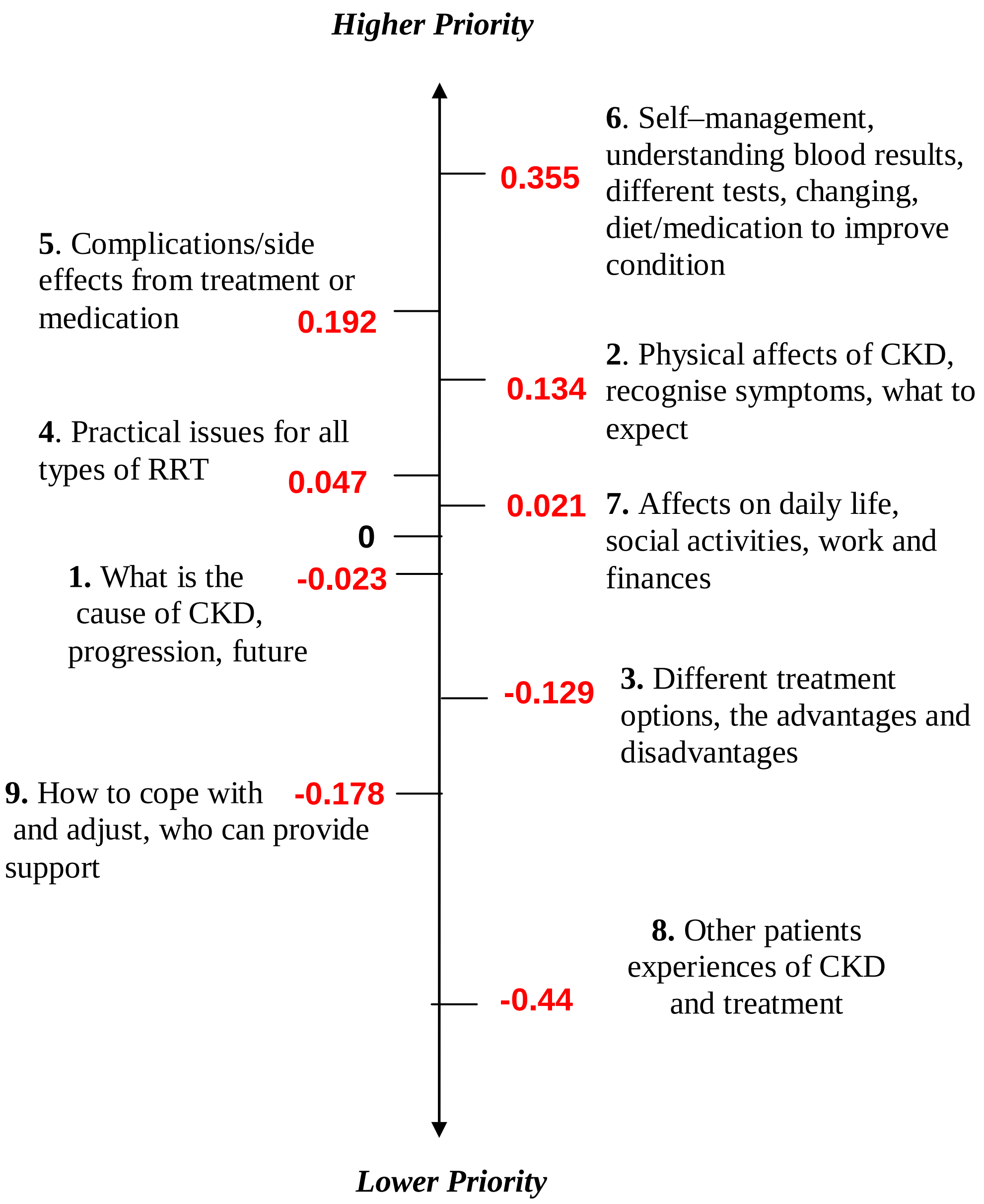
Priorities and Preferences of Information Needs

Thurstone Paired-Comparison Scale

The nine core information needs are presented in Scale 1, in rank order based on the priorities determined for the whole sample (n=89). Scale values highlight the priority patients gave to a particular item by rank order, the higher the value the more important this information need is compared with the others. Those with a negative scale value indicate that this item was preferred by less than 50% of the sample.

The items ranked highest comprise of information needs that enhance the understanding of what is happening to the physical self, recognising symptoms (item 2, scale value 0.134) and complications (item 5, scale value 0.192) and most importantly what they themselves can do about it (item 6, scale value 0.355). The lower ranked items were concerned with psychological rather than physical aspects, such as exploring the experiences of other patients (item 8, scale value –0.44) and information about adapting and coping with a chronic illness (item 9, scale value –0.178). It is notable that item 8 is the lowest ranked item corresponding with earlier comments that this information topic is of a lower priority for the majority of patients, and for some not relevant. One patient elaborated that ‘*talking to patients is useful but not vital*.’

Scale 1: Rank Order of the Core Information Needs using Thurstone Case V Scores



The type of differential scaling that the Thurstone approach permits measures the *distance* between scale items as well as the rank order (Steiner and Norman 2003). The greater the distance between any two items on the scale the greater the importance the participant places on the item. This is helpful to identify whether particular items '*stand out'* or whether items carry a comparable level of importance. In this study there was a significant difference (t-test, p<0.05) found in the distance between the top three ranked items 6, 5 and 2, and the bottom item 8, as well as the top ranked item 6 and item 9 second to the bottom. It is important to note that the scale diagrams used throughout this chapter to present the findings are not drawn to scale with respect to the distance between items but simply presented in rank order with associated scale values.

The findings show that patients consider information about how to manage their own condition (6), complications (5) and how to recognise symptoms (2) and a greater priority and more important than information about other patients experiences (8) and psychological support on how to cope and adapt with chronic illness (9). The cluster of items in the middle of the scale, such as; information about the practicalities of treatment (4); impact upon lifestyle (7); the cause of CKD and the expected future (1); and different treatment options (3), show no significant difference in distance indicating comparable levels of perceived importance.

Current Most Important Information Need Item

Prior to ranking the information need items using the paired-comparison approach patients were asked to select from the list of nine core items their current most important information need. For a small group it was particularly difficult to choose between the items in a list and as a result this question was deferred until after the paired selection had been completed.

The most important current information need identified by the highest number of patients (22.5%) was item 6 concerned with receiving information to enable them to self-manage their own condition. However, item 4 and item 1 were identified by only a fraction less of patients (n=18, 20.2% respectively), as the most important current information need. The least number of patients (2.2%) selected item 8, information regarding other patients experience as the most important (Table 32).

Table 32: Current Most Important Information Need

Item No.	Item Descriptor	Patients (N)	Patients (%)
6	Self–management, understanding blood results, tests, diet/medication to improve condition	20	22.5
4	Practical issues for all types of RRT	18	20.2
1	What is the cause of CKD, progression, future	18	20.2
3	Different treatment options, the advantages and disadvantages	10	11.2
2	Physical affects of CKD, recognise symptoms, what to expect	7	7.9
5	Complications/side effects from treatment or medication	6	6.7
7	Affects on daily life, social activities, work and finances	4	4.5
9	How to cope with and adjust, who can provide support	4	4.5
8	Other patients experiences of CKD and treatment	2	2.2
	Total	**89**	**100**

The current most important item (6) selected by the highest number of patients and the item (8) selected by the least number of patients corresponds with the highest and lowest ranked items determined by the paired-comparison approach.

When asked to rate their satisfaction level with the information they had already received about their current most important information need (on a scale of 1-5, where 1=very dissatisfied and 5=very satisfied): 29.2% were very dissatisfied or dissatisfied; 46.1% thought it was okay; 16.7% were satisfied or very satisfied. Whilst the majority of patients were either *okay* or *satisfied* with the information they had received to date on their most important information need item, their selection is indicative of the need for additional information to increase existing knowledge. One exception was noted with six patients who selected item 5 (complications and side effects), five of which expressed dissatisfaction with the level of information they had received.

Perceived Most Important Information Need for Newly Diagnosed CKD Patient

Patients perceived there to be difference between their own information need and the priorities of a newly diagnosed CKD patient. In the previous section, a higher number of patients (22.5%) selected item 6 as their most important current information need, but when asked what the priority would be of newly diagnosed CKD patient, 43.8% perceived that item 1 was more important at that time (Table 33).

Table 33: Perceived Most Important Information Need for New CKD Patient

Item No.	**Item Descriptor**	**Patients (N)**	**Patients (%)**
1	What is the cause of CKD, progression, future	39	43.8
3	Different treatment options, the advantages and disadvantages	16	18.0
2	Physical affects of CKD, recognise symptoms, what to expect	9	10.1
4	Practical issues for all types of RRT	8	9.0
7	Affects on daily life, social activities, work and finances	7	7.9
6	Self–management, understanding blood results, tests, diet/medication to improve condition	5	5.6
9	How to cope with and adjust, who can provide support	3	3.4
5	Complications/side effects from treatment or medication	1	1.1
8	Other patients experiences of CKD and treatment	1	1.1
	Total	**89**	**100**

This suggests that priorities for information need topics change over time and as the disease progresses. The majority of participants 39 (43.8%) identified that information about the cause and progression of CKD alongside understanding the future expectations (item 1) would be most important for new patients. Interestingly, 26 of the 39 patients who selected item 1 also indicated that they themselves did not receive sufficient information about this topic area when first diagnosed with CKD.

A further 18% of patients considered information to explain the different treatment options (item 3) as most important. Information about the complications or treatment and medication (item 5) and the experience of other patients (item 8) were selected as important by only one patient each. Overall 50% of patients highlighted that they themselves did not receive enough information about the item they selected for new patients.

INQ Instrument Reliability, Validity and Model of Fit

Agreement and Consistency in Comparative Judgements

Kendall's coefficient of agreement was applied to the Thurstone analysis to measure whether significant levels of agreement existed amongst participants when rating the scale items, or whether their selections were random. When prioritising their information needs the coefficient of agreement between the 89 participants was 0.06 ($p<0.05$) therefore it was possible to interpret that there was some degree of agreement.

An individual is allowed a maximum of 30 circular triads before they are considered to be inconsistent in their ratings. None of the 89 participants had 30 or more circular triads. The maximum number was 28 (one participant), the minimum 0 (five participants) with a mean of 9.29 (SD 7.045) and a median of 7.00. Therefore it was appropriate to conclude that all participants demonstrated a good level of consistency in their responses, with a small number being less consistent. Inconsistencies between an individual's ratings of particular items were observed during the completion of the INQ particularly when items were considered to have equal importance, and it was *difficult to choose between pairings.* Other instances were noted when an individual felt obliged to alter their selection pattern because they *hadn't picked it before,* despite reassurances from the researcher that this was not necessary or the purpose of the questionnaire.

Scalability of the Data

The Gulliksen and Tukey's measure of reliability (R^2) calculates the *scalability* of the data and measures the extent to which the Thurstone scale scores can account for the variability of the individual responses. The higher the R^2 score the more scalable the data. In this study the $R^2=0.6175$, which indicates an acceptable degree of reliability with just under two thirds (61.75%) of variance accounted for by scale scores.

How Well Does the Data Fit the Scaling Model?

The Mosteller chi-square test of internal consistency determines how well the data fits the underlying assumptions of the Thurstone scaling Case V and/or Case III statistical model (Sloan et al. 1994). For the data to fit the Case V model the chi-square and Mosteller p-value are used. A non-significant result indicates the scale values fit the observed data. In this study of 89 participants, the chi-square=52.21 (with 28.00 degrees of freedom) and $p<0.05$, produced a significant result. This indicated that the expected scale values were not a particularly good fit with the model, despite the Gulliksen and Tukey's measure indicated an acceptable degree of reliability.

Comparable results were observed when the data was tested for goodness of fit against the Case III scaling model. Although the fit was marginally better the chi-square=49.49 (with 20.00 degrees of freedom) and $p<0.05$, produced a significant result, indicative that the expected scale values were not a good fit with this particular model either. The Gulliksen and Tukeys measure of reliability (R^2) was higher ($R^2=0.6352$) for the Case III model, which again indicated an acceptable degree of reliability with again just less than two thirds of variance accounted for by scale scores.

The lack of fit with both scale models could indicate the sample size is not large enough to overcome individual inconsistencies or more likely that confusion existed amongst individuals in making the comparisons. To explore this further a sub-set of individuals who had circular triads of >16 (p=<0.90) and were thus considered to be less consistent in their responses were excluded from the analysis (n=16). The result of which then produced a lower Mosteller chi-square=31.791 and non-significant p-value ($p=0.283$) indicative of improved cohesiveness, a better fit between the data and the model.

Table 34: Mosteller Chi-Square and p-values for Sub-Groups

Sample group	Mosteller Chi-square	Mosteller p-value	
Whole sample (n=89)	52.21	0.0036	**Significant**
Whole sample excluding patients with circular triads >16 (n=73)	31.79	0.283	Non-significant
Males (n=53)	44.15	0.027	**Significant**
Females (n=36)	25.79	0.585	Non-significant
<50 yrs (n=28)	35.69	0.151	Non-significant
>50 to <60 (n=21)	20.13	0.859	Non-significant
>60yrs (n=40)	39.44	0.074	Non-significant
HD (n=38)	42.74	0.037	**Significant**
PD (n=28)	37.33	0.112	Non-significant
Pre (n=23)	12.85	0.994	Non-significant
Higher educated (n=36)	28.58	0.434	Non-significant
Lower educated (n=28)	51.82	0.004	**Significant**
Employed (n=22)	9.31	0.999	Non-significant
Unable to work- ill health (n=27)	38.59	0.087	Non-significant
Retired (n=35)	34.72	0.178	Non-significant
No co-morbidity (n=45)	48.66	0.009	**Significant**
Co-morbid condition (n=44)	26.21	0.562	Non-significant
<2 yrs receiving RRT (n=35)	26.95	0.521	Non-significant
>2 yrs receiving RRT (n=31)	40.12	0.065	Non-significant
<2yrs since diagnosis (n=21)	30.56	0.337	Non-significant
2-10yrs since diagnosis (n=27)	27.82	0.474	Non-significant
>10 yrs since diagnosis (n=41)	30.12	0.358	Non-significant

Similar results were found within the sub-group analysis where the data, for the majority of sub-groups, fit the model with smaller sample sizes producing non-significant results ($p>0.05$). Those sub-groups where the model did not fit as well (groups such as males, HD modality group, those with lower educational qualifications, and those with no co-morbidity) contained participants with a higher number of circular triads (equivalent to or >15) (Table 34).

This examination, particularly the sub-group analysis, confirmed that the goodness of fit between the data and the scaling model was influenced by the inconsistencies of a small number of patients. Inconsistent judgements may be diluted and overcome with a larger sample size, as the level of fit was shown to increase within the demographic sub-groups, where inconsistencies were minimal. However, it may signify that the paired-comparison method is not useful for a group of patients where competing information needs exist of equal priority, making it impossible to distinguish between them. It reinforces the importance of clarity when describing items to minimise inconsistencies and ensure accurate interpretation and understanding.

Demographic Sub-Group Analysis

Sub group analysis was performed on the scale value data to determine whether significant differences (t-test, $p<0.05$) existed between patients with respect to: age; gender; modality group (Pre, HD or PD); time since diagnosis; time/experience on RRT; educational qualifications; current work situation (employed, unable to work or retired); and co-morbidity.

In addition, the average preferred proportions were analysed for each item to investigate whether groups selected items differently and had contrasting preferences. In line with the Bonferroni correction statistical significance was $p>0.0055$. Again it is important to note that the scale diagrams used throughout this section to present the findings are not drawn to scale with respect to the distance between items.

Gender

The scale values, indicating the information need priorities, of both the male and female groups replicated the rank order demonstrated by the sample as a whole (Scale 2). Consequently, significant differences (t-test, $p<0.05$) were found in the distance between the top three ranked items 6, 5 and 2, and the bottom item 8, as well as the top ranked item 6 and second to the bottom item 9.

There was no difference found between the scale values of male and female patients. The average preferred proportions were the same for both groups indicating no significant difference between male and female patients' information need priorities.

Interestingly however, 24.5% of male patients the selected item 4 as their most important current item, with 22.6% selecting item 1, and 17% item 6 which was very different to the priority order shown by the Thurstone scale values. Although, item 6 was selected by the highest proportion of female patients (30.5%) as their most important current item, the second and third highest selections item 1 (16.6%) and item 4 (13.8%) were also not comparable with the overall Thurstone scale values.

Scale 2: Gender

Higher Priority

Male (n=53)	Female (n=36)
(0.35) **6**	**6** *(0.35)*
(0.19) **5**	**5** *(0.20)*
(0.11) **2**	**2** *(0.17)*
(0.04) **4**	**4** *(0.05)*
(0.02) **1**	**7** *(0.02)*
(0.02) **7**	**1** *(-0.07)*
(-0.13) **3**	**3** *(-0.10)*
(-0.16) **9**	**9** *(-0.18)*
(-0.44) **8**	**8** *(-0.44)*

Lower Priority

Age

There were some notable differences in the scale values assigned to the core nine items within different age groups (Scale 3).

For patients aged <50 years there was a significant difference (t-test, p<0.05) between the distance in the top-ranked item 6 (scale value 0.24) and the lowest item 1 (scale value –0.20). Information about managing their condition (item 6) and the impact upon their lifestyle (item 7) were of a greater priority to younger patients than information about the cause of CKD and the future (item 1).

In contrast, patients between the ages of 50-60 years ranked item 1 (scale value 0.25) the highest. The rank order of core items by patients over 60 years of age showed a significant difference (t-test, p<0.05) between the lowest ranked item 8 (scale value -0.95) and the distance between all the other core items. The experiences of other patients were considerably lower in priority to older patients, compared with patients in lower age groups.

On closer scrutiny the average preferred proportions for the three different age groups (<50years/ 50-60 years/ >60 years) demonstrated there were items that were not considered the same priority by the groups when compared against each other. Patients aged <50 years showed a significant difference (p=0.0001) between the average preferred proportions (or between the low scale values) given to item 1 (cause of CKD and the future) when compared with patients aged 50-60 years who gave it a higher scale value.

Scale 3: Age

Higher Priority

<50yrs (n=28)	>50-<60yrs (n=21)	>60yrs (n=40)
(0.24) **6**	**1** *(0.25)*	**6** *(0.55)*
(0.16) **7**	**5** *(0.19)*	**5** *(0.27)*
(0.12) **2**	**6** *(0.18)*	**2** *(0.19)*
(0.11) **5**	**2** *(0.07)*	**4** *(0.17)*
(0.02) **4**	**7** *(-0.02)*	**1** *(-0.11)*
(-0.11) **8**	**8** *(-0.12)*	**3** *(-0.04)*
(-0.16) **3**	**4** *(-0.12)*	**7** *(-0.06)*
(-0.17) **9**	**3** *(-0.21)*	**9** *(-0.11)*
(-0.20) **1**	**9** *(-0.23)*	**8** *(-0.95)*

Lower Priority

Patients in the two groups, <50 years and aged between 50-60 years, showed a difference in average preferred proportions for items 6 (p=0.004, p=0.001) and 8 (p=4.44E15, p=3.84E15) when compared with the preferred proportions of patients aged >60 years. The findings suggest that age is influential in the preferences and priorities of patients with respect to information need.

The selection made by patients within the different age groups regarding their current most important information need item varied considerably between groups and compared with the Thurstone scale value priority order. Item 1 (cause of CKD) and item 4 (practicalities of RRT), were selected by the highest proportion of patients aged <50 years (21.4% respectively) as the current most important item. A higher proportion of patients between the age of 50-60 years selected item 1 (23.8%) as the most important and a higher proportion of those patients aged >60 years selected item 6 (30%).

Modality/Treatment Group

Patients in the pre-dialysis group (waiting to start treatment) typically rated information about the practicalities of RRT (item 4) higher than patients in the treatment groups (HD and PD) (Scale 4). Indeed, there were significant differences recorded between the distance of item 4 (scale value 0.30) compared with the lower ranked items 1, 8 and 9 (scale values –0.28, -0.27 and –0.27 respectively), for this group of patients causing this item to *stand out.*

Scale 4: Modality/Treatment Group

Higher Priority

PRE (n=23)	HD (n=38)	PD (n=28)
(0.43) **6**	**6** *(0.38)*	**5** *(0.33)*
(0.30) **4**	**5** *(0.19)*	**6** *(0.27)*
(0.07) **5**	**2** *(0.13)*	**2** *(0.26)*
(0.06) **7**	**1** *(0.08)*	**1** *(0.07)*
(-0.01) **2**	**7** *(0.06)*	**7** *(-0.06)*
(-0.03) **3**	**4** *(0.04)*	**9** *(-0.07)*
(-0.27) **8**	**3** *(-0.15)*	**3** *(-0.15)*
(-0.27) **9**	**9** *(-0.18)*	**4** *(-0.17)*
(-0.28) **1**	**8** *(-0.54)*	**8** *(-0.47)*

Lower Priority

Of further interest was the low scale value assigned to item 1 (information about the cause of CKD and the future) by the pre-dialysis group compared with the higher priority given to this information need by both the HD and PD patients. A significant difference (p=0.001) was noted between the average preferred proportions for item 1 of the HD group when compared with the Pre-dialysis group, indicating that they were not the same for both groups.

For the HD and PD groups the top three ranked items were the same. Although for the PD group the highest ranked item changed from item 6 to item 5 signifying that information about complications and side effects was slightly more important. This could be because complications and side effects could impact directly upon their ability to dialyse and their awareness of this is raised during their training. The average preferred proportions of all items were the same for both the PD and HD groups.

Item 4, although not significantly different in distance was ranked lower by the PD group compared with both the other modality groups. Again the practicalities of treatment could be less of a priority for this group as they have sufficient information to manage their treatment at home independently. On closer examination a significant difference was identified between the average preferred proportions of the PD group for item 4 (p=0.00001) and item 5 (p=0.0005) when compared with the pre-dialysis group. The results suggest that pre-dialysis patients have different information needs and/or priorities than those receiving RRT.

The selection made by patients within the different modality groups regarding their current most important information need item varied considerably between groups and compared with the Thurstone scale value priority order. The highest proportion of HD patients selected item 1 (cause of CKD) and item 4 (practicalities of RRT), 24.3% and 21.6% respectively, as the current most important item. A higher proportion of PD patients selected item 6 (25%) as the most important and a higher proportion of pre-dialysis patients selected item 4 (29.1%).

Time Since Diagnosis

The analysis of different sub-groups focusing on time since first diagnosed with CKD showed significant differences (Scale 5). Patients who had been diagnosed less than 2 years gave a lower scale value (-0.05) to item 4 (practicalities of different treatments) for which there was a significant difference noted between this and the top-ranked item 6 (scale value 0.35).

Compared with other patients who had been diagnosed longer and whose ratings were slightly higher, those who had been diagnosed between 2-10 years gave the experiences of other patients (item 8) such low priority (scale value –0.35) that significant differences were shown with the distances between this particular item and the other core items.

A further difference was noted, for patients who had been diagnosed over 10 years, item 3 (different treatment options) was ranked lower (scale value –0.29) resulting in a significant difference between this and the top-ranked item 6 (scale value 0.44).

When investigating variations between the average preferred proportions of items again significant differences were noted between particular items and groups. A significant difference was found between the average preferred proportions of those patients diagnosed <2 years compared with those 2-10 years since diagnosis for items 6 (p=0.004) and item 8 (p=4.44E15). Similarly, a significant difference was found between the average preferred proportions of those 2-10 years from diagnosis compared with those >10 years since diagnosis for the same items, item 6 (p=0.004) and item 8 (p=4.44E15). However, the average preferred proportions for those patients <2 years since being diagnosed and those >10 years were the same for both groups.

Scale 5: Time Since CKD Diagnosis

Higher Priority

< 2 yrs (n=21)	2 yrs to <10 yrs (n=27)	> 10 yrs (n=41)
(0.35) **6**	**5** *(0.30)*	**6** *(0.44)*
(0.09) **2**	**6** *(0.22)*	**5** *(0.20)*
(0.09) **7**	**2** *(0.10)*	**2** *(0.18)*
(0.06) **1**	**3** *(0.08)*	**4** *(0.10)*
(0.05) **5**	**1** *(0.08)*	**7** *(0.05)*
(-0.05) **3**	**4** *(0.04)*	**1** *(-0.12)*
(-0.05) **4**	**7** *(-0.07)*	**9** *(-0.22)*
(-0.17) **9**	**9** *(-0.09)*	**3** *(-0.29)*
(-0.38) **8**	**8** *(-0.65)*	**8** *(-0.35)*

Lower Priority

Although it would appear from the findings that the information needs of patients change as time progresses from diagnosis, in particular, that information about the practicalities of RRT increases in importance, it must be viewed with caution. On closer examination of the sub-sample groups, for example those who had been diagnosed for less than 2 years, 52% were unable to work and 71% receiving RRT. These two factors most probably influence the low priority given to the information about the practicalities of RRT not necessarily the time since diagnosis.

When comparing the current most important information need items selected by the highest proportion of patients within each group differences can be seen. Item 1 (cause of CKD) was selected by a higher proportion of patients in both the <2 years (28.6%) and 2-10 years (29.6%) groups compared with item 6 (managing own condition) selected by 31.4% of those patients diagnosed over 10 years previously.

Time on RRT

The sub-group analysis of time on treatment was constrained by the sample size, given that the pre-dialysis group (n=23) were excluded from this grouping. As a result it was only possible to shape the sample into two groups; those with <2 years experience of starting treatment; those with > 2 years experience (Scale 6).

Scale 6: Time on RRT

Higher Priority

< 2 yrs (n=35)	> 2 yrs (n=31)
(0.35) **6**	**5** *(0.39)*
(0.21) **2**	**6** *(0.29)*
(0.13) **5**	**2** *(0.19)*
(0.10) **1**	**1** *(0.08)*
(0.03) **7**	**7** *(-0.03)*
(-0.06) **4**	**4** *(-0.05)*
(-0.08) **9**	**3** *(-0.13)*
(-0.17) **3**	**9** *(-0.22)*
(-0.49) **8**	**8** *(-0.53)*

Lower Priority

The top three ranking of items differed only slightly between the two groups with items altering in position, item 5 (complications, scale value 0.39) being considered the highest priority by patients receiving RRT for >2 years compared with item 6 (managing own condition, scale value 0.35) for those having treatment for <2 years. There was a significant difference (t-test, $p<0.05$) shown between all the top three items and the lowest priority item 8 for both groups (Scale 6). The average preferred proportions were found to be the same for both groups, indicating no significant difference between the group scale values.

For patients with <2 years experience of RRT and those with >2 years experience, it was found that the same two items (item 1 and item 6) were selected as the most important current information need items by the highest number of patients.

Current Work Situation

Three groups were compared with respect to their current employment, those employed, those unable to work due to ill health and those retired. The groups showed significant differences with regard to the distance and importance placed on specific items (Scale 7). Patients in full or part-time employment rated item 6 (scale value 0.40) and item 5 (scale value 0.29) as the first and second most important information needs but then rated item 7 (information regarding the impact of CKD on their lifestyle) as third highest (scale value 0.09). When juggling work and treatment schedules it is understandable that this information need has a higher priority. There was a significant difference (t-test, p<0.05) noted between the distance of the higher ranking items 6 and 5 (scale values 0.40 and 0.29 respectively) compared with the lowest ranked item 3 (different treatment options) (scale value –0.46).

Scale 7: Current Work Situation

Higher Priority

Employed (n=22)	Unable to work (n=27)	Retired (n=35)
(0.40) **6**	**2** *(0.22)*	**6** *(0.62)*
(0.29) **5**	**6** *(0.19)*	**4** *(0.31)*
(0.09) **7**	**5** *(0.16)*	**5** *(0.21)*
(0.08) **2**	**1** *(0.04)*	**2** *(0.09)*
(-0.09) **8**	**7** *(0.01)*	**3** *(-0.08)*
(-0.10) **4**	**8** *(-0.10)*	**1** *(-0.03)*
(-0.11) **1**	**4** *(-0.15)*	**7** *(-0.04)*
(-0.11) **9**	**3** *(-0.16)*	**9** *(-0.11)*
(-0.46) **3**	**9** *(-0.20)*	**8** *(-1.14)*

Lower Priority

The top-ranked item for those patients unable to work due to ill health was item 2 (physical affects and symptoms) with a scale value of 0.22. The importance of information on the physical impact of CKD may reflect their incapacity to work as a result of experiencing a number of different symptoms. There was a significant difference found between scale scores between items 5 (complications, scale value 0.16) and item 9 (how to adjust and cope, scale value –0.20).

For retired patients there was a significant difference (t-test, p<0.05) found between all the items and item 8 (scale value –1.14) the lowest ranked item, indicating the experiences of other patients is not a priority for this group of patients. This confirms the parallel finding demonstrated with the older age group (>60 years), the majority of who would also be retired.

The average preferred proportions between patients unable to work and those retired showed significant differences for item 4 (p=0.00007), item 6 (p=0.002), and item 8 (p=0.0000.) However, there were no significant difference between those unable to work and those employed indicating the average preferred proportions were the same for both groups.

The current most important information need item selected by the highest proportion of patients in the employed group was item 6 (28.6%). Similarly, item 6 was also selected by a high proportion of patients (25.9%) within the retired groups as the most important item alongside item 4 (25.7%). These selections mirror the priority order of items shown by the Thurstone scale values. However, for those who were unable to work due to ill health the current most important information need identified by the highest proportion of patients was item 4 (25.9%), shown to have a much lower priority with the Thurstone scale values for this group.

Education

There were some interesting differences in the rank order given to the core nine items between different education level groups based on formal qualifications (Scale 8). Patients with higher education qualifications gave a greater priority to item 5 (information about complications) and item 7 (the impact upon their lifestyle) compared with patients who had no formal or lower qualifications, who ranked item 4 (information concerning the practicalities of treatment) higher.

Indeed, for patients with higher education qualifications there was a significant difference (t-test, p<0.05) noted in the higher scale scores for items 6, 5, 7, and 2 when compared to item 8 that was given lower priority. Similarly, for patients with no formal or lower education qualifications the top three ranked items 6, 4, and 2 showed a significant difference (t-test, p<0.05) in scale value compared to the lower ranked item 8. The average preferred proportions however were the same for both groups and showed no significant difference.

Scale 8: Education Level

Higher Priority ↑

No formal/ GCSE level (n=28)	Higher /Degree or professional (n=36)
(0.37) **6**	**6** *(0.31)*
(0.21) **4**	**5** *(0.24)*
(0.18) **2**	**7** *(0.14)*
(0.09) **5**	**2** *(0.13)*
(0.07) **1**	**4** *(-0.01)*
(0.04) **3**	**9** *(-0.06)*
(-0.06) **7**	**1** *(-0.07)*
(-0.32) **9**	**3** *(-0.17)*
(-0.57) **8**	**8** *(-0.51)*

↓ *Lower Priority*

The current most important item selected by the highest proportion of patients in the highest qualification group was item 6 (25%). Whereas an equal highest proportion of patients selected item 1 (25%) and item 4 (25%) as their current most important item in the no formal and lower qualification group.

Co-morbidity

Whether a patient had an underlying co-morbidity alongside their CKD was observed to have no direct influence on their information need preferences and priorities (Scale 9).

Scale 9: Co-morbidity

Higher Priority

No Co-morbidity (n= 45)	Co-morbidity (n=44)
(0.36) **6**	**6** *(0.34)*
(0.22) **5**	**5** *(0.17)*
(0.11) **2**	**2** *(0.16)*
(0.03) **7**	**4** *(0.15)*
(0.01) **1**	**7** *(0.02)*
(-0.07) **4**	**1** *(-0.04)*
(-0.08) **9**	**3** *(-0.06)*
(-0.18) **3**	**9** *(-0.26)*
(-0.41) **8**	**8** *(-0.47)*

Lower Priority

The scale values for both groups were comparable, reflecting the rank order for the whole group, with only slight movement order of the middle items (1, 4 and 7). There were no significant differences observed between the information needs and priorities of patients with or without a co-morbid condition. The average preferred proportions for both groups were also the same.

A difference was noted between the current most important item selected by the highest proportion of patients in the no co-morbidity group (item 6, 35.3%) compared with those in the co-morbidity group (item 4, 27.7%).

Knowledge Levels of CKD

Patients were asked to retrospectively score their level of knowledge, to rate what they initially knew about CKD when they were first diagnosed with the condition (on a scale of 1-5, where 1= knew nothing, and 5=knew everything). From the 89 responses the majority 83.2% knew nothing or only a little about CKD, compared with 16.8% who felt they knew enough or quite a bit. There was no significant difference found between the initial knowledge levels of patients and their gender (ANOVA, p=0.682), age (ANOVA, p=0.267) and modality group (ANOVA, p=0.267).

When asked to rate their current level of knowledge of CKD, patients perceived that their knowledge had increased since they were first diagnosed (Table 35). The majority (94.4%) reported now knowing enough or more about their condition compared with 5.6% still only knowing a little. No patient indicated that they knew nothing about CKD.

Table 35: Changes in Knowledge Levels

		Current Knowledge Level (N)				
		Know a little	Know enough	Know quite a bit	Know everything	Total
Initial Level	Knew nothing	3	17	23	10	**53**
	Knew a little	2	4	12	3	**21**
	Knew enough	0	1	5	2	**8**
	Knew quite a bit	0	1	3	2	**6**
	Knew everything	0	0	0	1	**1**
	Total	**5**	**23**	**43**	**18**	**89**

The five patients who rated their current level of knowledge as *only a little,* were older (>60 years) and spread across each of the modality groups, although three were from the PD group. There was no significant difference found between the current knowledge levels of patients and their gender (ANOVA, p=0.779); age (ANOVA p=0.546); specific modality group (ANOVA, p=0.822); and time since their CKD was first diagnosed (ANOVA, p=0.472). However, there was a significant difference found between current knowledge level and time receiving RRT (ANOVA, p=0.036), with knowledge levels increasing with time and experience of treatment (Table 36).

Table 36: Current Knowledge Level and Time on RRT

		Time/Experience on RRT (yrs)					
		None	0 to 1yr	>1 to <2	>2 to<5	>5	Total
Current Level	Know a little	1	2	2	0	0	**5**
	Know enough	8	3	6	4	2	**23**
	Know quite a bit	10	9	11	7	6	**43**
	Know everything	4	2	0	6	6	**18**
	Total	**23**	**16**	**19**	**17**	**14**	**89**

Influencing Factors and Information Seeking Activity

There were additional factors linked to sense of control, self-efficacy and health beliefs that warranted further exploration with the larger sample of CKD patients, particularly when compared against a patient's need for information and information seeking activity. Additional questions posed on the INQ facilitated the examination of:

- How much information would you like?
- Level of information seeking activity
- Perceived vulnerability and illness control
- Perceived seriousness of CKD
- Perceived control over CKD
- Perceived control over CKD and treatment decisions

The findings identify that demographic differences exist between patients with respect to the factors explored, and some but not all of these factors influence information need.

How Much Information Would You Like?

When exploring how much information patients wanted it was observed that the majority of patients 60 (67.4%) would like to know as much as possible, 20 (22.5%) only needed to have basic level of information to make decisions, 7 (7.9%) only wanted information about what was going to happen next, and 2 (2.2%) participants did not want to know anything.

Although there was no clear proportionate difference across the different age groups, with respect to wanting as much information as possible, the 2 patients who didn't want to know anything were both older than 70 years of age. Interestingly, a higher proportion of HD patients (45%) needed to know as much as possible, compared with PD (30%) and Pre-dialysis (25%). Furthermore, a higher percentage of males (60%) needed to know as much as possible compared to females (40%), as did patients with higher educational qualifications (66.5%) compared with those with no formal or lower qualifications (53.6%).

Information Seeking Activity

Those participants who demonstrated a need for information generally actively sought out additional information to supplement what had been provided (Table 37). In fact all those patients indicating wanting only *to know what would happen next* also reported seeking out additional information.

Table 37: Information Need and Information Seeking Activity

	Seek Additional Information (N)			
Need for Information	Always	Only if don't understand	Never	**Total**
Need to know as much as possible	41	18	1	**60**
Only need basic level of information to make decisions	4	15	1	**20**
Only need to know what will happen next	2	5	0	**7**
Don't want to know anything	0	0	2	**2**
Total	**47**	**38**	**4**	**89**

The majority of CKD patients (98%) desire information, but differences existed between groups of patients with respect to how much. When asked about their information seeking behaviour around 5% more females (55.5%) tended to seek out additional information *always* compared with males (50.9%). However, there was no proportionate difference observed between information seeking behaviour and age. A higher proportion of pre-dialysis patients (63.6%) seek information more often than patients within the other modalities, PD (51.7%) and HD (48.6%). Employed patients (77.3%) were more likely to always seek additional information compared with those unable to work (51.9%) and those retired (40%). However, retired patients (63%) and those unable to work (48.1%) were more likely to seek additional information if they didn't understand something. Those patients with a higher education qualification seek information more often (61.1%) than those with no formal or lower qualifications (32.1%), who seek information when they don't understand something (60.7%).

Perceived Vulnerability and Illness Control

The majority of patients (76.4%) perceived their CKD to be under control at the present time and that it would continue to be in the future (64%) (Table 38). Considerably more male patients (73.7%) reported feeling at risk of developing complications than females (26.3%) at the present time. This increased feeling of risk indicated by male patients or inversely the reduced risk perceived by females did not seem to influence information seeking activity with a similar number of both males (67.9%) and females (66.6%) indicating they *would always seek* out additional information.

Table 38: Need for Information and Vulnerability

	Perceived Vulnerability at **Present** **(N)**		Perceived Vulnerability in the **Future** **(N)**	
Need for Information	Not under control at risk	Under control not at risk	At risk of complications	Under control not at risk
Need to know as much as possible	14	44	20	39
Only need basic level of information to make decisions	4	16	8	12
Only need to know what will happen next	1	6	3	4
Don't want to know anything	0	2	0	2
Total	**19**	**68**	**31**	**57**

A higher number of patients (63.2%), who felt their disease was not under control, seek additional information *always* compared to those who felt their disease was under control (48.5%) and not in any imminent danger of developing complications. However, those who felt their disease was under control would continue to seek out additional information when they don't understand something. One patient found it difficult to choose between the two categories of not being under control and at risk of developing complications and being under control and not at any risk, because of a lack of information:

> *'I cannot feel confident about a medical condition I know little about'*

Understandably feeling vulnerable that the CKD is out of control or open to risk appears to increase a patient's need for information but does not necessarily increase their information seeking activity, unless they do not understand something.

Perceived Seriousness of CKD

Overall, the majority of patients (80.9%) indicated that although they perceived their disease to be serious there were things they could do themselves to stay healthy. All indicated that they would seek out additional information either all the time or when they didn't understand something. There was a notable, although small, percentage (10.1%) of patients who perceived their disease to be '*life threatening'* and also reported feeling vulnerable and at risk in the future to developing complications. Despite this their information seeking activity and need for information was found to no different from other patients. Therefore the degree of seriousness patients place on the CKD does not seem to influence the already active information seeking behaviour reported.

Perceived Control over CKD and Treatment Decisions

When exploring the degree of control participants perceived they had over their disease and the influence they had over their future, only one important difference was noted. Over 50% of pre-dialysis patients felt some control but felt they were unable to anything to influence their future compared with the treatment groups (PD and HD) who indicated similar control but the ability to influence their future. It was interesting to compare this finding with the information needs scale values for the pre-dialysis group to find the importance of particularly item 1 (what is the cause, how will it progress and the future), was very low. This could signify a reduced feeling of control at this point in time for patients as they adjust and begin to develop their knowledge base regarding their condition.

