

BEING BELIEVED AND BELIEVING IN:  
THE IMPACT OF DELEGITIMATION ON PERSON-  
CENTRED CARE FOR PEOPLE WITH CHRONIC  
BACK PAIN.

Michelle Louise HOWARTH

Ph.D Thesis

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BACK PAIN.

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  - **Appendix 1b:** Copy of a paper submitted to the Journal of Inter-professional Care: Howarth, M, Warne, T, Haigh, C. 'Let's Stick Together'! A Grounded Theory Exploration of Inter-professional Working used to Provide Person Centred Chronic Back Pain Services. Revisions invited.
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## **Thesis Abstract**

Chronic back pain is an under researched area; the complexities of unseen pain in particular, present challenges to the sociological assumptions made about the concept of 'sickness'. The lack of 'visible' signs and symptoms means that some people are left without a diagnosis. If left undiagnosed, their experience of chronic back pain becomes delegitimized and could result in the erosion of self-esteem, self-identity and personhood. Undiagnosed chronic back pain can undermine a person's moral self through disrupting the person's biography and self-esteem. Ultimately, people with chronic back pain need person centred approaches to care that support the restoration of the self. The aims of this study were to generate a theory of person-centred care predicated on the experiences of people who have chronic back pain. The research design was influenced by a constructivist paradigm, which underpinned a Grounded Theory methodological approach. A purposive sampling strategy identified 17 people with chronic back pain and 4 multi-professional teams who were involved in their care. Semi-structured interviews with people who have chronic back pain, and the multi-professional teams captured the experience of person-centred care and explicated meaning about its key concepts. Data were analysed using a constant comparative approach through which theoretical sensitivity developed and eleven categories emerged. The 'conditional partnership' became a core category, which formed a substantive theory to explain the experience of person-centred care. The key findings highlight the significance of legitimation on the chronic back pain experience and exposes the impact that 'delegitimation' has on the individual's ability to mobilise resources and manage their pain effectively. This thesis presents the conditional partnership as a theory which explains the relationship needed to support person centred care. The theory suggests that person centred care for people with chronic back pain is underpinned by a conditional partnership which is made up of three conditions; being believed, believing in and non-maleficence which represent the expected conditions of health care and by health care.

## **Structure and Context of this Thesis.**

This thesis presents an exploration of the meaning and experience of person-centred care from the perspectives of people with chronic back pain who have been looked after by a multi-professional pain management team. The thesis was influenced by a constructivist Grounded Theory approach, which was used to generate a theory about the relationship and conditions associated with person-centred care. The theory was informed by psycho-social and ethical constructs and proposes that person-centred care is predicated on a conditional partnership that engaged participants within an ethical narrative through a co-validated relationship to repair the disrupted biography, recover the moral self and restore the(ir) person.

### **i. Overview of Chapter 1**

Whilst writing this chapter, I was reminded of a conversation with a colleague who suggested that a PhD is often inspired by both the individual's personal life and professional nursing experiences. At the time, I was not convinced, however, I now realise the extent to which these experiences have shaped the thesis. The first part of this chapter therefore presents an account of my personal location; the significance of chronic back pain and how this influenced the decision to explore person-centred care. The ways in which personal ontological assumptions have directed the research are explored later, after which an overview of the thesis structure, aims and context is provided. The chapter concludes with a comment by one of the research participants called Nina, to enable the reader to get an early 'feel' for the individuals' experience of chronic back pain.

### **ii. Personal Location.**

My interest in person-centred care originated through reflections on the care my father had received in his last years of life. Dad was 'ex-army' and had served in the Long Range Desert Rats (Group) during World War 2. He had an array of medals and was awarded the Military Medal for his bravery in defending his best friend, Tom, against a German attack. In later life, he documented his experiences in a short book and talked

extensively about the military campaigns he had been involved in. He was incredibly proud of his past and would often recall details about living in the desert, the specialist team he led and the dangers he faced. As a young girl, I listened to his stories and believed my dad was invincible. He taught me about bravery, compassion and commitment.

Due to chronic heart disease, Dad suffered from a number of heart attacks, and before he died in 1982, he had been repeatedly admitted to hospital where he became 'a patient'. He did what he 'was told' and complied with a system based on rigid traditional practice. On reflection, the nursing staff did not appear to see the person, and did not know how brave he was; they did not realise what he had achieved during his time in the army. The nurses treated dad as 'someone' who had suffered a heart attack – who needed monitoring and protecting, who had to have his pulse recorded, who wasn't allowed out of bed for a short walk because he could have another heart attack.

Two years previously, in a conference to the Commonwealth University of Richmond, the nurse theorist Virginia Henderson (1980) asked:

*“How can we make it possible for nurses to ‘get inside the skin’ of patients, or clients, and discover what help they need and can use; what sort of health regimen or plan of care can then be developed with them and their families that will foster independence, optimum coping behaviour, or a peaceful death.....She later added that “Humane service from all health workers is, in the last analysis dependent on what societies value. Nurses are part of these societies and do, of course, influence those values.”(Henderson, 1980 p 247)*

Henderson believed that understanding the individual was central to the essence of caring, yet, for many individuals with experiences similar to my father's, admission into hospital reflected a world where the ill become homo patiens, or a patient or a person bearing a burden or distress, pain or anxiety, a person wounded (Pellegrino 1976 p158). The concept of personhood is considered to “be a standing or a status that is bestowed on one human being, by another in the context of relationship and social being’ (Kitwood, 1997p8). Crucially, it is acknowledged that ‘personhood’ becomes compromised during illness, which can ultimately damage self-esteem as, it relates to the person's identity, personality, self-awareness and ability to be autonomous. Within

the context of chronic illness, helplessness may be exacerbated and can challenge personhood through increased vulnerability, ambiguity about rational choices and dependence on others (Pellegrino 1976). It is also understood that the 'patient's' reliance on others may be largely due to the way in which professional caring is predicated on the ethical principle of beneficence which can undermine autonomy and compromise personhood (Woodward 1997). The damage to personhood is also thought to occur as a result of the invisibility of pain, hence reported instances of people with chronic pain being disbelieved was frequently described in the literature (Glenton 2003, Sveilich et al 2005). Moreover, Reid et al (1991) described how people with chronic pain are often labelled as having 'malingaraphobia' which means that their pain was not seen as real. As such, many people with chronic pain have undertaken a pilgrimage in search of confirmation or as Reid describes 'moral affirmation" (p602). Increasingly, it acknowledged that person-centred approaches, which embrace the person rather than the patient, could reduce this vulnerability, enhance autonomy and help to legitimise the existence of an individual's pain. For instance, Clarke *et al* (2000), Clarke (2003), and Ford & McCormack (2000) suggested that facilitating a person-centred approach means entering into a partnership with 'the patient' as a person to facilitate their choice in care. Professional carers [health care staff] therefore have a hefty professional and moral responsibility to care for the patient to rescue the person and reform them to an independent state.

As a daughter, observations of the care my father received highlighted his vulnerability that ultimately led to his compliance with care; as a qualified nurse, I witnessed how the patient rather than the person was cared for predicated on the 'management of' signs and symptoms; as a lecturer in adult nursing, the demise of the individual was frequently described by students and now as a researcher, I have been able to 'get inside' the patients' world to better understand this experience.

### iii. The Significance of Chronic Back Pain and Person-centred Care

Chronic back pain is a significant problem affecting a large number of people in the United Kingdom (UK) and abroad, and the impact it has on the individual is profound. Chronic back pain is the most commonly reported reason why people seek medical advice accounting for almost 7 million General Practitioner (GP) visits annually; subsequently, costs to UK businesses are calculated to be £5 billion per annum. It is estimated that the NHS spends approximately £481 million per year on caring for people with chronic back pain, with a further £197 million spent on non-NHS costs such as private consultations and prescription (<http://www.backpainexpert.co.uk> accessed 25<sup>th</sup> January 2012). These figures indicate that people with chronic back pain represent a significant number of the primary care population receiving care from health professionals and other alternative agencies.

Chronic back pain can lead to depression, time off work and relationship breakdown, and can be a drain on both employer and health resources; hence, people with chronic back pain are also at risk of being labelled or falling into the stigma associated with chronic painful conditions or seen as 'heart sink' patients (Werner and Malterud 2005). It is acknowledged that the associated stigma impacts on the individual's self-esteem and can damage their personhood (Ware 1992). The person frequently becomes a patient through the operationalisation of the pain experience, measured through care based on medical models. Bendelow and Williams (1995 p140) concerns about the influence of the medical model on the care of people with pain illustrated this point when they suggested that:

*'The field of pain has traditionally been dominated by biomedicine and concentrates upon the neurophysiological aspects in much of diagnosis, research and treatment. Hence, scientific medicine reduces the experience of pain to an elaborate broadcasting system of signals, rather than seeing it as moulded and shaped both by the individual and their particular socio-cultural context' (Bendelow and Williams, 1995, p140).*

Bendelow and Williams (1995) views mirrored Jewson's (1976) original observations of the paradigmatic shift in a health care system, which historically based 'care' on the medical conception that the whole person consisted of a network of bonds of



microscopical particles. Similar to Bendelow and Williams (1995), Jewson (1976) argued that a health care culture predicated on the science rather than the art of care had emerged. The resultant belief in the person as an 'integrated conception' made up from the signs and symptoms they 'display', meant that the 'sick man' disappeared and had been replaced by the concept of 'the patient'. Reassuringly, contemporary professional health care appears to have recognised the importance of person orientated approaches and threats to personhood through disability such as chronic pain are slowly being acknowledged; however, the extent to which person-centred care has been affected is unclear particularly within the context of chronic back pain.

#### **iv. Person-centred Approach to Chronic Back Pain.**

The impact of chronic back pain on the population's health and well-being was globally acknowledged as a significant threat to public health which influenced the introduction of the World Health Organisation's 'Decade of the Bone and Joint 2000–2010' in an attempt to draw together multi-professional teams to tackle the disabling condition (Woolfe 2000). The complex issues associated with chronic back pain and its impact on the individual's physical health and mental well-being led to the development of multi-professional pain management programmes designed to help rehabilitate people with chronic pain. Learning to manage the pain rather than expecting a cure is the preferred approach usually needing the involvement and coordination of physiotherapy, nursing, medical and psychology health professionals to restore function and the person through re-instating self-esteem and independence. At the start of the millennia, the UK Clinical Standards Advisory Group (CSAG 2000) developed recommendations for the management of chronic pain. Their review of the contemporary evidence base identified the effectiveness of a multi-professional team approach to pain management that was unified and which embraced the complex needs of people with chronic back pain. Multi-professional working was also advocated by the Royal College of Anaesthetists (RCA) and the British Pain Society (BPS) in 2007 along with flexible working arrangements and referrals to specialist areas. It is recognised that multi-professional pain management

programmes (PMP) that use structured rehabilitation pathways are an effective approach to help people control chronic pain (Guzman et al 2002, Morley et al 1999, Dysvik et al 2004) and are now recognised as a fundamental rehabilitation approach (Howarth & Haigh 2007).

A pain management programme usually consists of 8 to 10 people with chronic pain who attend the programme over a defined period of time. Local NHS trust's and multi-professional teams direct the duration and frequency of the programmes. Invariably, the teams consist of a range of professionals and can include physiotherapists, nurses, clinical psychologists, consultant anaesthetists, and skilled professionals who have specialised in the management of chronic pain. Other approaches to chronic back pain management rely on a dedicated specialist's multi-professional pain management team rather than a fixed programme of care to support people with chronic back pain. These pain centres and teams have traditionally employed similar chronic pain management principles to those used in the pain management programmes. There have however, been some who have challenged the programmed management of pain. Historically, criticisms levelled at the management of chronic pain have questioned whether chronic pain management approaches have treated the person or the condition. For example, in 1987, physicians such as Waddell advocated that the person rather than the spine should be treated in order to maximise the rehabilitation potential. Since this time, pain management programmes have evolved and increasingly, the move from a medical model to that of a holistic person-centred approach has taken place. [Table 1 illustrates this shift].

British Pain Association Service Proposals 1997	Service Provision 2003
<p>The provision of services is shared.....but with varying degrees of responsibility. Recommendations included appropriate fixed resource sessions for medical personnel</p> <ul style="list-style-type: none"> <li>• Specialist nurses</li> <li>• A greater role for psychologists and Occupational Therapists</li> <li>• Inter-departmental relationships should be encouraged.</li> </ul>	<p>The provision of individual, inter-disciplinary approach for each patient and that co-operation exists between</p> <ul style="list-style-type: none"> <li>• Specialist pain medicine doctors</li> <li>• Primary care physicians</li> <li>• Specialist nurses</li> <li>• Clinical psychologists</li> <li>• Physiotherapists &amp; Occupational Therapists</li> <li>• Pharmacists</li> </ul>

**Table 1 Pain Management Service Development (Howarth & Haigh 2007)**

Personhood can be threatened by the advent of any illness, however; it is acknowledged that person-centred care is of particular significance for people with chronic back pain because they feel vulnerable due to the subjective and 'invisible' nature of the condition (Sveilich *et al* 2005). Yet, the experience of chronic back pain management remains an under-researched area, and the extent to which person-centred care is provided remains unclear, moreover, Sheard (2004) points out that there is a need to

*“understand person-centred care as a life philosophy – an aspiration about being human, about pursuing the meaning of self, respecting difference, valuing equality, facing the anxieties, threats and guilt in our own lives, emphasising strengths in others and celebrating uniqueness and our own ‘personhood’”*(Sheard, 2004 p24).

However, the reality of caring for people with chronic back pain is ambiguous. Crucially, it is acknowledged that person-centred services should be based on the individual's perspectives of what care is required within the context of their world (McCormack 2004). Hence, explicating the world of person with chronic back pain and understanding their experiences of person-centred care means first finding out *what care is like* for the person in pain and then *how* person-centred care is managed by a multi-professional team context. Remarkably, research that has explored the experience of person-centred care is scarce, and been largely supplanted by empirical research that has examined the physiological assessment and management of pain. Moreover, evaluations of the experience of person-centred care for those people who have been cared for by specialist multi-professional teams has not been undertaken, and given the complexity and impact that chronic back pain has on the individual, is unexpected. In determining the experience of person-centred care for people with chronic back pain, the following study aim and objectives were developed:

#### **v. Study Aim.**

To generate a theory of person-centred care predicated on the experiences of people who have chronic back pain.

#### **vi. Specific Study Objectives:**

- To become sensitive to and understand person-centred care through listening to the perspectives of people with chronic back pain and the multi-professional teams who cared for them.
- To generate meaning about person-centred care from the perspectives and experiences of people with chronic back pain, who were cared for by a multi-professional pain team.
- To understand the multi-professional team processes used to deliver person-centred care.

#### **vii. The Research Approach**

The research approach was influenced by personal ontological and epistemological assumptions that have shaped an interpretation and understanding of the world. These assumptions were informed by previous personal experiences and professional knowledge of pain. The ontological assumptions therefore acknowledged that reality is interpreted differently and is influenced by the individual's understanding of the social world in which they reside. Hence, it is accepted that people are active participants in a shared social world, which is inhabited by multiple realities which are interpreted in different ways (Playle 1995). For example, Margo McCaffery (1980) suggested that pain is entirely subjective; existing when the person says it does. This statement, published in the early 1980s, has significantly influenced nursing practice and continues to inform contemporary debate. Importantly, McCaffery's philosophy reminded practitioners of the subjective and value laden reality of pain and emphasised the need to accept the individual's description of pain. The complexities of pain have been re-visited and explored, yet, its subjectivity means that the person's interpretation of the experience of pain varies. Hence, it is difficult to reconcile that a single truth is achievable or universal and that an individual experience can be generalised. These assumptions are consistent with a constructivist paradigm which acknowledges that the person shapes reality and are unique; hence, social meaning is co-constructed between the researcher and

participants. This ontological perspective highlights the limitations of empirical approaches that have previously been used to measure and objectify the subjective phenomena of pain.

In seeking to understand person-centred care as experienced by the person with chronic back pain, and as interpreted by multi-professional teams, the emic or 'insider' perspective was needed to construct meaning. Constructivist assumptions accept the existence of multiple realities and use naturalistic methods to capture, describe and analyse the experience. Although the experience of chronic pain has been of interest to researchers, the complexities involved with discerning the pain experience are unique and a range of different methodological approaches have been used to understand the experience (Thomas 2000). Yet, there is little known about the experience of person-centred multi-professional care from the perspective of the person with chronic back pain, and generating meaning about person-centred care meant adopting an analytic method that would help engender new knowledge. Hence a Grounded Theory methodology was selected because it is considered to be appropriate when there is limited knowledge about a phenomenon (Corbin & Strauss 2008). Grounded Theory was useful because it enabled the experience of person-centred care to be explored through analytical processes that used a range of theoretical frameworks to reveal meaning and generate a theory about person-centred care.

#### **viii. Study Context and Locations**

The study took place between September 2006- 2011 and data were collected from 2007 to 2008. Semi-structured interviews with 17 people who had chronic back pain and four multi-professionals pain management teams were conducted and analysed using Grounded Theory methods. A constant comparative analytic process was used to develop sensitivity and generate a theory about person-centred care. The analysis commenced in 2007 and was completed through writing this thesis during 2007 – 2012. The participants were drawn from four local NHS trusts through support groups and pain management services. A total of eleven categories were identified out of which a core

category emerged which formed the conditional partnership as a substantial theory to explain the experience of person-centred care.

#### **ix. Aims of the Thesis**

The aims of this thesis are to provide a transparent account of the individuals' experience and interpretation of person-centred care and how the conditional partnership was developed as a theory. Using Grounded Theory provided an opportunity to use a range of analytic frameworks adapted from the fields of sociology, psychology and ethics to explicate meaning about person-centred care. The ways in which the frameworks and methods were used to explore person-centred care, complimented theory development and are discussed alongside the analytic memos and technical literature. Hence, the methodology and subsequent findings are presented in a logical and chronological manner to facilitate a transparent account of theory development throughout the thesis. The structure of the thesis is presented next.

#### **x. Structure of the Thesis**

The thesis has been carefully structured to reflect the research process and the events that have taken place chronologically. Chapter 2 provides an initial rather than a full review of the literature which is consistent with Grounded Theory and enabled early sensitivity about the concept of person-centred care to develop. The initial review exposed the challenges associated with person-centred care and is structured into four sections. The first section discusses the purpose of a literature review in Grounded Theory. This is followed by an analysis of the diverse professional ideologies that have influenced approaches to person-centred care. An exploration of the underpinning philosophies associated with person-centred care is presented in the third section, followed by an evaluation of the papers that have explored care from the person's unique perspective.

The key methodological approach of Grounded Theory is discussed in chapter 3 within the context of a constructivist paradigm. A particular focus has been placed on the development of the data collection and analysis methods that were used to explore the

experience of person-centred care. The research design and insight into the significance of sensitivity are discussed alongside the canons and procedures expected within a qualitative Grounded Theory study. Details about the combined purposive and snowball sampling strategy that was used to recruit 17 people with chronic back pain (participants) are included. A detailed description of each of the seventeen participants is provided in chapter 4 to provide insight into their biography and experience of living with chronic back pain. The four pain management sites are also described.

Chapter 5 discusses the analytic process used to explicate the categories from the interviews with participants who have chronic back pain. The chapter describes their experience of health care and reveals how they had become disillusioned with health professionals. The chapter later discusses the participants' perceptions of person-centred care and their descriptions of the teams informal caring processes that were used to validate pain. Being diagnosed meant being believed, which for many of the participants was an essential part of being a person. The delegitimation experienced by the participants reflected a system where they had been treated as a malingerer and as a result felt socially isolated. Although significant, being believed was a just the first step towards the authentication of the pain experience. The invisibility of pain is echoed in the evidence base, and highlights how understanding the experience of a person in pain is essential to any helping relationship (Carson and Mitchell 1998). The participants' experience of health care in the 'system' illustrated how lack of physical signs of pain resulted in disbelief and delegitimation of their 'sickness'. Hence, the legitimation of the participant's pain was a significant step towards understanding the pain and in the development of a trusting and person centred partnership. The latter part of the chapter discusses the participant's perspectives of the team and reveals how their faith in the teams empowered them to regain control of their pain.

Chapter 6 builds on the findings from chapter 5 to develop understanding about the team working and how this informed person-centred care. Four multi-professional teams participated in semi-structured interviews and focus groups to elicit how professional and social processes had influenced the team's ability to restore faith in

healthcare. The multi-professional teams are described and the chapter later discusses how Goffman's (1959) concept of dramaturgy was used to explicate the backstage work of the team. *Believing in* the team was crucial and early insight into the analytic process used to develop meaning about partnership working through a reciprocated relationship process known as 'co-validation' is discussed. The chapter concludes with an analysis of how the co-validated relationship influenced person-centred care.

Chapter 7 expands the findings of Chapter 6 and discusses the significance that believing in the team had on person-centred care. The findings in this chapter discuss the third condition of non-maleficence that appeared to be inherent within the relationship. The chapter describes how aspects of transactional analysis were used to analyse the third condition to understand the potential influence of this on person-centred care. The chapter later discusses how the three conditions; *being believed*, *believing in* and *non-maleficence* formed a core category of the 'conditional partnership' and concludes with a discussion about the emerging theory.

Chapter 8 discusses the theory of the 'conditional partnership' within a sociological framework to understand the relationship and significance of the first two conditions, *being believed* and *believing in*. Michael Bury's (1982) sociological concept of the disrupted biography is used to highlight why people with chronic back pain seek validation of their pain and the impact this has on their ability to control their pain.

Chapter 9 discusses the third condition of *non-maleficence* within ethical and professional frameworks. The conditional partnership is contextualised within the concepts of compliance and empowerment using the works of Sally Gadow (1976, 1994, 1995, 1996) to understand how the teams may have been influenced by a relational ethical approach to repair the participants disrupted biography, recover the moral self and restore the(ir) person.

Chapter 10 includes a reflection on the PhD journey and the quality of the study. Implications of the conditional partnership in the person, practice, research and



education are discussed alongside recommendations for future practice, research and education.

**xi Summary of the Key Findings:**

The key findings suggest that undiagnosed chronic back pain can present conflict between the individuals perceived notion of 'sickness' and their understanding of the impact that unseen pain has on their self. This dualist notion suggests that the body and self are seen as separate and often a diagnosis can help legitimise an individual's pain by helping restore self-esteem and the ability for the individual to manage the disruption caused by the chronic pain and manage resources accordingly. The conditional partnership helped to restore the(ir) self through first legitimatising the pain through a co-validated relationship that supported person centred care. The conditional partnership was predicated on the participants need to be believed and their 'sickness' to be legitimised which importantly, helped re-establish their faith in health care. Restoring faith in health care was a significant part of the partnership which was supported by a relational ethical approach used by the teams to engage participants in care.

## **xii: Finally, A Comment by Nina.....**

Nina was a participant in the study and the following extract from her interview provides a first glimpse of the journey to the pain teams, which the participants experienced.