There were no proportionate differences found between the degree of control participants perceived they had regarding their treatment decisions and the different demographic variables. The majority of participants (45%) indicated having full or equal control over treatment decisions with the doctors and nurses, some would like more control (29.2%), and others preferred the doctors and nurses to take control of decisions with regard to their treatment (25.8%). Of those that wanted the health care professionals to take control of the decisions, 43.5% indicated that they still needed to know as much as possible. This may be interpreted that relinquishing control over treatment decisions does not necessarily affect a patient's need for information, which remained high.

Indeed, those wanting the doctors and nurses to take control of treatment decisions exhibited similar information seeking habits to those who perceived they had more control. Although, they were less likely to *always seek* out additional information (10.6%) as opposed to seeking information when they didn't understand something (39.5%). Those patients who indicated they had equal control with the doctors and nurses over decisions or would have liked more control were more likely (83%) to *always seek* out additional information.

Information Provision

At the same time as identifying and examining the information needs of CKD patients it was logical to gather information about preferences regarding information provision. Patients were asked to select then rank their preferred methods of information provision from a pre-determined list of seven different methods. The overall percentage number of patients who ranked a method in their top three preferred selection (first, second and third place) was calculated. The percentage of patients who preferred not to have information delivered using a specific method was also noted (Table 39).

Table 39: Preferred Method of Information Provision

Method	**Rank Order**	**1st, 2nd or 3rd Selection (% Patients)**	**Would not like (% Patients)**
Face to face as individual	**1**	85.5	6.7
Face to face with family	**2**	70.9	28
Written information	**3**	62.8	9.0
Face to face in a group	**4**	25.8	47.2
DVD	**5**	25.8	32.6
Video	**6**	23.7	32.6
Audiotape	**7**	1.1	61.8

Giving information face to face to an individual or indeed for many with their family present remains the preferred method of choice for the majority of patients. Written information was the third option. However, comments suggested a combination of the first three methods was the best overall approach towards effective information provision.

A high proportion of patients felt strongly about the four lowest ranked methods with: 61.8% highlighting that they would not like information provided using an audiotape; 47.2% within a group; 32.6% using a DVD or video, respectively. No significant differences were observed between age, gender, type of modality, time since diagnosis and patients preferences for information provision. Although it was observed that the majority of patients (59.52%) who expressed a negative preference towards information being provided face to face within a group, were from the older age group (>60 years). In addition patients with a higher education level (>first degree/professional qualifications) showed greater preference towards written information compared with patients with no formal/lower qualifications.

Patients were asked whom they preferred to receive information from. The majority 53.9% (48) preferred the doctor, 23.6% (21) the nurse and a further 5.6% (5) either the doctor or the nurse. The remaining 14.6% (13) of patients had no preference and 2.2% (2) preferred to get their information direct from other patients. It was interesting to note that although the majority of patients (53.9%) preferred to get information from the doctor a third (33.3%) actually received most information from the nurse. A comment, provided by a patient, was the limited time doctors spent with patients during clinic visits; *'most of my meetings with doctors have been brief in the extreme' (86).*

Age and gender did not influence a patient's preference for whom should provide information. However, pre-dialysis patients reported getting more information from the doctor rather than the nurse compared with patients in the two other modality groups. A reason for this could be that pre-dialysis patients have less contact with nursing staff until they actually start RRT.

Overall 86.5% of patients expressed that they were either *okay*, *happy* or *very happy* with the information provided. However, one patient (aged >70 years) indicated having received no information but was unconcerned and another patient was dissatisfied having only received information from other patients. Additional comments suggested the manner in which information was provided could be improved.

> *'Doctors not listening to how a patient feels'*
> *'The way you're told, the manner regarding sensitivity, need to be more sensitive'*
> '(Need to be) *Treated as individuals – different levels of understanding'*

Information Sources

Analysis of information sources highlighted that the hospital consultant was perceived to be the most used resource for information about CKD, 82.1% (73) of patients rating the information provided as *okay* (15), *good* (20) or *very useful* (38). Similarly, the renal community nurse, renal unit nurse and the dietician were found to be useful information sources by the majority of patients (Table 40)

Despite other patients' experiences being given a low priority when ranked against other information needs, as a source of information other patients were found to be useful by 43.9% of patients. It is notable that information sources such as the General Practitioner, pharmacist, self-help groups/patient associations (which are generally active within the nephrology field) and NHS direct, were seldom used by the majority of patients to locate information about CKD.

Table 40: Information Sources and Use

Sources	**Never Used (N)**	**Not useful (N)**	**Limited Use (N)**	**Useful (Okay/Good/ Very Useful) (N)**
Consultant	3	2	11	**73**
Dietician	14	7	9	**59**
Renal community Nurse	15	0	1	**73**
Renal Unit Nurse	20	1	2	**66**
Other patients	38	0	12	39
Leaflets	38	4	11	36
Ward/Out-patient Nurses	46	1	0	42
Internet	50	0	3	36
Journal/Book	53	2	9	25
TV/radio	58	2	6	23
Magazines	58	3	5	24
General Practitioner	61	0	5	23
Self-help / Pt Associations	63	2	5	19
Newspapers	64	3	4	18
Pharmacist	66	1	2	20
Family and friends	68	1	2	18
Trial Nurses	75	0	3	11
Practice Nurse	75	1	1	12
NHS direct	86	1	1	1

Closer exploration of the different variables particularly modality, within the sample group, highlight some interesting differences. As could be expected, HD patients whose care is based in the hospital were less likely to use the renal community nurse as a source of information compared with community based PD and Pre-dialysis patients. Likewise, pre-dialysis patients were less likely to use the hospital based renal unit nurses. Again as a result of location, both pre-dialysis (65.2%) and PD patients (58.6%) were less likely to obtain information from other patients compared with HD (83.8%) patients.

It was also noted that 87.5% of older patients (over 60 years) did not use the Internet as a source of information about CKD. There was only a marginal difference found between patients with higher educational qualifications (>first degree/professional) and those with no formal/lower qualifications, and how much they use and access the Internet as a source of information, 50% compared with 40% respectively.

Summary

Previous chapters seven and eight identify that key information needs exist and that the level of priority given to an information need can be influenced by the context in which an individual patient may find themselves. However, further investigation was necessary to understand the priorities of a larger CKD patient sample; to explore the impact of demographic characteristics on information priorities; and given that CKD is a long-term condition a deeper understanding of temporal influences. This was achieved using the specific study instrument (CKD-INQ) creating both a valuable and reliable evidence base.

CKD patients have preferences and priorities with respect to information needs that are influenced by both demographic characteristics and time, although demographic characteristics are not seen to influence preferences regarding information provision. A summary of the key findings extrapolated for the whole sample, are collated in Box 11.

Box 11: Summary of Main Findings (Whole Sample)

- Significant differences ($p<0.05$) were found between certain information need items indicating preferences and priorities exist for CKD patients
- Higher priority items included information about managing own illness (6), complications (5) and the physical effects of CKD (2)
- Lower priority items included information about how to cope and adapt (9), and other patients' experiences (8)
- Information needs priorities differed between demographic groups (age, modality group, time since diagnosis, current work situation)
- The current most important item selected by highest proportion of patients was comparable to highest priority item on the paired-comparison scale
- 67.4 % of patients wanted as much information as possible, 22.5% needed only basic information to make decisions, 7.9% only what happens next and 2.2% don't want any information
- The top three preferred methods for information provision were, face-to-face to individual, face-to-face with their family present, and written information
- The majority of patients preferred to receive information from the doctor (53.9%), nurse (23.6%), or either the doctor or nurse (5.6%)
- 86.5% of patients were either *okay*, *happy* or *very happy* with the information provided
- The hospital consultant was the most used resource for information about CKD, closely followed by the renal community nurse, renal unit nurse and dietician
- General Practitioners, pharmacists, self-help groups/patient associations and NHS direct were least used as source of information about CKD
- Demographic characteristics such as age, gender and modality group do not influence patient preference of information provision method
- Information seeking activity was higher among those with higher education qualifications and those in employment

The findings highlight key demographic characteristics that influence patient information priorities and equally, highlight those characteristics that do not appear to have any influence (Box 12).

Box 12: Characteristics that Influence the Priority of Information Need

Do not influence the priority of information need

- Gender
- Time on RRT
- Formal education
- Co-morbid Condition

Influence the priority of information need

- Age
- Modality group
- Time since diagnosis
- Current work situation

The study instrument (CKD-INQ) was found to be a useful tool, the core information need items were relevant to patients and the degree of reliability of data scalability and agreement between participants was acceptable (Box 13). Although a number of inconsistent comparative judgements by a small group of patients reduced the level of fit between the data and the scaling model.

Box 13: Reliability of Study Instrument

- 70.79% of patients agreed all items to be relevant
- Acceptable degree of reliability for data scalability (R^2 =0.6175)
- Agreement found between patients (Kendall's coefficient 0.06)
- Good level of consistency found in patient responses (with a small number being less consistent circular triads >15 but <28)
- Not particularly good fit between data and Case V and Case III model (Mosteller chi-square=52.21, p<0.05, chi-square=49.49 p<0.05 respectively)
- Goodness of fit between data and model within demographic sub-groups

Inconsistent judgements may be overcome with a larger sample size, as the level of fit was shown to increase within the demographic sub-groups, where inconsistencies were minimal. However, it may signify that the paired-comparison method is not useful for a group of patients where competing information needs exist of equal priority, making it impossible to distinguish between them.

Chapter Ten
Discussion

Introduction

The original premise of this study was that CKD patients will have preferred key information needs, which are a priority to them, at different times during the progression of the disease. The findings support this hypothesis but more significantly provide a depth of knowledge that generates a clearer understanding of the complex contextual issues that influence the importance and expression of an information need. This chapter draws together and discusses the study findings alongside existing evidence in an attempt to *construct meaning* from the experiences of patients. The fundamental purpose of the study being: to generate new knowledge to shape and inform information exchange in clinical practice, provide an evidence base to guide clinicians, and facilitate patient-focused information provision by drawing attention to key interrelated and interconnected concepts that need to be considered.

There are five pertinent conceptual themes that arise from the study findings that warrant discussion:

- Information need priorities of CKD patients
- Information needs of new patients
- Contextual dimensions of information need
- Definition of information need in health
- Information and education provision

The chapter concludes with a discussion of the strengths and weaknesses of the study

Information Need Priorities of CKD Patients

All patients were able to identify information needs that were a priority to them at that time, although individualistic common themes did emerge that enabled identification of nine core categories of information need. The information topics considered highest priority were concerned with information about self-management, complications and physical symptoms. Of slightly less priority, in the middle range, was information regarding practical aspects of RRT, how it affects daily life, the cause of CKD, treatment options, and (less important) how to cope and adapt to life with CKD. The information need considered the least important was information from other patients about their experiences (Scale 10).

Scale 10: Priority Information Needs (Whole Sample)

Higher Priority

(0.355)	6 - *Self–management, understanding blood results, different tests, changing, diet/fluid and medication to improve condition*
(0.192)	5 - *Complications/side effects from treatment or medication*
(0.134)	2 - *Physical affects of CKD, recognise symptoms, what to expect*
(0.047)	4 - *Practical issues for all types of RRT*
(0.021)	7 - *Affects on daily life, social activities, work and finances*
(0.023)	1 - *What is the cause of CKD, progression, future*
(-0.129)	3 - *Different treatment options, the advantages and disadvantages*
(-0.178)	9 - *How to cope with and adjust, who can provide support*
(-0.44)	8 - *Other patients experiences of CKD and treatment*

Lower Priority

We know differences exist between people in their need for information but by examining the shared priorities of CKD patients with regard to core information needs then it becomes possible to construct an abstract level of collective meaning (Crotty 2003). This is useful in that it provides an overview of group needs, identifies differences between groups of individuals who share similar characteristics, and highlights important topics upon which to target information provision. Indeed these nine core categories could be used in the clinical context to facilitate discussion of information needs and tailoring of information. The different information needs are discussed in detail, categorised and grouped according to their scale ranking as high, medium and lower priority needs.

High Priority Information Needs

Patients prioritised information about managing their own disease, understanding and recognising physical symptoms, complications and side effects as the most important. Given patients construct meaningful self-management strategies on their daily symptoms and experiences (Leventhal 2003) it is not surprising to see these items ranked closely together. Gathering information that increases knowledge about the disease, through symptom management and overseeing aspects of treatment facilitates survival (Curtin and Mapes 2001).

The highest ranked information need, managing their own condition through controlling their diet/fluid intake and to a lesser degree understanding their blood results, was important to patients because it was concerned with aspects of their care for which they have direct control. With the majority of patients (80.9%) indicating that although they perceived the disease to be serious they were aware that there were things they could do to stay healthy. Fostering and encouraging patients' self care skills and increasing independence is a key driver within national policy and central to the renal NSF (DH 2004b), particularly to free up the availability of in-centre services for those patients for which self-care is not possible. Self-management information is key to patients at all stages of CKD, particularly those patients who are deciding which RRT to choose. Targeted education about self-care has been shown to increase the number of patients who go on to choose PD, home HD or self-care dialysis and remain independent (Piccoli et al. 2000, Manns et al. 2005). To identify that both patients and professionals are working towards the same priorities, is not only reassuring but also increases the possibility of developing a renal service that meets the needs of both groups.

Diet and fluid restrictions, impact considerably on the quality of life of patients (Bass et al. 1999) and information that could help them minimise the effects was a high priority topic area they wanted more information about (Groome et al. 1994, Schatell et al. 2003a,b, Harwood et al. 2005). Patients are often seen initially by a dietician, diet restrictions explained and then seen again if their blood results are high or they experience symptoms signifying the need for diet modification. Research indicates that whether or not a patient chooses to adhere to their treatment regime is not related to their level of knowledge (Shaw-Stuart and Stuart 2000, Christensen 2000). Contextual findings support this. Patients described tensions that existed in balancing diet and fluid restrictions with the wish to enjoy a normal daily life, or social events without the constant reminder of their chronic illness. It maybe that targeted information which enables a patient to safely set their own level of adherence balanced against their preferred quality of life goals and the potential risk of experiencing physical symptoms would be a more effective approach. Such an approach is likely to encourage self-care and places the responsibility for diet, fluid and medication management squarely with the patient and could eradicate and make redundant the professional notion of *compliance* upon which patients are measured.

Patients attending out patient clinic have blood taken to monitor their disease and treatment stability and, following their appointment, receive a letter identifying the treatment changes and blood test results. What the different blood results mean, what would be *normal* for them and what action could be taken to make improvements was important to patients. This corroborates evidence from other studies performed with CKD patients (Coupe 1998, Schatell et al. 2003a). Patient interviews revealed that not knowing was frustrating and that there were clearly unmet educational needs. As '*Renal PatientView*' (2005) becomes established throughout the UK (a system by which patients can access their electronic records including their blood results) then information and education that increases their understanding and knowledge of what these mean, is crucial for this initiative to be meaningful.

Information that enables a patient to recognise a physical symptom, complication and/or side effect and understand its cause was ranked closely together in second place. For many this information need was a priority because they were or had experienced symptoms/complications that they didn't understand and weren't aware that they could manifest, or that they could have prevented them until after an event or episode had taken place. Indeed they felt that the knowledge they possessed had been obtained through their own experience of problems or symptoms not through formal information provision, an experience reinforced in other studies (Curtin and Mapes 2001). Patients, in this and other studies stress the importance, even those asymptomatic (who did not experience any symptoms), of information about what to expect and how to manage problems, when and if they occurred (Niccum and Perez

2000). Contextual comments reinforced that this type of information, which helped them recognise physical symptoms and understand what they were experiencing was expected or *normal*, was to some degree reassuring, reducing feelings of uncertainty. The opinion as to the depth of information required was mixed; some patients raised strong concerns that too much information would increase anxiety whilst others wanted to know everything to be adequately prepared. The need to establish an individual's own preferred balance between the *'fear of not knowing'* and *'fear of knowing too much'* is considered integral prior to information being provided (Parker et al. 2007). What was interesting to note in this sample was the high priority given to these topics for patients who had been on RRT for many years signifying that an increase in physical problems and complications as a result of the disease progression. Similar findings in other studies indicated that long-term CKD patients value the importance of having the information and knowledge to be able to identify and report their own symptoms (Curtin and Mapes 2001). To increase patient control and self-management skills, information about physical symptoms and possible complications must be formalised (and be continued over time to prevent patients having to learn from experience in a disorganised and unsystematic manner).

Medium Priority Information Needs

There were a number of information needs clustered in the middle of the scale with minimal distance between them indicating comparable levels of importance for the whole sample. These included the cause of CKD and the future, practical issues regarding RRT and different treatment options, the affects of CKD and treatment on coping with and adapting to life with the disease.

Of interesting was the importance given to the information need about what CKD is and the cause. This was a particularly strong information need for some individuals within the interviews. Moreover, some patients clearly couldn't understand why nobody had told them why they had developed CKD even after many years, which meant the information need remained unsatisfied. A simple explanation identifying that CKD can be diagnosed without ever establishing the cause or underlying disease (Levey et al. 2003) would enable these patients to have a clearer understanding and go some way to satisfying or reducing the importance of this need.

A key aspect of theme 7 (information about the affects on daily life, social activities, work and finances) that emerged from the CKD literature at the start of the study and then was reiterated by patients during the verification and clarification of the wording of the theme was the affect CKD has on work. Concurrent with other study findings, sustaining a career and continuing to work was important to those who were the family breadwinner and/or single with no family to rely on for financial support (Whitaker and Albee 1996, Orsino et al. 2003). The lack of information on career advice was of concern (Juhnke and Curtin 2000) and was considered necessary particularly in the early stages of CKD when career planning and re-training was still an option prior to being debilitated by symptoms or complications. The sample characteristics indicated that 35% of participants who took part were unable to work or unemployed compared with 25% in full or part-time employment, the majority being retired (39%), the remainder in education. The early provision of targeted information addressing employment issues and realistic career advice would have a direct impact upon the number of patients able to work in the future (Rasgon et al. 1993). In addition, providing such support could reduce the number of patients starting RRT being forced to make a major lifestyle change, by giving up work, becoming dependent on social security benefits, managing a reduced standard of living or having unrealised life goals and low self-esteem. With this reality for many patients it is no wonder they find it hard psychologically to cope and adapt to CKD. Research that explores whether providing appropriate and timely employment information, career advice, and support could have such a widespread and positive impact on the psychological care of CKD patients is needed.

The semantic ambiguity found behind the need for information on how to cope and adjust to CKD and the difficulty teasing out direct or indirect information needs, gave rise to lengthy discussions in the early stages of the research as to the appropriateness of this theme. Nonetheless an important and critical finding uncovered from the latent analysis of interview text highlighted that psychological concerns and coping strategies formed the root of, or were embedded within, the stated goals/purpose of other information needs. For example information need about physical symptoms and complications being experienced, whether a person can continue working, eat their favourite food or go swimming, were based on needing information for the purpose of gaining reassurance, reducing anxiety, reducing uncertainty and feeling in control. This indicates that by exploring the purpose of an information need it is possible to develop a clearer understanding of the patient’s embedded psychological need for information. This significant finding provides an explanation for findings from previous studies indicating information provision can ward off depressive symptoms in dialysis patients (Korniewicz and O’Brien 1994, Rasgon et al. 1998, Klang et al. 1998). It maybe then that ‘information to help me cope and adapt to CKD, and where to find support’ does not necessary need to be a stand-alone theme, and could explain why it was ranked a lower priority, because it was already being satisfied to some degree by targeting information to answer other needs.

Lower Priority Information Needs

The lower ranking of the information need item concerning other patients’ experiences needs to be discussed. Within the literature review this theme was one of the less prominent topics (Iles-Smith 2005). Comments made by patients during the completion of the INQ intimated that although this was not considered particularly important there was a degree of pertinent information to be gleaned from others’ experiences, also highlighted by patients in other studies (Juhnke and Curtin 2000). Tweed and Ceaser (2005) suggest that patients receive reassurance and reduce feelings of isolation when they compare themselves with others. Indeed, the recently created CKD DVD’s developed by patients working collaboratively with Kidney Research UK provide practical tips on how they managed their treatment in their every day life. Two patients prioritised information from other patients as their most important current information need, suggesting it cannot be dismissed. However, the phrasing and formality of it as an information need theme might have been confusing because often the exchange of information between patients took place during informal conversations. This being the case, the evidence maybe points to the need to differentiate information from other patients as a useful information source or resource rather than a direct patient information need.

Information Needs of New Patients

The method of asking ESRD patients what information they think a new patient should be given (adapted from Groome et al. 1994) was very useful in demonstrating how CKD patients' information needs change over time as the treatment pathway progresses. Information that was seen to have the highest priority for new patients included information about CKD and the future, the treatment options and the impact CKD may have on their physical and social life (Iles–Smith 2005). Of those who suggested that new patients would want information about the future and the cause of CKD, two thirds identified not having received enough information on this topic area. Whilst the high ranking could be due to their own perceived lack of information on this topic, many other studies support this finding (Groome et al. 1994; Juhnke and Curtin 2000: Schatell et al. 2003b; Orsino et al. 2003).

Interview findings indicated that on reflection patients would like to have known that RRT was to be expected in the future, when first diagnosed. The reasoning behind why this may not have been disclosed at this time is that it may just not have been relevant. For example, the stage of CKD at diagnosis and the rate of kidney function deterioration may have indicated that RRT was not expected. For the clinician this highlights the difficulty in establishing the right time to introduce information, to bring forward unrecognised information needs and how this can be effectively managed. The overall feeling within this study was that there was the need for all information at the outset. However, a draw back of such an approach is typified by a patient who when told of her need for RRT was so frightened and shocked that she denied she had a problem for over five years and refused, until recently, to talk to anyone about it.

It was not a surprise that information about different treatment options was the second most important theme given that new patients, in the pre-dialysis phase, are required to choose which treatment would best suit their lifestyle (Breckenridge 1997). This type of information would appear fundamental at this point in time and is already the focus of many pre-dialysis education programmes (Klang et al. 1999, O'Donnell and Tucker 1999, Piccoli et al. 2000, Goovaerts et al. 2005). Indeed, less than one third of patients who selected this item reported not receiving enough information on this topic. This suggests that their own experience, of either having or not having sufficient information on a topic, did not influence what they considered to be important for new patients.

Given there is recent evidence to suggest that careful control of both diet and blood pressure can prevent further damage to the kidneys and mean that patients diagnosed with CKD could remain in good health for the rest of their natural lives without requiring RRT (DH 2004b), it was surprising that self-management was not given a higher priority. One reason for this may be that many of the established CKD patients were probably not on either diet or fluid restrictions prior to starting RRT, although this is possibly more common practice today.

Contextual Dimensions of Information Need

The advantage of building on and applying the knowledge gleaned from many years of Information Science research is demonstrated within chapter eight which describes the contextual influences of information need and examines the findings of the *person-in-context* (Dervin 1992, Allen 1996). Wilson's model (1999) of information behaviour guided the research to explore whether concepts that influence information seeking impinge on or draw out an information need in the first instance. It clearly provided a useful and invaluable framework to observe the interplay and understand the different motivations, influences and triggers of CKD patients' health information needs.

Influencing Variables

The emergence of information needs in context for CKD patients is both multi-factorial and multi-dimensional, with complex relationships existing between what Wilson terms as '*activating mechanisms'* and '*intervening variables*' (1999, p257). Evidence drawn from the interview data confirmed the existence and use of questioning (monitoring) and ignoring (blunting) coping styles (Miller 1987) that either activated or suppressed an information need (Savolainen 1993, Baker and Pettigrew 1999, Christensen and Ehlers 2002, Rutten et al. 2005). What was interesting was the transitory nature of coping styles and the observation that patients use both styles of coping simultaneously depending upon whether an information need was personally significant (Johnson et al. 2001, Julien and Michels 2004), relevant to current goals, their role and life situation (such as work or inability to work) (Pettigrew 1999, Case 2002, Neidźweidzka 2003), or as a result a particular event/situation or experience at that point in time (Dervin 1998, Julien and Michels 2004, Ankem 2006 Harrison et al. 1999, Attfield et al. 2006).

Similarly, information need was also influenced by perceived levels of self-efficacy (Arora et al. 2002, Thomas-Hawkins and Zazworsky 2005), preferred levels of control and preferences regarding independence and levels of self-care (Savolainen 1995, Cvengros et al. 2005). Those patients who preferred to be in control, independent and develop self-managing skills activated different information needs, but at the same time suppressed those perceived to be less relevant in reaching more important goals. Other patients, particularly pre-dialysis patients, preferred health professionals to take control and manage their illness, choosing to have a lack of knowledge regarding certain aspects of their treatment and care. Health studies suggest that some patients, to be able to cope effectively, want an abridged description about their condition rather than comprehensive information (Luker et al. 1995, Degner et al. 1997a, Leydon et al. 2000, Rees and Bath 2001). However, their behaviour was not constant, and again when a topic was salient maybe as a result of an event (needing to make a decision about which RRT, not understanding blood results), or an experience (physical symptom), then they too stimulated information needs.

Patients, across studies, have been seen to fluctuate between the desire for more and the avoidance of information at different times during their illness (Leydon et al. 2000, Rees and Bath 2001). Each patient has a definite preferred level of knowledge making the concept of *basic* level determined by a health care professional (Hines et al. 1997a) inappropriate if a patient is to determine their own need for information. Some patients when first being introduced to RRT, what CKD is and the expected treatment pathway found too much information distressing whilst others searched for as much information as possible (Leydon et al. 2000, Parker et al. 2007). It was apparent though for all patients, that information overload and managing multiple information needs at the same time, required that some information needs were perceived to be less important and deferred (Godbold 2006).

The study highlighted examples of reasons why information was needed by CKD patients, the purpose driving the materialization of the information need. Indeed an information need did not arise without a purpose, these included; to increase understanding, gain reassurance, reduce anxiety and uncertainty, to feel in control, make decisions, facilitate self-care, be prepared of what to expect, recognise physical problems and regain normality. Coulter et al. (1999) derived a generic framework for patient information need, and although the purposes behind the information needs of CKD patients were comparable in some respects, they were much more personal and pertinent to their real life experience of the chronic illness. Existing knowledge suggests that CKD patients need information to make decisions, reduce fear of the unknown, advice to enable them to live longer or to learn about their kidney problem (Schatell et al. 2003b, Fine et al. 2005). This study adds to and increases the depth of knowledge by extrapolating the wider purpose of an information need as well as identifying that many goals are derived from implicit psychological information needs.

Demographic Variables

Measuring priorities of information needs for CKD patients according to demographic characteristics indicated no significant difference between gender, time on RRT, education level, and co-morbidity, similar to studies of cancer patients (Browall et al. 2004, Ankem 2006). Although three times more male patients reported feeling at risk of developing complications than females, both groups indicated comparable levels of information seeking activity and ranked information needs in the same priority order. It was interesting to note that the time on RRT (less than 2 years compared with more than 2 years), and therefore increased experience of ESRD did not significantly influence the priority given to information needs. It may be that this characteristic would be more noticeable when measured with a larger sample group with a longer time on RRT.

Significant differences were noted in the priority rank order of information needs between age groups, modality treatment groups, the length of time since diagnosis, and those patients who worked compared with those who were unable to work. Indeed, between particular age groups (less than 50 years, between 50-60 years, and greater than 60 years) there were significant differences measured between the order and distance of information needs. Although patients from the younger and older age groups prioritised information about managing their own condition as most important, their second priority differed. Younger patients perceived that information on the impact of CKD on their lifestyle (maybe as a result of working and family commitments) was more important compared to older patients who wanted information about the cause of CKD and the future. Indeed information about the cause of CKD and the future expectations was the highest priority for patients in the middle age group of 50-60 years. This coincides with making plans for their retirement and could signify that for patients around this age it is an appropriate time for healthcare professionals to discuss or revisit information about future issues such as expected survival, and end of life care rather than discussing these issues in later years. Older patients placed a significantly lower priority on information from other patients about their experiences, possibly because they had sufficient information and/or had developed over time their own coping strategies that the interest of how other patients manage had diminished.

The treatment modality or stage of CKD disease influences the priority placed on different information needs. Pre-dialysis patients had different information need priorities compared with those patients at ESRD already receiving RRT. Information about the practicalities of specific treatment was more of a priority for this group. Many other studies reinforce that at this stage in the disease, prior to treatment, patients want information on the initiation of dialysis, what will happen and what the treatments involve (Groome et al. 1994; Coupe 1998; Juhnke and Curtin 2000; Schatell et al. 2003a; Orsino et al. 2003). However, it was a little surprising that information about the future and what to expect, was ranked lower by these patients compared to patients on RRT. Given that this was reported to be the most important information need for newly diagnosed patients, it may signify that they had been provided with sufficient information at the time on this topic. For patients receiving RRT, who were aware of the rigours of the different treatment regimes, information about the future and what to expect remained a priority. Not surprisingly, PD patients whose whole treatment focuses on the need to prevent infection placed a greater importance on information about complications and side effects.

Circumstances with respect to work, and being unable to work, significantly influenced the priority patients placed on different information need topics. For those employed, understandably information about ways in which they can manage their own condition, complications and the impact upon their lifestyle featured most prominently. The need for improved information and career advice (as discussed earlier) were essential components to enhance and facilitate sustained employment for CKD patients. Those unable to work placed the highest priority on information about physical symptoms, what to expect and what they could do to manage their condition. Experiencing symptoms can be debilitating and possibly was the reason that prevented these patients from working. Placing these information needs as high priority suggests that there is still an unmet need for CKD patients. This is reflected in other studies where dialysis patients were found to lack knowledge of both physical symptoms and complications with respect to CKD (Leino-Kilpi 1993), and many learned about symptoms by accident through experience (Curtin and Mapes 2001). Providing information about physical symptoms and complications before they occur gives the patient more control and understanding of what is happening, rather than being reassured at a later date that what they were experiencing was an expected symptom.

The most significant finding arising from measuring the difference between information needs of patients against the time since being diagnosed was how information about what caused the CKD diminished in importance over time. Time is a complex phenomenon with respect to information need that merits further discussion.

The Concept of Time

For CKD patients, as with other patients with a chronic or life threatening illness, time is a valuable commodity and influences the emergence of information needs in multiple ways. All the patients in this study could identify information needs that were a priority to them and the amount of information needed by patients appeared to be high whatever stage of the disease or time spent on the treatment pathway. Patients who appeared to have a very good knowledge of the disease and treatment demonstrated, similar to other studies, that new information needs continually emerge suggesting that information need is constant throughout the disease trajectory (Ankem 2006). This could be linked to being active information seekers or to the feeling that their life is threatened, time is limited and the more information they have could improve the quality of their life and help them live longer, a notion worthy of further research.

CKD patients' priorities for information topics change over time linked to specific situations, events, and/or contextual factors (Dervin 1992, Savolainen 2006b, Attfield et al. 2006). This was clear when a small number of patients indicated the irrelevance of what could be considered key topic areas, such as different treatment options and the practicalities of RRT. It is important to note that their irrelevance was a result of enough information rather than lack of interest, or that they were established on a particular treatment and thus did not feel the need to consider other options. As this treatment becomes less effective over time then it is reasonable to assume that information about different treatment options will become a priority again. This highlights that the priority information need is transient for each individual, and as the disease progresses and their life circumstances or treatment changes this influences the individual's priority and need for specific information. It appears that the core information needs may change in priority but it could be argued that they do not go away, the need identified by patients for repeated diet and fluid information supports this. It is the nature, depth and detail, as well as repeating information, within a specific core topic area that changes over time.

Julien and Michels (2004) provided a useful framework on how the aspect of time and importance of information need could be captured. They identified four time categories, crisis, short-term, long-term, and undetermined, as a possible way of organising information need priorities. This type of framework is extremely useful in generating an understanding of how CKD patients attempt to organise the hierarchy of their information need. Particularly if patients themselves can define information needs using time parameters and identify crisis or urgent information needs and short and long-term needs. Such a simplistic approach applied in clinical practice would enable staff to focus and target information provision to meet the critical and most important information needs of the patient first then progress onto short-term needs (Table 41).

Table 41: Examples of Time Organised Information Needs (based on patient data)

Time/priority	**Information Need**
Crisis/urgent	Need to know when going to start treatment so I can organise time off work (running out of sick days which will mean I will have to go back to work soon so my money isn't affected)
Short-term	Need to understand the practicalities of HD What happens when I go on the first day? Will it hurt when they put needles in my arm? What shift will I have? What can I do during the four hours of the treatment?
Long-term (deferred)	Want to go on the transplant list, don't know what this entails but will find out when I am settled on HD

As information needs are satisfied it can be expected that the time order of information needs would change as short-term goals increase in priority and become urgent. But clearly it is not as simple as this in that new information needs emerging (maybe as a result of an unexpected event) could just as easily replace existing urgent needs to a lower priority. Categorising long-term information needs could be a way of capturing and recording a patient's deferred information needs, recognising they have an information deficit but have more important information needs at that point in time to satisfy (Beaver 2004, Timmins 2005, Godbold 2006). This type of structure could enable patients to organise their own priorities (maybe through a diary) as well as provide transparency for health professionals as to what is important to the patient.

The same information needs could be seen to arise for different patients surrounding common events along the disease trajectory, for example having access surgery, starting RRT, diet and fluid restrictions, what is CKD, and going on holiday. This supports evidence from other studies (Echlin and Rees 2002, Hepworth and Harrison

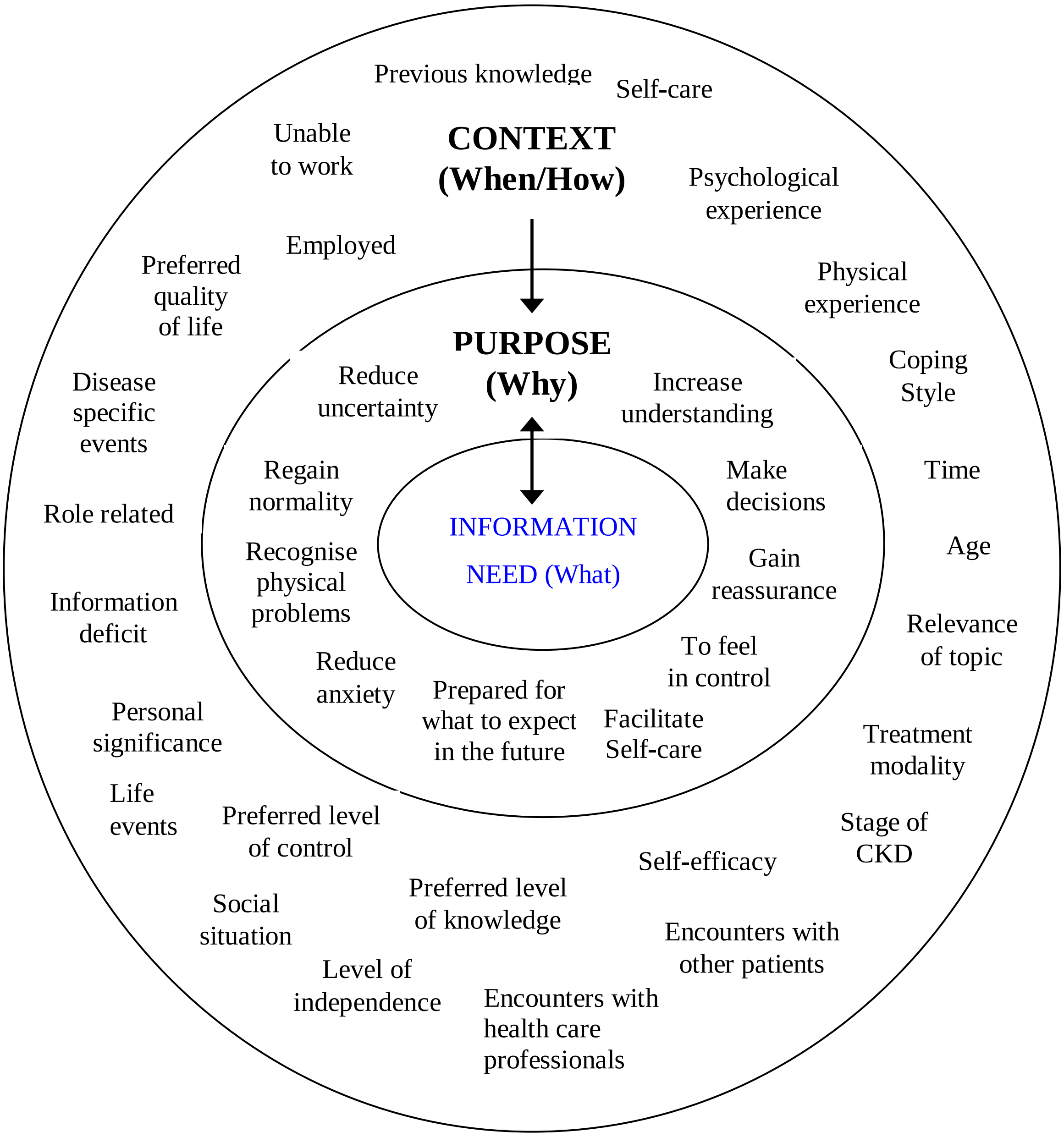
2004, Parker et al. 2007) and as a result timely information provision in anticipation of an event could be targeted by health professionals, taking into account the preferences and priorities of the individual patient. As well common triggers such as events could be used as topic areas on which to base the development of *information prescriptions* in the future (DH 2006).

Contextual Dimensions of Information Need Manifestation

The writings of Dervin (1992) summed up in the title of one of her papers '*From the minds eye of the user'* draws attention to the importance of viewing information need from the perspective of the individual. Building on the key concepts of the Sense-Making theory, *Context* and *Time,* it offers health professionals a patient-focused approach to understanding a patient's journey of making sense of CKD, their condition and the impact it has on their life, by identifying their need for information (Ford 2004). Raising the importance of the CKD patient-in-context, exploring the factors that influence the emergence and expression of an information need, alongside describing the personal characteristics of an individual that shape the choice, hierarchy and strength of an information need (Neidźweidzka 2003) was the purpose of this study (Diagram 7).

Diagram 7 presents a theoretical map of the pragmatic evidence generated which indicated the interplay of three central dimensions; context, purpose/goals, and information need, that combined provide a comprehensive and crucial understanding of what, why and when information needs arise. There existed dependent relationships between the three dimensions that fluctuated backwards and forward (signified by the arrows), with new information needs emerging, adapting as a result of new goals and/or altered contextual factors. In chapter eight, the graphic representation used was a set of balancing scales, to demonstrate that any one or a combination of more than one contextual variable (in the outer circle) could tip the balance towards activating an information need. Further exploration is required to determine whether one variable is more dominant than another. To be able to provide appropriate information to patients health professionals need to be aware of the underlying contextual components involved, that influence why and how a patient constructs a need for information. Using the new knowledge from this study to understand the context of information need, information provision can become patient-focused and target the information priorities of patients.

Diagram 7: Dimensions and Concepts of CKD Patients Information Need



It is important to note that the variables characterised by the data in the theoretical map (Diagram 7) although comprehensive are not considered exhaustive. Certainly research indicates that factors such as stereotypes, prejudices, emotions, memories, intuitions, attitudes, feelings, and personality (Wilson 1981, Kuhlthau 1991, Dervin

1992, Solomon 1997, Case 2002, Hepworth 2004, Ankem 2006, Kidachi et al. 2007) are would certainly concepts be worthy of further research in CKD patients.

Definition of Information Need

Throughout the emergence of health studies exploring patients' information needs there has been an inherent lack of study definitions that seek to clarify the underlying meaning of the term, it is often tenuously inferred, or left to the reader to determine. It was identified within CKD studies alone that the term information need was used synonymously with concepts such as education needs and goals (O'Donnell and Tucker 1999, Niccum and Pérez 2000, Schatell et al. 2003b); subject knowledge (Wilkinson 1998, Murray et al. 1999, Klang et al. 1999); and/or to identify what a patient needs and/or wants to know (Orsino et al. 2003, Fine et al. 2005).