*“you’re brought up to believe that you can cope with anything and when it’s you that’s not very well I think that your coping mechanism is that you just pretend that you are OK and that nothing is wrong so for most people in the group – they have got to rock bottom and hadn’t told anyone that they were rock bottom. A couple of people were on anti-depressants we probably all would have ended up that way if we hadn’t been offered the olive branch of the pain management programme group meetings I think.....I had stopped living really..... You felt free to say ‘oh look I’m having a bloody awful day’ I’m not very well or I’ve been up all night or my husband doesn’t understand me and he doesn’t know what I’m feeling and you know I’ve got no money cause I can’t work’ to talk as it really is really because everybody felt some of those feelings and when you’re got pain you’re alone its definitely a lonely – cause it’s something that other people can’t see, you might know if you have got a bad back, legs or whatever you’ve got – other people get used to that ‘oh are you not better yet?’ you know and when they ask you how are you? You know that they just want to hear ‘oh yes I’m fine’ whereas in that team you know that you can go in there and say ‘bloody awful’ and that’s good cause you know if you’re really feeling it you should be able to say it. And its verbalising it, when you’re keeping it locked inside cause you’ve put a smiley face on for everybody at home or work cause they’re all fed up of you being a miserable sod anyway, well if you can go in there and be a miserable sod and everyone else is nice to you they’ll bring you a brew, get you a biscuit and you know that they actually know how you feel. I don’t think that anyone can truly empathise I know cause I was good in my job at empathising and understanding people but it isn’t until you suffer something that you really know and you wouldn’t wish it on everybody you can’t although there are some people who you would go ‘oh you such and such and so’...you’ve always got one that’s nasty to you or rude to you or don’t understand – ‘what’s wrong with you now...isn’t it time you were better....you haven’t got cancer or ought you know so you’ve got these people who haven’t been understanding – they don’t see that you’ve got an ongoing problem that might last a lifetime. Well it is going to last a lifetime – if you’ve been on the pain management course it is going to last a lifetime and it’s not just about managing it’s about acceptance as well. ”. Nina*

## **Chapter 2: The Initial Literature Review**

The first part of this chapter explores the tensions associated with conducting a review in Grounded Theory and outlines the decisions made in determining the purpose and aims of the literature review. The second part of the chapter presents an overview of the different professional ideologies that have influenced meaning about person-centred care. This is followed by part three which includes an analysis of the fundamental concepts of person-centred care using professional, theoretical and philosophical perspectives to explicate the key issues. The chapter concludes in part four with an analysis of the technical literature, which has explored person-centred care from the perspectives of the person being cared for by health professionals.

### **2.1. Part 1: The Challenges of Conducting a Literature Review in Grounded Theory**

Traditionally, a literature review is undertaken prior to data collection to determine the extent of current knowledge and contextualise the subject area with contemporary research (Parahoo 2006). It is acknowledged that a literature review can help to identify common concepts and explicate key issues that could guide the study design. Although the review is influenced by the methodological approach and philosophical paradigms per se, the purpose and conduct of a review can vary considerably. This presents conflicting epistemological perspectives, which challenge the purpose of the review and can influence the point at which it is undertaken within the research process. When to conduct a review is significant for those using Grounded Theory as a methodology because it is believed that acquiring knowledge about a subject prior to theory development can influence the researcher's interpretation of the data (Hickey 1997). These tensions have evolved out of the divergent ontological perspectives between interpretivism and positivism about the role of the researcher in interpreting data. From the traditional positivist perspective, the literature review is undertaken at the beginning of a research study to identify, contextualise and summarize the knowledge base. From a constructivist perspective, undertaking a comprehensive literature review prior to data collection could potentially influence the analytic process (Corbin & Strauss 2008).

Hence, the ambiguity and controversy surrounding the conduct and purpose of the review has resulted in conflicting advice about the most appropriate approach to take.

In the context of a Grounded Theory methodology, the advice about when and how to conduct the review became significant because of the paradigmatic split between the original architects of Grounded Theory, Barney Glaser, Anselm Strauss and later, Juliet Corbin. Originally, Glaser & Strauss (1967) encouraged researchers to delay undertaking a review of the literature because it was thought to *interfere with* rather than support the development of theory (Glaser 1967). However, the later split between Strauss, Corbin and Glaser highlighted irreconcilable differences between their epistemological positions. From Glaser's perspective, explicating existing theories through reviewing the literature could negatively impact on the developing theory, which would be devoid of any theoretical basis. Specifically, Glaser remarked that;

*Perhaps we should warn that the discovery of a cache can actually restrict the development of a researcher's theorising... this kind of ownership can yield great depth of substantive knowledge but add little to social theory" (Glaser & Strauss, 1967 p168). "*

Alternatively, Strauss & Corbin's (1990) framework advocated that an **initial** as opposed to comprehensive review should be undertaken to '*stimulate theoretical sensitivity*' (p50) in order to enhance theory development throughout the data collection and analysis process. The initial review is thought to provide an opportunity to generate a feel for the subject area, which can support the design and conduct of the research. Indeed, Corbin (2008) advised that an initial review of the literature can help the researcher to explore areas of interest, engage with their own assumptions and guide the early stages of the research process. It is accepted therefore, that the way in which literature is used to form ideas about a subject can be a 'stimulus for research'. Corbin & Strauss's (2008) approach to the literature review was appealing because I was mindful of my lack of knowledge about the experience of chronic back pain and my unease at 'knowing nothing' increased. The purpose of the initial review was therefore predicated on pragmatic and theoretical assumptions; firstly, there was a need to obtain ethical approval to access the research field and was required to demonstrate scientific justification for undertaking the study. Secondly, developing a feel for the subject area

meant understanding some of the key concepts associated with person-centred care and the experience of chronic back pain that could later be used to support theory development.

## **2.2. Searching for the Unknown.**

In Grounded Theory, literature is categorised into a number of constructs, for example, policy, fiction, non-fiction, opinion, research and theory. Technical literature is a term used by Strauss & Corbin (1990) to describe research studies, theoretical and philosophical papers or "*papers characteristic of professional and disciplinary writing*" (pg 48). Further, 'non-technical literature' includes biographies, diaries, documents that are often used to compliment the review because they add to the body of knowledge about the subject area and, in Grounded Theory, can also be used as primary data to supplement data collection tools. Both technical and non-technical literature play a vital role in Grounded Theory and the decision to include all types of literature was based on a need to develop a feel for the subject area and generate an awareness of the key issues, challenges and practices associated with person-centred care. Deciding what to search for and where to search was daunting; the introduction of the World Wide Web has caused a proliferation in the dissemination of research findings and researchers are reminded that locating evidence is a skill that requires careful consideration and a well formed strategy to avoid the pitfalls of irrelevant evidence, time wasting and the inevitable frustration this causes (Brettell & Grant 2004). Mindful of the need to develop awareness and locate relevant literature, the search strategy included technical and non-technical literature from a range of databases and sources.

To enhance the relevance of the literature, limits were placed on the year of publication from between 1950 – 2011 and the language was restricted to English only. At this point in the review, and to develop a feel for the key concepts, a focus was placed on the concept of person-centred care rather than multi-professional care. Later, the ailment context, complaint or condition was searched to establish whether there were any literature that had specifically explored person-centred care from the perspectives of people with chronic back pain. Multiple combinations using Boolean operators were

included in each database search and after all the abstracts were read; papers were selected based on their relevance to the aims of the study (see table 2)

Data Bases	Year Parameters	Initial Search Terms	Expanded Search Terms
Cinahl MedLine Google Scholar Embase PsychInfo	1950- 2011	Patient, Patient-led, Patient-centred	Patient- centred care patient experience, patient centeredness, patient voice, patient focussed, participatory care
		Person, Person – led, Person-centred	person-centred care, personhood, personalised, individualised, people centred, service user focussed,
		Client, client-centred, client-centred	client led, client based, client focussed, family-centred, relationship-centred;
		Back pain, chronic pain	Muscular Skeletal, rheumatism, osteoarthritic, back injury, back complaint, painful back lumbago, bad back, aching back, back ache

**Table 2: Example of Search Terms and Databases Used to Locate Technical and Non-technical Literature about Person-centred Care.**

Through developing ‘a feel’ for the subject, the search was then divided into four key areas. These included the professional ideologies, political influences, theories associated with person-centred care, and research that had evaluated the experience of person-centred care and are discussed in part 2 next.

### **2.3. Part 2: The Emergent Professional Ideologies**

The technical literature was vast and concepts of person-centred care varied between the nursing fields of gerontology, learning disability, mental health, medicine and therapists. The different concepts highlighted the existence of divergent professional ideologies about the concept of care early on in the review. Significantly, the different professional ideologies initially presented a challenge and it became increasingly evident that they had influenced the language used to describe person-centred care. For example, the term ‘patient-centred care’ was frequently referred to in medical literature, whereas, gerontological, mental health, learning disabilities and rehabilitation nursing literature relied on the term ‘person-centred care’; conversely, physiotherapists, occupational therapist and counselling literature commonly used the term ‘client-centred care’. This often meant that the meaning of ‘person, patient or client’ centred

care was radically altered. The search also located a range of theories related to person/patient/client-centred care, which illustrated tensions between the ideologies and appeared to influence how person-centred care was understood. A particular challenge at the start of the initial review was to identify the different professional ideologies and subsequent idioms to ascertain to what extent these had influenced the published literature about person-centred care. The professional language of care is explored next.

### **2.3.1. The Professional Language of Care**

Initially, the review highlighted a discrepancy in the interpretation of person-centred care; and the reason why the term 'patient' was used by doctors, and 'person' was used by nurses and 'client' was used by therapist was ambiguous. This early confusion led to a naïve assumption that the variance was predicated on semantics, which from a political and professional/cultural perspective initially seemed logical. These early assumptions were also influenced by Sir Ian Kennedy's statement about care following the Bristol Inquiry (2004) during which he entered a plea about the use of language in the NHS:

*"The symbolic importance of language, the signals sent by the way an idea is expressed, are at the heart of modern politics. And look at the language used in the discourse about patients. We meet "patient safety", "patient consent", "patient focus", and "the patient experience. Leaving aside the grammatical infelicity and the lack of clarity implicit as a consequence, there is a deeper point to be made. It is simple. By these expressions, the centrality of concern for patients is undermined.*

He later emphasised the need to talk about patients as 'people' and stressed

*"I cannot emphasise too much how important is this battle (and it is a battle) for control of the discourse of care. It is not the pedantry of a fuddy-duddy. It is a supremely political issue, since it determines the place occupied by patients in the considerations of others..... The discourse is completely changed. We are now talking about patients as people, whose experiences and safety, are what we are concerned with. (Kennedy 2004 pg29).*

As Chair of the NHS Independent Standards Authority, Kennedy (2004) believed that the way in which language was used in the NHS affected health care. Kennedy's comments about the different professional ideologies were influential and highlighted how the resultant idioms informed language, which was later used to interpret person-centred

care. From Kennedy's perspective lack of professional consensus about the way in which care is defined was believed to have a detrimental effect on care and, correspondingly, his work illustrated the tensions caused by incompatible discourse between different professional disciplines. For example, the way in which the concept of 'the patient' rather than 'the person' dominated health discourse was highlighted. Kennedy's statement illustrated the professional tensions which contextualised the issues within the wider political arena and enhanced awareness of the influence of the different professional ideologies may have had on the interpretation of person-centred care. The influence of language used in health policy is more widely recognised and is thought to be a significant determinant of care, and, searching for literature identified nursing research from the USA, which frequently used the term client-centred care. The use of the term 'client' may be attributed to the influence of the regulatory authority of the Institute of Medicine (IOM) on health care in the USA. For instance, it is recognised that healthcare is privately funded in the USA which may explain why the term client is used as opposed to person. It is also acknowledged that the term client is associated with the concept of consumerism, which reflects health administration and fiscal management of health care in the USA.

Becoming sensitive to the challenges identified in the literature influenced the development of the search which later included technical and non-technical literature from the UK and abroad that discussed the difference in professional language in order to generate knowledge about the impact of professional ideologies on the interpretation of care. The literature also suggested that professional idiom of 'patient' had been adapted in some policies and indicated the way in which this had influenced the dialogue of nursing and other healthcare professionals. The rhetoric used in policy was also significant because of its potential to influence service development and approaches to care. The way in which policy may have influenced person-centred approaches to care is explored next.



### ***2.3.2. Political Rhetoric and Person-centred Care.***

In their original manifesto in 1997, the UK governing political party, Labour, called for increased participation of the 'service user' in the re-design and modernisation of services (DH 1997). A greater emphasis was placed on the 'patient voice' following which the term 'patient-centred' was frequently used (DH 1997). Over the next three years, from 1997-2000, Labour's 'Third Way' planned to re-shape the NHS into a more 'patient-focused' service. Interestingly, the benefits of patient-centred care such as respect, being heard and the ability to inform and shape services were highlighted in Derek Wanless' report (Wanless 2002). A later white paper published by the Department of Health (2005a): 'Creating a Patient-led NHS Delivering the NHS Improvement Plan' aspired towards developing an NHS that was 'patient-led' and outlined the key attributes of a patient-led service predicated on the human rights of patients underpinned by respect and understanding from the professionals involved in their care. Other policies used to promote patient-centred care included the Expert Patient Programme (NHS 2007), which has since implemented a range of programmes to empower patients to become experts through dedicated educative strategies. The patient and public involvement has subsequently paved the way for a more integrated approach to care in which the patient is believed to have a voice (Gillespie 2002).

Interestingly, a different language evolved within the context of learning disabilities, which had debated 'person-centred' planning for over 30 years (Dowling et al 2006). Here, a focus was placed on the person as opposed to the patient that culminated in the Department of Health white paper 'Valuing People' in 2001, which promoted active involvement of people with learning disabilities and their carers and families to improve their lives. This white paper was followed by the advent of the 'Personalisation Agenda' within the white paper: 'Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care' (DH 2007), which had been introduced to empower disabled people and facilitate choice and control of their lives (Dickinson & Glasby 2010). As a result of the introduction of personal budgets and direct payments, the Personalisation Agenda represented a key government policy to support and empower

adult services predominantly within social care and for people with long term disabling conditions. Originally, the aim of person-centred planning was to achieve equality and empower people to live as independently as possible. This involved constant planning, review and importantly, learning and listening (DH 2001a) whilst taking into consideration the views of the individual, significant others and their 'personal network'. It was acknowledged that this approach to care could benefit individuals and families in many ways.

In 2006 Dowling *et al* evaluated the person-centred approach and highlighted similar approaches to care within mental health and gerontology where they acknowledged that in these contexts, 'person-centred planning' was often referred to as 'person-centred care' and suggested that the changeable terminology emphasizes the philosophical foundations of practice. Although there were differences in terminology, person-centred planning was thought to be at the heart of learning disability services across health and social care and personalisation was acknowledged as being '*a cornerstone of the modernisation of public services*' (Department of Health, 2008: p. 4). An earlier and perhaps broader definition suggests that personalisation was '*the way in which services are tailored to the needs and preferences of citizens; equally, the overall vision is that the state should empower citizens to shape their own lives and the services they receive*' (HM Government Policy Review, 2007: p. 7). However, similar to Wanless (2002), problems associated with the concept of person-centred care and lack of clarity about how care may be personalised were mooted between professional groups. Ultimately, the Personalisation Agenda was designed to empower disabled people through advocating consumers as 'co-designers' of service. Choice, partnership and self-care are thought to be at the heart of service design based on approaches to listen and respond. Yet as Dickinson & Glasby (2010 p3) reported, there remained a 'high degree of confusion over what personalisation is' and the mix of idioms used by different professional groups to describe the concept appears to have exacerbated this ambiguity.

This ambiguity persists and, has been mirrored in UK coalition government policy in which the rhetoric of the 'patient' voice has recently re-surfaced (DH 2010) and services

that are ‘patient-led’ are advocated (see Table 3). However, whilst the political ideology of the ‘patient’ has been used to underpin adult health services; mental health, gerontology, rehabilitation and learning disabilities services and policies have continued to focus on the concept of the ‘person’.

1) Shared decision-making will become the norm: <i>no decision about me without me</i> .
2) Patients will have access to the information they want, to make choices about their care. They will have increased control over their own care records.
3) Patients will have choice of any provider, choice of consultant-led team, choice of GP practice and choice of treatment.
4) The system will focus on personalised care that reflects individuals’ health and care needs, and encourages strong joint arrangements and local partnerships.
5) We will strengthen the collective voice of patients and the public through arrangements led by local authorities, and at national level, through a powerful new consumer champion.

**Table 3: Department of Health. (2010) Equity and Excellence: Liberating the NHS**

Although the political rhetoric reflected a move towards empowering patients to become involved in care, the extent to which the idiom of ‘patient’ as opposed to ‘person’ or service user was influenced by political ideology was unclear. Concerns about the language used to support political policy have been previously reported, and in particular, the use of idioms such as ‘patient’ or ‘service user’ has influenced debate. For example, Williams’s (1998) examination of the context of person-centeredness presents a plausible rationale for the contrary language used in policy which reports that the term ‘people-centred’ is favoured because of the belief that ‘people’ centred referred to services being shaped around ‘people as people’ rather than ‘objects of interest’ (p84). The effect of language used in policy remains contentious and politically sensitive, and explains Williams & Grant’s (1997) sceptical assumptions about the symbolic link between client-centred care and consumerism which concluded that;

*“To be people- centred and to value individuals requires an appreciation of the totality of the individual and not concentration on a specific role. .... in treating people as patients they have reduced the individual and thus devalued them. To treat people solely as consumers is surely a similar act”* (Williams & Grant’s, 1997, p86).

Ironically, the use of the term 'consumer' within health policy appears to have ignored calls for the use of more appropriate terms as suggested by the recipients of care themselves. For example Stock's (1997) survey of psychiatric patients' perceptions about the term 'consumer' discovered that this term was thought to be pejorative because it removed the caring adjective of 'patient' or 'person' to one that was based on the consumption of a service. The term 'patient' and 'client' are synonymous in the literature and have been used interchangeably in policy. For some, the extent to which this reflected person-centred care was a concern and it is acknowledged that the political idioms used may not have considered the impact of using terms 'patient' or 'client' had on care. In addition, some have suggested that the term 'patient' disempowers the individual (McCormack 2003) and its persistent use in health care policy may exacerbate rather than reduce paternalism. Equally, language used by different professional groups to describe the 'patient' may be predicated on divergent ideologies, which ultimately inform services and care. This concern was discussed by Lloyd *et al* (2001) who explored professional preferences to care descriptors and identified a split between professional ideologies. Lloyd *et al*'s findings suggested that doctors preferred to use the term patient whereas allied health professionals liked the term client. Lloyd concluded that health professionals needed to listen to the voice of recipients, which includes understanding how they would like to be referred to. The inappropriate terms used to refer to people receiving care concurred with Wing's (1997) and Nair's (1998) findings and similar to McCormack (2003) suggested that terms such as client and service user may be considered inappropriate and disempowering. The literature highlighted that the influence of professional ideologies on language was significant and is discussed next.

#### **2.4. The Impact of Professional Ideologies on Person-centred Care**

A consistent pattern emerged in the literature that highlighted diverse professional ideologies and revealed tensions associated with the concept of person-centred care. Ironically, the divergent idioms caused by conflicting professional ideologies have been accused of neglecting the preference of the 'patient'. A case in point was Wing's (1997)

survey of 101 people with back pain about their preference for the terms 'patient' or 'client', which revealed that most people preferred to be known as a patient. Wing argued that the professional's use of idioms such as 'client' appeared to ignore the preference of actual patients. Wing (1997) believed that terms used to interpret person or patient-centred care were bound up in a symbiotic relationship between medical and nursing models of care; and suggested that terminology used by professionals to describe care should be practice specific, for example;

*"the terminology should be situation-specific: "patient" for the acute care situation and "client" for other situations (Wing 1997, p288).*

However, it could be argued that this assumes the condition rather than the person should take precedence, which reflects Jewson's (1972) and Bendelow & William's (1995) earlier comments about health. Surprisingly, the effect of professional idioms on care and subsequent empowerment has received little attention, and Wing (1997) and Stock's (1997) work represent the few studies that discussed this issue in any depth. Their work specifically explored the preference of patients, carers and families and identified that the attitude and language used by professionals played a significant role in the development of equal relationships between healthcare providers and patients. Hence, it has been acknowledged that the term 'patient' is perceived to be disempowering because of its associations with 'being ill' and subsequent dependency on others (Pellegrino 1976). McCormack (2004), for example argued that using the term patient distances the professional from the person and dehumanises the individual. Subsequently, the term 'person' is important because as McCormack (2004) remarked, it *"aims to capture those attributes of persons that represent our humanness"* (p32).

The influence of the term 'patient' has inspired research about the equality of the professional /patient relationship which has evolved over five decades. An early advocate of equality within the patient/provider relationship was Edith Balint whose seminal work in 1969 scrutinised the doctor patient relationship and proposed that the term 'patient-centred' had focused the consultation on the condition rather than the patient. Balint's (1969) work has been frequently cited in contemporary medical literature and has been used as the basis for the influential book 'Through the Patients'

Eyes' (Gerteis *et al* 1993) which recorded the paradigmatic shift in medicine from the person to patient and the impact this had on the (dis)-empowerment of individuals. Balint's work was unique because she was one of the first physicians to advocate that doctors look beyond the medical diagnosis and engage with the person as opposed to the patient and conditions. Despite this paradigmatic change, Balint still referred to the individual as 'the patient' as opposed to 'the person', and whilst this could be attributed to semantics, the extent of debate that has emerged out of the initial review indicates a more profound resilience to the terminology that has been inherited by current practices.

#### ***2.4.1. The Interpretation of Person-centred Care.***

Whilst professional ideologies appear to have influenced debate about the concept of person-centred care, other themes within the literature emerged which explored the outcome of person-centred care. A number of papers have been published that refer to the partnership and relationship between patients and professionals. In particular, the influence of perceived equality in relationships between health professionals and patients has been extensively explored and Gallant *et al* (2002), Hook (2006), Mead & Bower (2000) and Peplau (1952) are examples of some who have provided interesting commentaries on partnership working with 'patients', 'clients' and the 'person'. However, whilst research has focussed on partnership working, tensions relating to the way in which person-centred care is interpreted has presented a consistent challenge to a unified understanding of person-centred care.