From the outset at the heart of this research study was a definition of information need, favouring the notions of Case (2002, p5), that '*information need is a recognition that your knowledge is inadequate to satisfy a goal that you have'.* This explanation was grounded in information science research and incorporates the strong opinion that information needs emerge because of an underlying purpose, to meet a goal or activity (Derr 1983, Allen 1996, Wilson 1999, Case 2002, Watters and Duffy 2005, Lambert and Loiselle 2007). This builds on and brings alive the perception that an information need is a gap in knowledge (Dervin 1992, Scott and Thompson 2003), or something a patient needs to know (Timmins 2006), by adding a deeper dimension that is both meaningful and pertinent to an individual patient.

Acknowledging the dimension of purpose, when exploring and understanding patient health information needs would appear fundamental, particularly for clinicians who equipped with the knowledge of '*why people need the information, the question of what should be much more transparent'* (Consumers' Association 2003, p18). Indeed, applying such a definition in practice overcomes the ambiguity of the phrase '*what a client needs to know'* and prevents a health care professionals determining the information needs of a patient based on goals which they consider important (Coulter et al. 1999, Leydon et al. 2000, Timmins 2006). Despite this however not only in health but much of the research in information science of user information needs and information seeking, fail to ask the user why, the purpose of the information (Case 2002, Wilson 2006).

Often information needs in health are assessed by asking patients what information they prefer to receive from a health care professional, either by using a single or combined methodological approach (Pinquart and Duberstein 2004). Those using quantitative instruments describe the greatest drawback as being the lack of contextual evidence within which to explain findings (Scott and Thompson 2003, Hepworth and Harrison 2004). Studies with cancer patients highlight that they have priorities and preferences with regard to what information they need and when (Luker et al. 1995), but fail to generate any understanding of why. A key motive behind such an omission has to be the lack of a suitable definition of information need that exists within health research, practice and current national policy.

To develop patient-led services (DH 2004b, DH 2005a) and support patients with chronic conditions (DH 2007) identifying and meeting their information need is considered pivotal. The purpose-based definition used to underpin this study epitomises the key concepts of national policy, being the centrality and importance of the patient. However, as CKD patients approach and reach ESRD they begin on a rigorous care pathway of survival (a fundamental life goal) that involves a series of challenges for which they need information, the purpose of which is specific to an individual and the situation in which they find themselves. CKD patients, striving to survive, could also be experiencing a loss of control, coping with stressors, psychological and emotional distress, and the challenge to change long-term behaviour (Christensen and Ehlers 2002). Therefore for CKD patients, it becomes impossible to consider goals and information need without understanding the context and situation in which they transpire. It is the interplay of these three dimensions, context, purpose/goals, and information need that provide the comprehensive and crucial understanding of what, why and when information needs arise. It is therefore important that a definition of information need reflects all three dimensions (Box 14).

Box 14: Definition of CKD Patient Information Need (adapted from Case 2002, p5)

‘Information need is a recognition that your knowledge is inadequate to satisfy a goal that you have, within the context that you find yourself’

The research findings have brought to the forefront a working definition for information need derived from information science that is not only specific to CKD patients, but also sufficiently generic to be applicable to the wider health care arena. The definition provides a platform upon which to clarify national policy, inform and guide future research and develop information provision based on the needs and goals set by the patient.

Information and Education Provision

Appropriate education and information provision are crucial for a CKD patient to cope and adapt, to generate an understanding and learn about their chronic illness, as well as develop the skills to self-manage (Leino-Kilpi et al. 1993, Curtin and Mapes 2001). Current CKD education targets patients prior to receiving RRT and are seen as fundamental to achieving the best practice for the ideal pre-dialysis patient pathway (NHS Institute for Innovation and Improvement 2008), as well as effective in increasing knowledge levels (Klang et al. 1999, Devins et al. 2000). However, evidence from patients within this study indicated that they did not necessarily want to know the depth of information provided or that the timing of such information was inappropriate. Indeed after the formal pre-dialysis education and training programmes for specific dialysis techniques, education long-term throughout the disease trajectory appears unsystematic and informal often instigated as a result of an event, experience of a symptom or problem. The fact that information needs are observed to be continuous suggests that the long-term information and education needs of CKD patients are not being met.

National directives promote the need to develop patient-led services (DH 2004b, DH 2005a) and the need to encourage patients to be self-managing by developing effective skills, increasing confidence and knowledge of their chronic condition (DH 2007). In response to this, the findings of this study advocate the need to introduce a different (constructionist) approach to CKD patient information and education where the central aim is to enable the patient to learn by making sense. An approach that directly focuses on the information and education needs of the learner and of equal importance the context and situation in which they find themselves, their motivation, goals and experience at that point in time. It is these concepts that guide what information is needed and in turn provided. This study provides a comprehensive evidence base of CKD patient information needs using an innovative approach grounded in and tailored to the needs of the patients. Central to this informed approach is the concept of empowerment and developing self-management skills from the outset. Starting with developing the patient's ability to express information deficits that arise as they are learning to making sense of what is happening to them and having the appropriate tools such as information at the right time is fundamental to enable them to effectively cope and adapt to their illness.

The approach is characterised by simple yet fundamental questions that could be used to guide patient-professional interaction (Box 15):

Box 15: Information Need Questions

- What information do you need? (topic)
- Why do you need the information? (purpose/goal/context)
- What do you already know and understand? (existing knowledge)
- How much information do you want? (preferred depth/detail)
- How do you like information presented? (written/leaflets/other patients)
- What is the time frame within which the information is needed? (urgent, short-term, long-term)

This takes a similar form to Sense-Making interview techniques (Dervin et al. 1999) but has been adapted to remain simple, applicable and useable by health professionals in clinical practice. The patient responses to this type of questioning organised within a time coding framework (urgent/crisis, short and long term) by Julien and Michels (2004) would provide a clear structure of education and information provision and a complete record of patient priorities, preferences, context and purpose of information and how facilitates learning by making sense. This in itself would be an invaluable and powerful tool in understanding the information needs of CKD patients as they emerge. In addition this primary approach could be combined with resources and other supportive methods in response to the patient preferences to provide a comprehensive information and education strategy. This could include (Box 16):

Box 16: Examples of Supportive Methods and Resources

- Individual face to face information sessions
- Group sessions on rolling education topics (influenced by key priorities)
- Core information need topic guide
- Preparation and discussion prior to a clinic visit to focus information priorities
- Patient Information diaries, questions/time coding of emerging needs
- DVDs explaining the patient perspective of CKD
- Information prescriptions (where to locate high quality, unbiased information, key patient websites, information leaflets, books)
- Patients informing patients informally or access to Expert Patient Programme
- Patient forums and self-help groups
- Telephone contact of key nurse (CKD team, HD, PD)
- Clinician – Patient information need record document

The core information need categories identified within this thesis can be used to indicate information that is available alongside information prescriptions that provide lists of resources that the patient can explore and seek additional information. A diary kept by the patients could be used to log information needs or gaps in knowledge as they arise and provide the focus for subsequent discussions between the patient and clinician. Of course these are examples of the overall fluid approach that could be made available, rather than a rigid protocol or structure. There will always be patients who prefer their doctors and nurses to take control of decisions regarding treatment (25.8% of patients in this study), but studies show that even those who prefer not to have an active role in decision-making, still want information and have identifiable information needs (Caress et al. 2002). Whether *'active information seeker'* or '*passive information recipient'* (Schatell et al. 2003b, p17) this approach is likely to address the needs and preferences of all.

The perceived benefits of adopting such a strategic patient-led approach are numerous: the primary rewards being that information and education becomes based on the information needs of the patient (Lowry 1995, Wingard 2005) and patient-led (DH 2004b). Education is provided when a patient identifies a knowledge deficit and a need for information, not determined by the professional (Shenton and Dixon 2004, Timmins 2006). An individual would have the responsibility to recognise that they are missing information for a need to arise (Case et al. 2005) or the choice to ignore information that they would prefer not to know, or is not personally relevant (Rees and Bath 2000, Consumers' Association 2003, Haider and Bawden 2007). A patient would not be overwhelmed by information because they will determine how much, at what depth and when (Lambert and Loiselle 2007) and if information needs are fulfilled in this way this should reduce feelings of dissatisfaction, stress and facilitate coping (Timmins 2006).

By encouraging a patient to take control and feel empowered, it will in turn enhance self-management skills, self-efficacy and increase confidence in their own abilities (Favlo 1995, Oscar 1996) leading to more knowledgeable and competent patients (Larson et al. 1996, Lambert and Loiselle 2007). Information provision would no longer be unsystematic and disorganised but proactive, practical and meaningful, provided as and when needed over the entire disease trajectory (Beaver 2004), a continuous process (Juhnke and Curtin 2000).

This approach is not ground breaking but the underlying ethos would require an entire change in the way health professionals and members of the multi-disciplinary team view patients and their involvement in their own care for it to be successful in clinical practice. Patient-led means exactly what it says: led by the patient.

Strengths and Weaknesses

Measuring Information Need

Given the overwhelming data that emerged from this study it could be argued that a combined approach of both qualitative and quantitative methods is by far the most effective research strategy for measuring information needs, and a considerable strength of this study. This approach overcame the problem of quantitative findings where there is a lack of context with which to explain findings and added a broader more representative dimension to the findings than cannot be achieved from the smaller sample used within qualitative interviews, creating meaningful data.

The strength of information accumulated from the in-depth patient interviews, the depth of understanding gleaned through exploring the real experiences of patients cannot be underestimated. Common core information needs were identified then used to assess a patient's preferences and priorities using the paired comparison approach developed by Degner et al. (1998). This method enabled the distance as well as the rank order of items to be measured which was invaluable when interpreting the data and provided a deeper understanding than would have been achieved using a simple Likert scale. It was however, a cumbersome method, the questionnaire took months to develop to ensure items were accurate, and the analytical programs although readily available were complex requiring expert statistical support.

There remains a lack of consensus across studies as to whether particular characteristics with respect to information need, can be consistently associated with a specific demographic groups (Talja 1997, Case 2002). Unfortunately this study provides no further clarification on this issue. Measuring demographic variables in information need priorities across a larger group of CKD patients provided an interesting insight into the significant differences between age and particularly treatment modality groups. But given the quantity of contextual influences identified it would seem impossible to interpret these differences any further than at face value, which then continues to raise questions over the usefulness of such data.

CKD-INQ

The CKD-INQ was easy to complete and useful at identifying the information needs and priorities of a group of patients. Patients found it easier to choose between two items at a time than trying to choose one most important item from the list of nine. Administering the study instrument using face-to-face interviews, although labour intensive, facilitated the clarification of items and descriptor meanings. However, as a tool which could be used in clinical practice it would be both time consuming and of little benefit to the individual patient. Nonetheless compiled within a more condensed format (a topic guide) the nine core information needs could be used to initiate patient discussion and draw out more specific individual information needs, or used as an evidence base for deriving the content of education programmes.

One of the weaknesses of the study was the lack of fit to the statistical model more than likely distorted by the inconsistent comparative judgements of a small number of patients. Although the numbers of circular triads, from this group of patients, did not exceed the recommended maximum they clearly influenced data reliability. What is interesting to note is that from the studies using this method, with similar numbers of circular triads only Wallberg et al. (2000) report the results of the Mostellar Chi square or Gulliksen and Tukey’s measure of scalability of the data. Unfortunately despite efforts it was impossible to ascertain from the authors of the other studies details of these statistics. However, if this study reports only the Kendall’s coefficient of agreement like others then consistency between patients was demonstrated. Inconsistent judgements indicated that patients found it problematic to decide between particular items although when examined there was no pattern to the items involved. What it may signify is that many of the themes were personally relevant to the patient and the confusion was created when two or more were of comparable priority. When the inconsistent judgements were extracted from the sample, the data fitted the model. Thus it is possible that within a larger sample the inconsistent judgements may be less prominent.

In phase one an information topic identified from one study, Groome et al. (1994) indicated that CKD patients required information about the availability and quality of nursing and physician care and to a lesser degree what facilities were available.

Because of the lack of corroborating evidence either the literature or the patient interviews it was decided not to include this item. However, six patients suggested information about clinic visits, their consultant, and service delivery was a missing information need on the questionnaire, albeit not as important as the other core items listed. The majority of these patients had been re-located to a satellite unit and as a result expressed concerns about their reduced contact with the medical team and inappropriate clinic visits. Degner et al. (1998) warns about missing items that are important to some people. Therefore this issue cannot be ignored, even though it appears to be context specific, and future CKD-INQ testing within this patient population consider inclusion of this information need.

Coding systems to group patients with respect to ethnicity and occupation were applied after the data was collected and would have conserved time if they had been integrated as predetermined lists from which patients made a selection at the outset, when the questionnaire was being developed. The reason behind not including them was to give the patient free expression, but for categories such as these in hindsight it was an inappropriate notion. The cause of CKD however, would not be coded beforehand the patient descriptions of what had caused their CKD were interesting and provided a clear picture of different perceptions, a lack of knowledge and understanding.

The strength of using event ordering techniques to organise the flow of the interviews was invaluable (Deacon 2000, Martyn and Belli 2002). This enabled patients to organise their own thoughts as well as progressively guide the interview discussion and provided a helpful methodological tool to use when interviewing CKD patients.

Sample

The study managed to recruit 89 patients, just less than half of the expected patient sample. A contributory reason for this shortfall included problems identifying the sample in the first place, the shifting status of patients in terms of patients changing modality, being transplanted or admitted as an in-patient made the eligibility assessment of the of the sample population extremely difficult. Where status could not be confirmed potential recruits were lost to the study. Despite this only a quarter of those patients contacted chose to be involved, maybe because they valued their time when not on dialysis and therefore was understandable they were not prepared to encroach on it by agreeing to take part in research. Hines et al. (1997a,b) recruited 197 HD patients by interviewing them whilst receiving RRT. Although initially this did not seem appropriate, some recruits in this study preferred to meet during treatment indicating for patients it was a better use of their time. This additional strategy could possibly have increased the sample size and therefore should be considered as viable method in future research concerning CKD patients. Measures could have been introduced from the outset of the study to recruit a second study site, if a shortfall in sample had been anticipated, but as time progressed and the lack of response emerged time constraints meant this was not feasible.

A further weakness of the study sample was the composition and failure to recruit patients from ethnic minority groups, despite offering translation services. This was disappointing and prevented comparisons being made between different ethnic groups regarding information need for which there remains a clear lack of evidence and understanding. However, it reflected the wider problem of low prevalence rates within the local population signifying ethnic minority patients at risk of CKD were not being identified and referred to the service (Greater Manchester Renal Strategy Group 2008). To take this aspect of research forward a more effective strategy would be to locate a site where an established network existed, such as Leicester where community networks are being developed through the ABLE project (Kidney Research UK 2001). This way patient involvement can be secured within the design and implementation of a study with appropriate ethnic minority groups.

Importance of the Research Topic

There was a clear justification at the start of this study identifying the importance of the need to examine and describe the information needs of CKD patients because existing evidence was seriously deplete. This was confirmed from the CKD literature, which demonstrated that only within studies exploring decision making and evaluating education programmes had the information needs of patients been tenuously reported. Although the term *information need* penetrates many policy documents, espoused as the foundation from which to develop patient-led services, there is no clear definition as to what it actually means, or how best it could be achieved (Beaver 2004, DH 2004b, DH 2007).

The National Institute for Clinical Excellence are in the process of finalising a guideline for CKD management, the consultation period has just finished and it is expected to be published in September (NICE 2008). Within the full guideline they make recommendations for information provision targeting the core information needs of CKD patients based solely on the findings of this study. This acknowledges the value of the rigorous and comprehensive evidence generated from this research thesis, signifying that it was timely and responsive to a gap in the knowledge base. The study findings have already informed national policy, extended the body of knowledge and understanding of the information need of CKD patients and will in the future be used to develop clinical practice.

Summary

The focus of this penultimate chapter has been to draw together the key findings of the study and make sense of what the data revealed. There was clear overwhelming evidence contributing new knowledge to identifying, understanding and measuring the information needs of CKD patients.

The study has shown that it is not only possible to identify the information needs but also the preferences and priorities for information, of CKD patients. They exist on an individual level but as a group there is consensus about what is most important. Perceived to be a high priority for the majority of patients is information on self-care and given that this corresponds with national priorities, it bodes well for future service development.

Patient-led services are advocated as the way forward. It seems reasonable then to develop and introduce innovative patient-led information provision that meets the needs of patient over time rather than overloading them at the start of RRT, with information they don’t want or need. A deeper and more valuable insight could be gleaned by observing patients using a *learning-by-making sense* approach by developing their skills to self-direct their need or information, identifying their information goals and describing the context in which they arise. A continuous programme of this type with integrated outcome measures would generate far more meaningful information than a snapshot in time identifying the needs of a group.

The study identified a number of contextual influences that suppress or initiate information needs in different ways through complex of relationships. Coping styles have particular influence although there was evidence that demonstrated CKD patients used transient coping styles to manage different situations. Similarly their need for information on a specific topic could also be temporal, along the disease and treatment pathway, increasing and decreasing in importance at different times. For example information about transplantation, as the wait became longer, increased in importance for some patients. By introducing a coding system of priority (urgent, short-tem, long-term) when first identifying a patients information need and purpose of information, health professionals will be well equipped to provide appropriate information at an appropriate time, to an appropriate depth. The continual information needs of patients indicated that many needs were not being met, usually because after the flurry of information provision at the pre-dialysis stages information provision was then seen as an informal ad hoc process.

The wealth of information gleaned from this study will inform and direct the evidence base upon for practice and enhance information and education provision within renal services. There is need to view information provision and identifying the information needs of patients differently for practice to be advanced, patient-led and effective.

Whilst the study was successful in achieving its aim it has also highlighted the need and scope for future research on this topic, particularly with CKD patients. Based on the strong evidence generated recommendations for future research, practice and policy are presented in the final chapter. The study findings provide researchers with a platform upon which to build, a platform that itself was built from postulations and research originating from information science. The value of looking wider than our own *information field* within health is clearly evident.

Chapter Eleven

Recommendations and Conclusions

Introduction

The thesis explored, identified and described the information need, preferences and priorities of CKD patients, but more importantly it has gathered evidence to understand why patients want information.

> *'If we know why people need the information, the question of what should be much more transparent'* (Consumers' Association 2003, p18).

Information that meets the need of the CKD patient is an integral component in the patients learning journey and cannot be considered separately to theories of how patients make sense and construct meaning of their life with CKD. For health care professionals providing information, knowing what information and why is needed by whom and when is valuable evidence that will inform, improve and enhance the quality of care patients receive.

The contribution this thesis makes to theory is evident on multiple levels. A deeper understanding of the phenomena has been achieved by exploring wider perspectives than within the field of health. The modified information need definition, derived from information science, will within the field of health provide clarification and greater understanding of the term, to replace the current confusion and ambiguity (Timmins 2006). The integration and application of such a definition within future policy documents and guidelines would enhance understanding further. By exploring the contextual influences and the purpose of information need for CKD patients an empirical evidence base has been created, previously unknown, that illuminates the information need world of the patient. It is this crucial evidence that will inform clinical practice and facilitate the development of patient-led information provision in the future.

Recommendations naturally emerge from the findings of the study and are presented here as suggestions to improve and build on existing clinical practice, national policy and the scope for future research.

Recommendations for Policy and Practice

- Nine core information needs be used in a condensed format (a topic guide) to initiate patient discussion and draw out more specific individual information needs, or used as an evidence base upon which to derive the content of patient education programmes

- The working definition of *information need* be integrated throughout policy documents and future research within the wider field of health to generate a clearer understanding of what the term means and the dimensions surrounding the concept

- A change is recommended to the current approaches used to meet the information and education needs of CKD patients towards adopting a *learning-by-making sense* strategy, which would facilitate and encourage self-management skills, a patient-led service and effective information provision in clinical practice. Such a proactive approach could be implemented from diagnosis throughout the disease trajectory meeting the continuous information needs of CKD patients. Using integrated evaluation and measurable outcomes the understanding of the patient's journey could be further illuminated

- Healthcare documentation be developed and implemented to effectively capture and record the information needs of CKD patients as they emerge, the purpose of information, the influence of prominent contextual factors and the patient's own temporal goals

- A combined mixed methods approach, utilising both quantitative and qualitative measures to identify information need, purpose and context is recommended as the most effective and comprehensive research strategy to generate meaningful data surrounding the topic of information need

- The Renal PatientView initiative being rolled out within renal centres throughout the UK directly meets a demand for information highlighted by patients. However, for it to be successful and meaningful to patients there needs to be an input of education that clarifies the meaning of key blood test results, identifies normal and expected levels, and provides the patient with guidance on self-management strategies that would enable them to act on poor results. Without such concurrent information provision patients will continue to have a limited understanding of the information which this innovative initiative provides access to

- Information prescriptions within CKD, alongside formal collaboration between NHS library information scientists and clinicians, would enhance information provision and support an overall information strategy, identifying and locating high quality information resources targeting the information priorities of CKD patients

- Event ordering is a useful and valuable way of chronologically organising a research interview with a CKD patient, given that so many key and progressive events occur throughout their disease trajectory. These can be used to focus thoughts, feelings and experiences relating to many different research topics.

Recommendations for Future Research

There is a seemingly endless amount of research yet to be realised before health professionals can fully understand the information needs of patients. Collaboration between information science and health researchers in the future may well advance the knowledge base within health driving forward a greater understanding within both fields. Recommendations for future research provide ideas that warrant further investigation building on and confirming the evidence base developed from this study

- Further testing of the reliability and validity of the CKD-INQ with a larger sample to examine the influence of inconsistent comparative judgements on the internal consistency and scalability of the data

- Use the CKD-INQ to explore the information need priorities in the first instance of patients belonging to ethnic minorities. This could be achieved by collaborating with networks where relationships are already established within the community or where good practice exists (such as the ABLE project), although better ways of engaging with this cohort of patients need to be explored. Future studies within minority groups could involve exploring the influence of context and the purpose of information

- Consider the application and use of Sense-Making methods to further explore and examine the contextual factors surrounding and influencing a patient's need and purpose of information. This type of methodology may well provide a greater insight on the construction of meaning within this group of patients

- Measure the impact and effectiveness of a *learning-by-making sense* information strategy introduced within a clinical renal network for patients at different stages of CKD, as to whether it can improve information provision, meet the needs of the patients, enhance self-management skills, confidence and control by developing a patient-focused service

- Develop research to explore contextual factors such as personality, emotions, attitudes and feelings, highlighted in other research studies, and their influence on information need which may provide a clearer understanding of the psychological information needs of CKD patients that appear to underpin the purpose of an information need rather than being expressed

- Move the research agenda forward once the evidence base on information need is established for CKD patients to understand the totality of their information seeking behaviour

- A key information need arising from this study was concerned with work, in particular sustaining and continuing employment once diagnosed and suffering with CKD. There is a need for in-depth research that seeks to understand the complexities of being employed and coping with CKD. Identifying the type of information patients' need to facilitate decisions regarding their career, whether they are able to sustain or need to change their employment prior to starting RRT, and whether viable re-training opportunities exist. The timing of appropriate information is crucial to those with career aspirations who prefer to remain financially independent and working

Concluding Remarks

Never throughout the 10 years I have been developing and implementing health research has my opinion changed so much from the start of a study to the end. Initially the idea of testing the INQ paired comparison method within a group of CKD, similar to the developments made in cancer patient research, was the clear focus of the thesis. However, it soon became clear, particularly from the evidence base existing in information science, that the context of the individual was equally, if not more important, and as such the study was shaped to facilitate the exploration of these aspects in greater depth. After conducting the patient interviews and the subsequent analysis of the data the focus of the thesis shifted to reflect the enormous depth of contextual influence that surrounds information needs. This being the case I would be of the strong opinion now that identifying information needs of patients at one point in time provides limited useful meaning in the absence of understanding of the purpose and context of those information needs. Indeed the excitement and passion stirred as a result of this thesis signifies the beginning of a journey to explore the hidden depths of context alongside how the CKD patient constructs meaning and makes sense of information, in the hope of improving and advancing information and education provision in practice.

The study has achieved much more than it set out to do. It has generated a rigorous, high quality evidence base grounded from the patient perspective that:

- Identifies core information needs that are pertinent to CKD patients
- Develops and tests a CKD specific Information Need Questionnaire that measures the information priorities of patients

- Demonstrates that CKD patients have preferences and priorities of information need that change over time and as the disease progresses
- Explores and examines the contextual factors that influence the manifestation of an information need
- Highlights the personal and demographic characteristics of an individual that influence a need for information
- Suggests a simple patient-focused, *learning-by-making sense* information and educational approach to facilitate, improve and target effective information provision in clinical practice
- Develops and refines a working definition of the concept *information need* that is both applicable and relevant to health care practice and national policy
- Contributes to information need theory

The uptake of the findings as integral evidence upon which to generate a guideline for CKD management by such a nationally recognised organisation as NICE was an accolade of the highest standing, one that made all the hard work worthwhile.

Appendix 1 Example of Search Strategy (1&2) in Medline

Search 1 – Medline June 2005

1. *Patient Education/
2. *Kidney Failure, Chronic/
3. *Health Promotion/
4. *Health Knowledge, Attitudes, Practice/
5. *Health Behavior/
6. *Decision Making/
7. *Health Education/
8. 1 or 3 or 4 or 5 or 6 or 7
9. 8 and 2
10. information need$.mp. [mp=heading words, title]
11. 8 or 10
12. patient information.mp. [mp=heading words, title]
13. patient priorities.mp. [mp=heading words, title]
14. patient choices.mp. [mp=heading words, title]
15. patient participation.mp. [mp=heading words, title]
16. Empower$.mp. [mp=heading words, title]
17. informed decisions.mp. [mp=heading words, title]
18. 11 or 12 or 13 or 14 or 15 or 16 or 17
19. 2 and 18
20. End stage renal failure.mp. [mp=heading words, title]
21. End stage kidney disease.mp. [mp=heading words, title]
22. chronic renal failure.mp. [mp=heading words, title]
23. chronic kidney failure.mp. [mp=heading words, title]
24. End stage kidney failure.mp. [mp=heading words, title]
25. End stage renal disease.mp. [mp=heading words, title]
26. chronic renal disease.mp. [mp=heading words, title]
27. chronic kidney disease.mp. [mp=heading words, title]
28. Dialysis.mp. [mp=heading words, title]
29. pre-dialysis.mp. [mp=heading words, title]
30. haemodialysis.mp. [mp=heading words, title]
31. peritoneal dialysis.mp. [mp=heading words, title]
32. Kidney insufficiency.mp. [mp=heading words, title]
33. Renal insufficiency.mp. [mp=heading words, title]
34. 2 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33
35. 18 and 34

Search 2 – Medline June 2005

1. *Patient Education/
2. *Health Promotion/
3. *Health Knowledge, Attitudes, Practice/
4. *Health Behavior/
5. *Decision Making/
6. *Health Education/
7. 1 or 2 or 3 or 4 or 5 or 6
8. information need$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
9. patient information.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
10. patient priorities.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
11. patient choices.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
12. patient participation.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
13. Empower$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
14. informed decisions.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
15. 8 or 9 or 10 or 11 or 12 or 13 or 14
16. End stage renal failure.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
17. End stage kidney disease.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
18. chronic renal failure.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
19. chronic kidney failure.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
20. End stage kidney failure.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
21. End stage renal disease.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
22. chronic renal disease.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
23. chronic kidney disease.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
24. Dialysis.mp. [mp=title, original title, abstract, name of substance word, subject heading word]

25. pre-dialysis.mp. [mp=title, original title, abstract, name of substance word, subject heading word]

26. haemodialysis.mp. [mp=title, original title, abstract, name of substance word, subject heading word]

27. peritoneal dialysis.mp. [mp=title, original title, abstract, name of substance word, subject heading word]

28. Kidney insufficiency.mp. [mp=title, original title, abstract, name of substance word, subject heading word]

29. Renal insufficiency.mp. [mp=title, original title, abstract, name of substance word, subject heading word]

30. 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29

31. 7 and 15 and 30

32. 31

33. limit 32 to english language

Appendix 2 Inclusion / Exclusion Criteria

Stage 1 (abstracts): Inclusion/Exclusion criteria

Inclusion	*Exclusion*
Patient information needs determined by either the patient / staff Self-care /education training programmes (identifying programme content) Patient education needs determined by patients / staff Empowerment of patients Factors influencing patient education Patient expectations of service / treatment Education programmes derived based on patient need Patient choices and attitudes towards treatment/practice/service Cultural and ethnicity influences on education/ information provision Needs assessment Non-compliance / behaviour of patients Literacy levels / measures CKD Patients - pre-dialysis, PD, HD Nutrition / medication issues / education Measuring patient knowledge Evaluation of training/education programmes (validating content) Patient decision making Patient awareness of treatment options Patient involvement	Clinician information needs Methods / program descriptors of how education is delivered Clinician education issues ESRD risk factors / measuring risk / tools Clinical indicators / clinical issues / clinical research Transplanted / paediatric patients Patient disease patterns / outcomes Non-renal papers Quality of Life measures Professional practice issues (measuring quality care) Ethical dilemmas (hastening death, resource allocation) Teaching protocol / methods Economic papers Clinical case histories Care planning / management Management of anaemia Evaluations of teaching methods Non-English papers Clinical guidelines Clinicians role Patient modality selection issues Comments / interviews / opinion papers Needs of the family/ care giver Methods used to increase compliance Advanced directives

Stage 2 (Full article review): Inclusion / exclusion

Inclusion	***Exclusion***
1. Patient information needs • Originating and verified by patient • identified by health professional 2. Patient issues /choices/ concerns • raised by patient • raised by staff 3. Factors which influence a patients information needs (Psychological stressors, age, ethnicity, education level, modality, time/experience of renal replacement therapy)	No patient information needs identified Evaluation of educational intervention No description of educational course content Teaching method News item Continuing education articles Explanation of teaching tool only Explanation of educational team – service delivery Commentary Influences of patient personality only Locus of control issues Descriptors of compliance Measuring knowledge retention Patient opinion of services Educational strategies / methods Cost effectiveness Transplant decisions Advanced directives, End of life decisions Nephrologists decision making Short vs long dialysis QOL issues only Professional role in educating Case studies – clinical decision making Adequacy of dialysis Website evaluation of education material Ethical issues Decision to withdraw from dialysis Acute dialysis Theories of compliance Content of education/teaching program / learning needs / information / topic areas identified/suggested/provided by staff only/ or verified by patient Patient education tools/information sheets

Appendix 3 Critical Appraisal Framework

	Adapted from HCPRDU (2001) Framework	In line with NICE (2007)
Clear Aims:	Are the study aims appropriate for the review and inclusion of the study? Do the study aims elicit patient information needs surrounding a certain topic, look at factors influencing patient information needs, patient concerns, or patient preferences with respect to information?	Clear (+) Unclear (-) Not addressed Not Reported Not applicable
Study Type	What type of study is it? Is this appropriate to answer the study questions or aims? Has the type of study design been clearly outlined and a rationale provided as to why this approach was considered the best? Could a better approach have been utilised?	Clear (+) Unclear (-) Not addressed Not Reported Not applicable
Literature Review	Is the literature review comprehensive? Does it generate an argument for the current study? Does it draw out the pertinent points? Does it identify theories to consider?	Well covered (++) Adequately addressed (+) Poorly addressed (-) Not addressed Not Reported Not applicable
Perspective	Is the perspective obtained relevant to the study group? Are CKD patients/family members or health care professionals within the renal field involved? Is the perspective restricted will this influence the study findings?	Well covered (++) Adequately addressed (+) Poorly addressed (-) Not addressed Not Reported Not applicable
Sample selection	Is the selection of participants transparent? Have all variables within the sampling population been considered? Is a random or non-random method applied and is this appropriate? Could the sampling method have been improved? Are the inclusion and exclusion criteria appropriate to achieve the aims of the study? Have certain groups within the sample been excluded and is this appropriate?	Good (++) Adequate (+) Poor (-) Not addressed Not Reported Not applicable
Sample Size	Is the sample size and composition representative of the target population? Have sufficient participants been recruited?	Good (++) Adequate (+) Poor (-) Not addressed Not Reported Not applicable
Method	Is the method adopted explicit and appropriate? What are the good points and bad points of the	Good / Clear (++)

	approach? Is the method based on previously validated studies? Are previously validated tools considered and are they appropriate? Is the method of data collection appropriate to answer the study aims? Could the methods have been improved? Have ethical issues and consent been considered and described?	Adequate (+) Poor (-) Not addressed Not Reported Not applicable
Fieldwork	How the fieldwork is performed, is it described insufficient detail to be clear? When, where, for how long, and to whom, does the fieldwork target? Are there any problems with the way the fieldwork was approached? Who is performing the fieldwork is there potential for researcher bias? How is the reliability and validity of the data guaranteed?	Well covered (++) Adequately addressed (+) Poorly addressed (-) Not addressed Not Reported Not applicable
Analysis	Does the study have an appropriate analytical approach and is it transparent? Have the correct statistical tests been applied? Have appropriate qualitative approaches been applied? Are steps taken to verify and maintain the reliability and validity of the data emerging within the analytical process? Who performed the data analysis and is there any potential researcher bias? Have appropriate computer software been utilised? Is there theoretical sensitivity?	Good / Clear (++) Adequate (+) Poor (-) Not addressed Not Reported Not applicable
Results/ Findings	Is there evidence to support the results/findings emerging? Are statements and conclusions supported by relevant evidence? Are the findings discussed in relation to the current literature? Are theoretical and methodological issues/connections discussed and extrapolated from the findings? Are these appropriate?	Well covered (++) Adequately addressed (+) Poorly addressed (-) Not addressed Not Reported Not applicable
Limitations	Do the strengths of the study out-weigh the limitations? Do the weaknesses of the study invalidate the findings and conclusion? Could this study be replicated? Are there any suggestions that could to make it a better, more reliable study?	Well covered (++) Adequately addressed (+) Poorly addressed (-) Not addressed Not Reported Not applicable
Generalised	Is it possible to transfer or generalise the findings to a wider population or different setting/disease	Good (++) Limited (+)

	group?	Poor (-) Not addressed Not Reported Not applicable

Overall Quality Rating: based on combined ratings of individual sections

High / Good (++) Medium / Average (+) Low / Poor (-) Not Applicable

Appendix 4 Table 10: Critique of Sample

Study	Type	Main aim	Patient group	Sample selection	Sample size	No. of Sites	Appropriate / why	Overall Quality Rating
Wuerth et al (2002)	**Research** Exploratory qualitative	Patients' descriptions of specific factors leading to modality selection of chronic peritoneal dialysis or haemodialysis	ESRD patients from total population of 110 CPD and 240 HD patients referred to particular units *APPROPRIATE(+)*	Random from list generated from unit *GOOD (++)*	40 – 20 HD 20 PD small number in groups *ADEQUATE (+)*	3 sites (1 PD and two HD units – same Nephrologist)	Could have recruited more no rationale for sample size – appropriate sampling frame on dialysis long enough – *APPROPRIATE (+)*	**(++) GOOD**
Wilkinson (1998)	**Research -** Exploratory qualitative phenomenological approach	To identify and describe the information provided to patients prior to requiring a form of RRT	Group A patients who had received pre-dialysis information and had not yet commenced RRT Group B patients who had received pre-dialysis information and had commenced RRT. *APPROPRIATE (+)*	Poor insufficient explanation- patients divided into two groups, Patients selected at random from each group. No explanation as to what random means and out of how many. *LACKS DETAIL POOR (-)*	6 patients selected, no total patient number what percentage 6 patients represents of sample. No size rationale given except the time limits of the study? *POOR (-)*	One site North West England	No sampling frame identified and numbers so small cannot be representative of number of patients available No identification of age, gender, ethnic group of patients selected and how this was adjusted for *LACKS DETAIL POOR (-)*	**(-) POOR**
Whiltaker and Albee (1996)	**Research** Grounded Theory, Exploratory study	Factors influencing patient selection of dialysis treatment modality	HD or CPD less than 6 months and those changed from one modality to the other in the past 6 months were included *APPROPRIATE (+)*	Ongoing analysis guided subsequent interviews in order to ensure richness and depth of information, difficult to assess could have been more rigorous and larger more representative sample although state that 20 patients comparable to total population initiating dialysis during the given period –- Theoretical *ADEQUATE (+)*	21 subjects approached 1 female declined – 20 patients recruited, small number *POOR (-)*	Two diverse geographical areas and centres in areas not clear how many - could have recruited more representative sample	Very small sample size for large geographical area studied, appropriate setting and events but unable to fully assess appropriateness of sample. *APPROPRIATE (+)*	**(+) AVERAGE**

Orsino et al (2003)	**Research** Self-report survey design	To explore the age and gender differences in RRT decision-making preferences and information needs.	Patients on HD or PD patients *APPROPRIATE (+)*	All patients receiving dialysis who attended on consecutive clinic days *GOOD (++)*	Large number 197 and suggests 80% success rate so potential total number eligible = 246 patients *GOOD (++)*	One setting one country –	Informants and events appropriate and although approached during dialysis patients completed self-report in private – 197 patients, 64.3% on HD and 35.7% PD, mean age 52.8 years and 58.2% male n *APPROPRIATE (+)*	**(++)** **GOOD**
Schatell et al (2003a, 2003b)	**Research** Informal survey design	To gain a better understanding of CKD patients educational, emotional and concerns	CKD patients *APPROPRIATE (+)*	CKD patients referred by CKD educator – opportunistic sample (? Pre-selected at source) although not good results on knowledge gain suggest no pre-screening of patients Opportunistic *POOR (-)*	30 patients referred by educators, non random although not clear why not more, possibly limited by time - small number *POOR (-)*	Wide geographical area different sites	Sample breakdown provided but not referred to total sample population, no mention whether representative – higher number of African-American than in national ESRD population *POOR (-)*	**(-)** **POOR**
Hedman (1998)	**Descriptive - Opinion** One patient account	Own experience of being on dialysis - compliance	HD patient *APPROPRIATE (+)*	One patient *NOT APPLICABLE*	One patient *NOT APPLICABLE*	One unit – one patient	Useful for personal description and experience *NOT APPLICABLE*	*NOT APPLICABLE*
O'Donnell and Tucker (1999)	**Research** Evaluation of educational intervention and resource utilisation	To examine the patients perception of pre-dialysis education programme. To examine resource utilisation, length of stay as an outcome measure.	All pre-dialysis patients presenting to the service approaching ESRD (creatinine level 250mmols/l) *APPROPRIATE (+)*	All patients were selected presenting with ESRD admitted to hospital between April 1996-September 1997. 84 patients presented– *GOOD (++)*	61 patients recruited – 72% response rate 37=61% attended programme – 24=39% did not attend *GOOD (++)*	One site – nephrology service in UK	Pre-dialysis patients (whole group) prior to dialysis commencement, those who attended and those who did not attend education programme *APPROPRIATE (+)*	**(++)** **GOOD**
DeCuir (1998)	**Opinion** Personal account of surviving dialysis/compliance	Personal account of one patient strategies for surviving dialysis and promoting compliance	HD patient *APPROPRIATE (+)*	One patient *NOT APPLICABLE*	One patient *NOT APPLICABLE*	One unit – one patient	Useful for personal description and experience *NOT APPLICABLE*	*NOT APPLICABLE*