A case in point was Mead & Bower's (2000) review of the empirical literature, which demonstrated how the term 'patient-as person' was used to broaden the biopsychosocial model to include the person's biography. In this example, knowing the person through their biography helped professionals to fully comprehend the personal meaning of illness. Similar to Williams & Grant (1997), understanding the experience of the illness rather than the disease was believed to be important in ensuring that the patient or person was central to care. Hence Mead & Bower's (2000 p1089) suggestion that "*patient-centred medicine conceives of the patient as an experiencing individual*

*rather than the object of some disease entity*” resonated with Balint’s (1969) earlier principles of ‘seeing beyond’ the medical diagnosis and Jewson’s earlier (1976) concept of the disappearance of the sick ‘man’ and emergence of ‘the patient’. Crucially, the literature revealed the influence of professional ideologies on the interpretation of person-centred care, which explained the lack of consensus about the definition of person-centred care. The on-going debate about person and patient-centred care is significant and has influenced a plethora of literature that has exploited the meaning of person-centred care from the vantage point of the professional as opposed to the person in care. The different ideologies presented challenges to the way in which person-centred care has been perceived and understood and prompted the World Health Organisation (2001) position statement in favour of the term ‘patient’:

*“the term patient is the most appropriate word for someone who is in contact with and using health care systems. There is no better word or phrase, and it is not in itself a negative term..... Similarly the phrase ‘person with impairment or limited activity’ is both clumsy and often inappropriate. The word client suggests a different relationship, not the type usually found in health professional relationships” (WHO, 2001, p350).*

Yet, the WHO’s statement lacked detail about the influence of professional ideologies and presented a rather dogmatic stance that naïvely embraced semantics as a root cause of the confusion without acknowledging the potential ideological subtleties. It is less clear whether these ideological subtleties have influenced care delivery – or the extent to which the idioms reflect the way in which professionals care for people. The terms person and or patient are significant in the clinical context and retain currency with people with chronic back pain and professional staff. Thus both terms appear to be used interchangeably in the literature to denote the person or the patient with back pain. This should be of concern to health professionals because as Wing (1997) suggested earlier, there is a risk that attitudes and behaviours may be influenced by the terms people use.

Hence, criticisms levelled at the concept of ‘the patient’ such as Wagner et al’s (2005) exposition of empowerment, reflect an on-going debate that appeared to have influenced professional attitudes steeped in the traditions of power and socio-political norms. Similarly, Wagner *et al*’s (2005) critique of empowerment concurred with the

historical socio-political tensions that have repeatedly re-surfaced since Balint's early attempts to influence the perspectives of physicians. The continued use of the term 'patient' by physicians appears to signal a reluctance of doctors to shed a 'reductionist' mind set and embrace the person as an individual. This indicated why Balint originally questioned doctor controlled communication and relationships and why the continued use of the term 'patient' has caused concern. As suggested, the concept of the 'patient' infers a reliance on others and therefore appears to dismiss the wisdom, preferences, readiness, and experience of person. Moreover, the limitations to the person caused by the term patient were later reflected in Lauver et al's (2002) review of 'patient-centred' interventions which highlighted that *"the term 'patient-centred' can be defined in general as the extent to which clinicians select and deliver interventions mindful of and responsive to individual and family characteristics, such as affective states, beliefs, goals, and resources"* (p247). A significant point raised in Lauver et al's paper was the suggestion that the *clinicians select and deliver interventions* which indicated that care continues to be instigated by the clinician rather than the person.

### **2.5. Knowing the Person:**

Lauver et al (2002), Mead & Bower (2000) and Balint's (1957) work illustrated how professional ideologies may have influenced the concept of caring and is significant because of the potential impact on the understanding of person-centred care. Equally, it recognised that professional ideologies have influenced the type of knowledge used to support care planning. The different types of knowledge have been categorized by Liachenko & Fisher (1999) into three distinct constructs namely; case, patient and person. The classification suggested that knowledge about the case; patient and person are distinguishable forms of knowledge that are used by different professional groups to support care. Case knowledge implies an understanding of the condition, disease, its management, trajectory and pharmacological management. This knowledge is thought to be influenced by the medical diagnosis and is more often used by physicians. Alternatively, patient knowledge *"defines the individual within the health care system"* to facilitate their journey. Liachenko & Fisher (1999) purported that nurses frequently



used patient knowledge to become sensitive to the 'recipient of care', which enabled them to interpret responses to therapy. Finally, person knowledge is gained about the individual usually through biography to empathize, which is used by mainly therapists and nurses. Thus *"to know a patient as a person is to know what the recipient of care knows, what matters to the recipient and why"* (Stein-Parbury & Liaschenko 2007 p473). It has been suggested that people with short term acute conditions are less likely to develop a relationship because of the time constraints, hence, 'patient' knowledge may be used to support care (Liaschenko & Fisher 1999) and thus, the care provided is referred to as 'patient-centred' (Clarke 2003). However, as Liaschenko & Fisher's (1999) classification highlighted, those caring for people with long terms chronic conditions are able to develop a longer term relationship predicated on 'person knowledge' and are frequently referred to as 'person' centred. Typically the literature suggested that the type of knowledge used, informs the relationship and is ultimately influenced by time; hence, the 'intermittent consultations' commonly observed between patients and physicians that have been reported in the medical literature, are thought to provide limited opportunities to capitalise on and develop a relationship. Equally, using 'hit and run' tactics to elicit details about the person undermine the principles of person-centred care (Clarke 2000, Clarke et al 2003).

A common theme emerged within nursing literature, which indicated that knowledge of the individual is an integral part of the caring process and, demands a deeper understanding of the person (Ford & McCormack 2000). This was consistent with Liaschenko & Fisher's (1999) forms of knowledge and illustrates the need for practitioners to learn about the individual, through biography and person knowledge to better understand their lifestyle. The individual biography is therefore one that appears to support person-centred care and has been used with varying degrees of success in a range of professional clinical contexts to develop person-centred caring (Williams 2000). However, Liaschenko & Fisher (1999) acknowledged that seeing beyond the patient to the person requires time and a commitment to understanding the person from their frame of reference. Understanding an individual's biography can help generate an understanding of the person and support relationship development and the association

between a person's biography and person-centred care has been a subject of continued debate in literature. For example, McCormack (2003), Clarke *et al* (2003) and Clarke (2000) revealed how knowledge of a person through biography helped professionals to 'see beyond the patient'. Similar findings were described in Radwin's work in 2000, which concluded that knowing a person or patient was as relevant to therapeutic reasoning and was needed to ensure that care was individualised.

Biographical approaches in particular have been frequently referred to by McCormack (2003) and Nolan *et al* (1997) as fundamental in relationship development between older people and health care professionals. Correspondingly, Clarke *et al's* (2003) exploration of the biographical approach to caring evaluated the use of storytelling as a method to elicit the biography and centralise individuals in care. Clarke *et al's* (2003) findings suggested that the life stories within the biography, helped professionals to 'see the patients as people' which was conducive to the development of a therapeutic relationship. The significance of the therapeutic relationship has been regularly reported in the nursing literature, and is predominant within the context of gerontology and mental health. A popular campaigner of person-centred care in gerontology is Brendan McCormack (2004) who advocates that the personal biography is a fundamental part of person-centred care which encourages nurses to engage in humanistic caring practice to promote choice and partnership working. The classification of person knowledge as ascribed by Liaschenko & Fisher (1999) is consistent with the concept of personhood as described by others (McCormack 2003, Nolan *et al* 2004), which indicated why professional idioms could be influenced by the type of knowledge used and the associated professional ideologies. Hence, it is surmised that the language used is predicated by ideological foundations within different professional contexts (Dowling *et al* 2006). However, the literature also revealed the divergent approaches to caring reported in the nursing literature. The significance of the divergent caring ideologies within a single discipline is discussed next.

## 2.6. The Caring Ideologies within Nursing.

The divergent professional ideologies were significant and suggested how the interpretation of person-centred care may have been predicated on the condition and concept of the 'patient' as opposed to the person. This highlighted the conflict between professional ideologies which exacerbated ambiguity about person-centred care. This confusion was later compounded by the divergent ideologies identified within nursing that appeared to have become accepted 'norms' of practice. Although the term 'person-centred care' is frequently used in the nursing literature to describe care that is holistic and 'individual centred' (Edwardsson *et al* 2008), it has not been used consistently across all nursing disciplines. For example, the term 'person' is most commonly referred to in gerontological, mental health, learning disability and rehabilitation nursing to describe care for people with chronic or long-term conditions. Conversely, those who nurse people with acute, short-term conditions within surgical or medical units often refer to 'patient-centred care'. It could be deduced that these ideological differences might have been influenced by the individual's condition where traditional concepts of nursing practice have been historically predicated on medical models of care. Hence, a latent discourse about the philosophy of care has surfaced which supports a more holistic perspective of person-centred care based on a caring rather than professional ideology. In particular, Ford & McCormack's (2000) approach to person-centred care suggested that person-centred care should represent a philosophical shift in care as opposed to the traditional individualised concepts of practice. The fundamental shift encourages practitioners to adopt a philosophical understanding of the concept of person-centred care and in challenging the ideologies, Ford & McCormack (2000) emphasised the need for care to be based on the individual need rather than professional ideology.

Despite their plea, the divide retains currency in nursing specifically between the acute and rehabilitative disciplines; hence, whilst the ideology of patient-centred care appears to have influenced acute care nursing, the person-centred philosophy dominates the disciplines of gerontology, mental health, learning disability and rehabilitation nursing.

The challenges to health care professionals therefore reside in the ability to work beyond the ideologies to adopt a more sensitive and holistically charged approach that uses person knowledge. Whilst the principle of caring was implicit in the literature, the ways in which the professional ideology of care was translated into methodology were homogenous and presented a cogent approach to care, despite the philosophical tensions. The literature review revealed how the different contexts of care, policies and professional cultures involved have influenced the way in which care is perceived. Consequently a number of 'models' of person-centred care have since emerged which reflect some similarities between the professional cultures. Although differences were noted; the literature revealed papers that reported convergence between the professional ideologies. These commonalities are explored next.

### **2.7. Converging Ideologies**

Explicating the divergent idioms associated with person, patient, client-centred care revealed some similarities. For example, most professional ideologies include person-centred attributes such as respect, physical comfort, emotional support, sharing power, informed choice, mutual trust, understanding, respect for autonomy, involvement, collaboration and sensitivity (Nolan 1997, McCormack 2003, Balint 1957, Mead & Bowers 2000). This highlighted a broader concept of person-centred care that could be contextualised within any professional scenario. However, the amount of research in this area was small and generally predicated on the physiological markers of the condition derived through disease classification rather than the subjective constituents of care. Hence, papers that have explored person/patient-centred care have often focussed on the condition or illness rather than the person or care. Some exceptions were located, for example, Hobb's (2009) dimensional analysis of the concept of patient-centred care coded the literature according to the perspective, context, conditions, process, and consequences to identify the dimensions of person-centred care. Similar to Liaschenko & Fisher's (1999) knowledge constructs, Hobbs identified that person-centred care should alleviate 'patient vulnerability' through therapeutic engagement that is cultivated through getting to 'know the patient'. Moreover, Hobbs argued that

the interaction within the relationship was crucial but did not elaborate on the relationship itself. A similar methodological approach was used by Mead & Bowers (2000), who reviewed the conceptual and empirical literature on 'patient' centred care. Mead & Bower (2000) focussed specifically on the medical literature to develop a model of 'patient-centeredness' and assessed the best methods in which to measure this. Their analysis identified five conceptual dimensions as being significant for person-centred care. These included bio-psychosocial perspective; 'patient-as-person'; sharing power and responsibility; therapeutic alliance; and 'doctor-as-person', which similar to Hobbs, indicated that the relationship between the person and carer was central to the process.

Both Mead & Bower's (2000) and Hobb's (2009) work referred to the term 'patient' but interestingly described the relationship between the patient and professional using different concepts. For example, Hobbs discussed 'therapeutic relationship', whereas Mead & Bowers (2000) included the term 'therapeutic alliance' as a metaphor for the relationship. The therapeutic alliance between the doctors and 'patient' was supported by a bio-psychosocial approach and Mead & Bowers' (2000) paper has since been frequently cited in other reviews that have re-enforced the bio-psychosocial approach to person-centred care. The significance of adopting an approach to care that reflects the person's social and biological needs has traditionally been used in nursing to support care planning processes (see for example Roper, Tierney & Logan 1980). It is not surprising therefore that many of the papers published about the concept of person-centred care have focussed on the holistic processes used and the skills of the health professional in supporting this approach. For example Kitwood's (1997) influential work on person-centred care has inspired a number of authors and his principles of person-centred care are replicated within the literature (see Edwardsson *et al* 2008, Nolan et al 2004).

Kitwood's (1997) work was intriguing because unlike Mead & Bowers' (2000) concept analysis, Kitwood (1997) rejected the medically derived objective perspective of dementia and proposed an approach that was conceptually and theoretically developed. The approach embraced the person with dementia as opposed to the actual pathological

processes involved. This unique approach to care was reported in his paper 'The Experience of Dementia' (Kitwood 1997), in which the subjective world of dementia and the 'uniqueness of each individual's experience' were presented. Kitwood's observations of people with dementia illustrated the key principles of person-centred care. Equally, his appraisal of the person with dementia captured the meaning of the whole person including the person's self-awareness, individuality and agency. Based on this, Kitwood used a formula to outline the key principles of person-centred care, which drew attention to the person's health, biography, personality, neuro-pathological impairment and social psychology. It was argued that these principles emphasized that person-centred care was more than just 'seeing the individual'. The formula transcended the pathology of dementia and positioned personhood as something, which is developed *through* care giving. Kitwood's work (1997) provided a holistic perspective of person-centred care that highlighted caring for the person rather than the condition as a key attribute. Kitwood's work and others highlighted how the professional ideologies influenced care and revealed the complexities associated with person-centred caring.

### **2.7.1. Summary of Part 2:**

The ideologies and subsequent divergent idioms presented a dilemma about the focus of this review, and whether to explore philosophies of care, or concentrate on the reason for the tension and explore literature that pertained to this. The initial literature review initiated the beginning of what Strauss & Corbin (1990) refer to as 'literature sensitivity' which enhanced the analytic process by drawing on concepts from which literature is later used to develop theory. Hence, whilst the focus of the initial review was not to explicate personhood in any depth, it became apparent that this formed a significant part of the processes involved in person-centred care. In particular, caring is thought to resonate with the concept of personhood and is discussed in part 3.

### 2.8. Part 3: Restoring the Self and Person

For people with chronic pain, the need to be cared for is no different from anyone else, however, it is acknowledged that the permanence of chronic pain is a situated experience that many struggle to come to terms with (Clarke 2005). However, it is recognised that people with uncontrolled chronic pain endure a daily assault on their self and their individuality (Charmaz 1999), which is often compromised through the constant challenges of the illness trajectory. The subsequent loss of independence and self-worth resulting from the relentless attack of chronic pain was a common observation cited in the literature (Sveilich *et al* 2005, Clarke *et al* 2003, Clarke & Iphrofen, 2005) and presented a bleak picture of life living with chronic pain. The 'self' is therefore significant and according to Epstein's (1973) 'self-theory', the 'self' represents a bodily self [physicality]; an inferred inner self, [esteem, ego and emotions], and the moral self which seeks approval and senses good and bad. It is acknowledged that persistent pain can destabilise both the moral and inner self and force dependence on others (Blomqvist *et al* 2002) and suggests why the individual with chronic pain defines their self negatively. Hence, the damage to the 'self' as a result of chronic pain and illness can ultimately impact on personhood.

Kitwood's (1967) earlier definition of personhood suggests a symbiotic link between a person's standing and the relationship with others, hence, it is understood that the self is central to personhood. It is therefore acknowledged that person centred caring is consistent with the key principles of personhood because it embraces actions of listening, understanding, respect, serious attention and regard for another's 'self' (McCance 1997). Similarly, caring is a moral imperative which requires good interpersonal relationships to support therapeutic interventions (McCance 1997) and is predicated on the individual's epistemological values and underpinned by a moral imperative (Morse 1990). The association between person-centred care and personhood and the self is therefore significant and has been reported by McCormack (2003), McCance (1997), Nolan *et al* (1997) and Charmaz (2006), but Kitwood's (1997) work in particular, highlighted the significance between person-centred care and the principles

of personhood. Other authors such as McCormack (2003) and Nolan *et al* (1997) have since used Kitwood's (1997) work because it linked the concept of personhood with values, the beliefs held by individuals about their rights as persons to be respected (McCormack 2003). Person-centred caring suggests that one's assumptions are re-evaluated and that the person is treated with the respect and trust that every human being has a right to expect. A central tenet of which requires a paradigm shift from transactional levels of communication between people to an approach that recognizes the other person. In the context of health care, it is thought that this paradigm shift can provide meaning to an experience, which then enables professionals to 'go beyond the patient to see the person' (Barker 2001).

Seeing beyond the patient to the person through understanding their biography is thought to be one way to restore the self through an empowering approach that can help the rehabilitation processes (McCormack 2003, Barker 2001). The empowerment of people with chronic back pain is important and could help restore self-esteem and achieving this means developing partnerships that that enables the individual to participate in decision-making (Glenton 2003). Indeed, a recurring theme in the literature emphasised the value of partnerships that enable professionals to use the person's biography to understand the individual's needs and embrace their voice in decision-making. It is acknowledged therefore that partnerships that utilise the person's biography may help restore the self and re-establish independence. Partnering with patients through person-centred care is reported to be influenced by therapeutic relationships that engage with the individual to maximise independence. The importance of the therapeutic partnership was reported in the nursing literature by McCormack (2003) and has been recognised as a fundamental process that influences confidence in the professionals' clarity and values, and shared outcomes. A similar perspective emerged from occupational therapy literature, for example, Blanks (2004) used Carl Roger's (1959) principles of client-centred care that embraced respect, empathy and trust to evaluate the therapeutic partnership between clients and occupational therapists. Blanks (2004) qualitative approach illustrated how the relationship between the occupational therapist and the 'client' contributed to the



development of a partnership. Key findings from Blanks (2004) study highlighted the significance of the therapeutic approach that ultimately worked with the person as opposed to the client or patient. Equally, Lauver *et al's* (2002) summary of patient-centred nursing interventions discuss similar concepts and refer to Paulen & Rapp's (1981) paper which examined the values and philosophy of person-centred care in nursing and outlined the need for respect, humanity, and control. Further, Lauver *et al* argued that these attributes were central to person-centred care and were consistent with Radwin's (1995) Grounded Theory study of nurses' clinical decision-making. Radwin's findings reported the need to know the person and that understanding their experiences was crucial to the core processes associated with individualised interventions.

Historically, therapeutic partnerships were viewed as a medium for empowering equal alliances between the professional and the individual (Freshwater 2002) the key concepts of which have since been reflected in nursing and therapy literature and have influenced a number of person-centred models. Barker's (2001) seminal work within the field of mental health, the 'Tidal Model' (2001) is one example which presented an alternative paradigm to 'caring with' and highlighted the person as opposed to the patient. His work emphasised that partnership's should be centred on developing a 'power relationship' between health care professionals and advocated that nursing be re-focussed by emphasising the '*fluid changing nature of human beings*' (Barker 2001 p235). Similar to Blanks (2004) qualitative illustration of the therapeutic relationship, practitioners using Barkers (2001) approach engaged with the individual rather than the disorder or illness by discovering the person through dialogue and partnership working that engaged with the person, illness and health (Barker 2001). Similar approaches have been adopted by other nursing models of person-centred care and frequently refer to the same principles (see Nolan *et al* 2004). McCormack (2003, 2004, and 2006) in particular has been a frequent commentator on person-centred care in nursing and like Nolan *et al* (2004), has observed the practice of person-centred care within a gerontological context. McCormack's work is extensive and has consistently explored the paradigms associated with person-centred care.

In 2003, McCormack published a conceptual framework for person-centred care with older people, predicated on hermeneutic philosophy. In his paper, McCormack used conversation analysis and reflective account to highlight the nurses ability to ‘particularise the person who the patient is’ and explored the relationship between the patient and the nurse and the expectations that evolved. McCormack (2003) concluded that person-centeredness was predicated on an authentic consciousness, which was operationalised through five ‘imperfect duties’. Table 4 illustrates these imperfect duties.

<i>1. Informed flexibility: the facilitation of decision-making through information sharing and the integration of new information into established perspectives and care practices.</i>
<i>2. Mutuality: the recognition of the others’ values as being of equal importance in decision-making.</i>
<i>3. Transparency: making explicit the intentions and motivations for action and the boundaries within which care decisions are set.</i>
<i>4. Negotiation: patient participation through a culture of care that values the views of the patient as a legitimate basis for decision-making while recognizing that being the final arbiter of decisions is of secondary importance</i>
<i>5. Sympathetic presence: an engagement that recognizes the uniqueness and value of the individual by appropriately responding to cues that maximize coping resources through the recognition of important agendas in daily life.</i>
<i>McCormack 2003 p204.</i>

**Table 4: Five Imperfect Duties**

Fundamentally, McCormack (2003) argued that caring is driven by how professionals respond to and *intend* to treat other human beings; the subjective experiences and the physical response to therapeutic actions are the only ways in which caring can be understood. It is understood that the professionals intentionality, for example, the structure that gives meaning to experience, builds a bridge between the patient and professional through which the tensions between moral and professional obligations can be overcome. Ideologically therefore, practitioners grounded in a structure of intentionality respond to the person rather than patient. McCormack’s (2003) model of person-centred care outlined the need to go beyond the traditional boundaries of care to perform ‘imperfect duties’ that allow flexibility, freedom and choice. Hence, the health professionals ‘intentionality’ to provide care should embrace the persons needs

based on that person's beliefs and values. However, it is believed that through acting 'intentionally', health professionals can be [mis]guided by the principle of beneficence which is thought to undermine patient autonomy (Woodward 1997). This is particularly pertinent for the person with chronic pain because of the way in which chronic illness reduces the individual's autonomy and challenges their physical, mental and 'being' in their world (Pellegrino 1976 p33).

The key attributes associated with the process of person-centred care highlighted in the literature suggests that person-centred care is predicated by the professionals intentionality to care through understanding the persons biography, and importantly, seeing patients as people and restoring the 'self'. The frequency to which the concept of the individual and their beliefs was referred to in the literature suggested that the individual's biography is taken into consideration as part of a partnership process and a fundamental aspect of person-centred care. Explicating the key attributes of person-centred care highlighted the commonalties between research findings and links between cultural observations and the philosophy of care became apparent.

At this juncture in the review, insight into the theoretical concept of person-centred care had been developed. However, the *raison d'être* for undertaking this initial review was to generate a 'feel' for the subject area and develop sensitivity. Whilst this helped contextualise the key issues and tensions about person-centred care, it was largely based on theoretical and political assumptions created about the concept as opposed to the reality. Thus, in developing sensitivity and to enable a comparison between the rhetoric of person-centred care with patient reality, the review was extended to include literature that explored the individual's experience. Part four, the final section of this review, focuses on those studies, which have specifically explored the individual's experience of person-centred care.