Bath et al (2003)	**Research** Exploratory Phenomenological study	To look at haemodialysis patients' perceptions of their treatment to discover if a dialysis centre might benefit from a more formal system of psychological care	HD patients recruited having experienced HD for four months to 7 years, mean sample age 60 year**s,** *APPROPRIATE (+)*	Suggests random sample but identifies patients selection to represent differences in time on dialysis and age, gender. Would suggest sample too small to control for these variables appropriately. *LACKS DETAIL POOR (-)*	10 patients selected – no reference to total population so unable to determine whether sample representative of HD patients at the centre – although this is suggested *POOR (-)*	One site - UK	No information provided on the total number of HD patients cared for at the centre, no demographics on total population prevents comparison of actual sample recruited. Would suggest sample too small to control for these variables appropriately. *LACKS DETAIL POOR (-)*	**(-)** **POOR**
Curtin and Mapes (2001)	**Research** Exploratory-Descriptive study	To gain insight into the factors that are associated with some dialysis patients' ability to live long on dialysis	All patients receiving some form of RRT – no total population identified in numerical form, but inclusive of all the country *APPROPRIATE (+)*	Modified 'snow ball' sampling method. Initially patients surviving long-term identified and then other participants identified by other patients as 'information rich.' Theoretical sampling until data saturation achieved – could have used other sources to identify patients *ADEQUATE (+)*	18 patients, mix of patients having experienced all the different forms of RRT, - 10 male and 8 female, 10 Caucasian, 4 African-American, 4 Hispanic – age ranges of 38-63 years, small size *POOR (-)*	All centres across country explored	Would have been better to give total number of surviving patients to allow an overall impression of whether representative *APPROPRIATE (+)*	**(+)** **AVERAGE**
Andrew (2001)	**Research** Qualitative Grounded theory	Develop new theories and expand knowledge regarding pre-dialysis care	Pre-dialysis patients and their families *APPROPRIATE (+)*	Theoretical sampling but method not explained or described *LACKS DETAIL POOR (-)*	10 patients – not stated out of how many – families not described – who, small sample *POOR (-)*	One unit in UK	Very small study of 10 patients, poor paper with respect to presenting evidence to support claims, *LACKS DETAIL POOR (-)*	**(-)** **POOR**
Coupe (1998)	**Research - Audit** Evaluation of education intervention	Making decisions about dialysis options: an audit of patients' views	All patients audited 2-3 months after commencing HD or PD dialysis *APPROPRIATE (+)*	All Patients audited 2-3 months after commencing dialysis – patients not selected if dialysis not commenced - selected from site where the educational intervention operated referral process to pre-dialysis education programme clearly identified *ADEQUATE (+)*	228 questionnaires distributed and 172 returned (75.4% response rate) *GOOD (++)*	One dialysis centre.	Full outline of sample available presented and questionnaire posted to those patients *APPROPRIATE (+)*	**(++)** **GOOD**

Breckenridge (1997)	**Research** Qualitative grounded theory	Patients' Perceptions of Why, How, and By Whom Dialysis Treatment Modality Was Chosen	All patients receiving RRT – no overview of the total patient population offered *APPROPRIATE (+)*	Patients between 29-69 years selected, been on dialysis 4 months-19 years, ethnicity took into account 4 black, 1 white respondents higher than national ESRD population (3:1) – sample appears to reflect range of patients although difficult to determine without full breakdown, theoretical selection identified – patients first identified by managers of the unit then non-random selection but not stated how *LACKS DETAIL POOR (-)*	13 male and 9 female – 22 patients very small sample in relation to all patients receiving dialysis *POOR (-)*	Large tertiary centre on the East coast of the USA – involving patients from four different units, three HD units - outpatient, in centre and in-hospital, one CAPD out-patient unit	Sample appears to reflect range of patients although difficult to determine without full breakdown, theoretical selection not described on what based *LACKS DETAIL POOR (-)*	**(-)** **POOR**
Bass et al (1999)	**Research** Qualitative Exploratory study	The use of Focus Groups to Identify Concerns about Dialysis	Dialysis patients (HD and PD) Nephrologists, Health care professionals *APPROPRIATE (+)*	Patients: Stratified random sample according to first by dialysis centre, then type of dialysis then age (<55 or >55 years), ethnicity white and non-white (sample of HD and PD patients randomly selected Staff: Nephrologists – stratified according to centre, then academic or non-academic, experience (<5 years vs >5years) Other health care professionals stratified by professional discipline *ADEQUATE (+)*	8 HD patients, 5 PD patients, 8 Nephrologists, 9 other health professionals – no mention why less patients in PD group Small numbers of total population *POOR (-)*	Four different dialysis centres in Baltimore area	Good description of sampling frame and appropriate to patient population, representative of all staff groups APPROPRIATE (+)	**(+)** **AVERAGE**

Groome et al (1994)	**Research** Exploratory mixed method design	Content of a Decision Analysis for Treatment Choice in End-Stage Renal disease: Who Should Be Consulted?	All patients receiving RRT (HD, PD, Tx) at two hospitals *APPROPRIATE (+)*	Selected in consultation with 3 nephrologists and a transplant physician – as to those who could contribute for their wide range of treatment experiences, and selected according to age and gender (although age and gender not stated) Theoretical potential bias from selectors – How were staff selected? *LACKS DETAIL POOR (-)*	19 patients included (5 hospital HD, 4 self-care HD, 3 home HD, 4 PD, 3Tx,) 11 nurses, 8 nephrologists, 1 psychologist, 1 cardio/nephrologist =43 participants – represents what was achievable in the setting in the time frame available not what is representative 70% of participants responded to survey *ADEQUATE (+)*	Two hospitals Royal Victoria Montreal General in Montreal.	Wide sampling frame – small number of patients selected to represent larger group Lack of detail to assess whether representative as no age, gender or ethnicity stated however appears appropriate for informants experience of setting and events research is to capture *APPROPRIATE (+)*	**(+)** **AVERAGE**
Harwood et al (2005)	**Research** Qualitative exploratory study	To identify the implications for patient education and support needed in the care of patients with CKD –Explore the specific stressors patients with CKD who are on haemodialysis recalled experiencing as they approached dialysis	HD patients who had attended the CKD pre-dialysis program APPROPRIATE (+)	Random selection of patients drawn from hat – suggest theoretical sample and purposeful but unclear as should have adjusted for age and gender bias in sample. Could have used a wider sample of more patients but no total sample offered for comparison *POOR /ADEQUATE (-/+)*	Small number 11 participants, claim data saturation therefore did not extend to gain bigger sample – 9 men 2 women and all participants over 61 years not representative *POOR (-)*	One centre	Too many men in a small sample and high age group of participants, no mention of ethnicity or whether this represents target population, also retrospective recollection raises questions of accuracy (demonstrated with 4 out of the 11 patients not reporting any stressors) *POOR (-)*	**(-)** **POOR**
Niccum and Pèrez (2000)	**Patient education** Descriptive	A description of an educational strategy initiating a consistent flow of information to facilitate the identification, assessment, selection, media and means for its patient education activities.	CKD/ESRD patients *APPROPRIATE (+)*	No sampling frame described for survey which is referred to *LACKS DETAIL POOR (-)*	No sample identified or described *LACKS DETAIL POOR (-)*	The Renal Network covering 4 states in the US, 400 dialysis centres and 30,000 HD and PD patients, also 25 Tx centres	No sample identified, describes network and drawing out patient information and learning needs *LACKS DETAIL POOR (-)*	**(-)** **POOR**

Murray et al (1999)	**Research** Prospective descriptive study	To identify factors that influence the pursuit of kidney transplant by persons with ESRD	Dialysis patients waiting for a Transplant/ on Transplant list *APPROPRIATE (+)*	Each facility provided a list of all potential participants and then individuals randomly selected using a table of random numbers. Participants approached by nurses data collector and study explained – interview arranged at later date if consent given *GOOD (++)*	Target pop - 450 ESRD individuals currently undergoing treatment - 115 patients included in the study, 44.3% female, 55.7% men – overwhelming Christian Faith 90% GOOD (++)	Three dialysis facilities in a mid-Atlantic state	Sample appropriate, not representative cultural diversity but representative locally *APPROPRIATE (+)*	**(++) GOOD**
Hines et al (1997a)	**Research** Exploratory study	To determine whether informed consent for performing dialysis had been obtained from elderly patients and to explore the potential causes of inadequate informed consent.	All patients over the age of 64 years who were receiving haemodialysis at a unit within 80 miles of Morgantown West Virginia – US during Aug/Sept 1995 – *APPROPRIATE (+)*	Modified three-stage cluster design utilised, stage one identifying the 23 possible units, on contacting 19 units (? Why not all 23) all but two clinical directors gave consent for the study. Stage two involved selecting dates and times to interview patients at the consenting 17 units – interviews were conducted during at least two of the three schedules shifts on one or two randomly selected days for each unit. Stage three involved selecting patients over 65 years to interview on each shift. Random - opportunistic *GOOD (++)*	142 patients over 64 years receiving HD out of 157 contacted agreed to be interviewed 49% female and 51% male *GOOD (++)*	HD units within 80 miles of Morgantown West Virginia, US. Includes 23 units	Opportunistic random sample of those patients present on the day scheduled for interviewing Appropriate to target patients over 65 years for research and those on HD *APPROPRIATE (+)*	**(++) GOOD**

Hines et al (1997b)	**Research** Exploratory study	To study the EOL decisions of elderly HD patients	All patients over the age of 64 years who were receiving haemodialysis at a unit within 80 miles of Morgantown West Virginia – US during Aug/Sept 1995 – *APPROPRIATE (+)*	Modified three-stage cluster design utilised, stage one identifying the 23 possible units, on contacting 19 units (? Why not all 23) all but two clinical directors gave consent for the study. Stage two involved selecting dates and times to interview patients at the consenting 17 units – interviews were conducted during at least two of the three schedules shifts on one or two randomly selected days for each unit. Stage three involved selecting patients over 65 years to interview on each shift. Random - opportunistic *GOOD (++)*	142 patients over 64 years receiving HD out of 157 contacted agreed to be interviewed 49% female and 51% male *GOOD (++)*	HD units within 80 miles of Morgantown West Virginia, US. Includes 23 units	Opportunistic random sample of those patients present on the day scheduled for interviewing Appropriate to target patients over 65 years for research and those on HD *APPROPRIATE (+)*	**(++) GOOD**
Klang et al (1999)	**Research** Evaluation /Intervention study	Predialysis education helps patients choose dialysis modality and increases disease - specific knowledge	HD and PD patients all treated by a specialist in nephrology at a hospital out-patient clinic between 1991 and 1993 APPROPRIATE (+)	Evaluation Group all participants who met the criteria were selected and invited to take part. No clear idea of how control group were selected, does not state random sample or from how many, two sites used for Control Group sample which could introduce different variables not considered or discussed – Control Group already on dialysis treatment at two hospitals during the same time frame –received conventional information only – regular out-patient – not clearly identified ADEQUATE (+)	No target population stated unable to determine whether sample representative 38 patients agreed to take part (20 men and 18 women) and completed the educ. Programme, 28 were assessed 3-9 months after the programme (EG). However, 10 patients were not available at time of follow up, 4 had died, 1 had a Tx and 3 had not yet started RRT. 28 patients were recruited to the control Group (7 women and 21 men) *ADEQUATE (+)*	One setting for EG but two setting for CG variables between different setting not stated, conventional information giving not very clear	There is a lack of detail regarding the control group selection. It would appear that the only difference between samples in both groups was time the control group had on dialysis compared to pre-dialysis patients *APPROPRIATE (+)*	**(+) AVERAGE**

Tweed and Ceaser (2005)	**Research** Exploratory Study	To explore the decision making processes of pre-dialysis patients when choosing a renal replacement treatment (RRT) and to elucidate how these choices were made	*All patients in pre-dialysis phase who had indicated they made a decision about RRT and all attended information day* APPROPRIATE (+)	All patients in pre-dialysis phase who had indicated they had made a decision about RRT and all attended information day 2-18 months prior to needing dialysis – opt in form, self-selection to study, does not identify number of target population *LACKS DETAIL POOR (-)*	Small sample size (9 patients) Unable to explore variables within sample characteristics *POOR (-)*	One setting in one hospital	Appropriate source population of patients sampled but unable to determine whether sample recruited which is very small is representative of wider target population *LACKS DETAIL POOR (-)*	**(-) POOR**
Leino-Kilpi et al *(1993)*	**Literature Review**	To provide a brief overview of existing research studies concerning patient information, outline relevant perspectives on information giving, identify knowledge structures of four different patient groups	*Studies with respect to four different patient groups reviewed and compared – dialysis, surgical, cancer and psychiatric patients* *APPROPRIATE (+)*	No search strategy, protocol or criteria stated for study selection for review *LACKS DETAIL POOR (-)*	No identification of number of dialysis articles included and excluded *LACKS DETAIL POOR (-)*	NOT APPLICABLE	Unable to determine whether studies selected appropriate, only reviewed prior to- 1993 studies which limits applicability *LACKS DETAIL POOR (-)*	**(-) POOR**
Iles-Smith (2005)	**Research** Qualitative Exploratory Study	To elicit the perceptions and experiences of pre-dialysis patients prior to receiving treatment	*Pre-dialysis patient population* *APPROPRIATE (+)*	Purposive –consecutive sampling method selecting first 10 patients who attended the pre-dialysis clinic, English speaking only – sample method adequate but not sufficient recruited to allow for participant variables/demographics /characteristics Purposive – consecutive ***POOR/ADEQUATE (-/+)***	Small sample, 10 cannot be generalised, lack of detail prevents being able to determine whether sample representative of target population *POOR (-)*	One centre with pre-dialysis population	No details presented of target population numbers so unable to determine whether sample selected is representative and appropriate but suspect not due to small number *LACKS DETAIL POOR (-)*	**(-) POOR**
Juhnke & Curtin *(2000)*	**Research** Exploratory follow up survey design	Survey of what is important to ESRD patients with respect to education and information needs – to learn what, the when, how and who of information seeking people on dialysis	*Patients who contact education organisation to acquire more information – more information seeking active* APPROPRIATE (+)	Self-selection by patient to be involved – information seeking active patients looking for additional information, lacks detail on sample and how recruited for telephone interviews –opportunistic previously contacted organisation for information opportunistic *LACKS DETAIL POOR (-)*	Small sample 30 patients, self-selected and biased to information seekers No stated sample characteristics *POOR (-)*	One site telephone contact with patient education organisation but covers wide geographical area	Appropriate source population but limited detail of sample to be able to judge whether pre-selected sample *LACKS DETAIL POOR (-)*	**(-) POOR**

Fine et al (2005)	**Research** Survey design	To assess whether patients want voluntary disclosure by their physician of their survival should they need dialysis and if so why?	Patients attending nephrology clinic for first time in early stages of CKD but none of the patients appeared destined for dialysis in the future, limited by ethical restrictions *APPROPRIATE (+)*	Patients sampled from clinic list of first time attendees at nephrology clinic, consecutive /opportunistic sample. *GOOD (++)*	120 patients screened 100 patients recruited in sample (67% males, age range 50-74 yrs, 57% educated to high school graduation, 84% Caucasian) *GOOD (++)*	One site where nephrology clinic situated	Appropriate sample with respect to early CKD patients except limitation perhaps of the fact that they may never need dialysis in the future so their opinions are based on a theoretical situation rather than true reflection of their opinion when faced with the decision of treatment *APPROPRIATE (+)*	**(++)** **GOOD**

Appendix 5 Table 11: Critique of Methods

Study	Type	Main Aim	Type Methods / tools	Fieldwork / data collection	Generalise	Analysis method	Method / Theory Implications noted	Overall Quality rating
Wuerth et al (2002)	Research Exploratory qualitative	Patients' descriptions of specific factors leading to modality selection of chronic peritoneal dialysis or haemodialysis	Structured interview – open-ended questions based on literature and identification of key underlying questions to be answered. Clear methods and based on validated study GOOD (++)	Yes - Interviewed by experienced person not working on dialysis units But where and when interviewed not stated Same interviewer throughout to increase reliability ADEQUATE (+)	CKD patient groups HD and CPD, although limited numbers prevent further generalisation than local setting, although reliability increased as findings reflect other substantial studies GENERALISABLE (++)	Clear thematic analysis framework based on clinical judgment - transcribed interviews independently assessed by two different researchers both were from the CPD unit and both used their own clinical judgement to assess the themes of the interviews and develop the taxonomy based on patient responses GOOD (++)	Methodological relevance in the development of taxonomy for analysis and outcomes	(++) GOOD
Wilkinson (1998)	Research - Exploratory qualitative phenomenological approach	To identify and describe the information provided to patients prior to requiring a form of RRT	Poor described method- semi-structured interviews, no clarification of what made up the semi-structured instrument POOR (-)	Interview performed in patients own home, no duration of interview stated, no mention of whether interview tape-recorded or how data was collated. lacking sufficient detail POOR (-)	Hard to put findings into context without any description of educational programme undertaken – too small numbers to generalise - lacks detail NOT GENERALISABLE (-)	Grounded theory as method for study briefly describes constant comparative method for analysis of themes. To verify themes peer examination of data performed. Does not explain what difference peer examination made on those themes, whether there were differences or similarities in opinion and how this was handled – limited detail ADEQUATE (+)	Develop standard for nursing provision of information and content for all pre-dialysis patients	(-) POOR

Orsino et al (2003)	Research Self-report survey design	To explore the age and gender differences in RRT decision-making preferences and information needs.	Comprehensive - Self report survey (piloted on small number of patients) 19 pages long 69 questions, 30-60 minutes to complete O'Connor Decision Self-Efficacy standardised questionnaire to measure level of confidence in medical decision making GOOD (++)	Although approached during dialysis patients completed self-report in private – 197 patients, 64.3% on HD and 35.7% PD, mean age 52.8 years and 58.2% male ADEQUATE (+)	Sample reflects ESRD patients on Canadian Organ Replacement Registry so claim representative to population GENERALISABLE (++)	Statistical analysis – t-test allowed groups to be compared with continual variables, sample divided into two age groups (<53 years and above mean age) analysis of qualitative data from questions was not discussed- limited detail ADEQUATE (+)	Clear identification of variables and method of how to capture points	(++) GOOD
Whittaker and Albee (1996)	Research Grounded Theory, Exploratory study	Factors influencing patient selection of dialysis treatment modality	Good exploratory method –20 unstructured interviews During interview informants asked to describe their experience of choosing a dialysis modality. Further questions were asked to elicit clarification or more detail. GOOD (++)	Interviews tape recorded, 60-75 minutes duration, transcribed verbatim, performed after dialysis at the centre or majority in the patient's home. Interviews performed by two different investigators GOOD (++)	Good quality paper but too small sample to generalise results NOT GENERALISABLE (-)	Interviews transcribed verbatim, constant comparative thematic analysis, content analysis – patterns, categories and descriptions Not adequate- examples of how patterns and categories emerged not provided or results of content analysis method, benefits of using both not identified – limited detail ADEQUATE (+)	Two staged theory regarding decision making - Maintaining self-care evaluating threats and weighing up alternatives – both aspects of theory would influence a patients information needs Informed Choice: Passive acceptance / Listened to physician / Went against physician advice	(++) GOOD
Schatell et al (2003a, 2003b)	Research informal survey Design	To gain a better understanding of CKD patients educational, emotional and concerns	Poor method using Telephone interview by Social Worker – three questions stated 30-80 minutes – no rationale why used this method and why not better and more appropriate designs POOR (-)	Tape recorded telephone survey to assess knowledge level and what impact on and what they know ADEQUATE (+)	Small telephone survey –draws out some points but small sample - cannot be generalised to larger population but useful NOT GENERALISABLE (-)	No description of analysis method used to develop themes from recorded interview – no discussion either POOR (-)	Theoretical implications Active information seekers and Passive information recipients Too much information at one time – suggest future studies should include clinical information to understand patients needs as disease progresses	(-) POOR
Hedman (1998)	Opinion One patient descriptive account	Own experience of being on dialysis – issues of compliance and information	NOT APPLICABLE	NOT APPLICABLE	One patient experience NOT GENERALISABLE (-)	NOT APPLICABLE	Increased information increases compliance	NOT APPLICABLE

O’Donnell and Tucker (1999)	Research - Audit Evaluation of educational intervention and resource utilisation	To examine the patients perception of a pre-dialysis education programme. To examine resource utilisation, length of stay as an outcome measure.	Semi-structured patient satisfaction survey – pilot of questionnaire to 10 people prior to it being administered. Number of days stayed in hospital in preparation for commencement of RRT Successful Replication of method used in 51 GOOD (++)	Questionnaires sent to patients (presume through the post) Questionnaire content described, hospital data collection described ADEQUATE (+)	Education programme fully described – pre-dialysis group representative – to similar education programmes LIMITED (+)	Process of analysis not described. Not adequate evidence to support analysis: although some examples of patient comments utilised to support findings 0 lacks detail POOR (-)	Timing of information – important – develop standard pre-dialysis information – patient education works	(+) AVERAGE
DeCuir (1998)	Opinion Personal account of surviving dialysis/compliance	Personal account of one patient strategies for surviving dialysis and promoting compliance	NOT APPLICABLE	NOT APPLICABLE	One patient experience NOT GENERALISABLE (-)	NOT APPLICABLE	Clear information helps patient’s compliance, HCP needs to first understand a patients normal life before offering advice and information – to help maintain normality	NOT APPLICABLE
Bath et al (2003)	Research Exploratory Phenomenological study	To look at haemodialysis patients’ perceptions of their treatment to discover if a dialysis centre might benefit from a more formal system of psychological care	Semi-structured interview –asked patients about their concerns over restrictions, dependency, loss, image, and cure/duration of disease. Interview based on predetermined referenced psychological categories (Czaczkes and De-Nours/ Nichols Psychological Care Scheme not described in any detail) ADEQUATE (+)	Semi-structured interview – no mention as to when or where, or how long each interview took. Interview delivered by psychologist but lacks detail as to how undertaken, ethical approval not stated POOR (-)	Study findings set in broader context: findings and emerging themes referenced to similar studies and findings from larger studies on a similar population NOT GENERALISABLE (-)	Description of analysis brief - Interpretative Phenomenological Analysis – process of extracting an individual perspective of an event as well as the meaning of that event to the person. Analysis of individual interviews, highlighting themes and clustering themes together – master list of important themes produced then turned into narrative account, each interview transcribed verbatim and then analysed - selective patient comments support emerging themes ADEQUATE (+)	Variations amongst sample of preferences for knowledge – some low levels of knowledge and happy to remain so Patients felt information available but onus on the patient to elicit the information	(+) AVERAGE

Curtin and Mapes (2001)	Research Exploratory, Descriptive study	To gain insight into the factors that are associated with some dialysis patients' ability to live long on dialysis	Good paper with In-depth interviews which are described in depth to enable clear understanding of the processes performed on the data, appropriate in the exploratory study to generate theory of the phenomena In addition data collection ceased when each interview added little or nothing to the previous interviews and when information shared was beginning to be repeated. GOOD (++)	Long semi-structured interviews, lasting between 2-6.5 hours, tape recorded and transcribed. Very good description of interview technique. Interviews were continued until three criteria were satisfied; saturation, redundancy and the search for disconfirming evidence– satisfying these criteria provided 'completeness'. GOOD (++)	Small group – wide recruitment - but potentially small target population, unable to fully to assess whether representative of group in that exists LIMITED (+)	Content analysis initially by the authors moving from specific to more general themes, Checks 3 participants and 4 other long-term survivors of ESRD but not included in the study – verified themes Themes presented to 15 experts and agreed GOOD (++)	Open communication with adequate time and information increases participation in care Responsibility of care with patients – would have been better to look at unsuccessful self-management and compare attributes of group	(++) GOOD
Andrew (2001)	Research Qualitative Grounded theory	Develop new theories and expand knowledge regarding pre-dialysis care	Poor quality paper - Semi-structured interviews, insufficient detail on methods and analysis POOR (-)	Interviews, taped – no mention of interview length, where takes place or what asked and how - No depth POOR (-)	No wider context discussed – small sample not representative NOT GENERALISABLE (-)	Nudist – qualitative computer software – but no clear description as to how themes were identified and generated POOR (-)	Pre-dialysis patients require individual education	(-) POOR
Coupe (1998)	Research - Audit Evaluation of education intervention	Making decisions about dialysis options: an audit of patients' views	Good audit study of patient satisfaction with pre-dialysis patients, postal questionnaire, findings identify deficits in information provision, but positively evaluates the pre-dialysis nurse, (pre-dialysis nurse also the researcher possible bias) GOOD (++)	Postal questionnaire - Description of instrument used: patients asked about the level of information provided about RRT, CRF, how the kidneys work, what happens when they fail, HD, PD, medication, access, whether satisfied with the education nurse, written information, audio GOOD (++)	Sample representative of local group - only another pre-dialysis population receiving similar pre-dialysis interventions – even then restricted as would involve a different pre-dialysis nurse LIMITED (+)	Analytical method not described - Evidence provided in findings but cannot be determined how the findings were generated without analytical description POOR (-)	Satisfaction survey adequate method for evaluating educational intervention Patients need time to adjust and opportunities to review their decision once starting a RRT. Need to consider behaviour changes, possible grief and coping mechanisms which will impact on patients preference for information at a particular time along the continuum of acceptance (self-management strategies)	(++) GOOD

Breckenridge (1997)	Research Qualitative grounded theory	Patients' Perceptions of Why, How, and By Whom Dialysis Treatment Modality Was Chosen	Very informative paper on the decision-making processes for patients choosing RRT - Semi-structured in-depth interview - Patient Perception Interview Guide described in detail, interview schedule tested on two nurses who were patients and six patients prior to using ADEQUATE (+)	Good description of interview instrument and implies use during haemodialysis session (which has its drawbacks) or when patient attending PD outpatient clinic. Interviews lasted between 20 minutes- 3 hours, no mention as to whether interviews were taped. Patients had less than 24 hours to decide whether to be involved GOOD (++)	Needs further testing to generalise findings as small numbers NOT GENERALISABLE (-)	Constant comparative method – software programme Ethnograph used to facilitate coding and data management – no detailed descriptions POOR /ADEQUATE(-/+)	Identifies the emergence of two grounded theories from the data collated with respect to why, how and by whom the decision of which RRT is taken. Identifies factors that influence a patient's decision and in turn reflect their need for information. Significance of information provided by existing dialysis patients	(+) AVERAGE
Bass et al (1999)	Research Qualitative Exploratory study	The use of Focus Groups to Identify Concerns about Dialysis	In-depth paper of the domains and issues raised by patients/providers with respect to the impact of ESRD on a patients QOL, discusses the methodology of using focus groups to elicit such information. Focus Groups explored and used as an appropriate research design ADEQUATE (+)	Four focus groups with different sets of people, two with patients and two with providers – undertaken by external facilitator with no knowledge of ESRD except for preparatory reading. Audiotape of group sessions performed by assistant. Met at convenient time and location for all participants. Group discussion lasted 70-95 minutes. GOOD (++)	Sample too small to generalise NOT GENERALISABLE (-)	Clear framework of analytical process– reviewed independently by two separate researchers then checked separately by a third. Final groupings checked again by two other researchers and some categories combined (two of the researchers were nephrologists): Comments of reviewers addressed when whole study team finalized the list of content areas. – Groups rather than individual patients were the unit of analysis used in the comparisons. GOOD (++)	Compares more the differences between provider and patient – not really clear information needs examined but concerns of patients raised and problems experienced. Evidence suggests that the preference values that ESRD patients assign to their health on dialysis are independently related to their satisfaction with the information they have been given by their health care providers	(++) GOOD

Groome et al (1994)	Research Exploratory mixed method design	Content of a Decision Analysis for Treatment Choice in End-Stage Renal disease: Who Should Be Consulted?	Good study identifying information topics patients and staff think are important for new patients starting a treatment In-depth interviews of all participants and survey developed part way through - to measure the degree of importance of the various types of items GOOD (++)	In-depth interviews – majority face to face, three performed over the telephone, one telephone interview done with HD helper relaying answers After 43 interviews a 65 item survey distributed to all 43 participants and asked to rate importance of item on scale of 1-5 where 5= definitely needs to be discussed GOOD (++)	43 participants, 70% of which responded to survey, small number. Applicable only to ESRD due to nature of condition LIMITED (+)	Thematic analysis of interviews created basis of items and statements for survey – responses to survey statistical tests performed, Fishers exact test (two-tailed), Pearsons correlation test for comparison of the mean importance scores, paired t-test performed on interview items mentioned for the patients current treatment versus the mean number given for other treatments GOOD (++)	Good method used to gain unbiased information: patient is asked to place themselves in the place of a new patient coming to ESRD and requiring treatment what would they want to know to be fully informed or make an informed choice Methodological discussion regarding usefulness of using patients to identify items on questionnaire – indeed suggests professionals better	(++) GOOD
Harwood et al (2005)	Research Qualitative exploratory study (questionable whether poor evaluation of education programme)	To identify the implications for patient education and support needed in the care of patients with CKD – Explore the specific stressors patients with CKD who are on haemodialysis recalled experiencing as they approached dialysis	Qualitative study to explore the stressors of patients approaching dialysis – small number not representative of source population– semi-structured interview used to elicit stressors of patients who only experienced CKD programme – could have used total pre-dialysis sample more effectively ADEQUATE (+)	Semi-structured interview, performed by social worker – no mention as to whether the interview was taped therefore relying on the accurate recording of the social workers interview notes - difficult to appreciate the word for word extracts utilised in the findings could be recorded by hand without being taped. Interview schedule described POOR/ ADEQUATE (-/+)	Sample too small to generalise NOT GENERALISABLE (-)	Not described in any detail – four researchers reviewed the notes from the interviews using content analysis and extracted units of analysis, - themes generated from the notes and then confirmed by a fifth person. No mention of what was done if there was disagreement or discussion or whether consensus agreement used. Themes were supported by patient statements ADEQUATE(+)	This study supports the need for early intervention in CKD patients and identified educational and supportive interventions.	(+) AVERAGE

Murray et al (1999)	Research Prospective descriptive study	To identify factors that influence the pursuit of kidney transplant by persons with ESRD	Good paper highlighting the information needs of dialysis patients regarding kidney Tx to enable informed decision on whether to proceed – random sample structured interviews using new developed instruments GOOD (++)	Structured interviews using four instruments – took one hour in private room and unit/patients home –two experienced nurses collected data GOOD (++)	Limited because demographics and background of sample was not representative of the entire ESRD population of the US LIMITED (+)	Statistical analysis of closed questions on specific questionnaires, content thematic analysis of open questions, constant comparative method – two external reviewers to validate themes. Entire research team provided consensus agreement of established final themes. ADEQUATE(+)	Future educational activities for donor initiatives for families should include assessing and improving the accuracy of the patients' knowledge about success rates of kidney transplant. More attention needs to be paid to the family concerns and identify factors that make families resistant to donation	(++) GOOD
Niccum and Pèrez (2000)	Patient education Descriptive	A description of an educational strategy initiating a consistent flow of information to facilitate the identification, assessment, selection, media and means for its patient education activities.	Educational Program - polling patients on their needs then sharing this with the network staff. Develop tools and programmes to support staff with education – paper interesting only in the respect that patient identify what they want to know, no detail as to how polled patients views ADEQUATE (+)	Polling patients on their needs then sharing this with the network staff. Survey 1999 Patient and Family Needs and Interest Project – lacks detail of how this was undertaken POOR (-)	Wide target population available within the network of potential patients – lacks detail Unable to assess NOT GENERALISABLE (-)	No detail of survey analysis unable to assess POOR (-)	Learning rather than information needs but useful factors, learning regardless of age is a composite of three processes 1. Cognitive, which includes information and knowledge 2. Emotional, which includes attitudes; 3. Skill, which includes motor/behavioural processes. Each of these factors need to be taken into account during a learning situation Identify learning needs of ESRD patients Raise questions on when best to educate patients – affects of uraemia	(-) POOR

Hines et al (1997a)	Research Exploratory study	To determine whether informed consent for performing dialysis had been obtained from elderly patients and to explore the potential causes of inadequate informed consent.	Good study exploring the inadequacy of information provision to elderly patients and lack of understanding of what HD really entailed and questionable as to whether they would have given their consent to accept the treatment had they understood all the information. – Different tools piloted and used within structured interview GOOD (++)	Face to face structured interviews conducted by two trained interviewers, over a two-month period. Interviews lasted 45 minutes and took place whilst patient was receiving dialysis – the interview schedule was a pre-tested questionnaire (piloted on 15 elderly patients to ensure the questions were not confusing or obtained no response) The final questionnaire had 179 questions GOOD (++)	Elderly HD patients – large sample GENERALISABLE (++)	Scoring of questions very clearly explained, scores grouped to questions and analysed under themes, statistical tests applied to appropriate scores – chi square, three different regression analyses, inferential statistics GOOD (++)	Studies identify reduced cognitive functioning during dialysis, which highlights flaws in the methodology when measuring cognitive functioning as part of the research	(++) GOOD
Hines et al (1997b)	Research Exploratory study	To study the EOL decisions of elderly HD patients	Paper which reports the results of a study reviewed in another paper but tackles a different issue – EOL decisions GOOD (++)	Face to face structured interviews conducted by two trained interviewers over a two- month period. Interviews lasted 45 minutes and took place whilst patient was receiving dialysis – the interview schedule was a pre-tested questionnaire (piloted on 15 elderly patients to ensure the questions were not confusing or obtained no response) The final questionnaire had 179 questions GOOD (++)	Elderly HD patients – large sample GENERALISABLE (++)	Scoring of questions very clearly explained, scores grouped to questions and analysed under themes, statistical tests applied to appropriate scores – chi square, three different regression analyses, inferential statistics GOOD (++)	Studies identify reduced cognitive functioning during dialysis, which highlights flaws in the methodology when measuring cognitive functioning as part of the research Authors suggest that Problematic Integration theory goes some way to explaining the decision making process between doctors and elderly HD patients., although not convinced about this theory	(++) GOOD

Klang et al (1999)	Research Evaluation /Intervention study education programme	Predialysis education helps patients choose dialysis modality and increases disease -specific knowledge	Good paper of evaluation of educational intervention, good literature review at the beginning for CRF information provision – Intervention of education programme compared with not receiving education programme – Use of three questionnaires posted to participants ADEQUATE(+)	Three questionnaires used to evaluate the, knowledge, information and sense of coherence (SOC) mailed to participants once they had agreed to take part. Two of the questionnaires based on previous study instruments. Evaluation Group tested before educational programme and 3-9 months after, Control group tested 3-9 months after starting RRT. ADEQUATE(+)	Small numbers, three centres, one specific educational programme, can only generalise to areas with similar education programmes LIMITED (+)	Differences between groups tested using Students t-test and correlations between variables. Cronbachs alpha coefficient was used to measure internal homogeneity within sense of coherence scale. Open ended questions were analysed using content analysis ADEQUATE (+)	Study findings reinforce that chronically ill patients faced with alterations of treatment find the information they need. Evidence to suggest that seeking information is a common coping strategy but equally patients can use denial as a defence mechanism which prevents them from seeking the advice they need – this makes the interpretation of these results more difficult. (Refs other studies to support each argument)	(+) AVERAGE
Leino-Kilpi et al (1993)	Literature Review	To provide a brief overview of existing research studies concerning patient information, outline relevant perspectives on information giving, knowledge structures of four different patient groups	Well written and structured literature review, theoretical arguments discussed, informative wide literature base comparing different patient groups ADEQUATE(+)	No detail of search strategy, databases, inclusion, exclusion criteria and the structure of the review, unable to determine rigour in data appraisal POOR (-)	Reviewed papers across patient groups and within wider context NOT APPLICABLE	Section relevant to dialysis patients although review performed prior to 1993 and thus literature dated No detail provided on critical appraisal of articles included in the review Good comparisons drawn between patient groups and evidence presented compared and contrasted across groups ADEQUATE(+)	Provides limited evidence of the information needs with respect to medication Theoretical implications of information methods, outcomes Identifies variables influencing use of information	(+) AVERAGE

Tweed and Ceaser (2005)	Research Exploratory Study	To explore the decision making processes of pre-dialysis patients when choosing a renal replacement treatment (RRT) and to elucidate how these choices were made	Clear study method to explore the decision surrounding the choice of RRT using interviews, only limitation is the very small sample size which restricts wider application of findings Ethical approval obtained ADEQUATE (+)	Semi-structured interview schedule provided, two researchers to perform interviews together to ensure accuracy, relied on retrospective recall back to when decision was made, taped and transcribed GOOD (++)	Small sample size (9 patients) prevents findings being generalised Unable to explore variables within sample characteristics NOT GENERALISABLE (-)	Clear and well described analytical approach – Interpretative Phenomenological analysis, material coded separately by researchers, agreement reached, constant comparative method Verification of themes GOOD (++)	Clear presentation of findings, supported by patient data and discussed alongside wider literature Useful patient information needs, factors and concerns identified Social comparison theory	(++) GOOD
Iles-Smith (2005)	Research Qualitative Exploratory Study	To elicit the perceptions and experiences of pre-dialysis patients prior to receiving treatment	Very small qualitative study, such a small sample findings are limited, semi-structured interviews, poor description of analytical process. Ethical approval obtained POOR/ ADEQUATE(-/+)	Description provided of semi-structured interview and content used, informed consent obtained, although does not identify where interviews took place or for how long ADEQUATE(+)	Small sample, 10 patients thus findings cannot be generalised NOT GENERALISABLE (-)	Analytical approach unclear framework based on aims of the study, emerging themes not verified by independent researcher or patient – no summary of themes just examples of patient comments used to support findings POOR (-)	Identifies some useful information needs which are supported in other studies Highlights factors that impact on patient information needs	(-) POOR
Juhnke and Curtin (2000)	Research Exploratory follow up survey design	Survey of what is important to ESRD patients with respect to education and information needs – to learn what, the when, how and who of information seeking people on dialysis	Quick, low cost study to follow up patients who had contacted the education organisation and to elicit their views on what education and information is important Appropriate target population although limited to active information seekers, semi-structured telephone interviews performed over the telephone, method could have executed better to wider sample, ethical approval not stated POOR/ ADEQUATE (-/+)	Semi-structured telephone interview – although structure and content described, No ethical issues explained, although self-selected patients maybe provided consent when agreeing to be contacted, not clear, lack of detail on execution of interview and by whom POOR/ ADEQUATE (-/+)	Small sample 30 patients, self-selected and potentially biased active information seekers No stated sample characteristics LIMITED (+)	No explanation provided of analytical approach Themes described as general perspective but unclear as to how many participants agreed on what findings POOR (-)	No discussion within the context of wider literature and no references Identifies some useful information needs which are supported in other studies Describes information seeking behaviour Patient preferences for type and method of information provision	(-) POOR

Fine et al (2005)	Research Survey design	To assess whether patients want voluntary disclosure by their physician of their survival should they need dialysis and if so why?	Interesting study providing key theoretical evidence with respect to renal patients' information needs for prognostic information, Use of a validated tool with minor adaptations that were piloted and tested prior to implementation. Ethical approval obtained GOOD (++)	Questionnaire adapted from validated measure used with cancer patients Prefaced by description of survival on dialysis being varied between patients, depending on age and co-morbidity, without dialysis patient would die. Examples of different outcomes No comparable questionnaire exists for renal patients Adapted wording after pilot 3-5 point Likert scales used throughout Administered in out-patient clinic with option to take home and complete and return – Research nurse gained informed written consent GOOD (++)	100 patient sample sufficient to generalise, but cohort of patients in very early stages of CKD who may never have to make the decision to have dialysis restricts applicability of results to wider CKD population. LIMITED (+)	Analysis limited to use of inferential statistics and percentages to reflect majority of patient preferences No mention of sub-group analysis based on education level, age, gender etc ADEQUATE (+)	Cultural differences did not impact upon preference for information in this particular study – may need larger sample Identifies patient preferences and need for information regarding prognosis, although topic areas which were judged were predetermined by staff not patients	(++) GOOD

Appendix 6 Table 12: Quality Summary

- Sample judgement based on sampling framework, participant selection and representative of target population, number of participants recruited
- Method judgement based on methodology, description of fieldwork, recruitment method, data collection methods and analysis framework

In line with NICE (2007) quality assessment indicators, each section of the study was given a judgement of good (++), appropriate/adequate/average (+), or poor (-) depending upon the quality of the work and descriptions provided within the paper. The positive and negative aspects of each paper are stated and the relevance to the developing study identified.

High Quality = 12 (++)

Author	Sample Rating	Method Rating	Positive	Negative	Relevance to Study
Orsino et al (2003)	Good (++)	Good (++)	• Explores differences between age and gender in decision making • Development of comprehensive self-report survey – piloted 69 questions • Use of O'Connor Decision Self-Efficacy tool to measure level of confidence in medical decision making • Quantitative analysis methods clear • Good description of sample variables • Consecutive random sample – (during attendance for dialysis) • Ethical approval	• No clarity on how long questionnaires took to complete • Patients approached to participate whilst on dialysis but completed questionnaire in private – again still whilst receiving dialysis (cognitive impact of dialysis not discussed)	• Differences between age and gender influences sampling method • Clear variables of sample to consider (e.g. education diagnosis, treatment, duration) • Methods explain how to capture different aspects • Pt info needs, preferences, factors, and concerns identified

Wuerth et al (2002)	Good (++)	Good (++)	• Clear methods based on validated study • Open ended questions based on the literature - with independent interviewer to minimise bias • Random sample • Clear thematic analysis method – verified independently by the two researchers	• Small sample but findings reflect larger studies • No mention of analysis with respect to age or gender • No mention of ethics approval	• Open ended questions based on previous study (Concato & Feinstein) • Taxonomy of factors that influenced the patients choice of dialysis – to consider • Pt info needs, preferences and factors identified
Curtin and Mapes (2001)	Average (+)	Good (++)	• Good explanation of interview method and developing ‘completeness’ of data – three criteria stated • Very good explanation of theme verification, identified first by researchers then by long-term patient survivors, then 15 experts in dialysis field • Ethical approval obtained	• Would have been interesting to have also looked at patients, which exhibit unsuccessful self-management and compare group attributes – why some can and others can’t (personality issues?) • Could have used better method to identify potential long-term survivors rather than snow ball sampling – based on people known to participants	• Good explanation of interview method and developing ‘completeness’ of data – three criteria identified • Good method of theme verification • Look to see if can describe/identify personalities with respect to self-management and different attributes – look at personality influences • Pt info needs, preferences, factors, and concerns identified
Murray et al (1999)	Good (++)	Good (++)	• Random sample selected • Four different instruments utilised within an structured interview - Background demographic questionnaire / Kidney Transplant Knowledge Survey / Interest in a Kidney Transplant Scale / Open ended questions • Good method of analysis – themes verified by external reviewers then consensus agreement of research team • Ethics approval obtained	• Overwhelming sample from specific faith that could influence perceptions with respect to the issue of a transplant – needs replicating in different religions but of value	• Different instruments and descriptions of instrument content/ measures –aspects to consider and explore in interviews • Method of analytical verification – different stages • Pt info needs, preferences, factors, and concerns identified in relation to transplant

Hines et al (1997a)	Good (++)	Good (++)	• Good opportunistic random sampling method • Pilot tested structured interview as questionnaire to ensure wording appropriate - although final instrument 179 questions face to face interview only took 45 minutes • Clear description of content and format of instrument developed	• Interviewing patients on dialysis is inappropriate due to reduced cognitive functioning that takes place due to chemical imbalance, shown in other studies – flaws in methodology • Ethics approval not stated	• Good findings with respect to elderly patients and their levels of knowledge – influences potential information needs • Pt info needs, preferences, factors, and concerns identified
Hines et al (1997b)	Good (++)	Good (++)	• Good opportunistic random sampling method • Pilot tested structured interview as questionnaire to ensure wording appropriate - although final instrument 179 questions face to face interview only took 45 minutes • Clear description of content and format of instrument developed	• Interviewing patients on dialysis is inappropriate due to reduced cognitive functioning that takes place due to chemical imbalance, shown in other studies – flaws in methodology • Ethics approval not stated	• Need to explore links with problematic Integration theory stated by authors with respect to elderly decision making – influences info needs • Pt info needs, preferences and factors identified
O'Donnell and Tucker (1999)	Good (++)	Average (+)	• Successful replication of previously used methodology/satisfaction survey (see study 51) with addition of further outcome measure length of hospitals stay • Good sample size • Good description of education programme allows judgement on representative results to different dialysis communities • Ethics not stated possibly not required for patient satisfaction survey	• Insufficient details of analysis method although direct patient comments used to support findings • Potential bias from researcher being the educator • Problems with length of stay as an appropriate measure due to patients experiencing acute episodes which could explain the greater length of stay for some participants not just need for education – not isolated in figures	• Identify timing of information important • Pt info needs, preferences, factors, and concerns identified

Bass et al (1999)	Average (+)	Good (++)	Good use of focus groups External focus group facilitator – adequately prepared for data collection – assistant recording sessions – good method Clear appropriate stratified sampling frame – representative of staff groups and variables within patient groups although small patient numbers Constant checking and verification of emerging themes within the research team members – consensus of opinion	Could have been performed within a larger sample size to increase reliability Compares more the differences between provider and patient rather than exploring fully the information needs of the patient group Ethics approval not stated	Concerns of patients raised and problems experienced Good reference with respect to preference values of ESRD patients being independently related to their satisfaction with the information they receive
Coupe (1998)	Good (++)	Good (++)	Total sample available recruited – high response rate despite using postal questionnaire Comprehensive instrument developed and described Audit so ethics approval not obtained	Researcher also pre-dialysis educator introducing potential bias	Identifies aspects to consider for behaviour changes, grief and coping mechanisms that could influence info needs Pt info needs, preferences, factors, and concerns identified
Whitaker and Albee (1996)	Average (+)	Good (++)	Unstructured interviews - patients asked to describe their decision of RRT and their experiences – clarification through questions Clear presentation of results and findings alongside information regarding the factors that influence modality selection Ethical approval obtained	Questionable whether theoretical sampling best method, could use a more inclusive random sample, suggests sample representative Could have used increased sample size to add to the reliability of data No information whether dialysis centres specialise in certain treatment that could influence pts decision	Two staged theory regarding decision making - theoretical perspectives potentially influential to patient info needs Implications for patient education described Patient info needs, factors and concerns identified

Groome et al (1994)	Average (+)	Good (++)	• In-depth interviews used to develop 65 item questionnaire, rating the importance of each item in relation to needing to be discussed with patient • Method adopted provides unbiased information – patient asked to place themselves in shoes of new CKD patient • Use of appropriate statistical analysis combined with initial thematic analysis • Good analytical method described with respect to drawing out domains of the instrument and identifying percentages • Good evidence presented of how items were ranked and ordered • Ethical approval obtained	• Only 43 subjects recruited for study could have been larger sample – rationale provided that sufficient to fulfil objectives of first part of study • Initial selection of appropriate patients from Nephrologist based on those who could contribute the most (possible introduction of bias – best educated selected, more compliant) • Stratification of sample based on age and gender although not stated or discussed	• Good study identifying the information topics both patients and staff perceive to be important for new CKD patients • Use method of placing participant in the shoes of someone first diagnosed with CKD and when first starting dialysis to assess what the important information needs are at that time • Suggests professionals better placed to identify appropriate items for questionnaire • Classical Decision Theory
Fine et al (2005)	Good (++)	Good (++)	• Validated questionnaire tool adapted from other disease groups and piloted prior to use • Large sample recruited • Clear findings presented using simple inferential statistics • Key theoretical evidence with respect to renal patients needs for prognostic information • Ethical approval obtained	• Limited by sample and ethical restrictions, only able to target very early CKD patients who may never need dialysis • Could have performed more in-depth analysis particular sub-group comparisons would have been useful • Information topics pre-determined	• Identifies patient preferences and need for information regarding prognosis • Cultural differences did not impact upon preference for information in this particular study • Develops a new tool for renal patient group where no comparable questionnaire exists

Medium Quality = 6 (+)

Author	Sample Rating	Method Rating	Positive	Negative	Relevance to Study
Harwood et al (2005)	Poor (-)	Average (+)	• Identification of stressors to patient when starting dialysis – comprehensive list • Interview performed by social worker external to research team • Interview guide described • Ethical approval obtained	• Semi-structured interview with notes taken rather than taped – questionable accurate recording of data although some comments verbatim • Claim data saturation on 11 patients with no new stressors being identified • Sample weighted to male and elderly patients (>61yrs) would question true reflection of target population • Unclear mix of sampling method, random, theoretical and purposeful suggested • Interviews conducted during HD which raises ethical issues and cognitive recollection questions • Generalisations made on small numbers	• Patients identified stressors which concerned them prior to starting dialysis despite being provided education • Identifies some patients engaged in learning others just read what given • Factors impacting on patients described • Relationship of stressor to information need
Tweed and Ceaser (2005)	Poor (-)	Good (++)	• Clear semi-structured interview, content and method • Clear and well described analytical approach • Verification of themes • Clear presentation of findings, supported by patient data and discussed alongside wider literature • Ethical approval obtained	• Small sample size (9 patients) prevents findings being generalised • Unable to explore variables within sample characteristics	• Useful patient information needs, factors and concerns identified

Bath et al (2003)	Poor (-)	Average (+)	Semi-structured interview- based on referenced psychological categories (previous studies although limited detail of tools where categories originated) Appropriate analytical method described Themes generated supported with appropriate evidence	Suggests random sample to represent differences in time on dialysis, age and gender but sample too small (n=10) to control for these variables adequately No detailed information on sample or target population to allow verification of appropriate sample selection No details as to where or when interview took place or whether ethics or informed consent obtained	Presents some ideas of factors and concerns raised by small group of patients Identifies patients felt information available but onus on them to search for appropriate information that suited them
Klang et al (1999)	Average (+)	Average (+)	Use of validated tools to measure knowledge, information and Sense of coherence – good descriptions Good in the fact that identifies information needs, influencing factors, preferences and concerns regarding pre-dialysis education Ethical approval obtained	Two groups - educated group and control group (gathered from two different centres) - Poor description of what conventional information only is for control group and unable to control for variables and information seeking – also information provision since starting dialysis by nurse – control group not examined in pre-dialysis phase High drop out/ no- follow up of experimental group participants – reflects the need for larger sample	Good literature review of information provision in CKD Use of likert scale to measure perceived knowledge level of patient Useful patient info needs, preferences, factors, and concerns identified
Breckenridge (1997)	Poor (-)	Average (+)	Good description of interview guide and content – piloted schedule prior to use and tested content validity Ethnograph computer package used to organise themes – no details of how themes generated Ethical approval obtained	More focussed on choice of modality rather than information needs of patients Small sample size (22 patients receiving dialysis from four different centres) could have enlarged sample to increase reliability Theoretical sampling suggested but not sure what based on and how determined – could have used a random method for selection Patient had less than 24 hours to decide and suggests interview during HD – questionable approach	Limited usefulness regarding information needs, more focus on factors influencing need for information Two theories regarding choice of modality – patients choice vs. selection Good interview guide

Leino-Kilpi et al (1993)	Poor (-)	Average (+)	• Well written and structured literature review • Theoretical arguments discussed • Informative wide literature base	• Only small section relevant to dialysis patients • Review performed in 1993 and thus literature dated • No description provided of search strategy, databases, and the structure of the review	• Provides small evidence of the information needs with respect to medication • Theoretical implications of information methods, outcomes • Identifies variables influencing use of information

Low Quality = 8 (-)

Author	**Sample Rating**	**Method Rating**	**Positive**	**Negative**	**Relevance to Study**
Iles-Smith (2005)	Poor (-)	Poor (-)	• Description provided of semi-structured interview and content used • Examples of patient comments used to support findings • Ethical approval obtained	• Small sample, 10 patients thus findings cannot be generalised • Analytical approach unclear • Emerging themes not verified by independent researcher or patient	• Identifies some useful information needs which are supported in other studies • Highlights factors that impact on patient information needs
Schatell et al (2003a, 2003b)	Poor (-)	Poor (-)	• Useful theoretical ideas • Tape recorded – telephone interview to contact patients across wide geographical area • Interviewer a Social worker with renal experience not part of research team	• Suggests opportunistic random sample - Patients referred to research team from CKD educators could introduce bias– although poor knowledge levels suggests no pre-screening performed • No rationale offered to identify why small sample recruited particularly with choice of method • No description of analysis method • Ethics approval not stated	• Identifies relevance of obtaining clinical information to assess how far along patients are along disease progression continuum alongside findings • Pt info needs and concerns raised

Andrew (2001)	Poor (-)	Poor (-)	- Use of Nudist qualitative computer package - Appropriate target population	- No detail of interviews, length, place or what asked - No description of how themes generated using Nudist - Theoretical sampling used but unclear as to how - Small sample – 10 patients no rationale - Poor presentation of evidence to support findings - Ethics approval not stated	- Identified some factors impacting on info needs
Juhnke and Curtin (2000)	Poor (-)	Poor (-)	- Semi-structured telephone interview – structure and content described - Quick but effective study to elicit patient views - Appropriate target population	- Small sample 30 patients, self-selected and potentially biased - No stated sample characteristics - No discussion within the context of wider literature and no references - No ethical issues explained, such as consent for interview - No explanation provided of analytical approach - Themes described as general perspective but unclear as to how many participants agreed	- Identifies some useful information needs which are supported in other studies - Describes information seeking behaviour - Patient preferences for type and method of information provision
Niccum and Perez (2000)	Poor (-)	Poor (-)	- Evidence of polling patient views of what information needs are – Survey 1999 - Wide sample network - Description of methods used to provide information	- Not a research study but description of information network - Focus more on network – patients needs only briefly mentioned with no supportive evidence of how and what survey entailed	- Ideas of factors that influence patient learning - Different methods used to provide information

Wilkinson (1998)	Poor (-)	Poor (-)	• Peer examination of emerging themes • Random sample but questionable how • Appropriate target population	• No explanation of random sampling frame • Very small sample (6 patients) – no rationale • Semi-structured interview but no description of what asked and how • No description of education programme provided to one group and not the other • Conclusions sweeping with inappropriate generalisations • Ethics approval not stated	• Pt information needs and comments regarding education for pre-dialysis patients and concerns
DeCuir (1998)	N/A	N/A	• Personal account of one patients strategies for surviving dialysis • Identifies different coping mechanisms utilised in surviving dialysis	• One patient so not representative but still remains useful • Based on the opinion only of one patient and their experience and observations	• Patient does identify some information needs • Dialysis staff need to be knowledgeable to fulfil a patients needs
Hedman (1998)	N/A	N/A	• Personal descriptive account from a patient with 20 years experience identifying their own ideas regarding the importance of certain information topics and the information needs for patients • Concerns raised by the patients regarding dependence –independence issues	• One patient so not representative but still remains useful • Descriptive/ opinion account based on own perceptions as a result of his experience	• Useful identification of information topics and concerns which support other studies • Increased information increases compliance

Appendix 7 Semi-Structured Interview Guide

PATIENT INTERVIEW PHASE ONE:

Patient Research Code	
Date:	
Interview Start time:	
Interview Finish Time:	

DEMOGRAPHIC DETAILS:

DOB	
Gender	**M** **F**
Ethnicity *(as stated by the patient)*	

EDUCATION LEVEL:

Highest Qualification

ESRD HISTORY:

Diagnosis of ESRD			
Start date of Dialysis			
Current Modality	**Pre**	**HD**	**PD**
Duration on Current Dialysis			
Previous Modality Experience:	**Tx**	**HD**	**PD**

- **RENAL REPLACEMENT THERAPY**
  prrtinfo – what RRT (HD/PD) options, Independence (home HD/PD) vs dependence (in-centre HD), schedules, time required for dialysis, Access, adequacy of RRT, will need it long-term to stay alive –
  ptx – accurate info on Tx success rates, related donation, expectations of a Tx - Information of different types therapies, advantages and disadvantages How the service works
- **INFORMATION ON ESRD**
  pesrdinfo – information on ESRD, how the kidneys work, what's gone wrong, how will this progress, minimise the effects of the disease, will not get better – fatal disease
  Cause of CKD / Management of CKD
- **RISKS AND COMPLICATIONS**
  pcompdis – complications of the both the disease and RRT, renal bone disease, risks of infection, hypertension,
  How to avoid infection, Information to decide if condition worse than usual
  Anaemia, Renal bone disease, Hypertension and lipid control
  what other risks are there
- **WHAT EFFECTS CKD HAS ON THE BODY**
  pphysym – info on the physical symptoms that can be expected, physical side effects of RRT how to manage these problems
  pbodphys – affects on body image of RRT and ESRD, physical appearance
- **PSYCHOLOGICAL IMPACT**
  ppsycho – info regarding the impact of ESRD and RRT psychologically – stress, depression, anxiety, Independence vs dependence, coping
- **MEDICATIONS**
  pmedi – info on medication prescribed, what for what and side effects, expectations of medication
- **DIET AND NUTRITION**
  pdietfluid – diet and fluid restrictions
- **IMPACT ON SEXUAL FUNCTION**
  psexual – to continue having sex, impact on sexuality
- **TESTS AND INVESTIGATIONS**
  ptests – info on all the tests and investigations sent for and feedback on the results and what it means
- **IMPACT ON LIFESTYLE, SOCIAL LIFE, TRAVEL AND FAMILY**
  pTravel – organising holidays, ability to travel
  pfamsoc –leisure activities, have a normal life, maintain social life and lifestyle - Impact on the family
- **IMPACT ON WORK AND FINANCE**
  pworkfin – the ability to continue working, financial information
- **THE FUTURE/ SURVIVAL**
  psurviv – what are the chances of survival, realistic expected life span
- **STOPPING DIALYSIS**
  pwithdraw – info regarding withdrawing/stopping RRT, end of life decisions
- **PATIENT ORGANISATIONS**
  ppatorg – info on patient organisations and associations available
- **OTHER PATIENT EXPERIENCES**
  pothpat – Other patients experiences

END OF INTERVIEW QUESTIONS:

What is your current most important information need?

What would be the most important information topic for someone newly diagnosed with CKD?

What would you say is your level of knowledge about your condition?

1= know nothing	2 =	3 =	4	5= know everything

How do you prefer information to be provided to you?

Written/booklets	Videos/DVD	Face to face explanation
Other:	Other:	

Where do you prefer information to be given, which setting?

At the renal unit	In clinic	At home
During a home visit	Other:	

Appendix 8 CKD-Information Needs Questionnaire (INQ)

No:

Research Code:	
Date:	

Chronic Kidney Disease Information Needs Questionnaire (INQ)

Principal Researcher: Paula Ormandy

Phase Two: Identifying chronic kidney disease patients' priorities and preferences for information topics

Section 1: CKD History

1.1 **Date CKD diagnosed:**

1.2 **Cause of CKD:** *(if known)*

1.3 **Do you have any other conditions or illnesses?**
(Co-morbidity, IDM, CHD)

1.4 What treatment are you **CURRENTLY** receiving and what have you experienced **IN THE PAST** (Tick **one** box in first column and as many as apply in second column)

Date started current treatment: *(if applicable)*

	Treatment Now	*Previous Treatment*
Continuous Ambulatory Peritoneal Dialysis (CAPD)	☐	☐
Haemodialysis (HD) (in the centre/satellite unit)	☐	☐
Home Haemodialysis (HD)	☐	☐
Acute/emergency Haemodialysis (HD) (on the ward)	☐	☐
Automated Peritoneal Dialysis (APD) (overnight)	☐	☐
Kidney Transplant	☐	☐
Never experienced any renal replacement therapy	☐	☐
Pre-dialysis patient	☐	☐

1.7 How much **DID** you feel you knew about chronic kidney disease when they discovered there was a problem? (circle on a scale of 1-5 your initial level of knowledge)

1	**2**	**3**	**4**	**5**
Knew nothing				knew
everything				

1.8 How much do you **CURRENTLY** feel that you know about chronic kidney disease? (circle on a scale of 1-5 your level of knowledge)

1 **2** **3** **4** **5**
Know nothing know everything

Section 2: Information Needs and Provision

2.1 From the list below, please **TICK ONE** information item that you think is **MOST** important for you at this present time:

1. Information about what is chronic (long-term) kidney disease, what is the cause, how will it progress, what is the future ☐
2. Information about how the kidney disease may affect me, physically or in other ways, how to recognise symptoms and what to expect ☐
3. Information about the different treatment options, the advantages and disadvantages of each treatment, what the different treatments look like (such as machines etc) (Haemodialysis, Peritoneal dialysis, Transplant, Automated Peritoneal dialysis) ☐
4. Information about the practical issues of starting or changing treatment, what will happen to me and what can I expect (such as having a fistula, or peritoneal catheter, the frequency and length of time of treatment sessions or exchanges, fluid restrictions, base weight, ordering stock, using different strength bags, to up to date information on treatment changes) ☐
5. Information about what complications or side effects may occur as a result of the treatment or medication I'm taking ☐
6. Information about ways in which I can manage and influence my own condition such as food restrictions, medication, how to keep my blood tests/results stable or improve them ☐
7. Information about the ways in which the kidney disease and the treatment may affect my daily life, social activities, work opportunities and financial situation (benefits and allowances available) ☐
8. Information from other patients about what it can be like living with chronic kidney disease and receiving regular treatment (such as practical tips on what I can do) ☐
9. Information about how to cope with and adjust to chronic kidney disease and who can provide support if I need it ☐

2.2 How satisfied are you with your **CURRENT** level of information about the item you selected above? (circle on a scale of 1-5 your level of satisfaction)

1	**2**	**3**	**4**	**5**
Very dissatisfied				Very satisfied

2.3 From each of the following pairs, choose **<u>ONE</u>** information item that is more important for you to know at this present time (circle it and write number in box)

1. Information about what is chronic (long-term) kidney disease, what is the cause, how will it progress, what is the future 2. Information about how the kidney disease may affect me, physically or in other ways, how to recognise symptoms and what to expect	☐

3. Information about the different treatment options, the advantages and disadvantages of each treatment, what the different treatments look like (such as machines etc) (Haemodialysis, Peritoneal dialysis, Transplant, Automated Peritoneal dialysis) 9. Information about how to cope with and adjust to chronic kidney disease and who can provide support if I need it	☐

4. Information about the practical issues of starting or changing treatment, what will happen to me and what can I expect (such as having a fistula, or peritoneal catheter, the frequency and length of time of treatment sessions or exchanges, fluid restrictions, base weight, ordering stock, using different strength bags, to up to date information on treatment changes) 8. Information from other patients about what it can be like living with chronic kidney disease and receiving regular treatment (such as practical tips on what I can do)	☐

5. Information about what complications or side effects may occur as a result of the treatment or medication I'm taking 7. Information about the ways in which the kidney disease and the treatment may affect my daily life, social activities, work opportunities and financial situation (benefits and allowances available)	☐

6. Information about ways in which I can manage and influence my own condition such as food restrictions, medication, how to keep my blood tests/results stable or improve them 1. Information about what is chronic (long-term) kidney disease, what is the cause, how will it progress, what is the future	☐

2. Information about how the kidney disease may affect me, physically or in other ways, how to recognise symptoms and what to expect 3. Information about the different treatment options, the advantages and disadvantages of each treatment, what the different treatments look like (such as machines etc) (Haemodialysis, Peritoneal dialysis, Transplant, Automated Peritoneal dialysis)	☐

9. Information about how to cope with and adjust to chronic kidney disease and who can provide support if I need it 4. Information about the practical issues of starting or changing treatment, what will happen to me and what can I expect (such as having a fistula, or peritoneal catheter, the frequency and length of time of treatment sessions or exchanges, fluid restrictions, base weight, ordering stock, using different strength bags, to up to date information on treatment changes)	☐

8. Information from other patients about what it can be like living with chronic kidney disease and receiving regular treatment (such as practical tips on what I can do) 5. Information about what complications or side effects may occur as a result of the treatment or medication I'm taking	☐

7. Information about the ways in which the kidney disease and the treatment may affect my daily life, social activities, work opportunities and financial situation (benefits and allowances available) 6. Information about ways in which I can manage and influence my own condition such as food restrictions, medication, how to keep my blood tests/results stable or improve them	☐

1. Information about what is chronic (long-term) kidney disease, what is the cause, how will it progress, what is the future 3. Information about the different treatment options, the advantages and disadvantages of each treatment, what the different treatments look like	☐

(such as machines etc) (Haemodialysis, Peritoneal dialysis, Transplant, Automated Peritoneal dialysis)

4. Information about the practical issues of starting or changing treatment, what will happen to me and what can I expect (such as having a fistula, or peritoneal catheter, the frequency and length of time of treatment sessions or exchanges, fluid restrictions, base weight, ordering stock, using different strength bags, to up to date information on treatment changes) ☐

2. Information about how the kidney disease may affect me, physically or in other ways, how to recognise symptoms and what to expect

5. Information about what complications or side effects may occur as a result of the treatment or medication I'm taking ☐

9. Information about how to cope with and adjust to chronic kidney disease and who can provide support if I need it

6. Information about ways in which I can manage and influence my own condition such as food restrictions, medication, how to keep my blood tests/results stable or improve them ☐

8. Information from other patients about what it can be like living with chronic kidney disease and receiving regular treatment (such as practical tips on what I can do)

7. Information about the ways in which the kidney disease and the treatment may affect my daily life, social activities, work opportunities and financial situation (benefits and allowances available) ☐

1. Information about what is chronic (long-term) kidney disease, what is the cause, how will it progress, what is the future

3. Information about the different treatment options, the advantages and disadvantages of each treatment, what the different treatments look like (such as machines etc) (Haemodialysis, Peritoneal dialysis, Transplant, Automated Peritoneal dialysis) ☐

4. Information about the practical issues of starting or changing treatment, what will happen to me and what can I expect (such as having a fistula, or peritoneal catheter, the frequency and length of time of treatment sessions or exchanges, fluid restrictions, base weight, ordering stock, using different strength bags, to up to date information on treatment changes)

2. Information about how the kidney disease may affect me, physically or in other ways, how to recognise symptoms and what to expect ☐

5. Information about what complications or side effects may occur as a result of the treatment or medication I'm taking

9. Information about how to cope with and adjust to chronic kidney disease and who can provide support if I need it ☐

6. Information about ways in which I can manage and influence my own condition such as food restrictions, medication, how to keep my blood tests/results stable or improve them

8. Information from other patients about what it can be like living with chronic kidney disease and receiving regular treatment (such as practical tips on what I can do) ☐

7. Information about the ways in which the kidney disease and the treatment may affect my daily life, social activities, work opportunities and financial situation (benefits and allowances available)

1. Information about what is chronic (long-term) kidney disease, what is the cause, how will it progress, what is the future ☐

4. Information about the practical issues of starting or changing treatment, what will happen to me and what can I expect (such as having a fistula, or peritoneal catheter, the frequency and length of time of treatment sessions or exchanges, fluid restrictions, base weight, ordering stock, using different strength bags, to up to date information on treatment changes)

5. Information about what complications or side effects may occur as a result of the treatment or medication I'm taking ☐

3. Information about the different treatment options, the advantages and disadvantages of each treatment, what the different treatments look like (such as machines etc) (Haemodialysis, Peritoneal dialysis, Transplant, Automated Peritoneal dialysis)

6. Information about ways in which I can manage and influence my own condition such as food restrictions, medication, how to keep my blood tests/results stable or improve them ☐

2. Information about how the kidney disease may affect me, physically or in other ways, how to recognise symptoms and what to expect

7. Information about the ways in which the kidney disease and the treatment may affect my daily life, social activities, work opportunities and financial situation (benefits and allowances available) ☐

9. Information about how to cope with and adjust to chronic kidney disease and who can provide support if I need it

8. Information from other patients about what it can be like living with chronic kidney disease and receiving regular treatment (such as practical tips on what I can do) ☐

1. Information about what is chronic (long-term) kidney disease, what is the cause, how will it progress, what is the future

4. Information about the practical issues of starting or changing treatment, what will happen to me and what can I expect (such as having a fistula, or peritoneal catheter, the frequency and length of time of treatment sessions or exchanges, fluid restrictions, base weight, ordering stock, using different strength bags, to up to date information on treatment changes) ☐

5. Information about what complications or side effects may occur as a result of the treatment or medication I'm taking

3. Information about the different treatment options, the advantages and disadvantages of each treatment, what the different treatments look like (such as machines etc) (Haemodialysis, Peritoneal dialysis, Transplant, Automated Peritoneal dialysis) ☐

6. Information about ways in which I can manage and influence my own condition such as food restrictions, medication, how to keep my blood tests/results stable or improve them

2. Information about how the kidney disease may affect me, physically or in other ways, how to recognise symptoms and what to expect ☐

7. Information about the ways in which the kidney disease and the treatment may affect my daily life, social activities, work opportunities and financial situation (benefits and allowances available)

9. Information about how to cope with and adjust to chronic kidney disease and who can provide support if I need it ☐

8. Information from other patients about what it can be like living with chronic kidney disease and receiving regular treatment (such as practical tips on what I can do)

---

1. Information about what is chronic (long-term) kidney disease, what is the cause, how will it progress, what is the future ☐

5. Information about what complications or side effects may occur as a result of the treatment or medication I'm taking

---

6. Information about ways in which I can manage and influence my own condition such as food restrictions, medication, how to keep my blood tests/results stable or improve them ☐

4. Information about the practical issues of starting or changing treatment, what will happen to me and what can I expect (such as having a fistula, or peritoneal catheter, the frequency and length of time of treatment sessions or exchanges, fluid restrictions, base weight, ordering stock, using different strength bags, to up to date information on treatment changes)

---

7. Information about the ways in which the kidney disease and the treatment may affect my daily life, social activities, work opportunities and financial situation (benefits and allowances available) ☐

3. Information about the different treatment options, the advantages and disadvantages of each treatment, what the different treatments look like (such as machines etc) (Haemodialysis, Peritoneal dialysis, Transplant, Automated Peritoneal dialysis)

---

8. Information from other patients about what it can be like living with chronic kidney disease and receiving regular treatment (such as practical tips on what I can do) ☐

2. Information about how the kidney disease may affect me, physically or in other ways, how to recognise symptoms and what to expect

---

9. Information about how to cope with and adjust to chronic kidney disease and who can provide support if I need it ☐

1. Information about what is chronic (long-term) kidney disease, what is the cause, how will it progress, what is the future

5. Information about what complications or side effects may occur as a result of the treatment or medication I'm taking ☐

6. Information about ways in which I can manage and influence my own condition such as food restrictions, medication, how to keep my blood tests/results stable or improve them

4. Information about the practical issues of starting or changing treatment, what will happen to me and what can I expect (such as having a fistula, or peritoneal catheter, the frequency and length of time of treatment sessions or exchanges, fluid restrictions, base weight, ordering stock, using different strength bags, to up to date information on treatment changes) ☐

7. Information about the ways in which the kidney disease and the treatment may affect my daily life, social activities, work opportunities and financial situation (benefits and allowances available)

3. Information about the different treatment options, the advantages and disadvantages of each treatment, what the different treatments look like (such as machines etc) (Haemodialysis, Peritoneal dialysis, Transplant, Automated Peritoneal dialysis) ☐

8. Information from other patients about what it can be like living with chronic kidney disease and receiving regular treatment (such as practical tips on what I can do)

2. Information about how the kidney disease may affect me, physically or in other ways, how to recognise symptoms and what to expect ☐

9. Information about how to cope with and adjust to chronic kidney disease and who can provide support if I need it

2.4 Are any of the information topic items listed in the question above **NOT RELEVANT** to you? If YES identify which and why?

2.5 Are there any other information needs that you have at the present time, that are **NOT** listed? (if NONE please state)

2.6 From the list below, please **<u>TICK ONE</u>** item that you think is **<u>MOST</u>** important for people who have just found out they have chronic kidney disease:

1. Information about what is chronic (long-term) kidney disease, what is the cause, how will it progress, what is the future ☐
2. Information about how the kidney disease may affect me, physically or in other ways, how to recognise symptoms and what to expect ☐
3. Information about the different treatment options, the advantages and disadvantages of each treatment, what the different treatments look like (such as machines etc) (Haemodialysis, Peritoneal dialysis, Transplant, Automated Peritoneal dialysis) ☐
4. Information about the practical issues of starting or changing treatment, what will happen to me and what can I expect (such as having a fistula, or peritoneal catheter, the frequency and length of time of treatment sessions or exchanges, fluid restrictions, base weight, ordering stock, using different strength bags, to up to date information on treatment changes) ☐
5. Information about what complications or side effects may occur as a result of the treatment or medication I'm taking ☐
6. Information about ways in which I can manage and influence my own condition such as food restrictions, medication, how to keep my blood tests/results stable or improve them ☐
7. Information about the ways in which the kidney disease and the treatment may affect my daily life, social activities, work opportunities and financial situation (benefits and allowances available) ☐
8. Information from other patients about what it can be like living with chronic kidney disease and receiving regular treatment (such as practical tips on what I can do) ☐
9. Information about how to cope with and adjust to chronic kidney disease and who can provide support if I need it ☐

2.7 Do you feel you received enough information about the item you have selected above when you first found out that you have chronic kidney disease? (tick appropriate box)

Yes ☐

No ☐

Don’t know ☐

Not applicable ☐

2.8 From the list below place a cross (X) in those boxes of methods you would not prefer information to be presented to you. For those remaining rank the methods in order of importance, please place a 1 = most preferred method, then 2 next to second choice and so on.

Verbal face to face information on my own ☐

Verbal face to face information with my family ☐

Verbal face to face information in a group ☐

Written information ☐

From a video ☐

From a DVD ☐

From an audiotape ☐

Other specify: ☐

2.9 Who would you like to get information from?

Doctor ☐ Other Specify: ☐

Nurse ☐

2.10 Who did you actually get information from?

2.11 How did you feel about this?

Very Happy	☐	Unhappy	☐
Happy	☐	Very Unhappy	☐
It was okay	☐		

2.12 From the list below indicate which of the following you have used as a source of information **by placing a tick in the first column**. From the sources you have ticked/selected can you identify how useful you have found each one **by circling a number from 1 to 5** *(where 1= not useful and 5=very useful)*

		Not Useful				Very Useful
	Friends and family	1	2	3	4	5
	General Practitioner	1	2	3	4	5
	Practice Nurse	1	2	3	4	5
	Hospital Consultant/Doctor	1	2	3	4	5
	Renal Community Nurse	1	2	3	4	5
	Renal Unit Nurse	1	2	3	4	5
	Nurses on the wards/ Renal out-patients clinics	1	2	3	4	5
	Trials Nurse (Research Nurse)	1	2	3	4	5
	Dietitian	1	2	3	4	5
	Community Chemist/ Hospital Pharmacist	1	2	3	4	5
	Medical journal/book	1	2	3	4	5
	TV/radio	1	2	3	4	5
	Magazines	1	2	3	4	5
	Newspapers	1	2	3	4	5
	Leaflets	1	2	3	4	5
	Patient self-help groups	1	2	3	4	5
	Internet	1	2	3	4	5
	NHS Direct	1	2	3	4	5
	Other patients	1	2	3	4	5

Section 3: Information Seeking Behaviour and Health Beliefs

3.1 How would you best describe your need for information? Please **TICK ONE BOX** identifying which phrase below best describes you.

- Need to know as much information as possible ☐
- Only need to know a basic level of information to allow me to make decisions ☐
- Only need to know about what will happen next ☐
- Don't want to know anything ☐
- *Other please specify:* ☐

3.2 To what extent do you seek out information? Please **TICK ONE BOX** identifying which phrase below best describes you.

- I would always seek out additional information to support what I've been told, or out of interest to learn more about different issues ☐
- I would only ever seek out additional information if I didn't understand something ☐
- I would never ask for or seek out additional information ☐
- *Other please specify:* ☐

3.3 How vulnerable do you feel with your disease? Please **TICK ONE BOX** and choose between the two pairs of statements that best describe how you feel.

At the present time:

- my kidney disease is not under control and I feel unwell and at risk of developing complications ☐

OR

- my kidney disease is under control and I am not at any risk of developing complications ☐

When I think about the future:

- I feel at risk of developing different complications of chronic kidney disease ☐

OR

- I feel confident that my chronic kidney disease will be under control ☐

3.4 How do you view the seriousness of your disease? Please **TICK ONE BOX** identifying which phrase below best describes how you feel.

- I don’t believe my kidney disease is too serious ☐
- I believe that my kidney disease is serious and there is nothing I can do to reduce the risks to my health ☐
- I believe that my kidney disease is serious but there are things I can do to ensure I stay healthy ☐
- I believe that my kidney disease is life threatening ☐

3.5 How much control and influence do you feel you have over your kidney disease? Please **TICK ONE BOX** identifying which phrase below best describes how you feel.

- I am in full control of my illness and have the ability to influence my future ☐
- I control to some degree my illness and have the ability to influence my future ☐
- I control to some degree my illness but feel unable to influence my future ☐
- I have no control of my illness and I am unable to influence my future ☐

3.6 How much control and influence do you feel you have or prefer to have over the decisions made regarding your care and treatment? Please **TICK ONE BOX** identifying which phrase below best describes how you feel.

- I have control over the decisions made with my care/treatment ☐
- I have an equal control over the decisions made with my care/treatment with the doctors and nurses ☐
- I would like to have more control over the decisions made with my care/treatment but feel the control lies with the doctors and nurses ☐
- I would like the doctors and nurses to take full control over the decisions made with my care/treatment because they know what is best for me ☐

Section 4: Demographic Information

4.1 Gender: Male ☐ Female ☐

4.2 How old are you in years?

4.3 How would you describe your Ethnic Group?

4.4 Current occupation

4.5 (if retired/none) most recent occupation

4.6 From the options below please **TICK ONE BOX** which best describe your current situation with respect to work:

In full-time employment	☐	In part-time employment	☐
Unable to work due to ill health	☐	Unemployed	☐
In full-time education	☐	In part-time education	☐
Retired	☐	Other (specify)	☐

4.7 What is your **HIGHEST** level of educational attainment?

No formal qualifications	☐	GNVQ	☐
CSE/O Level / GCSE or equivalent	☐	College /University First Degree	☐
A Level / ONC/OND	☐	Higher Degree	☐
HND/HNC/BTEC	☐	Professional Qualification (e.g. RGN, City and Guilds)	☐
Other (identify which)	☐		

THANK YOU

Appendix 9 Patient Invitation Letter

Salford Royal NHS
NHS Foundation Trust
University Teaching Hospital

Paula Ormandy
Research Fellow
School of Nursing
The University of Salford
Allerton Building7th floor, C711
Frederick Road Campus,
Salford, Greater Manchester
M6 6PU United Kingdom
T +44(0)161 295 0453
F +44(0)161 2952241
p.ormandy@salford.ac.uk

Date…

Dear Patient

Are you be interested in being involved in a research study to identify the information needs of chronic kidney disease patients'?

The following people are part of a research team who are working together to undertake a research study which aims to identify the information needs of chronic kidney disease (CKD) patients'.

- Mrs Paula Ormandy, Research Fellow (Nursing), University of Salford
- Mrs Jane Macdonald, Lead Nurse, Nephrology Service, SRHT NHS Trust
- Dr D O'Donoghue, Clinical Director, Nephrology Service, SRHT NHS Trust
- Dr A Caress, Senior Lecturer, Manchester University
- Mr D Crane, a CKD patient

We are exploring if CKD patients have priorities and preferences for information topics, which includes understanding what information patients' need, when and how they prefer to receive it. To do this we need to talk to chronic kidney disease patients about their information needs. You have been selected to take part in this study because you are a chronic kidney disease patient cared for within the Nephrology Service based at Salford Royal Hospitals NHS Trust, either in the pre-dialysis stage or receiving haemodialysis or peritoneal dialysis treatment.