## 2.9. Part 4: Exploring the Literature for the Patient's Experience.

On the whole, concepts of personhood reported in the literature have been extrapolated using patient, person or client-centred frameworks. The terms 'patient' and 'person' have been used interchangeably and reflect the clinical context or professional ideology rather than the philosophy of person-centred care. Literature that had evaluated person-centred care was less well developed and illustrated a gap in the knowledge base about the experience of person-centred care. The majority of literature located had *measured* the quality of care in terms of patient satisfaction rather than *explored* the experience. Moreover, the literature highlighted a tendency for professionals, especially physicians, to operationalise and reduce person-centred care into something that has been empirically studied (Coulter 1999). Thus the initial literature review revealed a plethora of research that had measured patient satisfaction. Whilst these types of surveys can provide quantifiable data, the literature repeatedly points out that person-centred care is qualitatively different from patient satisfaction. For instance, Radwin's (2000) Grounded Theory study of oncology patients' perceptions of the attributes and quality of nursing care discovered that attentiveness, partnership and rapport were fundamental to successful person-centred nursing care. Radwin's (2000) work is one of a few qualitative study's that have explored chronic back pain. Other qualitative research findings have reported on the experience of chronic pain and their contributions to knowledge base about person-centred care have highlighted key concerns associated with the stigma of unseen pain. The limited qualitative research that has been undertaken has consistently presented a common concern about the pejorative experience that living with chronic back entails (White 2003, Glenton 2003). In particular, the qualitative literature located revealed frustration about the way in which people with chronic unseen pain have had to fight to be perceived as 'sick'. Paradoxically therefore, whilst the theoretical literature exposed an unwelcome truth about the concept of person being subsumed by the patient, qualitative research predicated on individuals' experiences of living with chronic pain highlight how many want to be 'a patient' and strive to be accepted as 'sick'. The significance of the 'sick role' is explored next.

### **2.9.1. The Significance of the 'Sick Role'**

It was previously asserted in this review that when 'the ill become 'a patient' they become reliant upon health care providers (Pellegrino 1976), conversely, the literature also reports that people with chronic pain want to be 'a patient' because it signifies acceptance and understanding of their 'suffering'. Later research by Jensen *et al* (1991) explored the individual's perception of the existence of pain, suggested that people with back pain often becomes a patient once treatment commences in an attempt to be accepted as 'sick'. Turk's (2005) work, broadened this analysis and described how rehabilitation services have used this knowledge to support people with chronic conditions to revert to a person;

*"It is acknowledged that patients are individuals who are awaiting or are already under medical care and treatment. Thus, diabetics are "patients" when in the clinic, but outside the clinic setting are they "diabetic patients" or rather "persons who have diabetes.....many rehabilitation programs focus on helping patients adapt to becoming people with persistent pain, not patients, when there is no cure". (p1)*

The concept of the 'sick role' was described by Frankenberg in 1980 as '*being the extent that the person's experience of illness is accepted by others in their surroundings*'. Hence, the concept of the sick role for people with chronic illness is important for the individual's personhood because it signifies the acceptance of a person's 'right to be sick' by society. This was illustrated by Glenton (2003) who reported people with chronic back pain need to adopt a 'sick role' because it meant their pain was legitimised. Glenton's (2003) qualitative study acknowledged the significance of the sick role and writes that "*individuals who experience bodily suffering but who fail to gain acceptance for this suffering find themselves with illness but without sickness*" (Glenton 2003 p2244). This places the individual in a no-man's land between being sick and being well and highlights the stigma associated with chronic back pain. Collecting data through an internet online discussion forum for people with chronic back pain enabled Glenton to discover that people wanted to be seen as sick because they believed their pain was not taken seriously due to the lack of outward symptoms. Although Glenton was unable to probe these issues in any depth, the findings re-enforced the significance of the sick role on society's acceptance of people with chronic pain and illustrated why people with

chronic pain, expect to be understood and treated accordingly. However, 'acceptance' may be difficult for some whose origins of pain remains ambiguous.

It is recognised therefore that the complexities of living with unseen chronic pain have incurred a number of challenges for the individual, not least because of the associated stigma and fear of societal rejection. Consequently, a range of different methods have captured the experience of chronic pain and highlighted the individuals desire to have their pain accepted. For example, Allcock *et al's* qualitative study (2007) explored the common challenges associated with chronic pain through focus groups with eighteen older people. The findings revealed that their pain relief was dominated by the search for a diagnosis and crucially, some participants felt as though the health professionals had 'fobbed them off' with pain killers. Allcock *et al* (2007) concluded a need for greater awareness of the expectations of the individual in pain and highlighted the influence that being taken seriously had on expectations of health care. Similar findings have been reported in more contemporary literature (Teh *et al* 2009), and illustrates the on-going challenges faced by people with chronic or stigmatised conditions.

The ways in which health professionals have supported people with chronic pain varies and often refer to the relationship between the patient and carer. Significantly, the influence of the relationship on person-centred care was frequently reported in the literature and was the focus of Teh *et al's* (2009) qualitative study which explored the patient-provider relationship from an older person's perspective. Teh *et al* interviewed 15 older adults with chronic pain about their experiences of seeking treatment and identified the participants need to 'be heard' and 'understood'. These findings highlighted the significance of the therapeutic relationship on person-centred care and in particular, how partnership working and listening to the participants had influenced individual's ability to take part in the decision-making processes. Teh *et al's* (2009) work represented one of the few studies that explored the individual's role in care planning and illustrated the importance of the therapeutic alliance previously mentioned in Hobbs (2009) concept analysis.

Not surprisingly, the plethora in literature that has explored the subjectivity of pain has been influenced by the complexities involved and society's acceptance of the person with 'unseen' pain. However, whilst the sick role is recognised as a key concern for people with chronic pain, insight into the experience of living with chronic back pain in particular is rare. Ironically, descriptions of the pain experience are significant because they provide a unique insight into the world of the person with chronic pain which can enable a greater understanding about the experience. The way in which pain has been described is explored next.

### **2.9.1. Describing Pain**

The experience of pain was commonly reported in the literature and studies have frequently focused on how the pain experience has been described, for example, Borkan *et al* (1995) used qualitative focus groups to explore the pain experience of people with lower back pain. Individual interviews and participant observation were also undertaken in primary and community care practices within three regions in Israel. Borkan's study specifically aimed to *"examine the personal and shared meanings of the phenomenon among primary care Lower Back Pain patients, to enter their world and explore their embodied knowledge and the nature of their suffering within its context.* Using a thematic content analysis, Borkan *et al* (1995) developed a patient-centred lower back pain classification and claimed that this was reliable because it had been predicated on the patient's own descriptions of pain intensity, duration, dysfunction and treatment. Borkan *et al* concluded that there was a need to develop a greater understanding of patient's experiences in order to improve services and outcomes. Ironically, it could be argued, that Borkan's classification of individual experience re-enforced a reductionist approach, however as Borkan *et al* argued, their work presented a unique explanatory model of pain that *utilised rich and well-defined vocabularies and metaphors to describe a personal and social world of pain sensation* (p4). Borkan *et al* concluded that patients had been unhappy with the medical care they have received, because it failed to take into account the social meaning of lower back pain and advised that the success of future doctor-patient relationships will be influenced by the ability of health

professionals to explicate the social meaning and understand the impact on the individual's self.

The vulnerability of the 'self' as a result of chronic pain was also reported by Blomqvist & Edberg (2002), who explored the older person's experience of living with chronic pain and focussed on how daily existence with pain influenced their sense of others. Blomqvist & Edberg interviewed 90 people who were receiving home care and described how often 'proud' individuals felt misunderstood and dissatisfied with their pain management. Consistent with Borkan *et al* (1995), Blomqvist & Edberg (2002) noted the need for the individual to be taken seriously and concluded that the older person's life could have been improved if health care staff had taken time to listen and understand their pain. This also concurred with White's (2003) auto-ethnography which detailed her experiences of living with chronic, non-malignant back pain. White was herself a sufferer of severe chronic, non-malignant back pain for 15 years, and her work was one of the few studies that explored the experience of chronic back pain from the individual's perspective. The auto-ethnographic approach revealed a pejorative experience of living with chronic back pain as having 'bred negative stereotypes and typifies the 'stigma'. The associated stigma meant that she was treated according to her condition rather than as an individual:

*"Rather than seeing me as an individual, with individual needs, I perceived that nurses were treating me according to various negative stereotypes"* (White 2003 p24).

White also identified a number of themes that she believed had influenced her experiences. Crucially, the reliance upon others was singled out which highlighted her loss of personhood through limited autonomy and her increased vulnerability. Other qualitative methods have been used to explore the persons 'lived experience' of chronic pain and examples, such as Sinfield *et al* (2008) used semi-structured interviews to capture an in-depth understanding of problems experienced by people with prostate cancer. Similar to Blomqvist & Edberg's (2002) study, Sinfield *et al* purposively selected people with prostate cancer to explore the experience of the treatment including the tests, decisions made and how treatment was explained. Using a critical realism stance, Sinfield *et al* found that participants wanted to be more involved with the decision-



making processes and concluded that individuals should be empowered to participate in decision-making. The empowerment of people to become more involved in decision making was also reported in Mårtensson & Dahlin-Ivanoff's (2006) qualitative study, which described a rehabilitation programme from the perspectives of people with chronic pain. Using focus groups and cards with statements to explore the experience of client-centred care Mårtensson & Dahlin-Ivanoff's (2006) discovered that the pain management programme had encouraged the development of partnerships between the health care professionals and the patients. The success of the partnership was attributed to the way in which professionals encouraged a sense of responsibility in the patients. Moreover, their work in particular highlighted how bio-psychosocial models that embrace the physiological and sociological impact of pain can be used to support care which reflects Kitwood's (1997) person-centred formula and concurred with the original knowledge classifications as ascribed by Liaschenko & Fisher (1999).

#### **2.10. Review Conclusion**

The limited number of qualitative studies that had been undertaken about the experience of person-centred care for people with chronic pain illustrated the need for high quality care as *defined by the person*. Key attributes described in many papers highlighted principles of personhood such as respect, involvement and information provision. However, there was a dearth of empirical literature that had explored person-centred care within the context of chronic back pain. Most of the studies located in the initial review reflected an increased trend towards recording and understanding the individual's experience of chronic back pain, however reports about person-centred caring have focussed on the professional ideologies and philosophies rather than exploring the key constructs from an individual's perspective. Hence, studies such as White (2003) and Mårtensson & Dahlin-Ivanoff (2006) represent the dearth in research that has explicated person-centred care for people with chronic conditions. The few papers that have explored the experience of living with chronic pain highlighted concerns about the individual's right to be taken seriously. Interestingly, the 'sick role' was singled out as a significant attribute to the acceptance of the person and their

subsequent 'rights to receive care'. Equally, the literature revealed the tensions associated with the concept of person-centred care, which appeared to have been influenced by the ideological split between professionals about the concept of the 'patient', 'person' and 'client'. Whilst the philosophical foundations of care differed between professional groups and clinical contexts, the care processes and models used shared common characteristics and highlighted the need for respect, autonomy, and trust within a caring and holistic approach. Although good research had been published about the concepts associated with person-centred care, such as, McCormack (2003 & 2006), Clarke *et al* (2003), Clarke (2000), Nolan *et al* (2004) and Mead & Bower (2000), there appears to have been a preoccupation with professional ideologies, which has meant that the rhetoric of person-centred care has taken precedence over the reality of care as experienced by the individual.

Despite the calls by McCormack (2003), Nolan (2004) and Kitwood (1997) to explore person-centred care, there has been an emphasis placed on patient rather than person-centred care which reflected the political and professional priorities as opposed to the experience of person-centred care. The initial review therefore did not identify a panacea of person-centred care, but instead presented challenges and questions about the nature and experience of person-centred care. This gap was also noted by Stewart (2001) who reported that definitions of patient-centred care have been used to exploit the activity, but have failed to capture the healing relationship.

*"definitions of patient-centred care seek to make the implicit in patient care explicit. Such definitions are, we recognise, over-simplifications which help in teaching and research but fail to capture the indivisible whole of a healing relationship. Perhaps qualitative research comes closer to conveying the qualities of such care"* (Stewart 2001 p444).

Moreover, Williams (1997) argued that by generating an understanding of the experience of being central within a multi-professional service, future pain management teams may help refine the services that engage with the person.

## **2.11: Chapter Summary**

The initial review of the literature helped conceptualise the key issues related to person-centred care and how that has been described by professional groups. The seminal works of McCormack (2003, 2004, 2006), Kitwood (1997), and Balint (1957), generated a feel for the main concepts of personhood within the context of person-centred care. The gap in the literature highlighted that the person's voice has been largely passed over for more formal structured service evaluations and the experience of person-centred care for people with long term chronic pain remain under-researched. The dearth of evidence about the experience of person-centred care was unexpected, but useful in providing scientific justification to take the study forward. The approach to the review mirrored Strauss and Corbin's (1990) logic of using a review in Grounded Theory and enabled 'a feel' for the concept of patient/person-centred care to be developed. Developing a 'feel' for the key concept associated with person-centred care highlighted the principles of personhood without providing a meaningless list of concepts, which influenced the research design. The next chapter presents the research design in context with the methodological approach of Grounded Theory.

## **Chapter 3: Grounded Theory Methodological Approach**

The initial review of the literature helped construct a 'feel for' the concept of person-centred care and highlighted the influence of the professional ideologies. These presented conceptual challenges and tensions between the notion of 'the patient', 'the person' and 'the client'. The ideological differences indicated reasons for the dearth in qualitative research that has explored person rather than patient-centred care, which also influenced the decision to adopt qualitative approach for the study. This chapter outlines and justifies the use of qualitative methodology and discusses the Grounded Theory research design in detail. The chapter concludes with an account of the challenges faced accessing the sample sites.

### **3.1. Methodology**

As noted in chapter 1, a constructivist Grounded Theory methodology was identified as an appropriate approach to use to capture the meaning about person-centred care. Compared with phenomenology, constructivism is a relatively new concept, which originated in the 1920s and 1930s. At that time constructivism offered an alternative perspective to that of traditional positivists' and provided a platform for the social sciences to focus on the way in which meanings were derived (Broom & Willis 2007). Prior to this, research was dominated by a positivist paradigm, which used quantitative methodologies to reduce, operationalise, control, manipulate and measure phenomena (May 1993). The impetus to measure social life was directed by a reductionist approach that resulted in findings, which were possible to generalise. The reductionist approach was thought to be unattractive to some because of its inability to explore the nuances of life and subjectivity of complex phenomena such as pain, love, loss or caring (Mills *et al* 2006).

The polarised paradigms between positivist and constructivist traditions led to a range of methodologies that have since been used to explore and examine phenomena (Gilbert 1992). However, and significant for the capture of experiences such as caring, the emergence of the constructivist traditions juxtaposed the positivist tradition by introducing a new paradigm from which social scientists were able to develop qualitative

methodologies to generate meaning about the subjectivity of the social world (Holloway & Wheeler 1992). The ontological position of constructivism is concerned with explicating subjective experiences from the social world through engaging with phenomena to construct meaning. Constructivism therefore acknowledges the existence of multiple realities and the need to explicate subjective experiences such as pain within the social world from the perspective of the individual (Charmaz 2006).

To capture the uniqueness of the social world, constructivists use qualitative methodologies to explore meaning to enhance conceptual depth (Charmaz 2006). Significantly, as highlighted by the literature review, the relationship of qualitative research to health care, and in particular the unique experience of pain, lends itself to the exploration of unknown phenomena. It is also acknowledged that qualitative approaches can help develop an understanding of the human experience; provide insight into caring, communication and how health professionals interact (Holloway & Wheeler 1992). Hence, the central concept associated with a qualitative inquiry and of particular interest to exploring person-centred care, is the potential of qualitative approaches to highlight the subjective meanings about person-centred care contexts, as understood by the person (Fossey *et al* 2002).

It is acknowledged that reality and the individual who observes it cannot be separated, which means that the ability to analyse events is often predicated on the researcher's relationship with the participants and how they look for meaning about a phenomena (Ponterotto, 2005). Although qualitative enquiry has its roots in many disciplines, Ponteretto (2005) suggested that researchers should 'locate' their study within a particular research methodology. This also acknowledges that the methodological choice is influenced by the researcher's ontological and epistemological paradigms as described by Crotty (1996), hence, locating a methodology that could capture a person's experience of person-centred care was crucial in order to develop meaning.

### **3.1.1. Grounded Theory**

As previously highlighted, a range of methodologies is used by researchers to capture subjective phenomena. Cognisant of Ponterotto's (2005) reflections on the researcher's role, I acknowledged that my experiences of patient rather than person-centred care alluded to in Chapter 1 could potentially influence the interpretation of the participants' world. Consequently, a number of methodologies were explored to determine an approach that embraced previous personal and professional experiences as part of the analytic process. Grounded Theory was adopted because of the way in which its ontological paradigms have evolved through the work of Juliet Corbin, Anselm Strauss (1990, 1998, 2008) and Kathy Charmaz (1999, 2006). Historically, Grounded Theory emerged out of the University of Chicago from within positivist and post-positivist traditions and was developed by Glaser & Strauss (1967) through their study of the dying. Significantly, the evolution of Grounded Theory by Strauss, Corbin (1990) & later Charmaz (2006) led to a change in its ontological and epistemological position that embraced constructivism and developed analytic ways of understanding the subjectivity of care. Hence, Grounded Theory was appealing because of the way in which it uses the relationship between the researcher and the researched to explicate meaning and theories hidden (grounded) in data (Corbin & Strauss 2008). Moreover Charmaz (2006) asserts that:

*"a constructivist approach places priority in the phenomenon of study and sees both data and analysis as created from shared experiences and relationships with participants and other sources of data" (Charmaz 2006 p 130).*

Ultimately, the analytic process used in Grounded Theory allows a person's interpretation of their reality to emerge. To facilitate this, the researcher acts as a medium through which meaning and theory are generated (Ponterotto 2005). Thus an emic approach is used to co-construct understanding based on the individual and researcher's interpretation of reality. Using exploratory techniques, such as analytic memos, which capture the researcher's interpretations, Grounded Theory fosters ideas through early analytical writing and enables the construction of theories (Charmaz 2006). A particular strength of Grounded Theory is its potential to develop 'theoretical

sensitivity' or deeper understanding about the subject, which is developed through the researcher's relationship with the participant.

Typically, researchers use Grounded Theory methodology to work with the data by applying analytic techniques such as constant comparative analysis. This approach relies on the researcher as the data instrument, through which they move in and out of the data to construct meaning by developing sensitivity to the phenomena. Theorising in this way, has been described by Charmaz (2006) as:

*"To theorise is to become sensitive.....to gain theoretical sensitivity, life is explored from lots of angles in an attempt to follow leads and develop ideas. Seeing possibilities, establishing connections and asking questions.....(Charmaz 2006 p135).*

Theorising through developing sensitivity involves identifying open codes within the data which Corbin & Strauss (2008) report are 'units of meaning used by the participants' to describe their world. The open codes often embrace the participant's exact words, which are referred to as 'in-vivo codes'. After transcription, the researcher looks for open codes through exploring each line in the transcript for descriptors or metaphors used by participants to describe their experience. For example, chronic pain may be described as '*a persistent toothache*', by some people, which could then be converted into an in-vivo code and explored further. A persistent toothache is perhaps a pain that most people can relate to and hence may be analysed to understand the experience of chronic back pain. It is during the analytic process that terms used by participants to describe an experience or situation can be identified. Corbin & Strauss (2008) also advised that the analytic process explores for the 'negative case', which is acknowledged as being the concept that doesn't 'fit'. It is thought that the negative case can strengthen the analysis and /or support theory generation providing a dimensional extreme or variation on the concept.

Corbin & Strauss (2008) suggested that open or in-vivo codes should be further explored for meaning through explicating the properties and dimensions of the codes such as context, time and synonyms that relate to emotions and consequences. Once properties and dimensions have been explicated, open codes become lower-level concepts, which are then analysed further and eventually form higher-level concepts. Explicating codes in

this way allows concepts to emerge from the data, which can be used to explore for meaning about phenomena such as person-centred care. Corbin & Strauss (2008) argue that concepts form the basis of the analysis and in doing so provide an “*analysts impressionistic understandings of what is being described in the experiences and spoken word.....*” (Corbin & Strauss 2008 p51). To elaborate the analysis, axial coding or cross cutting across the codes can help to identify patterns, trends and commonalities eventually forming categories and the development of theory. Using a constant comparative analysis enables higher-level concepts to generate meaning through the development of categories. Theoretical sensitivity evolves through this process and enables concepts and categories to be established, which, once formed are further developed through sensitivity to generate a core or key category (Corbin & Strauss 2008). Finally, as categories begin to emerge further analysis using existing theoretical frameworks can help to refine the core category. From the core category, a theory can be developed that best encapsulates the key experiences that is meaning which people attribute to person-centred care.

The analysis relies on the researcher’s ability to become sensitive through memo-making and analytic frameworks. Embracing a range of analytic frameworks, within a Grounded Theory methodology enables theory to be generated about complex phenomena. Collectively, memos and theoretical sensitivity form a substantial part of theory development and provide an audit trail of the analytic process. Grounded Theory and in particular, the way in which theoretical sensitivity is thought to enhance understanding, was attractive because of the potential to identify the unknown concepts associated with person-centred care and co-construct meaning with people who have chronic back pain.

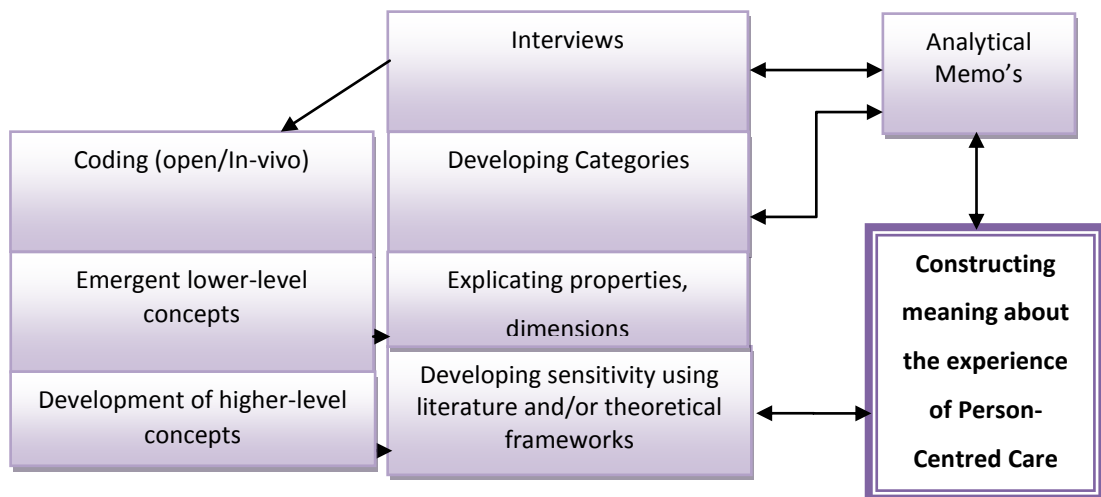
### ***3.1.2. Developing Theoretical Sensitivity.***

Qualitative analysis is a ‘shared craft’ (Miles & Huberman 1994), that sometimes uses a recognised format to process data (Sandelowski 1998), through which data are collected and analysed simultaneously. In Grounded Theory, a range of analytic methods can be built into the research design, but it is advised that analysis begins after the first data



collection activity to facilitate the constant comparative approach and support the development of the next part of the data collection cycle (Corbin & Strauss 2008). This is repeated throughout the data collection process as theoretical sensitivity develops. When the data collection methods become aligned with the emergent categories, theoretical sensitivity advances as the researcher starts to become analytically aware of the concepts through memo-making, reflection and the constant comparative approach. This is not without its critics, mainly from positivist standpoints who regard researcher involvement as a potential source of bias and prefer methods that remove or detach the researcher from the study to enhance objectivity (May 1993). However; it is suggested that the researcher role in the development and analysis of the research plays an integral and inseparable part, and as Charmaz (2006) noted, the constructivist approach places priority on the phenomena under study and sees both data and analysis as created from shared meaning with participants and other sources. This approach encourages the researcher to listen to the participants' experiences and through discussion, develop a shared understanding of the phenomena.

Corbin & Strauss (2008) asserted that the iterative analysis process helps to compare concepts, find categories and generate a theory that 'feels right'. Hence, the analysis in Grounded Theory is largely intuitive and needs confidence in the self to make the right decisions (Corbin & Strauss 2008). The role of the researcher is therefore fundamental to the development of categories taken from higher-level concepts, abstracts and subsequent theory (Corbin & Strauss 2008). Theoretical sensitivity develops through searching for concepts contemporaneously, for example, the meaning participants may give to person-centred care. It is acknowledged that in some cases, theoretical comparisons could be made through identifying metaphors to fully explore the concepts (Corbin & Strauss 2008). Over time data is revisited and concepts are explored in conjunction with other theoretical frameworks identified in the literature to enhance sensitivity.



**Figure 1: The Constant Comparative Analytic Process.**

Consequently, Grounded Theory uses data that are naturally obtained using a range of methods depending on the social context and research question posed. Figure 1 above provides an illustration of this process. Other methods of developing sensitivity involve embracing technical literature as mentioned in Chapter 2 to stimulate theoretical sensitivity through comparing or exploring emergent concepts with other literature. This helps to identify significant concepts that have been previously reported on which can elaborate the analysis.

As noted in Chapter 2, Strauss & Corbin (1990) also advised that including technical literature can provide accurate descriptions of reality which help develop sensitivity and explore for further evidence to delineate concepts. It is acknowledged that technical literature alongside philosophical, ethical and sociological frameworks can also direct theoretical sensitivity by providing ideas about where to locate or search for similar concepts (Corbin & Strauss 2008). This process strengthens theoretical sensitivity and offered an opportunity to facilitate a full exploration of person-centred care, so that meaning might be generated. Through developing theoretically sensitivity, concepts associated with the phenomena should emerge as sensitivity to the phenomena evolves. Hence, the quality of a Grounded Theory study therefore rests on the researcher's ability to explicate a transparent account of the study process and describe fully their role in shaping the analysis and findings. This requires close inspection of the way data is

handled and the influence that the researcher has in shaping the analysis as a result. Corbin & Strauss (2008) argues that “*quality in qualitative research is something that we recognise when we see it: however, explaining what it is and how to achieve it is much more difficult*” (pg 279). The quality and rigour of the analytic process is described next.

### **3.2. Quality and Rigour**

Quality is a contentious issue in qualitative research and there has been a concerted attempt to provide guidance for researchers in particular on how to ensure and judge the quality of their research (Seale 1999). From a philosophical perspective, quality assumes that the properties of a given phenomenon are able to be possessed, or as Pirsig (1974) commented in his writings about quality in *Zen and the Art of Motorcycle Maintenance*,

*Quality—you know what it is, yet you don't know what it is. But that's self-contradictory. But some things are better than others, that is, they have more quality. But when you try to say what the quality is, apart from the things that have it, it all goes poof! There's nothing to talk about. But if you can't say what Quality is, how do you know what it is, or how do you know that it even exists? If no one knows what it is, then for all practical purposes it doesn't exist at all. But for all practical purposes it really does exist. What else are the grades based on? Why else would people pay fortunes for some things and throw others in the trash pile? Obviously some things are better than others—but what's the “betterness”? – So round and round you go, spinning mental wheels and nowhere finding anyplace to get traction. What the hell is Quality? What is it? (Pirsig 1974 p 82)*

Pirsig (1974) never answered this question, because he did not see it as a question that could be answered. It is acknowledged that quality resides within the context and is bound by the temporal elements and the individual. The crux of Pirsig's argument therefore suggests that quality is indescribable because it exists. Pirsig (1974) tried to illustrate this through discursive excursions of ‘quality’ based on his life experience, ironically, as the reader progresses through Pirsig's account, the idea of quality become less transparent. Similar contentions inhabit philosophical literature and the debate about what constitutes quality continues. Hence, the dilemmas articulated in Pirsig's (1974) account of quality, also reside within the realms of research methodologies, because of ontological and epistemological divide between the research traditions (Lincoln & Guba 1995).

Despite this conflict, the criteria for assessing the quality of research remains contested. From a positivist perspective, quality is often underpinned by the extent to which the findings reflect 'truth' and the ability to relocate this becomes fundamental to the process (Robson 1993). Reliability and validity of the research is therefore perceived to be a gold standard within the scientific mentality of objectivism as espoused through modernism, however, those within the post-modern era would conclude that reliability and validity are alien concepts in qualitative research (Robson 2003) because of the ontological and epistemological influence of constructivism particularly in relation to the post-modern era, and the relativists' perspective of truth. Hence, it is acknowledged that the individual's experience represents their world view; an extrapolation to others is therefore redundant. Lincoln & Guba's (1985) seminal exploration of quality questioned positivist terms such as validity and reliability and introduced more appropriate ways to determine validity and reliability that were consistent with a qualitative paradigm. Lincoln & Guba (1995) argued that credibility of the research as opposed to reliability and validity should be established through 'member checking' processes. This process involves returning to the participants to ascertain the accuracy of the analysis and is the most crucial technique for establishing credibility (Lincoln & Guba 1985). Lincoln & Guba's (1985) attempts to shed the positivist mind-set of pre-determined criteria for quality were developed to support qualitative paradigms by accepting that multiple realities exist. However, Seale (1999) suggests that merely describing reliability and validity using different terms does not constitute a paradigm shift in the approach to the question of quality. Substituting terms reflects the constructivist paradigm, which, from an ontological perspective supports the generation of theory. Achieving consensus about the integrity of qualitative research therefore presents challenges, and although as Pirsig (1974) suggests, one knows quality when one sees it; quality in qualitative research remains a contested concept.

Alternatively, Corbin & Strauss (2008) develop this concept further and suggest that findings should be examined for their 'fit' within current practice. This means ensuring that the findings resemble contemporary practice through the presentation of ideas, discourse and other dissemination and verification strategies and assert that this process

should be transparent and provide an auditable account. Hence, establishing external validity, the transferability of findings can be attained through auditing processes that would ultimately replace reliability as it is conventionally conceived. It is acknowledged therefore that a self-critical account of the methodology, which embraces audit as a reflective activity can enhance the quality and rigor of a qualitative study and enable the dependability of a study to be recognised.

In exacting what should be auditable, Charmaz (2006) provides some guidance for qualitative researchers that echo Lincoln & Guba's (1985) theory. For example, Charmaz (2006) advocates that researchers should focus on establishing credibility through examining the research for its links between data, argument and analysis, originality (fresh categories), resonance (fullness of the experience of person-centred care) and usefulness (for example will teams be able to use this). Equal regard for a quality criterion was espoused by Strauss & Corbin (1990), who suggested that, when making the quality process explicit, the canons and procedures should be made clear:

*“Grounded Theory has specific procedures for data collection and analysis, although there is flexibility and latitude within limits... Just as the Grounded Theory researcher must know these procedures and associated canons in order to carry out a study (Strauss & Corbin, 1990, p6).*

The procedures and canons that Strauss & Corbin (1990) include, ensure that data collection and analysis are interrelated processes that progress theory development. Equally, there is a need to ensure that concepts, which form the basic units of analysis, are transparent and relate to the categories that are developed as a consequence. The credibility rather than the validity of the study can be ascertained through providing a transparent account of the analytic process which may also help to transfer rather than generalise findings to other similar contexts. Hence the transparency of the constant comparative approach is essential in determining the 'quality' of the study. Using analytic memos as part of the constant comparative approach provides an account of the researcher's analysis and can thus enhance transparency. Equally, a clear justification of the data collection methods selected presents a significant part of the analytic process as it determines the type, amount and recording of data. Insight into

the utilisation and design of data collection methods are a significant part of the process and are discussed next.

### **3.3. Interviews as a Research Method**

Corbin & Strauss (2008) assert that selecting the most appropriate data collection methods is fundamental to theory generation. It is acknowledged that the data for a Grounded Theory study can be derived from a range of different sources, which include interviews and observations. The ability to select an appropriate method that facilitates the generation of meaning is significant, especially when taking into account the gap identified in the initial literature review about the experience of person-centred care for people with chronic back pain. Importantly, getting a feel for the subject area through the initial review revealed that people find it hard to describe their pain and were very rarely listened to by professionals. This had implications for the choice of data collection tool because as Sveilich *et al* (2005) suggests, the invisibility of pain is significant; human nature is visually orientated which means that what is invisible often goes unrecognised. Thus, chronically ill patients often struggle to tell their story so that it is comprehensible to another; their “idioms of distress are misunderstood or glossed over” (Anderson 1996 p700). Hence pain, particularly chronic pain is often described rather than observed because it allows the person to fully describe that which is not visible. Examples from the literature such as Allcock *et al*'s qualitative study (2000) illustrated the complexities involved in determining patients' beliefs and expectations of a pain management clinic. In their work, focus groups were helped to generate understanding about the individual's experience of chronic pain. This study specifically employed open ended questions to fully explore the participant's perceptions of the pain management clinic. Other examples, identified in the literature review, such as Blomqvist & Edberg's (2002) study conducted qualitative interviews to understand older peoples' experiences of living with persistent pain. These studies illustrated the power of qualitative interviews in determining the individual's experience of chronic pain management and the development of knowledge. Hence, explicating meaning about person-centred care from the perspectives of people with chronic back pain and the multi-professional teams involved was crucial and interviews were selected because they are an ideal method for

eliciting detail about experience and social interactions (Gilbert 1992). Invariably interviews are recorded and transcribed verbatim to ensure that all the relevant data are collected. Analysing qualitative interviews is value-laden, and it is thought that the credibility of the analysis is therefore reliant on the translation of 'tape into text' (Tilley 2003). Hence interview transcription was carefully planned to enhance quality, Mergenthaler and Stinson's (1992) framework was selected to ensure that the context is not distorted through translation (see table 5).

**1. Preserve morphologic naturalness of transcription.**

The graphemic presentation of word forms, the form of commentaries, and the use of punctuation should be as similar as possible to the presentation and use generally accepted in written text.

**2. Preserve naturalness of the transcript structure.**

The printed format should be as similar as possible to what is generally accepted, like the printed versions of radio plays or movie scripts. The text must be clearly structured by speech markers.

**3. The transcript should be an exact reproduction.**

The loss of information resulting from the transition from a visual and/or acoustic to a written record of the interview should be as small as possible. A transcript should not be prematurely reduced but should be kept as a raw data form.

**4. The transcription rules should be universal.**

The rules governing transcription should, as much as possible, make the transcripts suitable for both human and machine use.

**5. The transcription rules should be complete.**

It should be possible for the researcher to prepare transcripts using only these rules based on his or her everyday language competence. Specific knowledge, such as codings stemming from various linguistic theories, should not be required.

**6. The transcription rules should be independent.**

It should be possible to transcribe various kinds of therapeutic discourse with the same set of rules. Transcription standards should be independent of the researcher understandable and applicable by secretaries and scientists.

**7. The transcription rules should be intellectually elegant;**

The transcription rules must be limited in number, simple, and easy to learn.

**Table 5: Mergenthaler and Stinson's (1992) Transcription Framework.**

Mergenthaler and Stinson's (1992) framework is designed to produce an accurate transcription and can help to avoid prematurely reducing text, maintain structure and facilitate a transparent record of the interview. The framework should support the

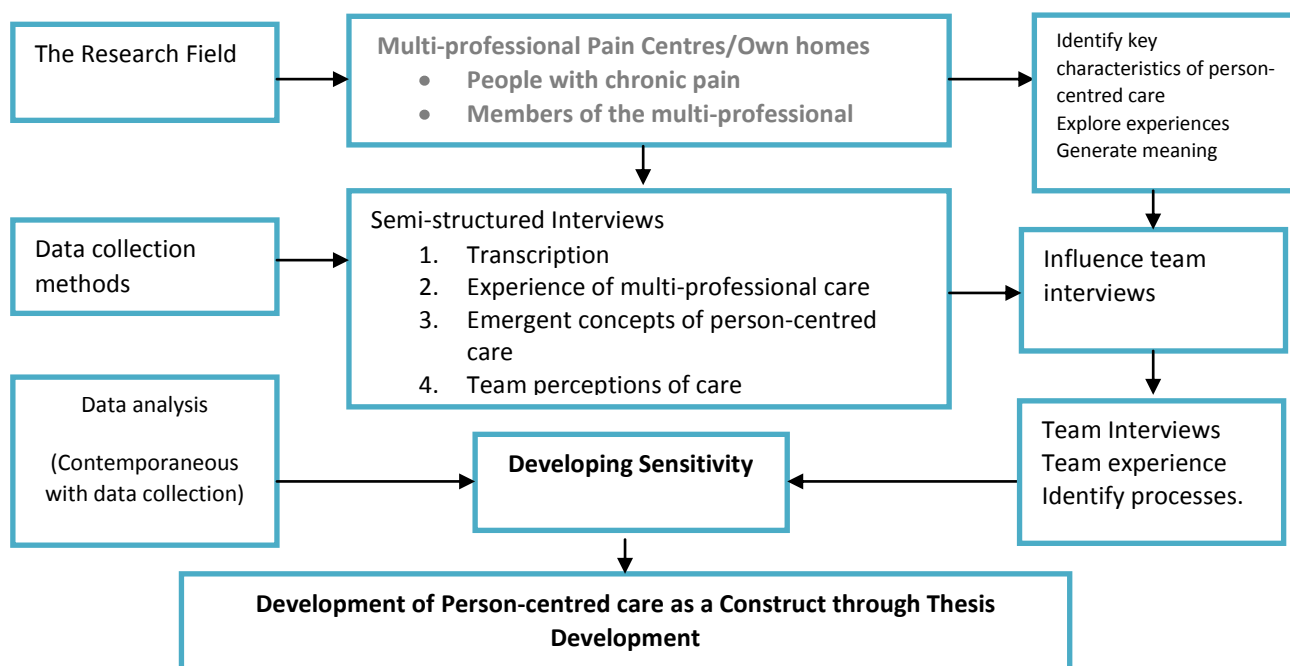
original context and provide a detailed account of the transcription process. For some this single activity undermines the value of research because of the inevitable introduction of researcher bias, yet, it is acknowledged that the role of the researcher in the study is essential to the analytic process and forms part of the construction of theory (Corbin & Strauss 2008).

### **3.3.1. The Research Design.**

Developing sensitivity and ensuring that the analysis is transparent can enhance the quality of the research and was therefore central in the research design. To achieve the aims of the study and to generate an understanding of person-centred care, the research design adopted a two stage approach which could facilitate sensitivity as the constant comparative analysis evolved through the data collection methods. The research design incorporated semi-structure interviews with people who had chronic back pain, followed by a series of semi-structured interviews with multi-professional teams who cared for them. It was not the intention of the research design to explicate the teams perspectives about individuals *per se*, but rather to capture the teams descriptions of care they provided to people with chronic back pain. It was planned that the findings from the original interviews with people who had chronic back pain, would help generate meaning about the experience of person centred care, which could then be further explicated through discussion with the teams.

The nature of Grounded Theory analysis means that often, the theoretical frameworks used to support the analysis cannot be predicted beforehand. The constant comparative analytic process develops over time during which, a range of analytic tools can help to explicate meaning about person-centred care. It is acknowledged that the constant comparative approach can lead to the discovery of new concepts and may require a range of theoretical frameworks to support the analysis and sensitivity. The flexibility of the Grounded Theory analysis framework was appealing because it could help to generate meaning and a potential theory about the experience of person-centred care from the perspectives of people who have chronic back pain.





**Figure 2: The Research Design.**

Designed within a constructivist framework, Grounded Theory approaches enables ontological and epistemological assumptions to emerge as a facilitative rather than restricting element that can co-construct meaning and enhance quality. Figure 2 above provides an illustration of the research design. The next section describes the design in more detail and outlines how the data collection methods were further developed.

### **3.3.2. Interview Location:**

The choice of the interview location is important and is not solely based on convenience for the participant or researcher. The location can provide additional details about the participant as well as enhancing the interview itself. It should be considered therefore within the social context of the individual and aims of the study and as such, the location of the interview plays an integral role on the way in which the interview is conducted and can influence how the participant responds. Hence, in seeking to understand the participant’s experience of person-centred care, interviews were planned to take place in the individuals’ own homes so that they would feel comfortable talking about their

experience and would retain some semblance of control over the interview process. This was important, because as the initial literature review suggested, people with chronic back pain need to be provided with space to be listened to and perhaps more importantly, somewhere where they feel physically comfortable to sit for a period (Gilbert 1992). Being comfortable in the environment enables participants to open up because they feel safe to do so; equally, the participant can terminate the interview if they no longer want to participate or become uneasy about the interview. It is also acknowledged that undertaking interviews in a familiar environment for the participants can help reduce any power imbalance between the researcher and researched (May 1993). The implications of location for the teams differed and presented separate challenges. For example, the logistics of facilitating a focus group or interview with busy practitioners meant that the interviews had to take place within the clinical context. Hence, the design and conduct of the team interviews is discussed separately in chapter 6.

### ***3.3.3. The Interview Questions:***

Interview questions in Grounded Theory should 'guide' the research and often start off quite broad and evolve during the research project (Corbin & Strauss 2008). Ideally they need to be designed with the intent to explore rather than interrogate (Charmaz 1990, Charmaz 2006). Interview guides and prompts are suggested as one way in which to elicit the participant's views about a subject (Charmaz 2006), however, interviews are invariably shaped through culturally shared tacit assumptions and often the data collection methods are designed that are 'internally meaningful' (Holloway & Todres 2003 p 350) to the researcher rather than the participants. Corbin & Strauss (2008) advise that the use of reflexivity in the research process can help researcher's identify their idioms and understand how this may inform the interview.

Corbin & Strauss (2008) believe that being open and reflective enhances the integrity of the work suggesting that "self-reflection is cathartic" and can help visualise whether this has 'slanted' the data. Acknowledging the role of reflexivity in the analytic process was helpful, and influenced the decision to develop questions that were meaningful for

people with chronic back pain. Having realised that the language used to develop the interview questions may not be meaningful for people with chronic back pain, and to generate insight into the *participants'* frame of reference, I enlisted an 'ex-patient' called Nadia through a local pain management support network to help develop the interview schedule. Nadia called herself an 'ex-patient', because she had recently experienced a multi-professional pain management programme.

#### ***3.3.4. Nadia's Help***

Nadia's advice was invaluable as a source of support and clarification. Over a short period of time, Nadia helped to refine and develop pertinent interview questions to elicit the participant's experience of the team. The serendipitous nature of the question development through the dialogue with Nadia opened up my frame of reference and ensured that the person's idiom was presented in the interview questions. Sensitivity developed through Nadia's descriptions of the experience of chronic back pain and the pain management programme processes. This helped develop a deeper understanding of the participant's world through sensitising existing experience with insider knowledge about chronic back pain. Nadia described the devastating effect chronic back pain had on people's lives, at which point, I realised the significance of Bion's (1962) assumption that 'the mind grows through exposure to truth' and thus recognised a need to recognise my assumptions through reflection in order to ascertain an 'appropriate level of knowledge' about people with chronic back pain (French & Simpson 2001) and generate an authentic account of their experiences.

#### ***3.3.5. Preconceptions Revealed.***

Talking to Nadia had a profound effect on my understanding of the individual with chronic back pain and listening to her experiences highlighted preconceived ideas I originally held about the key attributes of a 'successful' team. Previous experiences as an educator and knowledge gained through nursing influenced assumptions about the significance of good leadership and associated theories of team working. To capture this, the analogy of a football team had been included as part of the interview questions

to elucidate my preconceptions about the 'leadership concept' with the teams. However, Nadia's descriptions of care and her experiences of chronic back pain negated this assumption when she suggested that the pain team did not have a 'hierarchy' or definite leader because "they all appeared to be equal". Nadia provided an alternative question that asked the patients about the *part the team members* played.

During the discussion with Nadia, I reflected on Suprina's (2003) exploration the efficacy of a bio-psychosocial model by single practitioners [i.e. the notion of the individual *being* or replacing an integrated approach], I asked Nadia what she thought the outcome would be if the physiotherapist or clinical psychologists were removed from the team and whether an individual [as Freeman *et al* 2000 assert) has a major influence on the team (see also appendix 1a: Howarth & Haigh (2007) written to explicate the 'myth of patient centrality' during the early stages of the study). The anticipated answer was based on *my* understanding of the team, instead Nadia's response was surprising because she chose to describe the role of the clinical psychologists as an example of how they worked slightly 'outside' of the team. Nadia believed that in terms of information sharing, in this instance, removing the clinical psychologists from the team would not make a difference because she believed that personal information given to the clinical psychologists was confidential and therefore not shared.

Nadia highlighted the vulnerable nature of the patients and talked about the 'last chance saloon' analogy that many of her '*comrade patients*' used. She described the people on the pain programme as being very vulnerable and desperate. Many had lost faith in the system, therefore the relationship with the team needed to be strong. Nadia felt this was an important issue and advised that one of the interview questions should ask participants whether they 'liked the team'. Nadia suggested that asking whether the patients liked the team would provide an opening into their thoughts about the team and highlight the strengths and or limitations of the relationship. Nadia viewed the professional team as a 'jigsaw' of professional roles. Her analogy suggested that when the team was successful, the picture would become visible. Nadia reflected on her experiences as a patient on a pain management programme and remarked on how the

team knew each other's role. Nadia felt strongly that this appreciation of each other's roles was the glue that kept them as a cohesive whole. Nadia therefore felt it was important to ask participants to describe what the roles of the team were and whether there were any overlaps. Talking to Nadia about the interview questions was useful because it enhanced sensitivity and facilitated a broader outlook of the way in which teams and person-centred care could be described. The significance of Nadia's early input into the study and its influence on the quality was realised later during the analytic process when concepts began to emerge. For example, listening to Nadia highlighted how asking about a person's referral journey to the pain team was significant, and could invite a lengthy response. Following the meeting with Nadia, all the interview questions were changed to prompts and the schedule became less structured (see table 6).