Enclosed is an information sheet explaining all about the study we are doing and this letter is asking if you are interested in being involved. If after reading the information sheet you would like to participate then you can return the reply slip attached to the researcher who will then contact you, answer any of your questions and explain the study further. If you decide you do not want to be involved then you can just ignore this letter and you will not be contacted again. If the researcher does not receive the reply slip within 14 days it will be assumed you do not wish to participate. Your participation is completely voluntary.

Thank you for taking the time to read the information.

Jane Macdonald
Lead Nurse

Paula Ormandy
Research Fellow (Nursing)

REPLY SLIP: Research Code =

I am happy to be contacted further to discuss my possible participation in the research study described in the letter to identify the information needs of chronic kidney disease patients'.

My contact details are:

Name____

Address____
____
____
____

Telephone No: ____

If you are interested in being involved please return this reply slip in the envelope provided within 14 days, otherwise it will be assumed you are not interested in being involved.

To:
Paula Ormandy
Research Fellow
The University of Salford,
C711, Allerton Building, Frederick Road Campus
Frederick Road
Salford,
M6 6PU

Appendix 10 Patient Information Sheet

Identifying chronic kidney disease patients' priorities and preferences for information topics

What to do if you do not understand or read English?

If you do not understand or read English then help is available to translate and help you understand the information below and guide you through the information sheet. For a translation service for the following languages please telephone: 0161 234 3206 **Urdu, Punjabi, Gujarati and Bangla**.

Introduction:

A research team (Paula Ormandy, Research Fellow, University of Salford; Jane Macdonald, Matron and Dr D O'Donoghue, Clinical Director, Nephrology Service SRHT; Dr A Caress, Senior Lecturer, Manchester University; and Dennis Crane, Patient) are undertaking a research study to identify the information needs of chronic kidney disease (CKD) patients'.

We are exploring if CKD patients have priorities and preferences for information topics, which includes understanding what information patients' need, when and how they prefer to receive it. One of the aims of the research is to see if there is a difference between what information patients' want depending upon their treatment choice (when they are in the stage before needing dialysis, receiving haemodialysis or peritoneal dialysis). Another aspect of the research is to determine whether the age of the patient and their gender (male or female) influences the information they require.

Once we have identified a number of core information topic areas we will develop an Information Needs Questionnaire and ask a large group of patients to judge which information is the most important to them by prioritising topic areas. This will help us identify which patients want what information and when.

Why is the research study useful?

The study findings will identify core areas for information giving that CKD patients perceive to be important to them. It will highlight what CKD patients' priorities and preferences are regarding information topics and whether the Information Needs Questionnaire is a useful tool for identifying these within the CKD patient population. This information could inform the development of patient education materials (booklets/DVD's) and guidelines on information-giving which will help all members of the multi-professional team target what information they provide and when, responsive to the individual patients needs.

Why have you been asked to take part?

You have been invited to take part in this research study because you are a chronic kidney disease patient cared for within the Nephrology service at Salford Royal Hospitals NHS Trust, either in the pre-dialysis stage or receiving haemodialysis or peritoneal dialysis. You may receive dialysis at a different satellite centre, such as Bolton or Rochdale but you are still a named patient cared for in this clinical network, under the care of Dr O'Donoghue (Clinical Director). Your name has been randomly selected from all the possible patients that could be asked to be involved.

What will you have to do if you take part?

You have received this information sheet and a letter which has a reply slip. If you want to be involved in the research study you will need to send back the reply slip with your contact details on, within the next 14 days, in the envelope provided. Once the researcher Paula Ormandy receives your reply slip she will telephone you to answer any questions you may have and if you still want to be involved she will arrange an interview with you. The interview will take place at a time and place which is convenient to you and probably take 1-2 hours of your time. You will either be selected to take part in an interview for the first phase of the study or an interview for the second phase of the study.

If you are selected to be involved in the first phase of the study you will be asked to take part in a face-to-face interview to describe and discuss your own information needs. This interview will be tape recorded, if you agree. After the interview you will be sent a summary sheet of the topic areas you identified were important to you and you will be asked to make sure these are accurate and change anything you do not agree with. Once this is completed your involvement in the study is finished.

If you are selected to be involved in the second phase of the research study you will be asked also to take part in a face-to-face interview, this interview will not be tape-recorded. During the interview you will be asked to look at a number of paired 'core topic' areas and rate which one is more important than the other, this will be repeated in different orders until all the pairings are exhausted, this will form the Information Needs Questionnaire. A number of additional questions will be asked such as:

- Are there any other information needs which you consider to be important that have not been included?
- What your current top-priority information topic is and which topic would be most important for someone newly diagnosed with CKD?
- What your satisfaction level is with the information you already know about your top-priority item and whether you are happy with how much you know about your condition?
- Also how and where you prefer to receive information?

How will this information be used?

The information gained from all the patient interviews will be used to gain a deeper understanding of CKD patients' information needs and whether they have specific priorities and preferences with regard to specific information topic areas. No one will know you have been invited to be involved, as your name will be selected from a confidential trust database (known only to the clinical trust researchers, Jane Macdonald and Dr O'Donoghue) and attached only to the envelope.

Once you agree to take part and send back your contact details the researcher (Paula Ormandy) will know who you are. This information however, will remain confidential and any personal details regarding you will be placed on a password protected computer. All the interview tapes and information will be typed electronically onto a computer where it will be stored with a code so your name will not be attached and your identity will remain anonymous. The tapes will be destroyed when the study is complete. No one will know you have been involved in the study unless you choose to tell them.

What if you don't want to be involved?

Your participation in the study is voluntary. If you prefer not to take part you do not have to give a reason. Your care and treatment will not be affected in any way.

What happens now?

If you wish to take part in this survey, please complete the reply slip and send it back in the envelope provided to the researcher Paula Ormandy. If you have any questions please do not hesitate to telephone **Paula Ormandy 0161-295-0453**

Thank you

Appendix 11 Analytical Framework for Patient Interviews

1. Information about CKD, Progression of the disease, what, why kidneys not working
2. Information about Diet, what and why by who
3. Information about work related issues
4. Information about RRT – Dialysis issues
5. Information about Lifestyle issues
6. Information about the future, what to expect long term
7. Information about access issues
8. Lack of information about cause of kidney disease
9. Information about transplantation issues and having transplants
10. Information from other patient experiences, talking to other patients
11. Information about side effects of RRT and disease, what to expect
12. Information about complications of RRT and disease, what to expect
13. Information about medication
14. Information about financial issues
15. Information about symptoms of RRT and disease, what to expect
16. Provision of information, what given, timing
17. Staff issues regarding information provision
18. Family issues and information
19. Personality characteristics of patients with respect to needing information
20. Information about or evidence of Psychological issues, information about coping
21. Getting information, other sources
22. New patient information needs
23. Preferences for information
24. Experience of years on dialysis and information behaviour
25. Information on fluid issues and restrictions
26. Information from or about Social Worker
27. Information about tests, investigations and blood results
28. Information about transport issues
29. Need to know / information needs or not
30. Information about clinic visits, measure of need for RRT, contact with MDT
31. Other problems more important than CKD or bigger issue (such as co-morbid disease of greater severity)

Appendix 12 Table 23: Information Need Themes and Key Descriptors

KEY DESCRIPTORS	THEME 1: CKD, PROGRESSION OF THE DISEASE, WHAT WHY WHEN NOT WORKING, WHAT TO EXPECT IN THE FUTURE
Am I stable? Is there anything I can do to stay healthy? Don't tell me too much at this time What is the cause of my kidney disease? What do the kidneys actually do? What will happen what can I expect? How will the disease progress? What is the prognosis? How soon will I need dialysis? What is the future?	NOT TOO MUCH INFORMATION – TOO SOON I need to do what's gonna get me from now to the next clinic and that will be the same when I go on dialysis, you tell me what to do and I'll do it and don't second guess I don't see the point that's what they get paid to do…I just want to know that I'm stable as long as they tell me I'm stable the ins and outs of it I'll leave it to them to worry about (1) I would like to know what was going to happen… the sane side of my brain, the analytical side, says that would be good information to possess but the other more sensible side says oh you know live for today don't worry about tomorrow as long as you're doing the things you need to do to keep healthy then, and you're positive about the outlook that you're getting then too much information can become too big a weight to carry you know (1) That's the best way for me to handle it. Yeah, oh yeah, I don't look down the road as to what might happen (1) I don't want the information. It's a case of you know I'm very much a glass half full person rather than half empty you know so it's, and like I say, a need to know basis if I don't need to know …I don't know the possibilities of what's happening to my kidney and what it looks like because of the disease is erm no no don't want to know, that's the doctors let him worry about that you know (1) I would always put influences on it 'cause you don't understand it no matter what you see you don't really understand it so you can, so I can make a mountain into a molehill (1) (Are you the sort of person that would go out and seek information if you want to know) Probably not…Not actively, no not actively no I don't read pieces about dialysis in the paper…Or go on the Internet no I don't bother with that and whenever the evil day, when it happens, then I'll do something about it (is this the stage at which you will want information) Right… Yes….That's it that's exactly it. (So it's the stage of the kidney failure that determines what you want to know and when)…That's right that's it exactly, yes (2) No, no one has actually said, no one has actually put a name to my condition…I don't know why my kidneys are failing, I know they are failing, I don't know why they are failing I don't need to know why because I know they are failing and there is nothing they can do about it. (2) If it happens it happens, if it takes a long time to happen all the better but if happens sooner well we'll deal with it when it happens (when it happens, when you need dialysis will you have questions?) I would yes, basically I would yes (don't want to know before then)… Well there's too much involved in it for me to and I don't understand it you know what I mean and I'd have to start really studying and reading to understand it. (4) (Is there a better time?) Yes I mean… now my level of my filtration system is 15 now, I know that that's getting down now too, I mean I've seen on the letter … I could be done for transplant work up but because I'm you know stable they're leaving me alone….I've not even discussed I don't even know what is involved in that I've not discussed that transplant work up or anything you know not don't know anything about that but I know now's the time when it should be you know probably being discussed … I should suppose now I know its getting lower that I should re visit the different dialysis and what you know the EPO injections and transplant work probably should revisit that now …if I haven't been told all this information five years ago maybe now I would be more accepting of discussing it.(11) Not really I'm a firm believer in what I don't know doesn't harm me you know that's the way I've always worked unless its something that I've got to learn then I'll learn it then…(if it means you survive) Yes… I'd sooner just live day by day, have done with it. (20) CAUSE OF KIDNEY DISEASE (Anyone tell you about what was happening to your kidneys) No, No, I read about glomerulonephritits after that…(on the internet) No, at work there was a medical library and I got some medical books out and I read it for myself (6) I realised when it was a renal clinic that it was something wrong with my kidneys but nobody explained … Well yeah, that's it they never told you it was only I was well into years long that I found out (7) (never told what going on with kidneys, need to know) It wasn't until the thing started to fail that I was told it was the old problem that had reoccurred and I said well you know what did I have and that's when I found out that I had Vasculitis and then I looked it up and I realised it was an antibody disorder and if I had another transplant it would probably it would actually do the same thing unless they came up with some solution of stopping it doing it. (7) (Clearer explanation of cause of kidney failure and chance of reoccurrence) Yes I know what it is I looked it up in the library (do you understand what that cause is) (7) I guess I didn't understand what it meant at first, I wasn't overly concerned, I've got a reasonable standard of background knowledge (degree in biology) so I had a good idea what they were looking for, work with people working on renal disease that I knew I could talk to, once I found out I had IGA I went and found the girl and asked her what she knew about the disease, her information was technical but fairly clear but she told me it was fairly benign disease but it wasn't in me (8) Wrote out a sheet explaining exactly what vasculitis was and what the implications were, that it's incurable and that I will be on treatment for the rest of my life but it might go into remission which it did

	do so with regards to the initial amount of information given to me when they diagnosed the vasculitis it was quite good. (9) It took a long time for me to find out the name of the problem I remember being quite annoyed by this… well what are you looking for what's the problem and the lady there, the doctor, she said oh there's some problem with your kidneys…when I got my consultant appointment I don't know 2 months later that I actually found out what was wrong. (10) (What information would you want if it was you starting again) I'd want to know what was wrong…. I'd been with my doctor for years and all of a sudden he said do you know you've got pylonephritis he says that's what's wrong with your kidneys…when I found out how to spell it. I looked it up afterwards and they said it was constant kidney infections, but up to then I didn't have a clue. All I kept knowing was that I had these infections and I kept going to hospital, I knew nothing that was wrong with me apart from my left kidney was child's size and my right kidney was normal, but that's all I was told… I'd have liked somebody to sit me down and explain what was wrong with me, not push it under the carpet like I got, but there again it's not as far forward as it is today (12) What type of chronic disease that they have got, how long have I had it or how long will I have it (12) They couldn't give a definitive reason, the best they could come up with was I was either born with deformed kidneys or I'd had a massive infection after I was shortly born that had never been picked up. Both of my kidneys are deformed and small so that's what I was told (13) I like to know what I'm getting myself involved I know what I'm talking about and that helps me you know find the information so 'cause they could be telling you one thing and it don't mean nothing. Or they'll give you the medical reasons you know the medical wording and that you don't you don't understand that you want the English version (14) They said I had vasculitis which was inflammation of the red blood cells and it's quite serious apparently… my son took them (tablets) and showed them … the doctors said no way should she ever have been given two different strengths of the same tablet so whether that triggered it I don't know (not sure if cause of CKD) (16) Yeah I want to know about the cause (of kidney disease) they haven't really told me (17) WHAT THE KIDNEYS ACTUALLY DO? I would like somebody to talk to me …and explain everything…. how they think you've got the disease or whatever it is or what it's deteriorated why your kidneys are going. What your kidneys do to your body is another thing, then you realise then a lot of people I suppose you know I never give it a thought what my kidneys did. (7) (more specific information) Nobody had explained that no. (What CKD does to your body)… Yes, I'll get that from reading that book (9) Drew a diagram and of a kidney and he said that I'd had reflux as in the connection between my kidneys and my bladder was faulty and it allowed urine back up to my kidneys and it had burnt my kidneys and also there had been an infection and that's how he described it (10) Yes, yes…Oh yeah, I'd like to know (what your kidneys actually do)… I did have a bit of medical knowledge but a lot of people don't have any knowledge, I think they should have a lot more coming up to dialysis. (12) I think that would help 'cause I'd quite like to understand. All I virtually know is that they're small and deformed and that they don't work properly. (Need to know the function of the kidney and what's happening) (13) On its basic level yeah I know the ins and outs of that, I know what's wrong. I know why my kidneys aren't working; I know the reasons why they're not working I now know the problems that happen when you don't, when your kidneys don't work and how it affects you (what information he actually knows and was useful) (15) No, no they never mentioned about functions of the kidney… I think they should because you know when you lay it out various functions of the kidney it all becomes clear and I think a lot of people would benefit from that rather than just submitting to blood tests and other tablets and so on. (17) WHAT TO EXPECT - WHAT WILL HAPPEN? I prefer somebody to explain to me the ins and outs of everything you know erm how long this can go on for erm it's a chronic, if they explain to you right at the beginning it's a chronic disease so I read a chronic disease as it's chronic there is no answer to it then is there you know,. You can only prolong it as much as you can in certain ways so that should tell you something if you understand what chronic means, a lot of people probably wouldn't understand what chronic means but I was never told that I had chronic renal failure. (7) I can't remember anybody ever (saying the word chronic)… your functions down to a percentage…Yeah I don't remember anybody ever saying that to me (end stage renal failure) (7) (use of words and terms) After 5 years (they) tried me on some drugs to slow down the immune system and the disease. I was on the drugs for a few years then I'd gone to clinic and they said the drugs are just not working and you'll be on dialysis by the end of the year which came as a bit of a shock (8) I was quite ill and they took me into hospital and they took a biopsy and I'll never forget it 'cause I came up back from the biopsy in a fair amount of discomfort and the female Doctor…said oh your kidneys have gone, err you'll finish up on dialysis and that was it. In terms of delivering some bad news I can't think of a worse example… I hadn't a clue what was wrong with me…. but also you know instead of saying look I want to explain it to you…just your kidneys are gone you're going to need dialysis (9) What should I feel like with vasculitis (9) If I looked after myself then I would have another 15 years ok before I went on dialysis… they just said the word dialysis… he drew like a graph he said it will do like this your kidneys will decline and then when it gets to this point where they're not producing any urine you'll go on dialysis (10)

	No, I'd like to know that (why you're kidneys aren't working, the progression of your disease what affect it has on your body)…No, I need to know now really I need to know now (tell me when I'm getting worse and things are not working)(10) I just feel she came in and she gave me too much too soon. I just feel it was I didn't need to know all that at that stage, yes she could have a broad spectrum done it you know just a broad spectrum but not gone into the depth, maybe said right well when you get to this stage this is what will happen you know this will be on offer but we can, further into it, when the time's right you know when the results are showing us that you know your kidneys are down to a level where we need to start to look at that sort of treatment for you. Not give you the full wham bam thank you mam there's your lot this is gonna happen…take it one step at a time…give it to them on a need to know basis and yes sometimes I suppose that people do go out like you say with the questions you know well what's gonna happen next (11) People should know more at the run up. Not like I was… what is the next step for me to have and if it is something to go like say well eventually we'll be going on dialysis explain to them then what the dialysis is (12) After twenty years I'd totally forgotten about it. I mean I didn't really have any bad impact on me except I was getting warm I was getting more and more tired and other things were happening. It never really entered my head that it would get so bad, coz I'd forgotten about it virtually, 'cause I'd lived with it, it never really impacted till I got told I needed the dialysis (13) I would have liked to have known what the Acidosis was, yes. Now that I'd read it up on the thing I'd have known that was an indicator but up until then I didn't know it was just like there's more drugs for you… I asked then what it was.(13) I would have liked I think information when I was diagnosed, written information when I was diagnosed as to what could happen to you and I know I've had 20 years where I've been fine, not fine fine but you know what I mean it's been there but it's not had a huge impact and I think I would have liked to have known what could have happened, that I could reach dialysis stage (13) Yes they'd need some information as to what could possibly happen to them. (13) I got no information at all till Doctor had turned round and said what I'd got, the kidney was working about 15%, he says so it won't be long before your going on dialysis (12) Maybe I was just thinking it would all happen quick 'cause they told me I was such a desperate point originally I thought things would move quicker...I thought six percent was a pretty bad stage to be at but I don't know that stage is that you've got to have it. (13) I didn't put two and two together and I probably should have but if somebody would have said you know this is what can happen if you don't get in treated straight away but I guess that's the other side of the coin erm you know with experience of those sort of symptoms I should have probably been picked up maybe a few months before hand. I don't know (15) If I'd have known what the onset of the symptoms were that would have been useful because although I knew I had problems with my kidneys I didn't realise it was gonna manifest itself in the way that it did and it wasn't that it was scary it was just it was the unknown. Whereas if somebody had said well yeah this is what's gonna happen and this is how your gonna start to feel your gonna start getting strange tastes in your mouth your gonna start feeling as though your literally going in and out on consciousness when you're not you're all there but people when they're talking to you you're not really paying attention to them. (15) (Would it have been helpful at that point for you to have had information on what you might experience) Yes, yes because you know your kidneys are going wrong but you don't… with your kidneys you think if affects the way you go to the loo you don't think its gonna give you weight loss you don't think its gonna make you being sick all the time (15) Doctor just said I'll have to start dialysis based on the tests that they do. I have blood tests I used to visit them about once every three months…(did anyone tell you what to expect in the future) No…(so you thought they would just keep looking at the results and you would be fine) Yes… it wasn't mentioned until he said you'll have to go onto dialysis (17) I knew it was gonna be my life until I got a transplant (19) (aware dialysis long-term) My only complaint was I think they left me too long before they put me on it. (20) (needed to be explained why left so long without starting dialysis) Well this is gonna happen that is gonna happen you know. I wouldn't like to be told oh in ten years time or five years time this will happen (20) (would like to know short-term) PROGNOSIS / FUTURE What you would like to know is when and nobody can tell you that can they… Nobody can tell you that… ten years ago when I first went they said it would be in the next five years or so but here I am ten years on and I'm still no nearer (4) They never really offered a prognosis of when my kidneys would fail but I guess they can't give those ideas, the normal prognosis for IGA is that the kidneys won't fail in most people I guess that's what I was hoping (8) I think people should know the consequences before hand but that's my personal opinion and not everybody's opinion is the same… If somebody said to me, you've got cancer, well I'd want to know how long before it kills me (12) I know eventually it will kill me, the eventuality I know it will. But you try and tell your children that this will eventually happen, they don't believe you. I mean I'm sixty at Christmas and I won't be here forever, not on dialysis I'll not (12) I would have wanted to know because I thought they would (get better) and I had a word with my doctor and … I said I'm passing urine and he said well that's a good sign, he says now they could get better, so I've sort of been hoping in the back of my mind that they will. (prognosis) (16) See the thing I don't know whether there's any chance of it ever recovering…My own doctor did, he said there was a chance that it could now my son has a neighbour next door and he had kidney failure

	and he’d been on some remedies and enzyme and he’s kidneys are working again now and he will not need to go on dialysis and they were preparing him for it so you know I just don’t want to jump in and have a fistula done because you can’t undo it can you once its in (16) I’m also not quite clear you may know the answer, when they say a disease is in remission I assume that means it is still there you’ve still got in but its not active now I’m told that its in remission at the moment and does that mean technically that you’ve still got vasculitis? (9) Nobody. No (told him about the problems reoccurring) … they put down on the papers from the transplant unit ‘cause I asked what that meant “ten years half life”. It said on the expectancy thing ten years half life…I still don’t know what that means ‘cause I asked them, nobody said anything no (7) (Do you think people want to know that they will survive?) Well some people yeah I would have thought so…(do you want that information) No because I’m an old man anyway I’m gonna kick it soon enough (17) I pushed and I pushed and I kept saying I’d like to know what you know I said you can’t obviously keep sticking these needles in me arm (what happens when can’t put needles in anymore) I said so how long can that go on for? And she said well forever and then she said and then I pushed her and she didn’t half get annoyed but she said do you want me to tell you that you’ll be dead in 20 years? And I said well I’d like to know some definite things I have a life to live, what to do things to plan out if I know I’m going next week I want to know I’m going next week I didn’t want to be thinking I’m gonna be going on forever and they keep you in the dark and its always been like that as far as I can see. (Realistic information on the future)…. They never told, no nobody told me that no nobody told me that (that he could die) (7) Well the future is to be on dialysis and… (until get a transplant) Yes… That’s the way I see it yes yes (13) No I don’t really (what the long-term effect of CKD is)… don’t know what there might be in the future no I don’t know (what symptoms to expect)… Yes it would really (information on this useful) (16) Indefinitely I suppose (being on PD, what’s the future)… Well the booklet they give you talks about those things (described HD as a further option) (17)
KEY DESCRIPTORS	THEME 2: PHYSICAL SYMPTOMS AS A RESULTS OF RRT AND DISEASE, WHAT TO EXPECT AND INFORMATION, ALTERED BODY IMAGE / SEXUAL HEALTH
What physical symptoms to expect as a result of the disease? What physical symptoms to expect as a result of the treatment? What to do if you experience physical symptoms? How the treatment and disease could alter your body image?	PHYSICAL SYMPTOMS – SIDE EFFECTS FROM RRT /DISEASE– WHAT TO EXPECT No, only when it happened and it was my first admission when I was really dehydrated and they brought me in but no-one told me (6) (information about what could happen and what to expect) They tend to tell you all the kind of things that can happen and you’ll only see some of those so you know that some of the problems they tell you you’ll never experience, I think it’s good to know so you don’t worry (8) No, now I didn’t know whether this muscular pain was due to vasculitis or something else ‘cause nobody had ever explained to me so I raised the issue this week actually with one of the doctors and he said no it’s not the vasculitis it’s the fact that my leg muscles are not getting the exercise that they used to have because I’m spending first of all so much time in bed (9) Yeah I’d like to know how ill people feel (with vasculitis) yeah… I know what your getting at some people don’t want to know in case its bad news no I want to know (9) Presumably the hangover feeling I’ve got is due to dialysis the toxicity in my body (9) All of a sudden bang I started getting these headaches, they didn’t start at the beginning… why I get them nobody knows but the neurologist thinks it’s a form of migraine but only when I’m on the machine ‘cause I don’t get them constantly (12) No I didn’t know that before and I said ‘cause all my fingers were stiffening up and I said oh I’ve got cramp and she said you should have rang your buzzer (that she should warn the nurse when getting cramp)… sometimes I get really light-headed and dizzy and I think one time they had taken too much fluid off so I was sitting with a glass of water when I came off but I did tell them (16) Again the very first night I had a really bad head the other times I just have a bit of a muzzy head whether it’s ‘cause I’m tired I don’t know. A couple of times I’ve felt really quite shivery you know and I have said but again nobody seemed to be overly concerned or you know perhaps these… I thought about it myself you know are they taking too much fluid off or you know is my base weight right, I suppose these are things that just go through your mind I should ask. (18) (not sure whether problems are dialysis related nobody concerned lack of information) I’ve got sore legs and it feels like I’ve run a marathon you know when you’ve done exercise and the backs of your calves that’s how it feels so last night I asked the nurse who was putting me on and he said it could be I think he said potassium or it could be the phosphate I can’t remember whether he said one or the other and then at the end of my dialysis he said had the pain gone from your legs so I said well I’m not in pain its when I walk ‘cause its you know it feels like I’ve done exercise so its not pain they’re not in pain now while I’m sat here its when I get up and start walking. So I don’t think I don’t think he understood now do I ask the next nurse (18) I don’t feel as though I got the right kind of answer about my legs I might have done but I didn’t feel as though I did because he asked if I’d got pain well I haven’t got pain so was he I felt that he was thinking about a different kind of symptom… I didn’t know whether this was anything to do with dialysis or not so anyway I will keep asking… I will because it has been quite sore when I’ve been walking you know (18) (needs more information) I think it would be very difficult for somebody to sit down and say well you might experience this you might experience that you might experience a whole raft of different symptoms when you’re going through… Well no I think ‘cause you’re going through quite a big lifestyle change I think if somebody told you ok you’ve got these 50 things to watch out for half of it you’d take in half of it you don’t (15) I guess I’m experiencing similar problems to what I had first time round so you know if you get something more than once you can tend to relate it to your end stage renal failure, so my skins gone bad

Impact of disease and treatment on sexual health	again, I get spots and that's because my bodies a mess on the inside (8) I've never really had any symptoms the only symptom I get is that I get nauseous when my kidney function drops off, that happened last time I started vomiting no-one actually told me this is what you will experience when your function reduces but maybe I didn't ask (8) Yes that would connect with Kidney failure (what problems to look for swollen ankles, breathlessness) (16) WHAT TO DO IF EXPERIENCING SYMPTOMS When I had my transplant used to ring up when I had a cold or other symptoms just to make sure there wasn't something I should have been doing, it's good to be able to just ring up (8) Lets say I pick up a symptom or have a problem I would not wait for the next clinic appointment I would ring them up for advice (8) I'd know yeah well me ankles swelled up the other week (what to look out for if there is a problem) (12) Oh I couldn't walk, couldn't breathe, I was swelling up… he told me I had Acidosis which I didn't really know what that was and I'd probably need some drugs I did feel really bad so I did have an inkling that something was wrong. It was still a shock when he told me I was at a dialysis stage. (13) I was presenting symptoms and the easiest thing in the world to do then is when your sitting in front of a doctor and saying oh by the way I'm starting to itch... or I feel a bit woolly headed and that's when they start telling me what the symptoms are you know that's when it starts coming out (15) SEXUAL HEALTH Yes well I'm just not bothered about it so you know (unable to achieve an erection)…No, not at the moment you know. I should have done something about it at the time but I just got to the stage where I wasn't bothered you know so (not worried at present) (3) I don't know if I'm sterile or not 'cause I don't have children it's not something that worries me but there has not been any impact on my ability to perform but they didn't tell me about that I guess I didn't know whether that was a common problem or not (8) I did have problems getting an erection for a period of time when I was anaemic thinking back and I did discuss that with the nurse at the time (8) Yeah and yeah (warned of possible impact on your sexual health)… The nurse was very up front about that when I first started on CAPD she did bring it up and she said this is one of the things that can happen… (need to know) Oh yeah yeah I mean you know its something that somebody needs to bring up maybe once that's but you know it's quite an important issue you do need to know about it. (15) Can't have children cause my cycle stopped because I'm on dialysis I'm just one of those people and I find that really really upsetting… I just guessed found out my periods stopped right so I just thought I did ask and they just said oh well its stopped because you were on dialysis that's it and I sort of said would I get my period back if I got a transplant, yeah probably don't know this kind of thing that's what they said… Perhaps have children that's what they (10) ALTERED BODY IMAGE Well they showed me this tube and they kept saying it's not as long as this and I wanted to know how long it was you know and I think when they eventually put the tube in and I saw it I was really shocked because to me it was really really long… when they kept saying it won't be as long so I was expecting it to be quite small and most of it inside and it wasn't it was horrendous really (6) Not from my husbands point of view my husband has been really fantastic and he says the tube just doesn't bother him but it bothers me (6) (hates the look of the tube, altered body image) I wasn't prepared for that no (the way the fistula looks) No No they never, I'd never seen one at all no. I have since seen all of what they are all of what they you know like an inch wide or…(7) They tend to be minor cosmetic things like you look a bit bigger on your steroids or with 2 kilos of fluid inside which I guess could upset some people if they are quite conscious of their body image but I don't particularly have a body image to worry about (8) this nurse who's quite old says to me was and you'll go up two dress sizes and I was devastated by that never mind the idea I'm going onto dialysis never entered my mind it was going up two dress sizes upset me more, does that make sense (10) Well that changes really that sort of body image thing when I first had it done (PD tube) I felt like it was horrific I hated it really hated it, I don't think anyone can prepare you for (10)
KEY DESCRIPTORS	THEME 3: RENAL REPLACEMENT THERAPY (OPTIONS, ADVANTAGES AND DISADVANTAGES OF DIFFERENT TREATMENTS, PRACTICALITIES, ACCESS, SHIFTS, TRANSPLANTATION ISSUES)
What are the different	DIFFERENT TREATMENT OPTIONS FOR DIALYSIS Oh yeah (all the dialysis written information) I read all that 'cause you had to make a decision on which one to do you know but I read the other letters now especially from a good clinic then they're quite good (1) Make sure that's this dialysis which is right for them where that lady other lady I was talking to was on a smaller one on a better freedom of life so that's that would be my that would be me see if I'd have known about them I didn't know I would have said well can I not get on that smaller one but I didn't know they just put me on this you know what I mean they just put me on that so. (5) (right dialysis for you)

treatment options? What are the advantages and disadvantages of the different treatments? Why can’t I have a certain treatment? What does each treatment involve? How does it work? How effective are the treatments at replacing the functions of the kidney? When will I start? Transplantation what does it involve? Advantages and disadvantages of having a transplant? Different types of transplant?	No-one had really explained it to me I knew what dialysis was roughly but I didn’t know about PD I thought it was just HD and I wasn’t particularly keen on that, when they sat me down and explained that they had this other sort of dialysis you can do yourself and they went through PD, I did have a choice but I preferred PD, I was back to not being particularly worried again, they told me just what the system involved, found out more during my CAPD training after the catheter had gone in (8) Even with hindsight I don’t know but I guess I suppose if they’d shown me what dialysis meant or they shown me the procedure I’d have to do then maybe I would have been a bit more shocked or more realistic but I did used to go on the ward and you would see people on haemodialysis but they were all old they were all incredibly old and you just think that’s not gonna be you (10) I didn’t have a choice no they said what would be best for me would be CAPD at that point. I think you know the way I described my life I suppose I’m quite active and I didn’t want to be going to the clinic two days a week I find that very limiting I’d rather sort it myself… (they didn’t suggest home haemodialysis) No they didn’t its like the decision was made for me (10) I’d had one visit into the renal unit but I always think they need more than on visit, people coming up to dialysis need to know more information I didn’t get enough information. (12) Got nothing, no written information. If they wrote it all down…I didn’t get enough information even if it’s only a pamphlet about haemo, and what it entails, and how long your on it. Set it all out in sections… Well if I’d had known years ago that you could have got a book I’d have just gone and got it. But even in the library there was nothing like that there…. Anyone who wants to know information about the renal unit they’ve had it …unless they’ve got a computer of there own at home. (12) I think the most useful information I got was when the sister come and explained over the two choices of dialysis other than that I knew sod all I think people that are coming up to dialysis need to know more. (12) I now needed dialysis and I would be contacted by the CKD nurse and they would go through everything with me like the different types, he didn’t go through the different types with me, He just said…I’d probably need a transplant as well and he’d recommend me for a transplant. So that was enough for me to take in. So that was a shock in itself. (13) I went on the Internet, so that I was primed and so that I knew…Yeah (from a patient association website) it was called the patient guide and that gave me an awful lot of information so I just read up on all the different things. So at least I knew before she came and I’d have a good idea of what I wanted anyway (which dialysis best)… Yeah and when she came she just reiterated what I’d found out which was good anyway (13) Well she showed em a picture of what the machine actually looked like ‘cause from the internet you couldn’t really tell so that did help and she drew me the diagram if what it actually did how it went out of the body then back in to the body… I don’t think I would like to know the in’s and out’s of every minute detail, I was quite happy to know that there was a simple happens what were explained to me and that I wasn’t put out which was new thing for me I wasn’t put out. (13) I’d done all the research on the internet and I knew what was there and I knew when she spoke it all the way through to me so I was quite happy ‘cause it wasn’t different to what I had seen so but there wasn’t a lot I wanted to ask then it just its taken so long (13) No no I needed to know the information of what was likely to be like which is why I went on the internet, I did need to have in my head before somebody came yeah. I needed to know that at least some information as to what the impact was and you know what the three were I know the doctor had said there were three different types so I thought well I’d have a look at least get it into my head my own head before hand I think it would have been worse if I didn’t know anything and then been asked which one do you want at least I knew and I talked to my daughter and my family. (13) Yeah, it’s ‘cause I like to be in control of what’s going on. I know it can’t always happen but I’d rather know what’s going on and make my own decision about what’s happening (why needs information)(13) That wasn’t really an option now (home dialysis) whether I could have that later on then I don’t know … I didn’t want to deal with that straight off (13) It wasn’t a question at the time of this is what haemodialysis will do this is how you’ll feel on the back of it and this is what CAPD will do when I sat down with the nurse we basically just talked about my lifestyle and it wasn’t so much well this treatment is gonna fit your lifestyle it was right ok tell me about your lifestyle this is probably the best thing to go for so I was really steered down the CAPD route which is a good thing at the end of the day (15) (Did someone come and explain to you what dialysis was about why you might need it) No… (Would that have been useful)… Yeah I think it, if I’d have been taken in and shown a machine and see these people and say its painless really but I’d gone through this scan and everything was in a rush they had to it was urgent really (16) I can’t remember you see I think I was too poorly (whether the nurse explained dialysis) (16) Well I’d have asked what it was and what would they do and did it hurt really (what would you have wanted to know before dialysis) (16) There were two ladies in the waiting room on those machines and they said it suited them really well one did it at night and the other one had a young baby (you mean machines for your stomach not one where you put needles in)… Yes no I can’t put them…one preferred to do it in the day time and do that. And then the other lady said to her well did you not know that you can come off it you can stop it and come off it and then go back on it a little bit later and she didn’t know that (sharing information in the waiting room) (16) I would like to see one of these machines you know that you have for yourself and be shown what to do see if I could cope better with that than with a fistula. Yeah I would like to know about the other options really (16) I’d like them to tell me and then to give me information that you can pick up and read (about dialysis) because you do tend to forget I think I’ve been looking through the diet sheet and you do tend to forget what you can have and what you can’t (16) Before I went on it anyway they took me on the unit the main unit before the training unit was open and the Doctor shown me everything he explained everything and he said some people who have the blood pump can affect the heart sometimes he said we’re not saying in everyone and in many patients it can but yeah it was explained for me explained everything and he explained everything to my mam

How long will it survive a transplant, realistically what can I expect? Is there an age bias for transplants?	when she had to go and see him (19) (informed prior to starting HD about dialysis) Yes so they have the choice (20) (all the different treatments) When somebody first goes onto dialysis they should have what CAPD means what Haemodialysis means relative advantages and disadvantages…but that information came out in bits and pieces. (9) I tried getting Haemodiafiltration (HDF)…Yeah I've got all the pros and cons I gave him the letter and that and he was looking into it but I don't think it's financially possible at hope or something for HDF (information found about different options for better dialysis)…I you know I well I've looked on the internet and me friend at Accrington he does it so he told me all the benefits and that for HDF and it won't be benefit just me it will be more patients as well (information from other patients) (14) Yes I'd like that would put my mind at rest knowing because even though the other patients can't tell you that can they (what are your options for dialysis, or whether HD will stop or carry on) (16) They gave me a little booklet (describing types of dialysis) I don't know whether I've still got that. I opted for the machine overnight….Yeah PD but they didn't give it to me they did the what they do you know the all daytime three exchanges during the day (didn't get what asked for)…They didn't say (why not) really I asked them was it cost they said no (17) Well I asked for the machine because I didn't want to go for Haemodialysis 'cause it meant three visits a week to the hospital and I didn't fancy that but now I spend far more time doing CAPD than I ever would if I'd gone onto haemodialysis…I just wonder how busy they are and that you know whether they're overloaded or not you know I mean one of the things is how cleaver people are and there must be enough un cleaver people to keep them satisfied with haemodialysis you know…Well they won't give it to me 'cause its three months of training it takes three months and I think they want you to have a partner as well (17) (chance of changing RRT once decision made) More or less yes (you think that you would be free to do whatever you like during the day)…I would have gone for haemodialysis if that had been a night machine 'cause that's what I plumped for 'cause I thought there would be no trouble but then they come along with CAPD…(have you had any information about the machine) No and we've mentioned it a few times I think one if the things against it is I'm only a slow exchanger so I may have to I have to use a 24 hours (17) WHAT DOES THE TREATMENT INVOLVES – HOW EFFECTIVE? I thought I might try APD but I thought it was a couple of hours overnight but it turned out to involve ten hours, well I'm not in for ten hours in an evening so that was useful information without knowing that I think I would have chosen APD which wouldn't have suited my lifestyle at all (8) I would liked to have known a lot of this in the beginning actually I mean for example it's only by accident that I found out that dialysis is 5 to 10% as efficient as a real kidney well this is after 18 months. Now some people won't want to know that. (9) It would have been useful if you could have sat down in another room or sat down talking to someone who was on dialysis and saying well what does it involve? I didn't even know there was a special diet… if you could have sat down when I was told you were going on dialysis, even before I went on it, like nine months previous. Sat down in a room and talked to people that are on dialysis and what the diets about (12) I think its individual and I think it probably sounds contradictory because I do like to know everything and I try to understand what's going on around me and what's going wrong with me so I don't think you can ever have too much information…Yes yes (search out other information for yourself on dialysis)… Primarily it was on the internet yes (15) No 'cause I was on oxygen as well for my breathing and everything happened so quick (not in any fit state to understand information being given) that you know I was from the scan and then a quick biopsy then this push done and I didn't know anything really then and then I had this and then I was taken for dialysis and I went into shock when I saw…(the machines and tubes) Yeah so I was very seriously ill then (16) Well, so its been one thing after another so really I said to him I said no I said I want to just wait get me strength up and see you know then but since then I've been reading about well I was talking to a lady about there's another that you have in your stomach isn't there (still not fully aware of all dialysis options) (16) A patient and I was talking and she said I have my own machine and I said oh do you attach it to your stomach, she said yes she said I'll show you so she lifted up her blouse there was only us in like she shown me but even then it was a shock to see the size of the opening really but I thought well you know to have one or the other (another patient mentioned other choices) (16) No no (nobody spoken to her) they've given me a leaflet, they've given me this one I think it is. I mean they were very good, once I'd spoken to that male nurse and he said I said how long am I going to have to be on it and he brought me quite a few leaflets then on it. He said oh have you had nothing? I said no he said oh we'll sort something out so he did get me the information and then I got these given me so I'm getting there slowly (understanding what dialysis is)…Yes I think with being rushed in they had to act quickly yes (missed out on full preparation for starting dialysis) (16) Yes yes I would (like to know about what your kidneys did and now don't do all about how your dialysis works what it does) (16) I think they need to be told things like it draws there's blood and circulation in your gut in your abdomen and that is where the fluid comes from that goes out or the chemicals come from sorry and a little bit of extra fluid comes from (new patient) (17) This is what you're having done its doing the work for your kidneys like he said like we get rid of all our wastes and that the bags are getting rid of it through your body is getting rid of it through your fluids and that…(need to know this) Yes (19) (information about how dialysis replaces the function of the kidney) I went on Haemo I was explained everything about that I was explained everything about CAPD and then when he come like I say he took me to he sat down and explained everything about the transplant the Doctor in MRI and he said I hope all goes well and then just went but only lasted 6 week then I had to transfer me straight back to hope (19) (explained what she needed to know)