<i>Original prompts</i>	<i>Changes made</i>	<i>New/Additional prompts</i>	<i>Nadia's Rationale</i>
Can you tell me about your journey?	Who referred you to the pain team?		Nadia suggested that the term 'journey' would not be useful for the interviews. She felt that participants may interpret this quite literally as meaning how they got to the PMP, bus car etc and given the extent of the back problem – this could send the wrong signals to the participants.
		If you were to summarise your experience, or describe it to someone you know, how would you do this? How would you describe a team ?	Nadia advised that this question should come just before the questions about roles. This was useful as Nadia not only helped to develop some of the questions further, but also advised on the 'flow' and question progression.
		How would you describe the team to your friends or family?	Nadia felt that an important question to ask here would be whether they had actually discussed their experience with their family. She said that sometimes, the experience of the PMP was a bit like playing Solitaire
What were their roles Do you think that they worked well as a team? Why? Did you participate in care decisions? Did the team listen to your concerns? Please describe your experience. Did you feel valued?		Did the PMP team allow them to talk about their experience of pain?	Nadia saw this as important question to ask. From Nadia's perspective team working meant that she was able to talk about her condition and extended the team to her family. For example, the family in this instance was seen as 'valuable members if the team'. Team working then from Nadia perspective doesn't just involve the professional staff, but alludes to the personal family members as well. Whilst this is an aspect, which the health care team (and educators) are aware of, the fact that the patient sees the family as part of the team is interesting. Nadia raised the family on a couple of occasions, which makes me consider whether this should be raised as a question with the other participants.

**Table 6 Changes to Interview Prompts**

Meeting Nadia emphasised my potential influence on the collection of data and the significance this could have on the analytic process. Listening to Nadia and embracing her ideas facilitated sensitivity early on which ensured that the interview questions were meaningful for the participants. The next part of the research process involved determining the sample size and inclusion criteria. This posed some challenges and is discussed next.

### **3.4. Determining the Number of Participants.**

Coyne (1997 p630) suggests that there is no 'perfect' way to sample in qualitative research because it is a "*process that continues to evolve with the methodology*". Constructivists seek to understand the uniqueness of the social world; therefore the size of the sample is arbitrary. This approach is contrary to traditional empirical sampling strategies, which often seek large and representative samples in order to generalise (May 1993). Conversely, in qualitative research, the need to understand experience is context bound and consequently rejects the notion of generalisability (Appleton & King 2002, Robson 1993). Moreover, sampling in Grounded Theory is often guided by the analytic process and theoretical saturation by developing codes that are elicited from the data through constant comparative analysis techniques (Corbin & Strauss 2008). Hence, theoretical saturation is considered to be a defining feature of Grounded Theory studies (Bowen 2008) and is completed when there are no new insights into the phenomena under study, resulting in the completion of data analysis (Morse 1990). Concepts are therefore theoretically saturated, subsequently; sampling in Grounded Theory is recognised as distinctly different from other qualitative methodological techniques.

Confusingly, there are different schools of thought about what exactly constitutes theoretical saturation and how sampling helps achieve this. Concurring with Corbin & Strauss's (2008) idea of saturation accepts that theoretical saturation results from becoming sensitive to the phenomena hence the emergent concepts rather than the sample are saturated. Alternatively, it is also believed that the sample size should increase until data are saturated (Bowen 2008) which is consistent with Glaser's (1967)

original approach to sampling. Ontologically, therefore, generalizability conflicts with the constructivist paradigm because of its attraction to a single truth and unified reality. Hence, constructivism rejects the notion of generalizability in favour of sampling techniques that reflect the existence of multiple realities (Corbin & Strauss 2008). Crucially, qualitative research does not seek to attract large numbers of participants in order to generalise (Robson 1993) and instead accepts that improving the understanding of the experience is more important than generalizability (Marshall 1996). Sampling strategies in qualitative research therefore generate insight into unique and subjective phenomena, predicated on an 'adequate' sample size that is dependent on the experience and judgment of the researcher (Sandelowski 2000). On deciding to adopt purposive sampling, greater focus was placed on the adequacy rather than the size of the sample and selecting the appropriate people (rather than an appropriate number) to participate in the study was fundamental to the enquiry. Facilitating this meant seeking advice from pain teams to help identify an appropriate sample and develop the inclusion and exclusion criteria.

#### **3.4.1. Identifying the Sample Sites**

As previously highlighted, using a constructivist perspective suggests that there is a need to ensure that the participants of the study are able to provide insight and meaning about the concept under exploration. The sampling strategy focussed on accessing insight into the subjective experience of person-centred care rather than then attempting to claim significance about the value of person-centred care. Sampling in Grounded Theory is sequential and starts with purposively selecting the participants and then developing theoretical sensitivity once a theory begins to emerge (Draucker *et al* 2007, Coyne 1997). To ascertain an appropriate sample that could provide meaningful data, established multi-professional pain teams across the North West of England were selected. To obtain an appropriate sample of teams, programmes and patients, an existing Nurse Pain Association was contacted. This initial contact resulted in an invitation to present the research project aims at the pain nurses' general meeting. Working closely with the pain nurses helped to establish a contact list of the pain-

centred leads which was used to recruit teams into the study. Six pain centres were represented at the Nurses Pain Association, and four agreed to participate, these were; Fathersham, Poulton, Salisbury and Bracknell (pseudonyms). The four sites provided multi-professional care to a range of people who had chronic back pain and were geographically spread across the North West region. To contextualise the team, an outline of the team philosophy and pain management methods are described next.

### **Fathersham**

Fathersham was the only site that did not provide a dedicated PMP. Their philosophy was influenced by a medical model, which still utilised a multi-professional approach but in a different format than a traditional PMP. In Fathersham, pain management was considered to be a medical discipline and focused on the diagnosis and treatment of an entire range of painful disorders. Some of the participants at this site had already attended a PMP and continued with medical therapies such as facet injections, acupuncture and surgical interventions. The Fathersham team included a number of specialist pain nurses led by a senior pain nurse and a consultant anaesthetist. The anaesthetist was the pain lead and was one of four anaesthetists in the centre. The team members fluctuated, but the core team that delivered on-going support for people with chronic pain through the outpatient service had been established over the past 14 years

### **Poulton**

Poulton used a variety of interventions to treat chronic pain, such as 'Back to Work' physiotherapy programmes, acupuncture and medicines management. As such, the pain service held clinics in a variety of locations to ensure that patients received appropriate treatment at a suitable location. Poulton also ran a dedicated PMP which participants attended weekly for 6 weeks. The multidisciplinary team in the PMP was comprised of medical staff, nursing staff, clinical psychologists and physiotherapists. The team itself was well established and had been delivering the pain management programme for the past 8 years.



## **Bracknell**

Bracknell employed a multi-professional service to promote a comprehensive, approach to people with chronic pain. The team used a blend of physical and psychological rehabilitation as well as medical treatments. The team described the programmes as being quite in depth but also emphasised that the main aim of the programme was to *“rediscover that life can be productive and fun again, despite having on-going pain”*. A structured PMP was provided coupled with a specially designed ‘Back to Health’ fitness programme which was managed by the physiotherapists. The team included a consultant anaesthetist, physiotherapist (lead), clinical psychologists and a specialist pain nurse who had worked together over the past 6 years. The teams here were in the process of being re-located to a newer building within the hospital.

## **Salisbury**

Salisbury was a designated national centre for excellence in the delivery of interdisciplinary Pain Management Programmes (PMPs). The programmes at Salisbury were attended as an outpatient or as a resident. Salisbury used a structured PMP, which aimed to promote self-management through addressing the physical, psychological, social and emotional factors. Salisbury had the most intensive programme over two weeks whereby the participants had to attend on a daily basis. This was the largest team and was led by a consultant anaesthetist with a team of clinical psychologists (x4), specialist pain nurses, a consultant pain nurse, physiotherapists and other medics. The pain teams were mixed between new and existing members, but the programmes of care had been established for over 10 years. The model of care used was consistent between the sites and is a nationally recognised theoretical framework for chronic pain management and is discussed next.

### **3.5. The Main & Spanswick Model of Chronic Pain Management:**

Typically, PMP's and other multi-professional pain management approaches are underpinned by the Main & Spanswick Model (2000) of chronic pain management. The model is based on nine aims to an interdisciplinary pain management programme (Spanswick & Parker 2000 p255). These include;

- To improve patients management of their pain and related problems*
- To help patients improve their level of physical functioning*
- To help patients reduce their use of medication*
- To help patients become less dependent upon use of the healthcare system*
- To reduce patients level of depressive/anxiety symptoms*
- To improve patients level of self-confidence and self-efficacy*
- To address patients fear and avoidance of activity that may be painful*
- To help patients return to useful and gainful activities.*

Main & Spanswick (2000) view chronic pain management as based on self-control, the principle objective being to engage with 'patients' to assist them to regain control of their pain. An interdisciplinary approach promoted by Mains & Spanswick (2000) implies a partnership between the patient and team to help the patient manage their pain. Whilst individuals are referred to as patients, the general philosophy was consistent with some of the key principles of person-centred care such as respect, empowerment and trust.

People with chronic back pain and their families play a central role in the consideration of treatment outcomes, moreover there is a clear emphasis on negotiating programme aims with individuals. Although PMP's are led by Consultant Anaesthetist's, the day-to-day care delivery can be managed by any member of the team which means that a mix of approaches and philosophies are used. The teams were often led by the consultant anaesthetist, but in some sites such as Bracknell, the lead could be another member of the team such as the physiotherapist or the psychologist. The professional make-up of the team reflected the chronic and complex challenges associated with chronic back pain and usually included a clinical psychologist, specialist pain chronic and acute nurses, physiotherapists and others such as acupuncturists, pharmacists and external agencies from housing, social services or equipment suppliers. Collectively a range of

professionals and non-professionals came into contact with the patients whilst they were undergoing their treatment or course; table 7 below provides an overview of the teams.

	<i>Fathersham</i>	<i>Poulton</i>	<i>Bracknell</i>	<i>Salisbury</i>
<b>Consultant Anaesthetist (CA)</b>	The CA was the lead in this site. He worked closely with the senior pain nurse.	The CA was a key member of the team and advised on treatment and medication.	The CA was an active member of the team but did not take the lead.	The CA was the lead for this site. A number of other CA's and medical staff were involved.
<b>Pain Nurse (PN)</b>	Senior pain nurse managed the pain clinic. Ward based staff included a range of surgical and specialist pain nurses	PN's were central to the team. PN was mainly involved in advice and relaxation and helped with joint sessions.	PN's were central to the team. PN was mainly involved in advice and relaxation and helped with joint sessions.	A consultant PN was employed. In addition a number of PN's were involved in the pain centre.
<b>Physiotherapist (P)</b>	Patients were sometimes referred to physiotherapy for further treatment	PT's ran a 'Back to Health' programme and participated in the PMP	The PT was originally the lead in this site.	A number of PT's worked on site and were involved in the PMPs.
<b>Clinical Psychologists (CP)</b>	NA	2 CP's located at this site and helped manage the PMP.	1 CP using the Main & Spanswick model.	A team of CP's operated in the site and were very influential members of the pain team.
<b>Pharmacists</b>	Close working relationship with the pharmacists	Close working relationship with the pharmacists	Close working relationship with the pharmacists	Close working relationship with the pharmacists
<b>Acupuncturists (AC)</b>	Acupuncture was undertaken by the pain team	Referrals were made to the AC	Referrals were made to the AC	Referrals were made to the AC
<b>Administrative support (AS)</b>	The admin support were treated as part of the team and seen by patients as a good port of access	Unsure	Unsure	AS relied on heavily and counted as a team member
<b>External Agencies</b>	none	✓	✓	✓
<b>Main &amp; Spanswick</b>	✓	✓	✓	✓
<b>Medical Lead</b>	✓	✓	X	✓

**Table 7: The Multi-professional Pain Teams.**

In most of the teams, the consultant anaesthetists had limited daily input and mainly provided advice on analgesia. The majority of the care in three of the sites was managed by the psychologist, physiotherapist and nurse apart from at Faversham, where the team consisted mainly of the consultant anaesthetists and a number of specialist pain nurses. The four sites selected were typical of the pain management care offered to people with chronic back pain.

### 3.6. Identifying the Participants

During the design of the research, I met with pain teams to develop the participant inclusion and exclusion criteria. This was invaluable in developing a ‘meaningful’ sample that could help achieve theoretical saturation about the experience of person centred care. Table 8 details the inclusion and exclusion criteria that were developed based on the purposive sampling strategy and following discussions with the pain teams.

<b><i>Participant Inclusion Criteria.</i></b>
1: Who were receiving care/or have received care from the multi-professional pain management service.
2: Who have a confirmed diagnosis of chronic back pain/injury
3: Who have been registered with the service for a minimum of six weeks (apart from Faversham participants*).
5: Who were over the age of 16 years
6: Who could converse in English and answer questions
<b><i>Participant Exclusion Criteria</i></b>
1: those under the age of 16
2: People who were unable to converse fully in an interview
3: People who had been registered for less than six weeks.
<i>*Because of the intermittent episodes of care experienced at the Faversham sites, participants were only included if they had a prolonged experience of the pain team for 12 months or longer.</i>

**Table 8: Inclusion & Exclusion Criteria.**

The pain teams emphasised the need to select people who had completed the programme, thus ensuring that the full experience of the pain team was captured including the journey to the pain team and the outcome of care. At Faversham, the team advised that people who had been attending the pain clinic for at least one year should be selected because of the intermittent contact over a prolonged period of time

and the impact on their ability to describe the team in its entirety. Based on discussions with the pain teams, the decision was made to include those people who had either successfully completed a PMP or in the case of Faversham; those who had been under the care of the team for at least one year.

### ***3.6.1. Accessing the Participants- Gaining Ethical Approval.***

Once the inclusion criteria had been formed, the next challenge was to gain ethical and research governance approval from the relevant organisations. It is widely accepted that ethical approval is needed before any study can commence and significantly, research conducted in the NHS also needs approval from the local research ethics committee (REC) and the host organisation's Research Governance Committee. A number of professional frameworks are available to researchers to guide researchers and support them through the ethical application process. The Economic Social Research Council Research Ethics framework (ESRC 2006) is a framework that guides researchers through the myriad of ethical dilemmas, constraints and areas of research that require consideration. The ESRC advocate 6 key principles, which researchers need to consider in the design, conduct and management of their research. The principles reflect the need for the participant's safety, rights and highlight the significance of ensuring that risks of the research are comprehensively addressed. The ESRC principles are predicated on the World Medical Association Declaration of Helsinki (1964), which advocates a humanist approach to those involved in biomedical research. This approach prevents harm to the research participant through the consideration of beneficence, non-maleficence, veracity, trust and fidelity. Hence, all research conducted with patients and vulnerable groups have to comply with the ethical principles (see table 9).

As a student, I also needed ethical approval from the university ethics committee as well as the NHS sites involved. As a fairly experienced researcher, completing the requirements for ethics was not arduous and whilst the form was time consuming, the questions encourage applicants to examine whether the research proposed was methodologically and ethically robust. Although the topic area was not thought to be 'sensitive', I acknowledged that any interview with participants could attract an element

of risk and discussing any chronic disabling condition may promote feelings of anger, upset, or pain about their sense of loss. To address any sensitive or distressing issues which could arise, the pain teams were asked if they could be available if any participants needed to discuss concerns with them following interview. In addition, the participants and both ethics committees were reassured that should any participants feel distressed or upset by any of the interview discussion, the interview would be stopped and the participant provided with an opportunity to contact the researcher at a later date or see a pain nurse. I also felt that as a qualified nurse with over 10 years' experience I would be able to use my professional skills to comfort participants who became distressed.

<b>ESRC Framework for Research Ethics</b>
Research should be designed, reviewed and undertaken to ensure integrity and quality
Research staff and subjects should be fully informed about the purpose, methods and intended possible uses of the research, what their participation in the research entails and what risks, if any, are involved
The confidentiality of information supplied by research subjects and the anonymity of respondents must be respected.
Research participants must participate in a voluntary way, free from any coercion.
Harm to research participants must be avoided.
The independence of research must be clear, and any conflicts of interest or partiality must be made explicit.

**Table 9: ESRC Framework of Research Ethics.**

The ESRC ethical principles state that the proposal should clearly outline how confidentiality will be maintained and ensure that the participants are fully informed about the intentions, expectation and publications associated with the research. Hence, Data Protection (1998) requirements were addressed and an account of how participants would be supported if they wanted to withdraw from the study was included. Approval was gained from the two ethics committee approximately 6 weeks

after the original application. No amendments were requested and the ethics committee was satisfied that the proposal had considered the ethical implications.

In addition to ethical approval, any research hosted on NHS or social care premises with staff or patients requires Research Governance approval from the host organisation. Similar to the ethical process, gaining research governance approval meant addressing the safety and well-being of the participants in the study and ensuring that the design was scientifically and financially sound, of relevance to the NHS and would be disseminated in a manner that would represent the views of the public (DH 2001b). Importantly, researchers are only able to access NHS sites once approved by each of the Research Governance committee in each site. This has a significant influence on the research process because external researchers are required to obtain honorary contracts from the NHS organisations in order that they can proceed with the study. This process can take some time, however approval for the study was uneventful and access to NHS sites was granted three months following application.

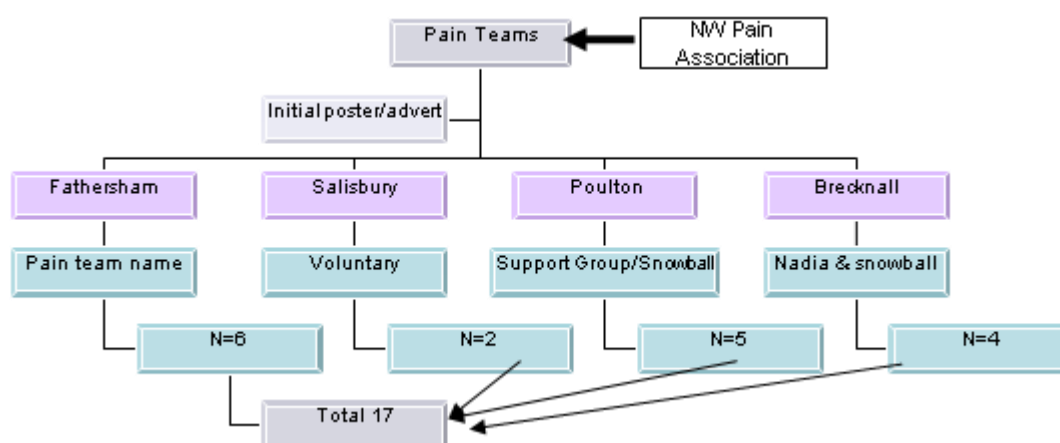
### ***3.6.3. Approval Gained – Access Denied.***

Although ethical approval was granted, accessing the participants presented some challenges. The Data Protection Act (1998) had a big impact on the recruitment strategy as external researchers are not allowed access to patients' files or personal details. As such, the teams were fundamental in generating a contact list of people, (with consent) who had recently been through a PMP. Once satisfied with the overall design of the study, and following ethical and research governance approval meetings were held again with the pain teams to gain their support for the study and help with the recruitment process. All the teams except the Salisbury site were happy for the study to take place and were keen to help; however, the team at Salisbury were reluctant to provide access to their patients because they had concerns about the sample size, which originated through questions raised in the meeting by the clinical psychologists. This was interesting for a number of reasons, but mainly because it highlighted a paradigmatic tension between the positivist ontological position of the psychologists' need to seek out a single truth and to generalise with the constructivist's assumptions about reality and

'transferability of findings (Lincoln & Guba 1995). Following further negotiations with the team at Salisbury, access was finally granted.

### 3.7. Recruiting the Participants: Blending Snowball and Purposive Methods

Recruiting the participants from each site took place over a 4-month period. Using a blend of purposive and snowball sampling (respondent driven) techniques, 17 participants were recruited (see figure 3). Snowball sampling is frequently used in qualitative research to exploit initial contacts to locate information rich participants (Creswell 1998). Moreover, Penrod *et al* (2003) suggest that snowball sampling is underpinned by populations who are familiar or who have something in common with others in that population.



**Figure 3 Participant Recruitment**

This approach dovetailed with the inclusion strategy and overall study aims and was also a suitable method of choice for sampling within natural interactional units (Biernacki & Waldorf 1981). Although there are some who argue that snowball sampling can produce bias that exaggerate interrelationships (Berg 1988), it is also acknowledged that the interrelationship between people who had managed chronic pain was a necessary and interesting part of the methodology (Corbin & Strauss 2008). Using the combined approach helped to recruit seventeen people with chronic back pain to participate in the study. Once approval was gained, each site was provided with information packs about the study to give to potential participants. In addition, posters were displayed in each



clinic, which advertised the study. The response was quite slow, in particular, only two people from Salisbury volunteered. Once consent to share contact details had been obtained, the staff at Faversham supplied a contact list which was used to invite other participants for interview. This strategy led to 6 participants from a mix of social backgrounds. A similar recruitment strategy was used at Poulton, and an initial contact with another ex-patient called 'Mark' provided details about a support group that was managed by people with chronic painful conditions. From this contact, a further five participants were recruited. Finally, at the Bracknell site, a similar snowball sample was used to recruit a further 4 participants.

### **3.8. Chapter Summary**

The research design was influenced by a constructivist approach using Grounded Theory as a key methodology to explicit the experiences of person-centred care. Semi-structured interviews with the people who have chronic back pain and the teams were planned. A constant comparative analytic technique was included in the design to support theoretical sensitivity and the saturation of concepts. Interview questions developed collaboratively with Nadia helped identify and manage preconceived ideas about the multi-professional teams, working and discussions with the team facilitated the sampling approach. The next chapter discusses the participants in more detail.

## **Chapter 4: The Sample: People with Chronic Back Pain.**

The ability to enter into another's world is fundamental to the constructivist understanding of reality, and is crucial in determining meaning about a phenomenon. Exploring the individual's experience of person-centred care using semi-structured interviews was exciting because it provided an opportunity to listen to their experience of chronic back pain from the perspectives of people with chronic back pain in their language. As McCormack (2003) suggests, engaging with the individual to explicate their experience means first listening to and conversing with the person to gain a glimpse of the biography and is instrumental to the process. This chapter describes rather than analyses the participants to provide an insight into their background, biography and the impact that living with chronic back pain had on their lives.

### **4.1. Participant Characteristics**

The recruitment process adhered to the ethical framework and participants were made aware of their rights to withdraw from the study at any time. An information sheet was given to each participant two weeks before the interview, and contact details were provided to enable participants to raise any additional queries before the interview. Written and verbal informed consent was obtained prior to each interview following a description of the study and after an opportunity to ask questions. The participants ages ranged from 34-80 years old and they all had suffered with chronic back pain for a number of years. Interestingly, although adverts were placed in prominent places throughout the four sites, the majority of participants who volunteered to be interviewed were female (n=16). Five of the participants were still employed. JP worked in a supermarket, Elaine was a civil servant, Jay was self-employed and Mary worked as an administrator in a PCT. The other twelve participants had retired either on medical grounds or due to natural retirement processes. Of these, two were ex-registered nurses, and two were ex-auxiliary nurses. The only male who volunteered was Roger who used to be a car proprietor. The other participants had varied employments, Sue was a civil servant, Shona was a model, Kelly used to work for BT in credit control, Connie was a government officer, KT was a hairdresser, Doreen was a home help,

Lindsay was a cook, and Phyllis was a medical secretary. All the participants spoke English as their first language. Each participant provided a unique perspective and was instrumental in developing an understanding about the experience of chronic back pain and person-centred care. A description of each participant is provided to help contextualise the impact that chronic pain had had on their lives and subsequent experience of person-centred care. All the participants were assigned pseudonyms to protect their identity and preserve confidentiality.

#### **4.2. Getting to Know the Participants:**

##### **Sue**

Before she retired on medical grounds, Sue was a full time Civil Servant. Sue called herself 'a fighter' – someone who doesn't give up easily. At the time of the interview, Sue was 41 years old and lived in a semi-detached house with her husband and three children. Although her children were grown up, two remained at home because they were unable to get a 'foothold on the property ladder'. Sue enjoyed looking after her two children and was very proud of her eldest son who was in the army. Sue had a dog – Barney, which was present throughout the interview, and she enjoyed walking him. Sue had been suffering from a painful condition for more than 20 years, but it became unbearable in the past 4 years and had recently been forced to go on long term sick leave. Prior to being referred to the pain team, Sue had had a year of physiotherapy twice a week followed by a course of acupuncture after which she had been referred to see the Clinical Psychologists. Sue had lots of different interventions before being referred to the pain team – but none seemed to last. It was the clinical psychologist who suggested that Sue needed to attend a PMP. Sue was quite chatty throughout the interview and talked fondly about her garden after the interview.

##### **Nina**

Nina was a 50-year old retired specialist diabetes nurse who lived in a bungalow with her husband and two children. Her youngest son was 14 years old and suffered with type 1 diabetes, which Nina helped managed. Nina says that she is kept active by her son

because she was always running him around to various cricket matches for the school team. Nina was initially referred to the pain team in 2007 when she went to see the consultant anaesthetists, who prescribed pain relief. At this point Nina was still working and was taking strong opiates to control her pain, but found it difficult to work due to the sedative effects of the morphine. Nina became worried about the impact of the opiate effects on her nursing practice and the safety of patients, so she stopped taking the pain killers, but the pain became unbearable and she had to resume the medication. It was after this experience that Nina was referred by her GP to the pain team. She was initially assessed by a clinical psychologist, who felt that a PMP would be a good option for Nina. Since this time Nina had retired on medical grounds but was managing her pain well. Nina missed her job and would like to return but felt that the pain and strong analgesics would compromise patient safety. Nina is quite tearful about this, because she felt that she was a good nurse and still had a lot to offer. She believed that having chronic back pain had taken away something of 'herself', which had taken a long time to repair. Nina was optimistic and talked fondly of the people she had met during her treatment by the pain team, and four of these became firm friends.

### **Helen**

At the time of interview, Helen was a 44-year old lady who had been medically retired from her position as an auxiliary nurse because of her back pain. Helen was referred to the pain team by her GP after she had been 'signed off' work. Helen lived with her husband in a terraced house and suffered from depression. Helen's interview took place in her front room which felt quite oppressive because it was a sunny day and the curtains were closed. The room was quite unkempt and there were a number of stains and cigarette burns in the furniture. Helen was an interesting lady, but came across as very depressed and at first it was quite difficult to talk to Helen because she was reluctant to describe her feelings in any depth. Helen wanted to participate in the study because she wanted to help others in a similar position. Helen had suffered from chronic back pain for a number of years and had become depressed because of her loss of job and because she felt that no one believed her pain. Helen described how upset she was

when her husband told her to 'get a grip' and never seemed to believe or understand that she had pain. Helen knew Sue and Nina from attendance at the pain team and found solace in others who had experienced the same problems. Helen now enjoys seeing Sue and Nina and has regularly met with them for coffee and Pilates for the past 2 years.

### **Elaine**

Elaine was a 50-year old lady who, at the time of interview was still employed as a full-time Civil Servant. She lived with her husband and three children in a large detached house. Elaine had suffered from Rheumatoid Arthritis for a number of years, which had caused her pain and distress but she had refused to have any surgical interventions. As Elaine described it " it just got where it was every day, every day and it was getting me down and I felt like I could not cope with it really". The impact of the chronic pain on Elaine's life resulted in her inability to care for her twin children who were quite young when she was diagnosed with rheumatoid arthritis. Elaine talked about her frustrations when she was unable to lift or carry her small children and how she used to get angry with herself and her husband. She talked fondly about her husband who had been 'incredibly supportive' over the years and seemed to understand her needs. Elaine was referred by her Rheumatologists to the pain team where she met Nina, Sue and Helen and formed a social relationship, which has been maintained since. Elaine said that she enjoyed her time with the pain team and valued the friendship she had developed with Nina, Hannah and Sue. Elaine is now 'pain free' and is happy continuing with her work and supporting her children through university.

### **KT**

When KT was 19 she had an accident, which left her with a lot of pain in her back. At the time of her interview, KT was 37 and lived on her own in a small townhouse. KT had originally trained as a hairdresser, manicurist, and wigmaker but was working as a cashier sales assistant when she had the accident. She had not worked since the day of her accident. KT has since suffered two relationship breakdowns because of her 'flare

ups' and the chronic nature of her back pain. KT described how her partners had not been able to tolerate her and could not understand her pain. She said that because they could not see an injury, she felt as though they did not believe her pain existed. KT was a very upbeat individual who smiled and chatted throughout the interview and seemed really happy that someone was listening to her experience. KT was initially treated by the physiotherapist for 6 months following her accident. After this point, KT was referred to and seen by 8 different consultants both privately and NHS. KT then attended a Pain clinic in 1994 for 3 weeks, which she described as being "absolutely fantastic because it got me out of a wheelchair and walking with sticks". However, after the pain course KT was referred to the physiotherapist again for 'gym' work, which did not help. She was finally referred for medical management where she continued to receive care. KT enjoyed going to see the pain team and referred to them as her friends.

### **Shona**

Shona was an 80-year old retired model who developed back pain a number of years ago. At the time of the interview, Shona lived in a large bungalow with her husband who was dependent on her for care because he was blind. Shona talked a lot about her modelling days; who she worked for and the type of clothes she modelled. She was very proud of her career and said that she had met her husband when she was on a modelling contract. Shona was surprised that she ended up with chronic back pain because, as she remarked, she had 'always had to have a straight back for her poses and modelling'. Shona suffered a lot of back pain, and attended the GP practice on a number of occasions. After repeated visits to her GP to manage the pain, Shona was referred to an osteopath. Shona's back pain gradually became worse and eventually, she went to a private hospital where an MRI scan highlighted multiple stenosis, which had caused 4 or 5 discs to crush the spinal cord. Following this, her private care continued and she was placed on morphine patches which made her have hallucinations. She stopped taking the medication and became frustrated because she was unable to manage the activities she was familiar with. Finally, her husband had 'heard about' the pain team at Fathersham, so Shona asked her GP to refer her. Her husband came into the interview

half way through and talked about his frustration because he knew that his wife was in pain, but nobody would do anything about it.

## **JP**

At the time of the interview, JP was a 51-year old lady who worked in a local supermarket. She lived with her husband in a small town house. JP enjoyed going long walks with her husband and particularly liked taking her caravan to the Lakes for a few days. She enjoyed trying to 'fathom out some of Wainwright's walks'. JP was involved in a minor car crash and was shunted into another car. The resultant back pain was significant and she was referred for physiotherapy, which she said made her feel worse. JP said that the physiotherapists asked her to do exercises, which made the pain worse and she quickly became disillusioned with the care they provided. JP said that there was no obvious injury from the car crash, but she remained in pain. She described the pain as a constant toothache but in her back. After the treatment by the physiotherapists, JP was referred for an MRI scan, which detected a bulge in the lumbar region. JP smiled when she recalled the day she received a diagnosis and said that this proved that there was something wrong with her. JP talked a lot about her daughter who had been in some pain following a fractured shoulder – but she remarked that her daughter received painkillers when and as needed and did not seem to suffer the same indignity that she had. JP was then referred to attend a PMP, but she turned this down because she was getting mixed advice from friends. JP was prescribed a range of analgesics but these were largely ineffective. JP began to suffer at work and became reliant on stronger opioids to manage her pain. JP said that by the time she got to work after taking all her medications, she was able to walk upright –so no one really understood the true amount of pain she was in. Eventually, JP was referred to the Faversham site where she has regular medication reviews and facet injections to control the pain. JP continues to be cared for at Faversham.

## **Kelly**

Kelly was a 78-year old retired British Telecom worker who had persistent back pain because of an accident at work and the onset of osteoporosis. At the time of the interview, Kelly was a widow who lived in a semi-detached house in a quiet suburb. She was close friends with her neighbours who were all widows and she relied on her neighbours to help her in the garden when her back became painful. Kelly had recently lost her husband to cancer and although she was originally able to manage, she was finding it increasingly difficult to manage her garden. Her two children lived far away, so befriending her neighbours was a 'lifeline'. Unfortunately, Kelly's pain was compounded through being hit on the ankle by a skateboard, during a shopping trip. The accident caused damage to the ankle and Kelly had to have an operation to repair the damage. Kelly was quite frustrated with the ankle injury because it had stopped her mobilising and getting to Bingo with her neighbours. The ankle was also painful and Kelly had to cope for some time with the pain in her back and in her ankle until the tissue damage was repaired. During this time, Kelly was referred to Faversham for pain management and medical interventions. Kelly still receives medical treatment for her ankle and back.

## **Doreen**

Doreen was a 68-year old lady medically retired home help. Doreen was diagnosed with rheumatoid arthritis when she was 37 for which she received treatment. During this time, a series of life events such as the death of her husband and her battle with cancer caused the arthritis to worsen. Doreen was quite optimistic and said that the pain hadn't stopped her gardening and showed off her garden and talked about her plans for the garden. She said that more recently she had to rely on her next-door neighbour to mow the lawn – but he did a better job than her – so she was quite happy. Doreen was very proud of her involvement in the Expert Patient Programme and she was keen to describe how this had helped her. Doreen has always been keen to help others and never looked to feel a burden, so did not seek help with her back pain for some time. Consequently, Doreen suffered a great deal of pain, which was originally being 'managed by' the Rheumatologists, but, Doreen was later referred by the Rheumatologist to the pain team



for medication review and medical intervention to treat her back pain. Doreen enjoyed her 'trips out' to see the pain team. She said that it got her out of the house and she enjoyed having a cup of tea whilst she waited to see the pain team.

### **Connie**

Connie was a 77-year old retired government officer who had had an accident a number of years ago which damaged her spine. Connie lived alone in a warden controlled flat and had difficulty getting around. As a young girl, Connie was part of an amateur dramatics association and was rehearsing when some scenery fell onto her head crushing her spine. Since this event, Connie has battled with her pain and has received a number of care interventions. Connie seemed to have a very dry sense of humour and talked about setting up an 'am dram' group in the flats, but could not get anyone to 'take the bite'. Connie was also proud of her new flat and the inbuilt bathroom/shower, which she loved. She loved reading, but her eyesight was getting progressively worse so she was using more 'talking books' to help her. Over time Connie was referred to a range of different doctors and has since developed alkalising spondylitis of the spine. Connie uses a Zimmer-frame to mobilise and often gets lonely in her flat. The warden of the flats often visited Connie just 'for a chat'. Connie was referred by her GP to the pain team to manage the pain episodes a few years ago and she looks forward to seeing the team every 6-8 months. I spent a long time with Connie talking about her past which she enjoyed reminiscing about.

### **Roger**

Roger was the only male to volunteer to participate in the study. He lived in a large detached house with his wife and disabled daughter. At the time of the interview, Roger was 54 years old and was a retired car proprietor who had a car accident when he was 18 years old. It was after this accident that Roger began to suffer with chronic pain. The car accident was a catalyst for events that followed in which Roger was referred to and treated by a range of specialists. Roger was keen for me to understand the events that led up to his back pain and described how a car accident resulted in immense damage to

his muscles and deterioration of his joints causing severe pain. The treatment provided for his shattered legs altered his gait, which then affected the curvature of his spine. The result was a chronic back pain condition for which his GP referred him to the pain team. Roger became addicted to morphine and at one point was drinking heavily because he could not cope with the change to his life. Roger was also depressed because he felt unable to look after his disabled child. He said that he had to reach an all-time low to rebuild himself – and now he was an advocate for other people in similar situations. Roger is now an active member of a local support group that had been set up for people with chronic painful conditions. Roger gets great satisfaction from helping others in similar situations and had worked tirelessly for the past few years with the support group.

### **Lindsay**

Lindsay was a 54-year old lady who had to retire from work because of the heavy lifting involved in her catering job that exacerbated her back pain. Lindsay lived with her husband and daughter in a small council house. Lindsay had recently become a grandmother and has spent the past few months helping her daughter with her grandson. She said that she really enjoyed looking after him, but remarked that this would have been impossible a few months ago because her back pain was so bad. Lindsay stated that her back pain was caused by her neighbour, who assaulted her by hitting her on the head with a large spanner. The attack damaged her spine and Lindsay had been in a lot of pain since the event. Until the assault, Lindsay was a cook and then a cleaner but found it difficult carrying objects such as vacuum cleaners. Lindsay was referred by her GP to the PMP because of the unresolved pain. Prior to this, she had been treated by a chiropractor and physiotherapist, but these referrals had proven unsuccessful. Lindsay said that she was 'eternally grateful' for the pain team because they put her back on her feet again.

## **Phyllis**

Phyllis was a 52-year old retired medical secretary who worked part time and enjoyed her job. At the time of the interview, Phyllis lived with her husband in a bungalow, which they had recently re-furbished and renovated. Phyllis had suffered from rheumatoid arthritis for a number of years and had originally been cared for by a rheumatologist. Phyllis was a quiet lady and although she wanted to participate in the study, she sometimes found it difficult to describe her experience. Phyllis also said that she did not want to participate in all the group activities with the pain team but that the team understood this and helped her. Phyllis loved walking and she often went to the Cotswolds with her husband and enjoyed the local walks. Phyllis said that the frequency of their walks had diminished since the onset of her back pain, but they were beginning to get out a bit more since her treatment. After a series of unsuccessful attempts to manage the pain, the Rheumatologists wrote to her GP requesting a referral to the pain team. Phyllis had felt a bit let down by the NHS because she was left waiting so long for a referral to the pain teams. Once referred, Phyllis was keen to undertake the course but had to wait a further nine months to start the programme. She said that by the time she got to the pain team she was on so many medications that she had to give up driving which she hated because she felt that she had lost her independence.

## **Jay**

At the time of the interview, Jay was 53 years old and was self employed. She lived in a large detached house with her husband, daughter and 'future son-in-law'. One of Jay's hobbies was bird watching –and during the interview, Jay's bird-sound recordings occasionally played. Jay has been an ornithologist for some time, but found it increasingly difficult to observe the birds for any length of time due to her back pain. Jay was keen to describe the medical conditions that had caused the back pain. These included rheumatoid arthritis, lupus and adult Still's disease. Despite the pain, Jay had always been reluctant to take pain-killers so had tried to cope with the pain since she was 35 because she was worried that she would become addicted to strong pain killers. She had witnessed other people becoming dependent on such medication and did not

want to lose control of her 'faculties'. Hence, Jay struggled with her pain for a number of years and eventually her GP conceded that Jay needed specialist help with her pain. Jay had a lot of admiration for her GP and stated that her GP just wanted the best care so referred her to the pain team. Jay was referred to the pain team at Bracknell and she enjoyed the experience. She liked all the team apart from the nurse, who she said had a personality clash; but otherwise she benefited from the pain programme and had since taken up bird watching again.

## **May**

May was a 52-year old medically retired community auxiliary nurse. At the time of the interview, May was living with her husband in her son's house whilst her own house was being renovated. May described her back pain as resulting from "an accident at work" and put off going to the GP and continued to self-medicate until the pain became intolerable. May felt 'silly' for having the back pain because she believed that it had been caused through 'lifting' a patient's legs. May pulled her back whilst dressing and lifting a patient's legs but did not seek help and the pain deteriorated. May finally went to see her GP and an MRI scan revealed nerve damage in her neck, which she was told was inoperable. May was devastated by this news because it meant that she could not continue nursing. It also meant that she became afraid to pick up her grandson because she thought that she would drop him. May was referred to the community physiotherapist, but the referral was largely unsuccessful. However, it was the physiotherapist who told May about the PMP. May has not worked since and misses her job as a nurse. She became depressed at first but over time, felt able to cope again. May could not remember whether the GP or the physiotherapist referred her to the pain team. May also enjoyed her time with the pain team, and often sees other 'ex-patients' at social events. She liked catching up on gossip and chatting generally to people who have been through the same experience.

## **Mary**

Mary was 42 and worked as an administrator for the local PCT. At the time of the interview, Mary lived on her own in an inner city council flat. Mary recalled that the referral was “kind of vague... I was mainly off because of the pain and I don’t like taking medication”. Her recollections of her experience before being referred to the Salisbury pain team were vague, but Mary remembered having surgery in 1997 and then suffering from flare ups in 2006/7 following which she thinks that the occupational health department referred her to the pain team. She remembers the pain team fondly and was happy that she attended the pain programme because at first she felt too shy and did not really want to mix with other people. She believed that the majority of people with chronic back pain would be ‘old’ and have arthritis, however, she realised that chronic back pain affects all age groups, which she said was reassuring – because it meant that it ‘wasn’t ‘just her’.

## **Liz**

Liz was 42 and worked full time as a retail manager for a charity shop. Prior to this, Liz was a nurse, but she had to give this up because of her back condition. Although Liz enjoyed her current work, she valued nursing because she felt that she was able to help people. At the time of the interview, Liz lived in a small townhouse with her daughter and managed quite well with regular pain medication and support from her daughter on occasions. Liz was referred to the pain team by her GP because the analgesics she had been taking were no longer effective. Liz did not discuss the cause of her back pain or provide any details about the referral to the pain team. Liz was a quiet lady who wanted to talk about her experiences, but also came across as quite reserved.

### **4.3. Sites Attended**

#### **Fathersham Site**

Patients from Fathersham were KT, Shona, JP, May, Connie, Doreen, Kelly. Most of the patients had been on a similar referral route to the other PMP patients, but at Fathersham, the participants relied on medical interventions. All the participants had been attending the pain centre for a minimum of five years. They all had a good relationship with the staff and all were still receiving minor or medical interventions. The consultant anaesthetist at Fathersham and the nurse also performed acupuncture alongside provision of analgesic advice and follow up care. Two or three interventions per year were provided for people with chronic back pain.

#### **Poulton Site**

Participants from Poulton included Lindsay, Phyllis, Jay, and Roger. At Poulton, patients attend the clinic once a week for seven weeks. The timetable was fixed and the start time was 9am. The day finished at 4pm. Participants in this site complained about the early start time because they felt that they were unable to drive safely in the morning due to their medication (some participants were still on morphine). They all attended a regular support group, which is funded by a charitable organisation which was allied to the local pain clinic.

#### **Salisbury Site**

Two participants;- Sandra and Mary volunteered to be interviewed from Salisbury. This was a large site and the staff involved with the pain management programme included the clinical psychologists and physiotherapists. Usually, there are between 8-10 people who attend the pain management programme. Both Sandra and May enjoyed going to the Salisbury and liked the team.

## **Bracknell Site**

Elaine, Nina and Helen attended the Bracknell site. Elaine and Nina had also attended the “Back to Health” programme. All the participants felt that this was an intensive course and Elaine struggled to get time off work to attend. This site offered a traditional PMP, where the participants were encouraged to attend the PMP once a week for seven weeks. The timetable was structured and each day started at 9am and finished at 4pm. The average group size was 8 people.

### **4.4. Chapter Summary**

The range of conditions that had caused chronic back pain varied. Some participants were keen to describe the origins of their back pain, but just talked about the pain rather than the cause. All the participants had waited a considerable time before being referred to the pain teams, during which they had often received less than adequate pain management. The majority of the participants were unemployed or were medically unfit for work and some of the participants had suffered from and still continue to suffer from depression. Those participants who described themselves as being depressed were keen to say that prior to the onset of their back pain, they had not really experienced depression. For the vast majority of patients, referral to the pain team occurred after a number of years ‘in the system’ during which time, the patients had experienced care from many different health care professionals.

## **Chapter 5: Listening to the Participants**

People with chronic back pain have a story to tell and listening to the participants' descriptions revealed significant events in their 'journey' through healthcare. For some participants, sharing their experience was cathartic and highlighted the complexities of living with chronic pain. This chapter provides insight into the analytic processes used to generate meaning about their experience of person-centred care. The first part of the chapter discusses the methods that were used to explore the participants experience and outlines some of the key principles of Grounded Theory that shaped the approach. The second part of the chapter presents the analysis and uses raw data extracted from the interviews, which includes examples from the analytic memos that helped to explicate concepts and develop categories. The final part of the chapter illustrates the significance of being believed and how the category of co-validation was developed.

### **5.1. Meaningful Reading.**

Data were collected over an eight-month period during which 17 in-depth semi-structured interviews were conducted with people who have chronic back pain. The interviews took place in their homes for convenience and to facilitate a conversation in an environment in which they felt comfortable. It was a privilege to visit the participants in their own homes, but it also presented some challenges. For example, interviewing in unfamiliar territory was anxiety provoking at first because it initially felt intrusive. After the first interview with Sue, it became apparent that the interview had provided an opportunity for Sue to talk about her experience of care to someone outside of the healthcare context. The benefits of participating in research interviews have been reported elsewhere and it is suggested that that qualitative research interviews can be cathartic, healing, and provide a voice for the disenfranchised (Hutchinson *et al* 1994). This could explain why all the participants were very welcoming and keen to talk about their experiences, and although the interviews were quite lengthy, often lasting between 1 – 1 ½ hours, participants frequently continued talking about their lives after the interview had concluded. The interview questions were open ended and provided an opportunity for an informal conversation about their experiences, during which, the



participants revealed significant and very personal challenges that they had faced. Leaving their homes with their personal details recorded on a digital recorder was therefore quite daunting, and memos were made after each interview to capture these challenges and generate meaning about their experience.

It is acknowledged by Bortoft (1996) that reading needs to be 'meaningful' and represents more than just repeating the spoken word. Reading therefore needs to present an 'act of true interpretation' that enables the generation of meaning (Bortoft 1996). This meant first being able to accurately record the details of conversation. Thus, interviews were digitally recorded to capture all the relevant details, following which the whole interview was transcribed verbatim and analytic memos were recorded to support the analysis. Early transcription was an essential component of the analysis because it facilitated the construction of the participant's experiences. However, there is some debate about whether the interview is transcribed in its entirety or if partial transcription results in loss of significant data. Miles & Huberman's (1994) suggest that the steps taken in data reduction through the transcription process are based on what the researcher decides to leave in and take out. In acknowledging that partial transcription may put the context at risk and undermine the rigour of the transcription process, interviews were transcribed in their entirety. This provided opportunity to return to the data to listen again, check for missed accounts, which ensured that the transcription and interpretations present an accurate reflection of the participant experiences. Although time consuming, self-transcription meant close attention was paid to the interview which Lapadat & Lindsay (1999) argue supports interpretive thinking and can help construct the participant experience.