	WHEN WILL I START When is my next op and will I get the dialysis after that op really 'cause if that's delayed then I'm still the same boat I still haven't you know I've not moved on anywhere since October and although I'm not too bad its just the thought that its there somewhere when is it gonna be (what's happening when will get next op, when will start dialysis)… Its like no mans land at the moment I think that's the hard thing (13) TRANSPLANT OPTIONS Yeah I was given quite a lot of information about that and sort of the transplant co-ordinator is very good… again I think I've got enough information of the difficulties after the transplant…Well I think if you are going for a transplant and they called you for transplant then I think they should give you as much information as possible to prepare you so you can get back to normal but it's not like that at all (6) LRD is not something I would have liked because I would have felt obliged to the person to behave in a certain way so if I wanted to stay out all night I should be able to do that without feeling guilty…you know my transplant lasted 5 years and I would have felt uncomfortable loosing it if it had belonged to someone I knew, I don't have anyone who would be a potential LRD so I don't need to justify my reasons to anyone (8) I considered going to India for a transplant but the Doctor said it wasn't a good idea….Well he said there's no guarantee of standards and the transplant nurse in the renal unit repeated this and said that they had had five cases of people coming back from India with transplants and four had died. (9) So I'm hoping if I get a transplant, for example there's 5000 on the waiting list they do about 450 a year and as you know it's the luck of the draw I sometimes wonder whether there's an age bias people may say the guys 74 you know they say not (9) I had a clear knowledge that was the best thing from a long term point of view… I went to MRI where they actually do the transplants and they have not an open day but you know you get to sit down with a consultant he explains exactly what happens going through the procedure of a kidney transplant, how you will feel going through it, how long you'll be in hospital what the regime is immediately following the transplant going up to 6–12 months afterwards so I was fairly comfortable that... Yeah yeah it was good (15) Yes, that was discussed a few times (LRD)… No it was brought up first of all by the transplant nurse when we were talking about different types of transplant waiting for a cadaver or the living donor and I didn't want to go down that route so it was explained to me and it was explained quite thoroughly what would happen but I didn't want to go down that route 'cause I've got a brother and a sister but I didn't want to put them through that. (15) But the overall survival rate of the transplant not the patient the overall survival rate of the transplant was 50% after 5 years (was it what you expected)… Now it was a bit I thought it would be better than that…(was it good information to have to know) Yes because it's made me feel its transplants not worth doing really …I've got to wonder is it worth doing at all from my age point of view when there's other people who would benefit better you know 'cause you've got younger people who need a transplant I think they should get the transplant not me (17) I thought that was the bee all and end all (transplant) yeah yeah oh I yeah nobody told me and I said how's what's the success rate? Great success rate it wasn't till when I'd had the transplant a few years that I found out what the success rate was after six months, that was a success as far as they were concerned you know and of course the people you talk to when I was in the transplant unit they've been brought back for different things like you know and they all seem to be 18 years and 20 years and I thought this will be great this isn't it…Nobody said to me and it was only then when me kidney was failing that I found out about the success rate and that's..(7)
KEY DESCRIPTORS	THEME 4: PRACTICAL ASPECTS OF RENAL REPLACEMENT THERAPY
What are the practicalities of having the treatment I selected? How does it work, what happens during	PRACTICALITIES OF HAVING RENAL REPLACEMENT THERAPY They brought you in and trained you on the PD system during the day but at Hope they trained you at home which was better, your home is geared around your life and you can see where the dialysis fits in your surroundings (8) They didn't even explain to me what was in the bag and it was only later when I was in talking to one of the nurses that I asked what is the terrible smell from the bags because they'd just changed the bags over and so she told me there was a lot of glucose in the bags and they'd never told me that…(6) First of all precisely what is going on you know I'd never heard of peritoneal and so explain to them what is going on and the well apart from the mechanics of you know actually doing it which they've got to tell you simply what's going on and in particular what to look for in terms of possible infection (9) In a very general way yes in a very general way yes (what's happening with the actual dialysis) (9) That you have to have monthly bloods taken I didn't know that! That you had to have your blood taken every month to check your levels, nothing like that came out, not until you went on the dialysis. (12) Yeah I want to go for the half eleven one really 'cause I've got to work in between so that was easier for me (different shift options) (13) Yeah I'll assume I'll understand much better once I'm on 'cause at the moment its just like its theory to me I know I'm to go I know I'm to turn up I know I'll have a bed I know I'll have a machine I know they're gonna put two needles in and I don't even know if its gonna feel uncomfortable or not I'll just know that's what I'll have to be there and be there for four hours (13)

dialysis? What does the training involve? Base weight Shift times and changing shifts (HD) Number of exchanges (PD) Using different strength bags (PD) Amount of stock and supplies Transport issues (HD) Need to have access for dialysis – what is the involved in creating access? What are the different types of access? What access problems can occur, what can I expect? How do I care for my access? Can I choose where my access is positioned? What happens if access fails?	I went in it was just like a quick visit all the beds were taken and I saw the first bed just asked him how he was and he'd been doing it a while and that's all I did I just wanted to see the actual machinery. (13) I said oh can I brings me books 'cause I read and she said yeah no problem you can do what you like when you're here (13) They didn't really do that to me 'cause I was brought up with it they probably thought I knew all that anyway so they didn't show me like the machine… I know they do it to the new starters who coming in now I see them showing em around and showing them fistula's and lines but I know all that so I don't think they needed to do that. (14) Yes (told about how machine replaces kidneys do) (14) Oh yeah I appreciated what was going through yes I knew what was happening and why it was going you know why it was going on (as an emergency admission for dialysis) (15) The nurses made quite a big thing of needling which I can understand with a lot of people it is a big deal with mw personally it wasn't but it was almost like oh your gonna have to start needling yourself how do you feel about that and everybody asked me that every time and you start to think shit should I be worried, should I be worrying about it and it wasn't you know it was one of those things for me personally it wasn't a big deal (15) I'd say everything the training was good, the back ups been great I've never felt isolated even though I'm dialysing at home if I've had a problem I've been able to get through to people and talk to them, explain exactly what's going on and they've told me what I need to do to fix it. (15) What would happen if you missed out on it for one day because well this is what I told the doctor when I said I didn't want a fistula yet because me blood pressures got right, my ankles are not swelling and I'm feeling better in myself and I'm keeping a steady weight (still thinks will get better not aware of future) No not really no… (nobody discussed future yet) (16) Its just crossing my mind now whether to get my own machine and do it like that I don't know how much they are though I know they'll be a lot of money (thinks she will buy her own machine, you don't pay that)…Oh do you not. (16) The very first time said this is the kidney what did she... the something kidney erm on the machine you know but no they don't explain that it tells you, you know you can look at the machine and see how long you've got to go, I've no idea what all the buttons are for I've no idea (18) (more information about the dialysis machine) (What the machine actually does to replace your kidneys) No I don't think so or if they have it might be that CKD nurse told me a long time ago you know that's the other thing as well I suppose I'm thinking about I mean I can't remember if she did tell me. (18) There's one girl there… I says ooh your early today so she said yes I'm going to a party tonight so I've gone in earlier. So I thought oh because I'd got a theatre visit already booked before I'd started dialysis so I thought I wonder whether I can ask too see whether I can so I did so yes they've put me on a early you know they don't tell you things like that you know that you know its all (18) (information about the ability to change your shift times to suit lifestyle) Well I think it might be worth somebody you know when the nurse comes to see you or like when I went round the dialysis unit I think yes I think you know if they told you, you know the practicalities of the unit and I suppose they did tell me things like about the waiting around and things like that but it is a shock and its something that you don't expect so much of , I think I expected it more of people who lived a long way a way rather than somebody who lives on the doorstep why I should think that I don't know but I did (18) HOW TO DO IT You need to be told several times really you don't just need a mind you whether it's altered now I don't know. (about dialysis) (7) Cleanliness more than anything else and always stick to the routine that your told….That should be stressed and never try to side step anything do anything quicker than they should. (7) (new patient starting on CAPD) I want to know exactly what's going on (9) One of the issues which causes the most puzzling is this concept of the base weight (9) That's the other thing about it nobody ever explained for quite a long time what this wash back thing was they'd say oh were putting 500 on and I'm not so sure I understand it now. (baseweight, fluid management) (9) It all seemed to be a mass sort of performance of paraphernalia of bags and cleaning of hands and cleaning of this cleaning of that and I sort of maybe its wrong but I've discovered that you don't need to go through all those procedures to keep yourself well (10) I would say that get an adequacy test make sure its done sooner rather than later, my adequacy test was like twelve months after ok and they found that I could actually cope with three bags a day not four (10) At the hospital they said its got to be every four hours on the dot well I would like to tell someone that it doesn't have to be every four hours ok so if you're gonna get swollen fingers then obviously you have to cut down your drinks don't you well you have to fit it round your life that suits you rather than this you know regimented kind of system that they have me believe (10) When I first went on the APD machine they said you can only do one or the other and I said I looked at it and I thought well shall I its just the same stuff really isn't it you know what I mean four bags they're all at night time surely I can swap so I can go away at the weekend so I did myself and now 'cause they deliver two lots for me, why didn't they say it could be more flexible (10) Well we skipped the semi permanent stuff 'cause I knew all about that and we just had training and yes they did tell me I think, one of the things they told me for instance was that you may well change the % of glucose in the bags put different bags on in order to draw fluid extra fluid but they said they will decide that not me so that was a useful piece of information that they would decide (17)

Changes in treatment regime or changing to a different treatment Long term effects of RRT, What can I expect? How long for? What happens if run out of access options? How often do I need blood taken, and what for? What is my tissue typing, how are kidneys matched? How will I know that I'm on the transplant list? What are the risks of having a transplant? What are the complications or side	They didn't teach me the explanation of what was going on actually they just told they just gave me an instruction sheet and told me to follow the instructions and it wasn't until I'd started thinking about it all and doing it off my own back almost that I realised first of all there's a drain out and then there's a drain in and you do all the switches and its all logical so at the start I didn't have a logical picture of what I was doing and that was an important failure I though… Yeah and why you're switching this valve so I think I think the information wasn't so good on the training (17) I think you should teach them teach them what's going on if in theory about the drain out and the drain in…(did you know this) No I think they thought that they were going on the I think they were going on the basis that nobody is intelligent enough to know I think that was behind it you know. (17) (Is it important information?) I think a lot of people would understand it better 'cause now I don't refer to the instructions 'cause I know what I'm doing where as when they first told me I didn't know what I was doing (17) Yeah they told me things like the window shouldn't be open and that sort of thing yes (practical tips on setting up home environment) (17) The theory of doing the dialysis and what your doing when your switching the valves and that I was all at sea even though I'm a biochemist and a scientist you know I'm used to working valves and all that sort of stuff I still didn't understand it until I went into hospital and I hadn't got my instruction sheet so I did it myself and that was the start of me understanding it and doing it on the basis of understanding… why you know the thing there why you're putting the things in the various places plugging things in and pulling them out and that (new patient) (17) Now I don't know whether that base weight is right for me how do I know how do they know I'm trying to put weight on which I keep telling them so are they going to always go back to 46 so even if I go and I weigh 50 kilos does that mean they're going to take that much fluid off me when I might have put some weight on. Do you see what I mean so I don't think enough is explained about it… they don't run away from telling you but obviously they tell you it's your fluid what they don't do is go into detail (18) (need more detail, what happens on dialysis what does baseweight mean) AMOUNT OF STOCK They should be told what it would be like or even if just really explain what your boxes are for and all this carry on because it were I was just walking in a blind alley I didn't know till I got home I'd get all them and I didn't know what it were which they could be aware of you know (5) (supplies) No, No, (information about amount of stock) because the boxes are an absolute nightmare I know people might find that quite funny but I have dialysis boxes everywhere, I have the backyard full of dialysis boxes because you have no where to put them and then you've got to go and find somewhere yourself and I order skips to get rid of them all you know but they are quite a lot of them (6) (Were you prepared with enough information about the practicalities of PD?) No not at all… Yeah there was all this stuff and there was tons of it … they were good in a sense that they built an extra shed in the garden and got things out of the house because I wanted the freedom…(would you have planned it differently if you had known) Yes (6) I wasn't warned about the quantity no (number of boxes for CAPD)… Well yes and I actually cut the quantity down you know, I don't have any back up stock and I've still got 60 odd boxes and I have no back up stock so. (7) They said you would have a lot of supplies but no-one ever showed me a box of fluid and said they will be delivering 30 of these so I never realised just how much stuff you were gonna get (8) No that was a surprise they came with half a ton of supplies on the first visit they hadn't warned me about that (not enough information on amount of supplies) (17) Nurses who used to come out explained everything before I come home and they visited the house and all that so. (19) (informed about supplies and amount of stock) TRANSPORT ISSUES (HD) Oh they don't tell you how long you have to wait at the unit, they provide the transport… Your hanging around, and when you get to the unit your hanging around and it's not ten or fifteen minutes it's and hour, hour and a half two hours… It's awful the waiting time for transport, it's horrible…It would help other people if they turned round and said well look if you're coming in by transport do you realise you're gonna have to wait to come on the machine, do you realise it takes so long for the machine to clean which I didn't know at the first. I didn't know it takes about an hour (12) Well now I asked that, I said am I able to drive backwards and forwards 'cause that's easier for me and she said yes I can do the driving, (how to get to HD) (13) So they don't tell you that they pick you up sometimes it can be early they can pick you up at three o'clock the other day nobody picked me up and I rang the unit and they said oh it doesn't look as though you've been out down… what else they don't tell you is that when you get there you could have hours to wait and they don't tell you that you can have hours or a while to wait at the end for your transport home do you know what I mean. So that is quite a shock really. (18) ACCESS FOR DIALYSIS (FISTULA / TENCHKOFF) Nobody ever…Nobody ever asked when they were putting the tube in because one of the sisters said that they could ask where would I like to place it and no-one ever asked and it's really high up and it's up here and I wished it was down here a bit because at least it would be below my waist line and I really have to be particular on what clothes I wear for starters because you can see through and nobody asked me that (6) (choice of where tube sits) They explained that they were putting a tube in but that was about the sum total of it. (not enough information)…I think that's the main thing you know what exactly is going on where are you putting this tube.(9) Things like that yeah (how noisy your fistula is) all these little things that do happen that you don't, I mean I suppose I've been on it that long or I've had the different things that long that you forget about them (7)

effects of having a transplant? How long can I expect to wait for a transplant?	No not really the only thing I would say was the issue of a fistula was never mentioned for the first year of which I was on dialysis… (so used a temporary catheter) It's nearly 18 months now yeah. And so far there's been no infection but it would have been helpful if at the beginning they had said look there are 2 possibilities a line or a fistula and the relative advantages and disadvantages are… but I was just told your having this and then 18 months later or 15 months later the issue of a fistula came up. Now whether the reason for that period was they wanted the dialysis to settle down I don't know. (9) No nobody explained all the different advantages and disadvantages of a line or a fistula with regard to a fistula per say you know what were gonna do the nurses are very good they know exactly what they're talking about (9) The thing I wanted to mention was this notice about the fistula about the squeezing of the ball and they really should say if you've got to squeeze` it two or three hundred times a day say so not just squeeze a ball… But it wasn't explained (9) Yes especially now (choice as to where tube is placed)…I sleep on my right but I can't sleep on my right now 'cause it traps the tubes so that's extremely annoying when my machine alarms or they could have maybe put the tubes somewhere else couldn't they so I could sleep on my side so that's really annoying me at the moment but you know you change and adapt don't you (10) I got one visit they didn't tell me what the fistula was going to entail apart from an artery and a vein was going to a u-turn and that was it… I never got told it would come like this. With constant use and what have you, I never got told anything like that.(12) I got told yeah your going on dialysis, yeah your having a fistula done and that was it as far as I was concerned. I think they could have done more pre-checks and let you go and see more people I mean some people have lines some people have fistula's but they don't explain enough about the fistula's, I don't know about the lines 'cause I've never had a line. (12) I just knew when I saw the surgeons they'd cut there and twiddle with the vein and that would be it… Oh yes. I did visit the unit to see what the machines looked like and I saw a patient who'd had his fistula done so I had a look at that…It didn't actually look too bad I was expecting a lot worse…It didn't look too bad I was quite surprised (13) No that's what I was more worried about, would I feel anything but no it was alright actually (during fistula operation) (13) They did when they did the fistula op (explain how to look after it)…what I had to do when I came out with the ball and the exercises (13) No yes they did but… I think they should explain it better how they do it 'cause it's really a nightmare (what having a line is like)… It's just like how they do it they think when they put them in they think it's like its nothing but its quite traumatic time especially when you have like 16 like me (14) I was dreading last Christmas when I had septicaemia and needed to take it out 'cause not getting another line and I didn't have the fistula so…(didn't know what would happen) (14) Well it's just what probably, could you do better if you got poor access you know if there's more tests available I know they do a fistula gram and that but if there's any more things you can do with bad access. (14) No (wasn't told that they would continue to use places for different access) Yes that's it (only given more information when one failed) (14) From a personal point of view that I didn't find disturbing but I felt almost out of the loop was when I had a problem with this fistula and I had to have a new fistula created, it didn't although it seemed as though there was a plan in place and these are the steps that they had to follow the hospital it didn't seem as though that was explained particularly well to me at the time or that it was actually followed through in the way that it should have been (15) I'm sure if at the time I'd have said I don't want it up here or down there, then that would have been taken into account but you know you go for the easiest access like you know at the end of the day and looks really are secondary on it I guess (15) Not to go swimming and if I have a shower I put a plastic bag over and seal it at the top so I don't go swimming, no (advice on how to look after catheter)… I could always phone up if I had any problems (16) Patients and because I've just said they want me to have a fistula what is it and they said oh it's just they attach the dialysis to it you see and I said can I have a look at one a bit cheeky but can I have a look please and they've shown me you know this fistula (information from other patients)… I thought oh I didn't know it was so bad no I didn't like it (16) Some had had three places you know it wouldn't work in one and try in another and then he said they'd have to attach a vein to an artery so I said well, he says shall I put your name down and I said well I'm not I don't feel ready for that yet (not prepared for fistula so refused) (16) I wasn't ready for it but I didn't feel I knew enough about it or the other options so I don't want to have a fistula put in if I could have something there and I'm quite happy actually with this you just screw it on clean it and screw it on (temporary catheter) (16) Well they just said you can get infected and that can be very serious if you get infection well one man said he'd had his in five years and it was alright, so you get all these you've got to think (warned of possible infection in catheter) (16) They were moving too fast for me (not prepared enough) (16) I thought that the graft would end up with something that the machines were attached to I didn't realise that then you would then have to put needles in. so and I didn't realise that there was an artificial tube in I do now but I didn't at the time so I don't I can't remember whether Mr Campbell told me he might have and it went over my head I don't know but I didn't know, I do now and I know now that I have to have needles. (18) Yes, yes. (Enough information about access operations)… Yeah 'cause it well when you've had them done anyway they give you a sheet explaining about your fistula, how to look after it how to needle it, how to keep it clean and everything yeah I understand all about that (19)

CHANGES IN TREATMENT REGIME

To change the tube they put me on haemodialysis for about eight weeks whilst they put the tube in and that put me in a depression that did there was a big tube sticking out of my shoulder and I had to tuck it in my bra… but I had to go into work like that… nobody told me how much time it would take up and what they didn't tell me was that it would be so difficult was the fluid you had to be so restricted with you fluids and the haemodialysis I found that really really difficult to have only 500 in one day and I found that really difficult (6) (temporary HD time consuming, catheter protruding from shoulder and restricted fluid, lack of accurate information)

… I said I pulled them up I said hey can you leave that on a bit longer I said 'cause that's not killed all the germs that are on the outside of that surely you three minutes would a lot for it you know (they have found that betadine doesn't make any difference after so long) ... Well why won't they say that? (7) (information on changes in dialysis procedures)

No in the back of my mind when I was told that it was gonna be a problem I sort of approached it not from two separate ways but I was always fairly optimistic that I would get a kidney fairly quickly so it wouldn't impact my job or my lifestyle too much (did anyone warn you that you may go on PD but it may fail you may need haemo so while you fit and well think about your future employment) (15)

As soon as I came home I changed my regime. I don't do three days a week I do alternate days so one week its three times one week its four… I explained what I was gonna do before I did it and I talked it through with the sisters and the nurses on the training unit and also with the doctor as well and they were fine with that as a regime… I don't necessarily do it every time the minimum that I'll do is three and a half hours so I'll just knock half hour off more often than not I'll do fours and I'll feel better on the back of it… When I was actually going on haemodialysis I was reading about a study that they were doing over in the states of daily dialysis where by you'd go on for about two or three hours and you do it every day… it seemed like a good idea… I was thinking well perhaps that would be better for 'cause if I go on and it is only two hours a day that would be great… I started doing the alternate days and that was that's been fine for me (15) (knowledge of other options read about)

DIALYSIS LONG-TERM

I tried to ask him about things like my peritoneum…. if you avoid high bags high strength bags then the length of you're the lifetime of your peritoneal will be longer than someone who uses high strength bags eventually your peritoneal gets all scarred anyway they don't really know 'cause they haven't had anyone on dialysis for over 15 years that's it really (10) (10) (how long it will last on PD)

(Once I start dialysis where does this take me, what's my journey, would you find that sort of information useful) Yes, especially once I'm on it… it's just no mans land for me at the moment. I'm neither One thing or the other is sometimes how I feel. (13)

Oh yeah but you do at the end of the day yeah you know yeah there's no point in sitting there and thinking god I'm gonna be here for 8 years or 10 years or however long its gonna be (optimistic view) (15)

it was a very slow build up I couldn't believe it when they told me that me function was crap because I felt alright you know I was again your body adjusts I think to all the toxins that are building up in your body and you don't tend to feel poorly… I struggled to comprehend it as I said because I felt no worse than I did six months beforehand even though I was… No it was just you know it was a case of well this is what we can do so and this is what your gonna have to carry on doing it's gonna get worse it's not gonna get better or the alternative is Haemodialysis and that you know those were my choices (15) (when type of treatment is failing)

Well the thing was I didn't know how long I'd be on dialysis and after I'd been going it was about four weeks I naively said how long will I have to be on dialysis and the nurse the male nurse he says has nobody told you I said why why what is it and he said you're on it for life… Me heart sank a bit I just thought you go into hospital have an operation you get better come out you know so that was a bit of a shock to me that (16)

Well yeah like they should be told it should be mentioned but like I say I wasn't told anything when I was at Pendlebury and I wasn't even put on the transplant list (19) (what the future is)

I'd just ask just ask like you say either the consultant or the nurse like if I've got problems on the unit and when I want to know anything I always ask the main sister I don't ask the nurses I always ask the sister the main one like she's the one whose been sorting it out with all my access and that and like I've been having problems she sits down and explains everything if my access keeps giving in or the line gives in and then the only option is a kidney, she said and then you would have to be put on the emergency list. (19) (realistic information about future options)

LISTED AND WAITING FOR A TRANSPLANT

I just want to know when they'll stick me on that transplant list. (3)

I actively search out information when I went on PD this time there was also the option to go back on the transplant list and I went away and so did the Doctor and read the current research regarding transplant and my disease and we decided to wait two years before I go back on for the disease to die down (8)

The disease did reoccur in my transplant which was a real disappointment they say that you will always get some but it came back quite hard (8)

When I went on the transplant list last time they said it could take any time at all but I knew all the people in the tissue typing labs and found out I had the commonest HLA tissue type so I knew that I wouldn't have to wait too long and I was only on PD for 15 months so I was quite fortunate, but you never know I was prepared to wait years they can't give you any guarantees (8)

I didn't ask anyone about the transplant operation I thought it would be a lot bigger than it was it was a bit of a shock that they wanted me to get out of bed the next day, the transplant operation was not a problem but I never experienced any problems so I was fortunate (8)

I tried to ask him about things…chances of a transplant he did give me very qualified but un black and white answers 'cause he doesn't know (10)

Funnily enough no they didn't to be honest I'd been on a transplant list for 5 – 6 years I only really found out about having a rare tissue type a year ago no one told me and I was quite upset about that do

	you see what I mean, I'd been waiting patiently on the transplant list… they must have known that information for years they didn't choose to tell me though (10) No, all I got told is I'd have me transplant, they didn't tell me anything about it. I got to know more by talking to a woman who's had a transplant. I got to know more from her…she told me about the anti rejection drugs nobody else. It's always been her if I wanted anything 'cause I still keep in contact with her… Yes, I mean as far as I'm concerned I don't know what tablets I have to take… she's been saying you wont take any of them all you'll be on really is your anti rejection drugs. (12) I didn't want another lot on top of what I am already taking (when transplanted)… He said no it would come down if the transplant was successful it would reduce the amount of drugs (13) No, I know that's what they want the bloods for (tissue typing)... (Would you like to know what that means?) Yes I would be interested to find out how they actually do it (13) For me that's something in the future I just wanted to get the dialysis bit sorted and get some benefit of feeling better (no more information on transplant) (13) I'm gonna know what I'm doing (with HD) and then I'll as and when transplant appears, because I haven't got a lot of information on the transplant as there is an information pack but I haven't asked for it yet 'cause they haven't got any left so I thought oh it would only probably scare me (13) Yeah they put it out like you know the complications but you know the greater risk is worth having 'cause your off dialysis and you can lead a semi normal life with a transplant and they put all the risks and what you'll be on with tablets…. go for it 'cause you know even if it lasts a year it's a year off dialysis going to the hospital three times a week… (should know) you get other side effects like with the anti rejection drugs with like growth and bleeding gums I had as well other little things that I can't remember now but yeah there's side effects with all tablets and you've got to be no close contact with like people with chicken pox and anything like that (what to tell new patient about Tx side effects) (14) What they'd do, well they'd put me on the priority list for a transplant that's what they did at Christmas time. (If can't get access) … I said they didn't think they could put another line or fistula in then so they put me on the priority list … Yeah well they've changed the rules now so everybody's got a better chance now. (14) I was under the impression right ok I'll be on CAPD for maximum of two years I'll have a transplant and everything will be back to normal because the average wait for a transplant down was two years (15) No they've gone into a fair amount of detail (about tissue typing)… I mean I'm the most common blood group and I was a little surprised after sort of two years I still hadn't heard I hadn't even been called up… I was speaking at one of the regular check ups that I have at the hospital with one of the doctors there and they wrote to the transplant people just to find out exactly what the problem was and why I hadn't been matched or had anything back … I know I've got certain genes, which I didn't know before hand, and as a consequence that makes the match a little bit more difficult but in saying that they also give like a not only a mean but a medium like a minimum length of wait and a maximum length of wait (15) They seem to have given me an awful lot of information (about transplants) yeah I mean short of going down to the actual nuts and bolts and knowing exactly, there's not an awful lot more that they can sort of give me and even the stuff that they haven't told me I've been able to go away and research it on the internet because you know people don't want to go into the ins and outs of what's wrong with them (15) When you go in for a transplant your gonna have to have anti rejection drugs… I understood that and I knew that and again they said the closer the match of the kidney the less the drugs that you're the less drugs your on the better (15) Its not necessarily gonna be that your gonna get a kidney straight away, you do have to be aware that you could be on the list for an indefinite length of time (new patient needs to know about Tx list) (15) No I've heard people mention transplants but no I don't know anything about that (16) But they would still send me the information wouldn't they, I might not be on the list I might still be going through all the processes… But I could ask then at the unit who's the transplant co-ordinator. (18) (unconfirmed whether on transplant list) I asked him and he said well the only they told you when you had your first kidney transplant that you're because it only lasted so many weeks you'd only accept a member family one….And like he said we're gonna have to get your family in and discuss who will want to give you a kidney. (19) (transplant information and update)
KEY DESCRIPTORS	THEME 5: COMPLICATIONS AND SIDE EFFECTS OF RRT AND DISEASE, WHAT TO EXPECT AND INFORMATION
What complications	DON'T WANT TO KNOW POSSIBLE COMPLICATIONS Yeah I don't think I'd want to know (if someone explained all the complications possible)… 'cause I'm quite happy knowing what I know (3) I don't think you need to know all the bad things that can go wrong, with the best will in the world things will go wrong but you don't want to make people more nervous because they are nervous enough (8) WHAT TO DO IF EXPERIENCING COMPLICATION – HOW TO RECOGNISE A COMPLICATION – WHAT COMPLICATIONS TO EXPECT That's bothering me (sore exist site) and I'll ring them today and see what they have to say ….Yeah its inside to me that what I'm bothered about, I'm worried about. (5) (exit site problem and tube change when) I didn't know when your shaking and all that that there's problems you know I thought oh I've got I can't get warm I'm freezing cold, I was freezing cold and my temperature was sky high you know. (7)

to expect? How to recognise a complication? What to do if experiencing a complication? How to avoid complications? What is the chance of getting a complication?	(no idea of how to recognise complications, septicaemia) a few months after I had another do but I was expecting that because the Doctor had said whether it was correct or not I don't know but she had said you don't always get in out of your system the calcium and it can lodge in places and it can move about again and then it can go back to the brain and that can cause the same problem again and when I started to go a bit funny again (good bit of information given) Yes well that's one time that I got something (7) I mean they warned me that they're a chance of infection (on PD) (9) I'd been on dialysis for so long without any infection I didn't know what it was but I kind of guessed you know so but it was not what I expected it was really sharp pain, really sharp pain (10) (complications and how to recognise them) Yes! (Tell you about the complications of Haemodialysis)… I have gathered a few as I have gone along, if you don't have the dialysis your fluid can build up and you can end up with a heart attack and things like that but there's a lot missing, a heck of a lot missing (12) Complications like my bones and that ok they're painful and that but I can live with that… they said the side effects 'cause of you know the kidneys don't produce calcium and all that, you don't think what your kidneys are do… I also had problems with my growth I was on growth hormones (14) (14) They did tell me to watch out for peritonitis they did tell me that (17) I collapsed on the machine and what basically happened was I had a blow up here and it causes the whole thing to clot and that fistula packed up at that time… (Provided with the information to know what to do)… Yeah when I came round I took myself off that wasn't a problem. (15) He explained all that about peritonitis and all that yes infections in your exit site… (useful) Yes (19) Information about what complications to expect) No not really I know you find things out from other people don't you…I don't know whether I do really (understand possible complications) I suppose I would have only asked that if like now (experiencing a problem)… Yes I suppose so I think yes I suppose if they told you a little bit at a time. (18) (would like information about complications but a bit at a time) HOW TO AVOID COMPLICATIONS Nobody told me that when I had this thing in me neck it was dangerous to do anything and I, anything involving dust and all that because I stripped, we had a settee and the seats were going a bit whatsit so I thought oh I've got a bit of time I'll strip it all off and re spring it and all that and got septicaemia didn't I (7) (no warning of how should care for tem access in neck to avoid complications) CHANCE OF GETTING A COMPLICATION I was thinking of these questions myself really possible osteoporosis and he did give me very qualified but un black and white answers 'cause he doesn't know (10) Not really (know the complications of haemodialysis) I didn't think there was a problem with the machines (13)
KEY DESCRIPTORS	THEME 6: MEDICATION INFORMATION AND POSSIBLE SIDE EFFECTS
Side effects of medication Why am I prescribed this medication, what is it for?	SIDE EFFECTS OF MEDICATION I think with the side effects what happens is that no-one tells you that until something happens and then it's oh you need to go on this tablet because of such and such or you know they don't really tell you ...(6) I went on the triple therapy, nobody as you've said nobody said anything to me about the side affects if I'd have known what was going to happen 'cause in the first year I got cataracts and within a fortnight I couldn't see I thought I was going blind, now if someone would have told me that tablets can give you this in your eyes well that might have I might have been I might have felt a bit better about it 'cause they could do something abut it but I actually thought I was going blind…Not half well yeah there was a reason for it and nobody had said anything about it. (7) (experienced side effects and nobody warned him which frightened him) I said about the medication with my transplant about the problems with that nobody mentioned at the time …they send me to Christies for cancer…I went back in and had a little talk and we think you've got it from the medication from your transplant and I know they never said anything about that to me, it was like they didn't say anything about the cataracts to your eyes. (7) Nobody told me about erm the side affects I keep saying the side affects for my tablets and when you read about them give you the same problems that you had with your condition and I say is that worse is there nothing that they can give me that doesn't worsen my condition. No answers are they (7) They did go through the side effects of the drugs and one was sterility but I was in my mid 20s they said it wouldn't be a problem (8) I had bad anaemia for a long time and I think that was drug related but it was hard to convince the renal Doctors (8) WHY AM I ON THIS MEDICATION – WHAT IS IT FOR? I thought oh why did they put me on triple therapy and I asked the doctor and he said oh you needed them it wasn't any explanation of why you needed them, we don't always give a single we sometimes

	give triple or double you know and we decided to give you triple therapy (7) (More realistic explanations) In the Library I used to sit there and go through all the medicines that I was on and all that you know and see the side effects of everything and realised that you know the problems I was having with my legs, possibly it was something to do with the medication I was on at that particular time because when I was taken off that medication my kegs were alright you know (7) No-one talked me through my medication of about my blood pressure but then I never asked them to I was fairly happy with what medication I was on and what it was doing, when the Doctor prescribes something I will always ask what's it for and what does it do in case I don't think it is necessary, I do know what my pills are doing… I can find out from other people and don't just rely on the consultant or nurse for that information (8) I don't take it (EPO) but I should take it it's another issue of compliance. (10) (lack of understanding) I didn't want to know I don't want to know all the ins and outs and the tablets just give me the tablets didn't want to know about it its only gradually I've found out things picked things up myself or maybe I wanted to find them out then does that make sense (10) They said if I had any questions but its pretty you know detailed (information provided on medication) really and that's for another drug that I had with it and this was affecting the kidney with steroids so I had all these (16) No (not told about any drug side effects) (17) I was on blood pressure medication (knew what they were for) Yes… Yes the need for the blood pressure tablets has been reduced (17) Yeah they've explained when I've came here they did explain why the medication they put me on… the Alpha calcidol and like a greasy medicine but Doctor took me off that he said no you don't need that now just the Alpha Calcidol but when I came here they explained what it was for the cholesterol one…. I'm on eprex now and he explained that and anything you have to go on. (19) (different medication explained)
KEY DESCRIPTORS	THEME 7: FAMILY AND LIFESTYLE ISSUES AND INFORMATION
What impact RRT will have upon your lifestyle? How best to fit dialysis round your life? Planning holidays and increased costs	IMPACT OF RRT AND CKD ON YOUR LIFESTYLE Told how your life, 'cause it can totally life changing isn't it (7) (need to be told affect on lifestyle) I had an inkling of what would happen that my life would have to revolve around the dialysis, but right at the very beginning I did not know that my life would go bang, stop, and dialysis takes priority. (12) I know eventually it will kill me, the eventuality I know it will. But you try and tell your children that this will eventually happen, they don't believe you. I mean I'm sixty at Christmas and I won't be here forever, not on dialysis I'll not (12) Oh very much so yeah I mean we used to go out an awful lot we used to socialise an awful lot but then when you can't drink and you can't eat an awful lot you end up just sitting in the corner and being the designated driver and its dull you know and again its things you adapt to and you do different things but yeah that was a bit of a shock at the time (15) Its your lifestyle but at the end of the day you've got something that's very seriously wrong with you and you've got to prioritise you know in my opinion I needed to try and keep myself as well as possible so there's nothing you can really sort of nobody can tell you this is what's gonna happen and therefore you've got to do this that and the other because then you just end up worrying about it all the time, there's nothing you can do on that. (15) That was good I would say yeah that was fine (enough information given about understanding what lifestyle change)(15) Even though you might be told something by the nurse who comes to see you I think it also is worth somebody else on the unit even telling you the same thing because there's so much going on in your life because you've got to get used to the fact that you're going to be going on dialysis…even though I knew that eventually I might have to you know you still think that it's a change in your life completely this you know everything about it you know going on holidays doing this doing that (18) FITTING DIALYSIS ROUND YOUR LIFE I think they have been clear that it doesn't have to rule you life and I guess it's whether you take that on board or not I certainly did and it was both an active work life and an active social life and I wasn't prepared to loose either (8) At the hospital they said its got to be every four hours on the dot well I would like to tell someone that it doesn't have to be every four hours ok so if you're gonna get swollen fingers then obviously you have to cut down your drinks don't you well you have to fit it round your life that suits you rather than this you know regimented kind of system that they have me believe (10) I think they should be telling you about the process of dialysis and how you can fit it into your life, look there are concentrate on solutions rather than the problems (10) HOLIDAYS AND TRAVEL (Lived abroad and travelled before needing dialysis) So had some sort of consciousness to make sure that I did something like that do you see what I mean whilst I still could and yet again I lived the life of riley…if I hadn't had kidney failure I wouldn't be back in the UK ok but as the NHS is free and fantastic as a service then of course I moved home (10)

	I wish I'd talked to someone who'd said oh I've been on holiday and I took my machine 'cause that's what I do now so I've got it ordered and I'll go on holiday with my machine I mean it is do able. (10) Well I lot harder 'cause you can't go a lot of places unless you want to pay and its silly prices for dialysis and insurance 'cause we won't mind going to America but we've found out its like £200 a session so and then if you get insurance that's so I lot of money… and you got to do it in advance you can't just say weekend oh lets go on holiday next week 'cause of the bloods and sorting your shifts out (14) How it would affect your life and that and your families life really… like that like ok it won't ever compare to your normal kidneys working but it will keep you going and give you a suitable life to lead (14) I've got some leaflets on having (holiday) dialysis but I don't feel ready to go just yet… Yes well I've collected it there is information in the waiting room (16)
KEY DESCRIPTORS	THEME 8: WORK AND FINANCIAL RELATED ISSUES AND INFORMATION
Need to continue working Need to be financially independent What dialysis would be best for me to continue working? How long can I expect to be able to work for? Will I have to give up work? How will the dialysis fit in with my work? Possible impact on career progression	ABLE TO CONTINUE WORKING It didn't dawn on me that I couldn't go that it was impossible for me to go back to work, if somebody had said and it when I was training 'cause I had all my dialysis (7) That was the most important thing for me was to carry on working you know (7) Well you need different things at different times don't you really you know, right at the start you need well I did I need to be told that there's a possibility that I wouldn't be able to work which was never told to me because they like everybody to go back to work don't they? (7) Well they'd want to know how it would affect them work wise, how it would affect their quality of life and how would they get over it… How do they (deal with it) what's the solution to it? (7) Well the most important thing for me to know at the time was how could I fit my work in with what I was doing you see (7) I wish I could tell people yeah actually you can work and you can you have a better quality of life if you work and why don't they have people to help them get jobs or to give them support (10) How long I can keep working for you know how many other people are working, what do they do (future) (10) I'm fortunate I feel quite strong but I wish that for me I was always gonna work always going to work to be independent I didn't like the idea of being dependant on my family… I want to be working and independent … It's just really really hard really hard (10) (needed to continue working and be independent) They wouldn't dream of saying to me in your future it will be like that 'cause I was asking him things like…because I went into teaching late I need to buy extra years for my pension but then what's the point if I'm not going to make it till I'm 60 working is it the likelihood I'll be able to keep working till I'm sixty the answer basically is dressed up as don't know (10) I think we need to know how long you can keep working on dialysis, what are the long term effects (10) As a teacher full time I feel quite trapped now really but we'll see how it goes you know…I'm in a no win situation really 'cause obviously now that I'm a dialysis patient and they do they will accommodate me for example my headmaster said if you need to go down to like four days a week for a term then we'll let you do this we'll get a supply you know but the reality of being a teacher is that you have to work really hard well I do anyway… I appear I want to look as if I can cope so I can compete and get other jobs and promotion so I don't discuss my dialysis particularly at work (10) (lucky to be in employment can't risk moving careers) (Information about impact of HD on work) Not really to a great extent, I will just work off it when it happens. They know I need to work, I have to work, and I can't go on part time or anything. I have to be full time. (13) The only downside of haemodialysis meant that I had to give up work but because I haven't been feeling too great I wasn't performing as well as I had been doing before hand anyway so I was starting to struggle anyway so from that point of view it was probably a bit of a relief really (15) FITTING DIALYSIS ROUND WORK Yes but it wasn't suitable for me (CAPD) I should have gone through to haemo really but like I said I wanted to carry on working as well so. (3) (chose PD because allowed him to work) I could actually cope with three bags a day not four I was actually doing three bags a day myself … I was a teacher so I couldn't fit in another bag … you have to fit it round your life that suits you rather than this you know regimented kind of system that they have me believe (10) (Used and adapted information to suit her own lifestyle to enable her to work full-time) (How are you going to work on the days you are…?) I'm going to work on the days that I am not on dialysis, and they'll pay me full pay. So that was one good thing. (13) I wanted to continue working and the job I was doing I was travelling up and down the country and I was overseas occasionally as well, and it would have been impossible to carry on working doing the job that I was doing when I had to go back into hospital three times a week where as CAPD would give me that additional mobility and I was able to fit my working life around CAPD a lot better than I could have done at the time (15) I just physically I couldn't do it that's why I was starting to struggle. I've been able to do it before and I could do it very very well and that's what I couldn't get my head around but with going onto Haemodialysis I couldn't physically do that job anymore so yeah I had to give up work. (15) I was thinking about working maybe two or three days a week so I was putting pressure on them to get me home as quickly as possible so I could carry on working and then the insurance scheme came out and other alternatives were discussed and all of a sudden there was no pressure on me to be up and running (15)

How will I feel if I had to give up work? What benefits am I entitled to if I have to give up work? Will it affect my standard of living? Will I be able to manage financially?	If I needed to I could work and again that wasn't a problem… the training unit will actually fit in around you and what you want to do and that was great for me. (15) (planned HD round being able to continue working for 3 days out of 5) IMPACT ON ABILITY TO WORK, CAREER PROGRESSION AND SELF-ESTEEM When I went on CAPD for the first eight months they just couldn't get it right… felt really unwell and missed loads of work which wasn't good at the time because I was in a more senior post to this and it didn't help… Yes it's affected my work, my thinking and everything because I was so poorly all then time… (Did you have to give up your position)… Suffered the results and got moved sideways… (Must have been hard)… (Sigh) Yes it was… but that's in the past now and I just have to let it go but it wasn't nice at the time but it didn't help certainly being on dialysis didn't help (6) I am absolutely knackered I mean usually …Monday I'm really quite good and Tuesday very good, today I'm feeling okay because I didn't come in till 1.30pm so I slept all morning but I don't have an option at the moment of being part-time and I don't think they will offer me part-time on a Managers post and I don't want to back again in my career… (6) (Impact of giving up work) on my own my feeling of self worth at the time because I thought I've always worked and I've always done fairly well and I had a good job and I'd been promoted regularly even with the start of dialysis and going through all of the problems I had on my health side I was still performing very well as with what I was doing and with struggling for the last twelve months… I couldn't put the hours in I couldn't do what I needed to do and also I think I was loosing my sharpness I didn't feel as I don't know the words really, I started to feel muddled headed which I wasn't before I was I used to know what I wanted to do and how to be able to do it and put in action plans to do things and I was struggling with basic things really and that was affecting the way I was doing my job (15). FINANCIAL IMPLICATIONS Then the next thing was no money. (7) (would have liked more information on work and finances not able to continue working) They were sorting out saying what the people worry about and they said well if you come off work and you don't know if you've never been on the social before you don't know what to do you know and people have said, look can't you work out and put something simple down what people have to do you know?… Oh yeah things like that would be useful (7) (information about what benefits entitled to) There was a lot of expense going out and not knowing whether we could meet these expenses or not. She (social worker) wrote letters to them filled the forms in all the forma and everything she filled in for the DSS or whatever it was then. (7) I wish there was proper you know what I mean support of for work or part time work another time as well I was really upset with being a teacher so I took the day off work one day and went down to the citizens advice bureau to find out about benefits I thought can I get away with not working and get incapacity benefit but you can't 'cause its rubbish you couldn't afford your mortgage with it (10) I did ring up my union my teachers union to find out about pensions … but they were unhelpful (10) (looking for information on pensions) (Financially you won't be any worse… having dialysis three days a week) No I won't be any worse off the only difficulty being at the moment 'cause it's taken so long is that I'm running out of sick pay now. So that's my difficulty…(opportunities to speak to a social worker) No (about your rights and sick pay) No (would you find that useful) Probably Yes (13) It would be better for benefits as well if you had proper benefits that you could claim without fighting for it.(14) (information on benefits) We've got no financial pressure at the moment and I would imagine we would probably be having a very different conversation if I didn't have that buffer (15) (had to give up work temporarily but company scheme means gets financial compensation)
KEY DESCRIPTORS	THEME 9: DIET AND FLUID RESTRICTIONS, WHAT AND WHY
Different treatments have different fluid and diet restrictions, what are the pros and cons? What you should and	DIET AND FLUID RESTRICTION INFORMATION FOR DIFFERENT RRT Yeah they gave me diet books and allsorts they were very good (6) I got facts sheets on low potassium and low phosphates which were really useful. To be honest I tend to ignore most of it because if I thought there was a problem I would cut down on those foods anything that I know id very high in potassium like bananas and other minerals I'll completely cut them out (8) I downloaded a dietary list also for renal units and other places and some of them were conflicting but overall I know what you've got to avoid tomatoes, mushrooms… (enough information)(9) Appointments every 6 months… a senior registrar might shout at me one time you know 'cause my figures (blood results) were rubbish …I'd get upset and I'd start crying and then within about three or four days I would just forget about it… They stressed about the importance of keeping well and having low salt and taking your tablets. (10) I saw a dietician at the very beginning when I was told about me kidneys and then I saw the Doctor, she explained a lot then but she was of the old school who did explain but I didn't know a quarter of what I needed to know… I think you do need a heck of a lot more, especially like the younger ones who are coming up now, which will eventually go on dialysis (12) I'm not on fluid restrictions, they did tell me but because I can go to the loo and pass urine I've never been on a fluid restriction (12) I would be on a fluid restriction yes yes they explained that to me so I thought well I'm not on it yet so that's fine by me but yes they did I think that will be the hardest thing 'cause I do drink and whether its part of I just drink. I like to drink water. Juice I do drink a lot so I know that will be hard when they say its only a little it might only be 500 I thought its not a lot (13)

shouldn’t eat and why? Why you need to be on a fluid restriction? How different foods affect what blood results? How to fit the diet restrictions round your lifestyle, finding the right balance?	The diet and fluid is better on CAPD what I know of ‘cause my friend used to do it so maybe if they tell them all the like pros and cons the only bad thing I see about this CAPD is having it constant through the day but that’s when you work it out you probably doing less than you would Haemo so you would have to work out the pros and cons. (new patient) (14) Gentler to you about fluid and diets mainly and like attitude and that… I hear a few staff members ok you know we know you know fluids that bad but you don’t have to keep on top of them and that making them feel like a child… its easy not drinking what would you do when its hot and summer you know dry its hard really and they don’t see it like that (more understanding) (14) Yes but I forget I think everybody forgets what’s acceptable and what isn’t you need updating. (Regular information on diet)… I used to just ask the nurse really and they’ll give me a leaflet or something or they’ll say don’t forget this don’t forget that (10) I think what would be a good thing as well certainly for me would be every three to six months actually sitting down with a dietician and just going over again what you can and can’t eat and how your eating, even keeping a diary of what you do and don’t eat over a couple of weeks and not sitting down and thinking right ok well I’ve got to do this I’m gonna eat well for the next two weeks but just eat as you do normal (more structured information repeated) (15) No well I don’t need to watch what I’m eating I’ve not I haven’t got problems with potassium and all that stuff they don’t bother telling me, all I had done was a concentration on vegetables which I’ve been doing now for about four or five years and its very helpful (17) Yes that’s why I’ve carried on so long ‘cause I’ve done so well like sticking to me diet, me fluids I mean like I say I’ve not ate grease for 23 years I’ve just have everything boiled like potatoes meat and veg. (19) (this information important if patients don’t want to get problems or want to last long on dialysis) I enjoy my food except when it gets stuck I don’t like that having to throw up ‘cause I don’t know whether it’s a reaction I’ve got its just something that’s happened recently, I must tell the consultant (experiencing problems eating) (13) No what would happen (18) (not been told why fluid restriction and what would happen if didn’t follow it) FITTING THE DIET RESTRICTIONS ALONGSIDE YOUR LIFESTYLE I don’t think any renal patients follow it (diet) if they’d be honest… Well I just limited myself I don’t like go say if I have chocolate I won’t say I’ll have chips or crisps on the same day but I won’t stick to a renal diet (14) I’d say eat what you like but don’t go mad on like you don’t eat like a bunch of bananas or something but you know just go enjoy (new patient) (14) I struggled initially and I still struggle to an extent with diet and that’s not because people haven’t told me but… I guess everybody goes through it its sort of trial and error and you find what you can eat and what you can’t eat but initially I found it difficult (15) Its important, diet and what you eat is important but you shouldn’t let it rule your life and you should be able to take things in moderation (new patient needs to know about diet)… I used to get shouted at quite regularly…I’d go in and my blood results would be all over the place and that’s because I’d I wouldn’t be paying too much attention to my diet and I still don’t now and but I think there’s got to be a balance that you can achieve between eating the right things and not eating the right things (15) The thing that struck me there’s a little old lady she must have been about seventy odd at the time and because it was coming up to Christmas she was getting really excited ‘cause it was the first time she thought she could have a mince pie and she was so strict on her diet that having a mince pie was a real treat for her and I was quite that’s no way to live (15) They’re going out like I say to parties and whatsit I don’t begrudge them doing that ‘cause I mean its not nice everyone else having a good time and you’re just sat there watching everyone else, no like on occasions yeah I do agree with them in that way but I wouldn’t go and do it all the time like just on occasions but I wouldn’t like tell them to eat every time they go out oh do this do that. (19) (would advise other patients to enjoy themselves but stick to the diet most of the time)
KEY DESCRIPTORS	THEME 10: TESTS, INVESTIGATIONS AND BLOOD RESULTS
What are the key indicators in my blood levels that I need to be aware of? So I can monitor	WHAT SHOULD MY BLOOD RESULTS BE – WHAT CAN I DO ABOUT IT? It would be good if they send you something with these are your blood results and maybe a target and this is what you need to do (6) I think don’t worry about the diet just worry about your what your blood results look like and if everything’s fine just carry on, at clinic I always ask about my potassium and phosphates and things just so that if they don’t tell me I will know myself. I quite like the clinic letters because I do understand what my creatinine and urea are (8) Yeah I do yeah I think so, so you can control it. (know what the different blood results mean) (10) Well what was my blood results on Tuesday, this is Thursday and Oh well I’ll find out in a bit for you Hilda, but in a bit never comes. Do you understand what I’m saying? … (Do you know what those blood results mean)…No I haven’t a bloody clue… I’d know if my potassium goes up I’d have an idea why but, that’s the only one I know about the others I haven’t a clue. (Would you like that sort of information) … Yeah but they don’t do that(12) All my blood results and what is what is what is what for why is that high why is it low why is it normal what do all them letters stand for ‘cause I haven’t a clue, I haven’t a clue (12) I ring up after I do my blood test every month anyway I usually ring up the surgery what my creatinine and my urea is and that’s how I know that I’ve actually gone down, ‘cause it was quite high… I can

myself, what is the target level that they should be? What can I do to make sure they stay within acceptable limits? What affect will raised levels have on my body?	tell anyway 'cause usually if I'm feeling off (13) I know most of them anyway (what blood results mean)…Yes yes I know like potassium (14) I think its better on the training unit that the main unit 'cause they (other patients) don't get their blood results or they don't tell them stuff (they don't get told anything) … No so I think main unit needs to come up a gear or two like the training unit… (pass on more information) Yeah yeah well I know some I suppose fifty, like you say some might want more and will help them out and some will say whoa what's all this I don't need all this I'm having hard enough time coming getting stabbed or whatever but some might just think like say you could you know potassium 7 they think 7 seems alright but if you know yourself its high and that so like that people might need to know stuff like that then just say look what food your eating and that and tell them why its you know what it can do to you that's I think they should tell you stuff like that (14) I've got the sheets downstairs and I've got something that I do refer to so I can see what the normal sort of range is and whereabouts I sit in that and what you would expect from a typical kidney patient and whether I sit within that or if I'm outside (someone told you about your blood results and what they mean).. I think its very useful yeah because the flip side of it is you can feel or you can come symptomatic of something for example I itch occasionally and I know that's because of high potassium and what have you as a consequence I need to cut down on things like chocolate and if you don't know that then you carry on quite happily doing whatever you do or if you over loaded you start feeling fuzzy and you feel like your skins too tight for your body so you cut down on drinks and you know its simple things but if you don't know the reason behind it (15) Know your own body bear it in mind these are the symptoms that your gonna feel and if you come up with those you've just got to be aware of it and certainly in the early stages going through and having regular blood tests and checks to make sure that you are you know your controlling things (new patient needs to know) (15) No I don't know (what blood results mean)…Well I'll probably ask him about my blood count again and has it come down (16) (what wants to ask the Doctor) Yes well I think they should do get together about once a month like and have your bloods and they should get them all together and tell them what the results are but like I mean its like now you don't have a clinic appointment and you don't have like Doctor's coming on the unit like years ago on a ward round we have our blood took every month and then we've got to wait to ask them what your results are 'cause they don't come and tell us we have to ask them (19) (would like more regular information about monthly blood results) They don't give me the blood results and I don't bother I think well some people might want to see them since they know what they mean (doesn't want to know) (17) Well they tell you what you yeah your creatinine and all this yes a lot…. (do you know what they mean) Not really no… (want to know)…I'd never been bothered I mean I've been going for years and I've never asked so… they understand what they all are, if I mean there are certain things I would probably asked over the years obviously. (18)
KEY DESCRIPTORS	THEME 11: PSYCHOLOGICAL ISSUES, COPING, FEELING DOWN AND FED UP
How best to cope and adapt to life with dialysis? Other people's experiences of how they cope? How to recognise when not coping? Who to talk to about how you are feeling? Where to get	HOW TO COPE – NORMALITY - STAYING POSITIVE No I look an dialysis as just a positive you know well not positive but you've got to be positive with it , is just a thing that's gonna have to be done. It's just like taking tablets but its putting erm putting cords tubes into another tube you know (1) It's not a major impact on your life if you don't let it be if you think as it as I'm a dialysis patient then it takes over your life If you see it like I do that it's just something I've got to do so often a day and I'm just going to carry on as normal (8) I think if you see yourself as ill and getting problems then you will get problems but if you're like me and you are bloody minded and I think you are not gonna stop me doing anything I want to do (8) You've got to be up haven't you, up beat a bit really (7) No not yet no (anyone talked to you about the psychological affects) (3) Nurse was fantastic she was really good she sat down she was very empathetic she very understanding about what I was going through and it wasn't just you know there is a shoulder to cry on, she came up with some very constructive things as well so she did start to sort of say well you might start feeling like this as well, yeah it was good I would say that side was very good. (15) I just take every day as a bonus really (not on dialysis) (11) The only thing I do to keep myself what sit is keep myself active do things round the house and that get out to my sisters shopping with my mam. That's the only way I can but its just if I'm sat in and then its only if I'm sat, sat in and then I start thinking things that's when I start feeling down (19) PEER COMPARISON Nobody talked to me about the psychological impact of the disease… probably because I don't worry or stress over things at all, I'm not an anxious kind of person....I'd seen my dad die of cancer and my mum suffer for years with lung disease so I'd seen people go through some horrific illnesses and I was asymptomatic I was feeling fine and it was just a slight inconvenience really so it was not something worried about (8) I've kept going because if I get engrossed in my work I forget I do know just listening to people a lot of them sit around all day watching day time television and you know it's a living death (9) Well it's got to be done and that's the end of it, I don't bother there's no two ways about it. I mean come on, I've had a good life, and before I went on dialysis I was very very fortunate, not a lot of people

support? Who to talk to?	are as fortunate as I was. (12) I wish I had met other patients on dialysis who could tell me the ways that they had learned to cope before. I feel as if I've had to find my own way. (10) ADAPTING TO THE SHOCK OF NEEDING DIALYSIS The nurse does try and tell you I think that you know its going to be a big change and I knew myself it would be but its only just now I think obviously what's happened to me is because (gets upset) (18) (only just realising what a restriction to lifestyle it could be) I think in retrospect they could have prepared me more it was a real shock to me (6) (more information to prepare psychologically for the shock of needing dialysis) I got quite upset and oh my god its such a change to my life I wasn't expecting this and I remember the sister saying to me now come on its not that bad and you know, after I left I thought how could she say that to me, what do you mean its not that bad I'm forty years of age you know and I've just been told I'm going to die and that sort of thing you know that it's the end of my life I'll be on dialysis you know that (6) (when first found out needed dialysis) When I was first told I went to pieces, don't get wrong I did go to pieces when they said I was going on dialysis, and it wouldn't belong and I thought how am I going to cope? But I did cope, I thought, well you've got no choice, your choice is two things you have it done or you die. (12) Again its things you adapt to and you do different things but yeah that was a bit of a shock at the time (15) (hard to adapt social life to restrictions) THREAT TO SURVIVAL I do get my days where I'm feeling really down… I'll say to my mam well what if we can't do owt else and they've tried the family and they can't give me a kidney (realising running out of options now threatening survival)… I was alright at first but since I've been doing all these (attempts to get good access for dialysis) and they packing in now I said to me mam I said I don't know what to think now (worried about future) …I said to me mam it doesn't look as though they're gonna get things done what I want them to get done (19) (threatening survival and achieving life goals) DENIAL – DEAL WITH IT WHEN IT HAPPENS Ok don't have any salt in your food and take your tablets your blood pressure tablets and that's it… I went into denial and I didn't follow my diet and I didn't take my tablets. (10) I think its because it was shock and I just couldn't deal with it I really couldn't deal with it at all and I didn't feel…I looked very well so and also I had no symptoms I couldn't feel any symptoms so I didn't want to deal with it at that time (10) Appointments every 6 months… a senior registrar might shout at me one time you know 'cause my figures (blood results) were rubbish …I'd get upset and I'd start crying and then within about three or four days I would just forget about it… They stressed about the importance of keeping well and having low salt and taking your tablets. (10) I was first informed that I would be on dialysis so I was finding out about dialysis and I found it too shocking 'cause I knew it was gonna happen anyway but now ok now I'm a bit more mature and trying to make some better plan and not in denial well maybe I am a bit in denial but a bit more coping better I'd like to know about my future (10) my philosophy as well I'm still me I'm no different to how I was yesterday they're not saying right, every time I do go to clinic I do get worked up 'cause I think oh are they gonna start you know saying right this is happening that is happening you need to this you need to do that so I do get really stressed before I go to clinic but other than that its like well lets deal with today. (11) No like I said I'm one of those I'll just go along until it happens and when it happens it will happen there's not a lot I can do about it. So why worry about it between now and then… I don't even think about it normally (4) FEELING DEPRESSED –DISCUSSING EMOTIONS I don't know how I mean I've stood here myself since, how I got over it I have really but like I say I was that ill but me confidence had gone I couldn't talk to anybody like I'm talking to you now it was all gone, anybody wanted to boss me they could boss me well I wasn't like that. (5) (Depressed) The worst things is the liquid restriction I'm restricted to 750 mls a day …the thought that this may go on for the rest of your life is actually quite depressing…. at times you get so fed up with the whole thing (9) I remember going in and just being massively depressed really you know lost quite a good job and salary and one of the first things this nurse who's quite old says to me was and you'll go up two dress sizes and I was devastated by that never mind the idea I'm going onto dialysis (10) (prospect of the future was depressing) I hate it I hate being connected to a machine really but its something that you've just got to face and get over (10) (hates the tube and being connected to a machine) I felt very isolated I couldn't talk to my family or friends about it they had no idea (10) I think that emotionally its really important for you to be you have to be strong emotionally to be a success …I don't think I'm necessarily very successful is part of it is managing emotions (10) You tend to find that don't you you like manage emotions isn't it the being constrained and controlled and all those sort of issues I do get upset about it all the time its just managing it really isn't it… they don't talk to you about your emotions. (10) (lack of psychological care) No it's functional they don't talk to you about your emotions no (need more discussion of emotions, support not information)… Definitely but maybe I'm a very emotional person who knows or maybe

	I'm a person who needs to talk about it who knows but I wish there was somebody there… I don't want to see some clinical specialist you know about these personal problems of mine do you know what I mean I would rather share it with other patients but there seems to be limited access to that and patient groups seem to be about tablets and diet rather than talking about emotions you can I don't know its really hard it's a hard thing isn't it. (10) Well your gonna have your bad days on dialysis you know it really gets to you I don't think sometimes they realise how much it means to you, they keep when you moan and that they say oh were keeping you alive but you know I don't think they know what how it means to keep coming three times a week for like seven six years constant even at Christmas bank holidays, they have two weeks off and whatever but we don't so its more probably understanding might help (14) Maybe it might be well it could warn them or something (should people be told that they might feel depressed) I think it should be warned 'cause like I say I've been through it few times even with my transplant 'cause if your look in my notes I'm gonna be I didn't take my anti rejection drugs 'cause I was so down and that to me I have hurt my own self by doing that anyway being on dialysis I hold my hands up and admit that but I didn't get no (information)… now I can (recognise the symptoms) because like I say I've been to the physiatrist and that with the tablets but at first I didn't and it could have went on for weeks and months and this time around I was lucky I caught it early enough (14) That's it but it's just more talking to them and you know when you're depressed you know helping you out and that… I've seen the psychiatrist at hope and I'm on tablets and that with depression and that….(hard to keep positive) Yeah it is that's why I say you know your family's good but what if you've not got family and that its a lot to come too hospital three times a week…I can (recognise it now) because like I say I've been to the psychiatrist and that with the tablets but at first I didn't and it could have went on for weeks and months and this time around I was lucky I caught it early enough … I'm alright I go and talk to the sister and whoever and tell them now (14) it is it has been getting to me 'cause I'm not at home I'd rather do it at home than dialyse here 'cause I'm been used to doing it at home (19) (more depressed 'cause not in control of own dialysis anymore)
KEY DESCRIPTORS	THEME 12: OTHER PATIENT EXPERIENCES – TALKING TO OTHER PATIENTS
What experiences have other patients had? How do other patients manage? Practical tips on what has worked for them What is dialysis really like? Give advice to other patients	OTHER PATIENTS EXPERIENCES You also saw people rushing in, in the middle of the night, chances are they had let it get too far without getting in touch, made me realise that needed to ring up if had a problem before it got too bad (8) One thing I did find useful was being on the ward talking to other patients I don't tend to believe Doctors when they say it won't hurt I would rather find out from someone whose had it done (8) I think talking to patients was one of the most useful things I ever did I got more information from them than I did from the medical team if you were going to offer a renal service a patients representative to talk to then you'd have to select someone who isn't going to try to just worry people but give them a good and clear picture (8) Yeah I'd like to know how ill people feel (with vasculitis) yeah… I know what your getting at some people don't want to know in case its bad news no I want to know (9) I wish I had met other patients on dialysis who could tell me the ways that they had learned to cope before. I feel as if I've had to find my own way. (10) I wish I'd met other young people who said actually you can get round it by doing this really you know now obviously I take more risks but I don't feel guilty well they're more like calculated risks aren't they (10) I wish I'd talked to someone who'd said oh I've been on holiday and I took my machine 'cause that's what I do now so I've got it ordered and I'll go on holiday with my machine I mean it is do able. (10) Yeah. (more visits to the unit to see what was going on with other people)…It would have been useful if you could have sat down in another room or sat down talking to someone who was on dialysis and saying well what does it involve? I didn't even know there was a special diet… if you could have sat down when I was told you were going on dialysis, even before I went on it, like nine months previous. Sat down in a room and talked to people that are on dialysis and what the diets about (12) Well if they are anything like me they should be told a lot more information, go on a group of people who would be willing to discuss what dialysis is like… somebody on dialysis to come an speak to you, not ten or fifteen twenty minutes or even an hour, to give you a good two hours talking or literature written down (12) When you see a nurse whose been going out and she's in the community… they tell you what other people are trying and what's working and what not for them. (practical tips) (15) There were two ladies in the waiting room on those machines and they said it suited them really well one did it at night and the other one had a young baby (you mean machines for your stomach not one where you put needles in)… Yes no I can't put them…one preferred to do it in the day time and do that. And then the other lady said to her well did you not know that you can come off it you can stop it and come off it and then go back on it a little bit later and she didn't know that (sharing information in the waiting room) (16) I've had a few patients asked in the unit how have you coped all these years how've you carried on all these years said through looking after myself keeping myself well and exercising and that and just getting on with it 'cause there's one young lad he's waiting to go home he said what's it like dialysing at home, I said its all right I said its better dialysing at home than it is in the hospital 'cause you can please yourself when to go on, what time you go on get off I said (19) (advice to other patients) OPPORTUNITY TO TALK TO OTHER PATIENTS No (did you speak to other patients)…Well I think it would be yeah (useful) (7). When I came in for my catheter done this time there was guy waiting for the same and he was fairly clueless like I was first time round, so I told him what other patients had told me, he was concerned he

	wouldn’t be able to go away on holiday or that it as going to take hours to do his exchanges and these are things that people don’t feel comfortable asking Doctors, I was chatting to them saying it’s not a major impact on your life if you don’t let it be (8) I was talking to another patient on the ward who wasn’t doing that well and I said hang in there because you will get a transplant eventually and he said I’m not sure I want one I’ve heard they put you on all these nasty drugs that make you get lots of infections and you can’t go near crowds of people so I don’t know where he’d got that information from but I was able to say don’t worry about it soon you’ll be better off than you are now so long as you are sensible I guess some people worry all the time about everything (8) I guess if you don’t have problems you won’t have the interaction with other patients that I found really helpful and I don’t know how you can formalise that without it being uncomfortable for some people (8) I wouldn’t go to a PD support group if they created one if I’m honest because I can’t think of nothing worse than surrounding myself with sick people, if someone asked me to talk to another patient I would (8) (Would you have liked to have spoke to other patients) No I’m happy to not, I wouldn’t want to hear horror stories I don’t think before hand... I wouldn’t want the scary stuff before hand… no there’s only so much I could deal with so no I’m quite happy with knowing he said have the needles put in and I’ll deal with that happens.(13)

Appendix 13 Table 24: Comparing Themes, Categories and Key Descriptors

Literature – Categories and Key Descriptors	Interview – Themes and Key Descriptors	**Theme Generated**
Chronic kidney disease information *Information on ESRD* *How the kidneys work?* *What's gone wrong?* *How will the disease progress?* *How to minimise the effects of the disease?* *Will I get better?* *What are the chances of survival, realistic expected life span?*	CKD, progression of the disease, what why when not working, what to expect in the future *Am I stable?* *Is there anything I can do to stay healthy?* *What is the cause of my kidney disease?* *What do the kidneys actually do?* *What will happen what can I expect?* *How will the disease progress?* *What is the prognosis?* *How soon will I need dialysis?* *What is the future?*	**1. Information about what is chronic kidney disease, what is the cause, how will it progress, what is the future**
Physical symptoms / body image *Information on expected physical symptoms, physical side effects of RRT how to manage these problems* *The affects on body image and physical appearance of RRT and CKD* *Information on sexual health/sexuality*	Physical symptoms as a results of RRT and disease, what to expect and information, altered body image / sexual health *What physical symptoms to expect as a result of the disease?* *What physical symptoms to expect as a result of the treatment?* *What to do if you experience physical symptoms?* *How the treatment and disease could alter your body image?* *Impact of disease and treatment on sexual health*	**2. Information about how the disease will affect my body, how to recognise symptoms and what to expect**
RRT and transplant information *What are the RRT (HD/PD) options?* *Independence versus dependence (home HD/PD) (in-centre HD)* *Accurate information on transplant success rates* *Related donation* *Expectations of a transplant*	RRT (options, advantages and disadvantages of different treatments) what they involve *What are the different treatment options?* *What are the advantages and disadvantages of different RRT?* *Why can't I have a certain treatment?* *What does each treatment involve?* *How does it work?* *How effective is RRT at replacing the functions of the kidney?* *When will I start?* *Transplantation what does it involve?* *Advantages and disadvantages of having a transplant?* *Different types of transplant?* *How long will I survive with a transplant, what can I expect?* *Is there an age bias for transplants?*	**3. Information about the different treatment options, the advantages and disadvantages of each treatment (HD, CAPD, Transplant, APD) what the different treatments look like**
Practical issues of RRT *Schedules, time required for*	Practical aspects of RRT *What are the practicalities of having the treatment I selected?* *How does it work, what happens during dialysis?*	

dialysis, Access *Adequacy of RRT* *Will I need it long-term to stay alive?* *Information regarding withdrawing/stopping treatment* *End of life decisions*	*What does the training involve?* *Base weight, Shift times and changing shifts (HD), Number of exchanges (PD), Using different strength bags (PD), Amount of stock and supplies, Transport issues (HD)* *Need to have access for dialysis – what is the involved in creating access?* *What are the different types of access?* *What access problems can occur, what can I expect?* *How do I care for my access?* *Can I choose where my access is positioned?* *What happens if access fails?* *Changes in treatment regime or changing to a different treatment* *Long-term effects of RRT – What can I expect?* *How long for?* *What happens if run out of access options?* *How often do I need blood taken for transplant list, and what for?* *What is my tissue typing, how are kidneys matched?* *How will I know that I'm on the transplant list?* *What are the risks of having a transplant?* *What are the complications or side effects of having a transplant?* *How long can I expect to wait for a transplant?*	**4. Information about the practicalities and facts about what happens when I start, or change a particular treatment, up to date information on treatment changes (access, shifts, schedules, fluid restrictions, base weight, ordering stock, adjusting regimes)**

Complications of both disease and treatment *Complications of the both the disease and treatment, renal bone disease, risks of infection, hypertension*	Complications and side effects of RRT and disease, what to expect and information *What complications to expect?* *How to recognise a complication?* *What to do if experiencing a complication?* *How to avoid complications?* *What is the chance of getting a complication?*	**5. Information about what complications or side effects I can expect as a result of the treatment or medication I'm taking**
Medication *Information on medication prescribed, what for what and side effects*	Medication information and possible side effects *What are the side effects of the medication?* *Why am I prescribed this medication, what is it for?*	

Diet and fluid restrictions *Diet and fluid restrictions with respect to different treatments and prior to treatment*	Diet and fluid restrictions, what and why *Different treatments have different fluid and diet restrictions, what are the pros and cons?* *What you should and shouldn't eat and why?* *Why you need to be on a fluid restriction?* *How different foods affect what blood results?* *How to fit the diet restrictions round your lifestyle, finding the right balance?*	**6. Information about things I can do something about diet, medication, how to keep my blood tests stable or make them better**
Tests *Information on all the tests and investigations sent for and feedback on the results and what they mean*	Tests, investigations and blood results *What are the key indicators in my blood levels to be aware of?* *What is the target level, so I can monitor myself?* *What can I do to make sure they stay within acceptable limits?* *What affect will raised levels have on my body?*	

Family and social life *Organising holidays – ability to travel,* *Ability to perform leisure activities* *Have a normal life* *Maintain social life and lifestyle*	Family and lifestyle issues and information *What impact RRT will have upon your lifestyle?* *How best to fit dialysis round your life?* *What do I do about going on holiday?*	**7. Information about the impact chronic kidney disease and the treatment will have on my daily life, social activities and work opportunities**
Work and Finance *The ability to continue working* *Financial information*	Work and financial related issues and information *What dialysis would be best for me to continue working?* *How long can I expect to be able to work for?* *Will I have to give up work?* *How will the dialysis fit in with my work?* *Possible impact on career progression* *How will I feel if I had to give up work?* *What benefits am I entitled to if I have to give up work?* *Will it affect my standard of living?* *Will I be able to manage financially?*	

Other patients experiences *Other patients experiences or treatment and coping*	Other patient experiences - talking to other patients *What experiences have other patients had?* *How do other patients manage?* *What practical tips have worked for them?* *What is dialysis really like?* *How do some patients manage work and have RRT?* *What can I really expect?* *Other people's experiences of how they cope?*	**8. Information from other CKD patients, what is it really like living with CKD and receiving treatment, practical tips on what I can do to make things easier (what are other peoples experiences)**

Psychological impact *Information regarding the impact psychologically of having CKD and experiencing the treatment – stress, depression, anxiety, independence vs. dependence, coping*	Psychological issues, coping, feeling down and fed up *How best to cope and adapt to life with dialysis?* *How to recognise when not coping?* *Who to talk to about how you are feeling?* *Where to get support?* *Who to talk to?*	**9. Information about where I can get additional support if I'm feeling fed up or depressed and need someone to talk to**

Appendix 14 Patient Verification of Information Need Topics

1. Information about what is chronic kidney disease, what is the cause, how will it progress, what is the future	*Yes*	*No*	*No Comment*
Easy to understand	13	2	1
Appropriate/relevant to a CKD patient	13	0	3
Makes Sense	13	0	3

Comments about the theme content and wording:
'The future is the most important'
'What is the future – presumably you mean what is the future regarding likely developments in treatment'
'Each patient is an individual so maybe difficult to predict timescale of progression'
'The wording hard to understand but otherwise okay'
Comments about their own experiences:
'It is essential that patients make sure they understand what they are told. As I was really down when I was told and did not understand it at all'
'Causes never really explained to me'
'I would like more information on this theme'
'Sometimes too much information is scary for a patient to understand in one go. Every patient will have an answer'

2. Information about how the disease will affect my body, how to recognise symptoms and what to expect	*Yes*	*No*	*No Comment*
Easy to understand	13	1	2
Appropriate/relevant to a CKD patient	14	0	2
Makes Sense	13	0	3

Comments about content and own experiences:
'You need to know what a symptom means again for the future'
'Very useful but list of symptoms would be good'
'How it will affect my body and what the symptoms are never really explained'
'Having cramps and muscle pain at the present time during the last half hour of dialysis'

3. Information about the different treatment options, the advantages and disadvantages of each treatment (HD, CAPD, Transplant, APD) what the different treatments look like	*Yes*	*No*	*No Comment*
Easy to understand	14	1	1
Appropriate/relevant to a CKD patient	15	0	1
Makes Sense	15	1	0

Comments about the wording and content:
'No idea what HD, CAPD and APD are?'
'Would like to know which treatment would benefit me personally'
'This is important! Patients must make an informed choice, I didn't have this information properly explained to me'
'It's easy for me but people who are just beginning need to know more and put it into words they can understand'

4. Information about the practicalities and facts about what happens when I start, or change a particular treatment, up to date information on treatment changes (Access, shifts, schedules, fluid restrictions, base weight, ordering stock, adjusting regimes)	*Yes*	*No*	*No Comment*
Easy to understand	13	0	3

Appropriate/relevant to a CKD patient	14	0	2
Makes Sense	14	0	2
Comments about the wording and lack of information on this topic: *'I think this is spot on'* *'Knowledge helps us to understand what will happen in the future with our treatment'* *'When a patient really understands it's all right, but can be hard at the beginning, everyone is not as quick learning it at the first few times. Then it is like you've always been on it'* *'The information is not covered in sufficient detail'* *'I need more information'*			

5. Information about what complications or side effects I can expect as a result of the treatment or medication I'm taking	*Yes*	*No*	*No Comment*
Easy to understand	14	0	2
Appropriate/relevant to a CKD patient	12	2	2
Makes Sense	12	1	3
Comments on content and importance of topic: *'This information needs to be provided at an early stage as possible in the treatment process'* *'This is important, if you know what to expect, you can contact the doctor immediately. However, if you expect to have a side effect imagination is a powerful thing'* *'I did not know some side effects at first, but with time I understood more about them, which I should have known from the first'* *'Be good to include details on how best to avoid or ameliorate these symptoms/problems* *The information is not covered in sufficient detail'* *'This was not properly explained to me'* *'A lot of people don't understand about all the medication and what it's for, as no-one tells you* *It could mean for anyone not just renal'*			

6. Information about things I can do something about diet medication, how to keep my blood tests stable or make them better	*Yes*	*No*	*No Comment*
Easy to understand	11	3	2
Appropriate/relevant to a CKD patient	12	1	3
Makes Sense	11	2	3
Comments about content and timing: *'Could help explain it better'* *'To be given early on in treatment process'* *'Would understand the diet better once on dialysis'* *'Never been explained'* *'This question is a bit difficult as your monthly bloods go up and down'* *'Once the damage is done to the kidneys isn't it almost impossible to reverse CRF?'*			

7. Information about the impact chronic kidney disease and the treatment will have on my daily life, social activities and work opportunities	*Yes*	*No*	*No Comment*
Easy to understand	14	0	2
Appropriate/relevant to a CKD patient	14	0	2
Makes Sense	15	0	1
Comments about content and own experiences: ***'Seems okay'*** *'Including the impact on those around me (family)'* *'Being told your life need not change is a great lift'* *'Again I had to work this out for myself'* ***'I have never had information about how it will affect my daily life'***			

8. Information from other CKD patients, what is it really like living with CKD and receiving treatment, practical tips on what I can do to make things easier (what are other peoples experiences)	*Yes*	*No*	*No Comment*
Easy to understand	13	1	2
Appropriate/relevant to a CKD patient	14	0	2
Makes Sense	13	0	3
Comments about the content and lack of this information: *Not all people would want this info* *'This depends on whether experiences are good or bad. Bad experiences can have a very, very negative effect'* *'I think this is really useful. I certainly found other patients experiences invaluable as it gives a truer picture of what to expect'* *'I have never been introduced to other PD patients'* *'When asked, other patients have talked to me about their treatment. I have been shown a fistula and a PD patient has explained hers to me'* *'I wish I had more patient contact'* *'I never met any kidney patients on dialysis before I went on so it would be nice for other people if they are a support group'*			

9. Information about where I can get additional support if I'm feeling fed up or depressed and need someone to talk to	*Yes*	*No*	*No Comment*
Easy to understand	14	0	2
Appropriate/relevant to a CKD patient	12	1	3
Makes Sense	13	0	3
Comments about content and timing and own experiences: *'In latter stage of the disease'* *'No-one really told me about this, vague ideas about patient associations which seem to be for older patients'* *'Yes it would be nice to speak to someone when I feel down'* *'Never been explained'* *'I have been very depressed more than once but the nurses at the renal unit have been good and helped me a lot'* *'All the nursing staff are good listeners and will bring information when asked'*			

Is there any theme/ topic area that you think is missing?
Information about benefits/allowances available and how to help claim them

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