It is also acknowledged that transcription is a 'theory laden component of qualitative analysis' and as such needs to be rigorous and trustworthy; hence, the credibility of the analysis relies on the researcher's ability to translate 'tape into text' (Tilley 2003 p752). Using Mergenthaler & Stinson's (1992) framework maintained structure and prevented premature reduction of the text, which facilitated a transparent record of the interviews. Consequently, the naturalness and context of the interview data was preserved which

provided an auditable account of the transcription process. This enhanced the analysis as transcripts were re-read to clarify or further develop a concept. Analytic memos were written throughout the transcription process and provided an opportunity to critically analyse the participant's descriptions of their experience. The on-going reflection through the memo-making process enabled sensitivity to develop early on in the analytic process, which later facilitated the development of concepts and categories. This helped ensure the academic integrity and honesty regarding how meaning was constructed about the participants' experience. Hence, raw data was not used in isolation and a rich picture of the participants' experiences of healthcare was generated. Extracts from the memos and interviews have been inserted throughout the analysis chapters to ensure that the analytic process is transparent and auditable and an example taken from the interview with Jay is presented in appendix 2.

## **5.2. Fine-tuning the Interview Prompts.**

In-depth interviews were an ideal medium to elicit participant viewpoints and construct meaning from their experiences. As the analytic process progressed, the original interview prompts developed with Nadia's help were refined through talking to the participants which, when integrated with the memos and reflections helped to identify, explore and construct concepts and then categories. Over time, the interviews became more unstructured and adopted a conversational style that allowed greater exploration of the key issues perceived to be significant by the participants. To ensure that that the participant's interpretation of the experience had been captured and to construct meaning, each person was asked to highlight any question(s) they thought would be useful to ask the next participant. These were used in successive interviews, which later enhanced sensitivity. For example, Phyllis suggested that other participants should be asked about what they 'got out of the programme' and whether they felt listened to; Roger thought it would be useful to find out how participants felt when the programme came to an end. Asking for examples of future questions highlighted what they felt was important that hadn't been explored in the interview. From Phyllis's perspective, the pain team empowered her and Phyllis felt as though she was able to return to a 'normal'

life; in particular, she felt as though the team had listened to her. Equally, Roger suggested a question that highlighted the significance of the relationship between the teams and participants, and ultimately how they felt when the relationship came to an end. Hence these questions and others were included in successive interviews.

As interviews progressed, sensitivity developed and questions became more focussed on emergent concepts. For example, an early concept identified related to the scepticism of some health professionals which was experienced prior to referral to the pain teams and appeared to be a significant issue for participants early on in the study. Once identified, the concept was developed into the category entitled '*the sceptical professional*' and explored for its properties and dimensions which enhanced sensitivity. Developing sensitivity was a fundamental part of the analytic process that helped generate meaning about the experience of person-centred care. How the analysis was developed is explored next.

### **5.3. Identifying Open Codes**

To elaborate on the analysis, Corbin & Strauss (2008) proposed a range of ways in which data are interrogated. Prior to axial coding, open coding is advised which involved breaking down sentences line by line to identify data that could later be used in 'blocks' to develop and refine concepts. During this process, *in-vivo* codes, for example, actual words used by the participants, were identified and sensitivity was developed through undertaking a line-by-line analysis. This was enhanced through meticulous reading and re-reading raw data to extract meaning (Corbin & Strauss 2008). This method worked well both in the early and later stages of analysis and helped explicate and refine categories such as the *sceptical professional*. As each open code was identified, a further micro-analysis was undertaken to explore for properties and dimensions which later generated meaning. Sometimes synonyms were used to aid this process and other times, analytic memos helped to generate meaning about a specific word. This meant frequently returning to the raw data to ensure that the context of the participants experience was not lost. Writing memos helped analyse the key issues and facilitated an account of the reflections about the emerging concepts, which later helped to develop

categories. This analytic process facilitated a view of the participant's world, which compared, analysed and built ideas. Importantly, the interval between each interview varied between two days to one week, during which time, memos and analysis were consolidated and previous interviews were re-read. Dipping in and out of the data, through a constant comparative process provided a range of vantage points, which were used to refine subsequent interviews questions to help develop conceptual clarification (see Figure 4).



**Figure 4: Developing Sensitivity.**

At the start of data collection, the majority of the codes were *in-vivo* and sensitivity developed through identifying properties and dimensions, which revealed early concepts about the meaning of person-centred care. The codes varied in each interview and were difficult to interpret at first, but as the analysis progressed, sensitivity developed and eventually higher-level concepts and categories were formed. Using memos and reflections facilitated the analysis and generated understanding of the participant's experience. The codes were 'blocked' or grouped which provided a helicopter perspective of the higher-level concepts that were later used to develop categories. From a constructivist perspective, this process formed part of the constant comparative approach that opened up the data to scrutiny and provided what Charmaz (2006) refers to as an 'analytical handle' on the data.

#### 5.4. Managing Preconceptions through Reflection & Memos

As suggested by Corbin & Strauss (2008), analysis began when the first interview took place. To facilitate a transparent and auditable account of the analysis, all the codes were highlighted in grey throughout the analysis. Examples of this have been included in the thesis to illustrate how concepts were developed. In addition, significant memos that enhanced the analysis have been inserted to illustrate how and which concepts were identified and then explored for their properties and dimensions (see fig 4). Analytic memos were useful because they helped to construct meaning and interestingly, drew attention to the way in which the questions were sometimes driven by previous nursing experiences. The example below is taken from an interview with Elaine, and illustrates how Elaine's comments influenced the analysis;

*“the nurse just sort of seemed to sit there and I kept thinking to myself – why, why do we need a nurse on this team to be honest – was she there to support you if you had an incident with the exercises – I am not too sure – she did do the relaxation and took charge of that and sometimes I wondered when she disappeared – where she was actually going – whether she had other commitments and other people to see or what” (Elaine).*

Ambiguity about the nurse's role as highlighted by Elaine was intriguing because it conflicted with previous interpretation of the nurse's role. Using analytic memos helped acknowledge the impact that this experience had on the interpretation of the participant's experience. Memo 6 below was written directly after the interview with Elaine and illustrates the conflict that arose.

##### **Memo 6. Following interview with Elaine.**

Elaine did not seem to know what the nurse did, was this because she did not receive much input (care) from the nurse. Of interest, and something which was also referred to by Elaine was her perception that unless the individual had direct input into her care, she did not consider them to be 'part of the team'. The lack of transparency of the nurse's role seemed to influence her perceptions about the team. Elaine had experienced poor care from other professionals before, maybe care wasn't perceived unless direct hands on care was given – because she needed to know that her pain was real. Maybe the nurse wasn't the person who enabled this?? What were her expectations of the nurse? *Does this mean that the nurse is not seen as part of the team? How do I explain this? I am struggling with the 'invisibility of the nurse' because of my own professional context. Accepting the participants view is difficult because it seems to compromise the nurse's position and I think undermines their role. I feel quite disappointed about this, but realise that it is Elaine's perspective that is important.*

The role of the nurse was later explored with other participants; however, Elaine's ambiguity about the role of the nurse appeared to be a unique perspective that did not reflect subsequent descriptions by other participants. This suggested that Elaine's views could have been a negative case, which according to Corbin & Strauss (2008) can provide a fuller explanation through adding to the richness and depth of a concept. The early concept of '*role ambiguity*' was initially highlighted as a possible 'negative case' and later explored with other participants. Excerpts taken from memos 18 and 19 highlight how the memos helped to explore the negative case.

**Memo 18.** When asked to describe the roles, Phyllis had no difficulties in talking about each of the roles. She felt that the Clinical Psychologist set tasks mostly through group work, setting goals and teaching them how to 'pace' themselves. The Physiotherapist provided advice about different exercises and the doctor prescribed painkillers. The nurse was seen the most frequently and she provided a range of advice and support and undertook the relaxation and meditation exercises. Phyllis believed that they were all needed – and she liked the variety.

**Memo 19.** For many of the patients, roles were not particularly important or relevant. Their main concern rested with how the team helped them as a collective rather than the individual roles per se. They were just happy that the team believed in them and could offer support because previously, nobody had appeared to care. Maybe I am just focussing on role because of my knowledge about role overlap and role ambiguity as a recognised barrier to inter-professional working? Am I transposing my assumptions?

Over time, the interviews revealed how the nurse was seen as being a supportive team member and participants often described 'the team' rather than individual team members, which suggested that roles were not seen as important as the team function itself. After exploring the data and subsequent interviews for other examples, the findings appeared to suggest that Elaine's observation of the nurse was uncommon. The early concept of role ambiguity played a significant role in the early analysis because it reinforced the purpose of analytic memos as a tool to aid sensitivity and highlighted the value of looking for the negative case. Acknowledging researcher experience and its impact on the analytic process also reflected the significance of the canons described by Corbin & Strauss (2008) and ensured the transparency of the analytic process. Working with the data through analytic memos and developing sensitivity is explored in more detail next.

## **5.5. Working with Data to Develop the Categories.**

Working with the data through moving in and out of the interview transcripts and the analytic memos, revealed lower and higher-level concepts, which were later developed into categories. In total four categories emerged which generated meaning about the participants world and their experience of person-centred care. The four categories related to '*the sceptical professional*', '*validation*', '*becoming a person*' and '*regaining control*' and reflected the participant's experience of health care from the moment they developed chronic back pain. In moving from a descriptive to an analytical position, the higher-level concepts were further analysed to theoretically saturate meaning about the participants' experience of person-centred care. This process revealed how they were empowered to '*regain control*' which had later helped to repair their self-esteem. Regaining control of pain underscored the participants' journey through health care and reflected the loss of control they felt as a result of the chronicity of their condition. The next part of this chapter explores the analytic process that was used to identify categories, such as insight into open codes, memos and reflections that were used to create meaning about the participant's experience of person-centred care.

### **5.5.1. Sensitising**

Re-reading the transcripts, re-visiting memos and elaborating the memos helped develop a broad understanding of the participant's world, which was sharpened through an emerging sensitivity to the data. An important component of analysis and subsequent category development was the way in which the analytic process enabled sensitivity to develop. Being sensitive to the participant's world was a significant part of the analytic process that emerged at the start of the study and deepened as the analysis thickened. The significance of this wasn't realised at first and memo 3 illustrates an initial confusion with the participants need to be believed and how this began to inform the analysis. The memo provides insight into how knowledge acquired from previous interviews with participants was used to capture and explore meaning with subsequent interviews. This example of constant comparative analysis illustrates how this approach generated meaning early on in the study through sensitivity.

### Memo 3

Nina liked the accessibility of the team. Being believed gave her the confidence to just call on one of the team if she needed. She said that on the way to the PMP room, she would pass all the offices of the team – which made them more accessible as a team and provided reassurance for others they were there for.

Helen viewed the team based on their ‘hands on’ input into her needs. Helen’s experience of health care professionals before being referred to the pain team was quite negative. No-one had believed her pain. Similar to Nina, Helen needed to be believed. Helen mentioned that it was reassuring seeing all the team’s offices on one corridor – she said that you could see the offices so you knew if they were in or not. *Does this mean that she felt they were accessible?* Helen liked the fact that more than one person was listening to her concerns; and for Helen, being believed was important. Her ability to talk about her pain appeared to be significant – for example, whilst someone from the DSS came to speak to them, she did not see them as part of the team – but she did think that the doctor was part of the team – even though he had only been a couple of times because he talked about how they could manage their pain. So being believed was important for her.

*So why is being believed significant? Does this mean that that the participant’s pain was invisible? Helen & Nina waited a long time to be accepted. Maybe the pain team enabled the invisible to become visible? Did they make the person become visible?? I need to explore exactly what I mean by visibility.*

The need to be believed was emphasised by the participants early on in the study, which suggested that this was significant and may have influenced their experience of person-centred care. Further probing about ‘*being believed*’ encouraged the participants to talk about their relationships with the team and the impact that this had on their perceptions of health care. The participants’ previous experience of scepticism exhibited by health professionals appeared to have generated mistrust and these findings suggest that the treatment which participants received before being referred to the pain teams was significant because it influenced their later perceptions of person-centred care. Liz’s description of her experiences was typical of other participant’s descriptions of care prior to being referred to the pain teams:

*“So often you find that when you have a chronic pain problem – most professionals don’t have time for you and you find that they see it as an excuse either to get out of working cause a lot of us in the group that did not actually work or as an excuse for medication” (Liz).*

Liz was concerned because the health professionals very rarely had time for her and she felt disbelieved. Liz was upset by the way in which some health care professionals had treated her with suspicion. The condition and context of the participants’ experience was a powerful tool in negotiating meaning, which helped to generate understanding



about their experiences. Through listening and writing reflection and memos, a common concern emerged which exposed the way in which health care professionals had treated the participants and had undermined their confidence in health care. Although it was not an intention to include the participant experience *before* they were referred to the pain centres; listening to their experiences about being doubted indicated the impact this had on their trust of healthcare professionals. Re-reading the transcripts and further analysis of the properties and dimensions of the concept of '*visibility*' highlighted the impact this had on their ability to cope with their pain. More significantly, the doubting professional became a category, and when further analysed, was later labelled/coded as '*the sceptical professional*'. Becoming sensitive to '*visibility*' helped develop the sceptical professional as an early concept, which became increasingly significant as the analysis thickened. The development of categories is discussed in greater detail next.

#### **5.6. The Emergence of Category 1: The Sceptical Professional.**

The participants' previous experiences of health care were similar and highlighted the plethora of professionals they had accessed before being referred to the pain team. Some participants had sought private treatments and nearly all had accessed alternative modes of treatment such as acupuncture. Each of the participants disclosed comparable concerns predicated on the way in which they had to '*fight for a diagnosis*' from the health professionals. The participants thought that health care professionals would believe and understand their pain; conversely, the negative and systemic attitudes of some health care professionals towards people with chronic back pain were highlighted. Although the early descriptions of the sceptical professional originated from the interviews with Liz and Shona, the category actually evolved through later interviews with other participants. However, Liz and Shona's experiences initially illustrated how they were disempowered and unable to receive further treatment, which highlighted the significance that being disbelieved had on their management of pain.

Before the advent of their chronic back pain, Liz and Shona described themselves as being active and confident individuals who had never experienced chronic illness, depression or pain. Their descriptions of care received by the GP in particular were

revealing, For example, they were both told that the doctor could not ‘see anything wrong with them’. They explained that they were referred to the pain teams after being told by GP’s that ‘they had tried everything’ which they interpreted as the GP giving up. This explained why other participants saw the pain teams as a ‘last chance saloon’ and a place where the ‘unfixable’ went. The GP was one example of how the sceptical professional had influenced the participant’s perceptions of health care. Table 10 presents an example of how the analytic memos were used to explore the category further.

Memo Extracts	Excerpts from Interviews
<p>7. The GP told Shona that he could not see anything wrong during a physical examination.</p> <p>8.9 the terms ‘don’t have time’ for you and ‘seeing it as an excuse’ (lines 157 – 158 page 5) suggest that previously, professionals hadn’t believed Sandra’s pain – so again belief here is seen as important – perhaps one of the best attributes a team offer is the collective validation and belief of the persons pain – demonstrable through observed understanding. This is echoed by other participants who have commented on similar concerns about being disbelieved and poorly understood.</p> <p>9.2 seeing the same faces is important- not reaching a ‘dead end’ (Pg 7 line 209). This seemed to signal that consistency in the team and familiarity with the team members supported the participants and the extent to which they felt understood and believed. Other participants in the groups were helpful because they had been through ‘the same pain’ and therefore could appreciate the lack of understanding experienced by so many, Mutual support from other participants was needed and helped generate an atmosphere of support.</p>	<p>Shona “so I went to another doctor and she had my leg up on the couch going this way that way and the other way and said that she could not see anything wrong – so take some paracetamol. Well it got so bad that the following week I went to see a different doctor because I still could not see my doctor and he did the same thing – and I said that ‘you’re doing the same thing as the other doctor and I can’t walk I’ve got this terrible pain and I can’t walk’ well I can’t see anything wrong and he told me to take pain killers” (Shona)</p>

**Table 10 Exploring the Sceptic Professional:**

The perceived damage that the sceptical professional caused had meant that the participant’s expectations of health care were not met. During the interviews, participants alluded to feelings of being demoralised and blamed this on the way in which they felt disbelieved. Significantly, the description of health care suggested that they had been undermined rather than supported. Shona’s and Liz’s descriptions of their

visits to the GP were similar to many of the health care experiences described by other participants. Shona's example detailed in table 10 generated some understanding of the way in which disbelief expressed by a professional was interpreted. This insight into Shona's world enhanced the analysis and provided a powerful image of the 'care' she had received. The following memos, made after the interviews with Nina, Sue, Liz and Shona, illustrate how becoming sensitive enhanced understanding about the significance of their journey prior to referral to the pain teams.

**Memo 21. The Journey to the Pain Team: Early Thoughts.....**

21. 1 Listening to the participants made me realise how significant their referral to the pain team was and influenced sensitivity. From the outset I was surprised by the detailed accounts provided by the participant's about their experiences of a 'system' before they were referred to the pain team. For the majority, the PMP was the final stage of their journey and one in which they at last felt believed. The participants so far have described a negative journey in which their expectations to be understood and cared for have not been met. I wonder how influential this journey has been on person-centred care and whether it has been detrimental. The term 'system' can also signify some structure and organisation, but in the context of the interviews, it seemed to denote a more negative connotation.

21. 2: I am really surprised that the participants' pain was not believed – I reflected on McCaffery's (1980) original statement that suggested that pain is what the patient says it is .....*so what has happened here? Is this my nursing experience and hence expectations of care?* I am still unsure why this is so significant for person-centred care. I expected that the participants would describe their care whilst on the PMP and with the pain teams, but so far, they have all talked about being disbelieved. I asked Jay about this and she stated that 'it' was about being believed, being trusted. 'It' was being treated as a person – being believed, being understood...from Jay's perspective, having to 'battle' with health care professionals to get a diagnosis or even convince them that there was something wrong was demoralising and led many of her friends to depression. *Why were the participants allowed to become depressed, why did not someone act and respond to their pain? Was this because they had been treated in a 'system or had become lost in the 'system'?* Given that chronic back pain is a major health issue in the UK, why did the health professionals doubt the participant's pain? *What impact has this had on their experience of person-centred care? From the descriptions so far, the 'person' appears to have been overlooked.* Although the pain teams were excellent – it seems that they were the only people to really believe that the participants had pain. *Obviously their journey to the pain team was significant but I don't want to focus on this – or maybe this is an area that I need to understand.* It appears to have shaped their experiences and interpretations of the care they received from the pain teams. What the participants expected and what they received was disappointing and certainly did not reflect a person-centred approach.

Collectively, the descriptions enhanced sensitivity and facilitated understanding about the experience of care. The findings revealed that participants felt as though they had been 'dealt with' rather than 'cared for' and differed significantly from their original expectations of a caring health professional. Returning to the raw data and memos helped explicate this further and generated meaning about the sceptical professional. As

the analysis thickened, axial coding was used extensively and contemporaneously with memos to help shape and explore the emergent concepts.

### **5.6.1. Higher-level Concept: The 'System'.**

The sceptical professional made some feel as though they were in an unsupportive 'system' rather than a caring environment. Nina was an ex-specialist nurse who had to retire early from her profession because she was declared 'medically unfit' for work. In particular, Nina's previous experience of being a nurse suggested that she was already familiar with health care processes, but as a 'patient' Nina became disillusioned with the 'system' that seemed to take over her life. The following example from Nina's interview illustrates this point:

*And it was like you know sometimes when you've been round the system like many of us have, the GPs tried all the drugs on you, there isn't anything that they are going to do surgical wise because often the intervention may make the problem worse and they've explained that to you and in a way it's become prior to going on the PMP a hopeless situation where you think that you're never going to be well. (Nina).*

Nina used the term 'system' which suggested that she had encountered an oppressive process that she had found difficult to negotiate. The negative connotation was also used by others, which suggested that this experience was common. For example Jay talked about being round 'a system' where she had been seen by a number of professionals:

*"To be honest because I see so many different consultants it's hard for me to remember but I have been round the system so to speak.....no one seemed to understand and you felt like you were a fraud"(Jay)*

Similarly, Rogers experience suggested that the 'system' was a place where you can become trapped:

*"I was suffering a lot of leg pain, back pain, which I did not know was early arthritis and I did not know that it was mechanical pain due to my injury trapped nerve and disks and I had seen loads of people and been around a system – it was never ending" (Roger)*

Nina also stated that being within 'a system' felt as though she was not able to progress; subsequently, health care was perceived to be a hurdle rather than a supportive process. The term 'system' was a pejorative rather than positive term used to describe their

experience. During her journey through the '*system*', Nina met other people who had similar experiences and felt hopeless. This was consistent with other participants and highlighted a lack of faith in the care they had received. These perspectives revealed dissatisfaction with health care because health care staff appeared to doubt their pain.

Using a continued process of constant review and axial coding helped examine concepts such as '*the system*' for the properties and dimensions. Eventually, the '*system*' became a higher-level concept that informed the category of the '*sceptical professional*' which was later saturated throughout the interviews as sensitivity deepened. The findings suggested that being '*disbelieved*' was a common experience which had been described by all the participants. The frustration they felt with health care professionals was significant; the sceptical professional had become a catalyst, which impacted on their experience of health care and expectations of person-centred care. Equally, the sceptical professional may have been the reason why healthcare was negatively referred to as a '*system*'. Listening to the participants revealed the significance of *being believed* and how the *sceptical professional* had damaged their understanding of pain and personal belief in their own pain. The scepticism appeared to exacerbate the participants' need to have their pain validated and legitimised. The decision therefore to develop *validation* to a category seemed appropriate because it was described as a significant concern by the participants.

### **5.7. Category 2: Validation.**

Listening to the participants highlighted how living with chronic '*invisible*' pain had influenced their perceptions of the health care system. They viewed health care professionals with scepticism and appeared to have lost faith in the ability of health care professionals to care. The '*sceptical professional*' compounded the negative experience and exacerbated the participant's vulnerability. Open coding, revealed early lower-level concepts such as '*visibility*' and '*unseen pain*' as significant and were later compared through the process of axial coding.

Cross cutting through concepts strengthened the analysis and helped establish validation as a category. 'Unseen pain' was discussed by all the participants, but listening to Jay in particular helped develop some understanding of the devastation that being disbelieved appeared to have caused.

*"My illness is unseen as well I mean on Thursday I was diagnosed with Lupus on top of my Adult still disease and my vasculitis. So I have already got 2 auto-immune problems and now I have 3<sup>rd</sup> one and I have had to fight for the diagnosis of the Lupus. This has been going on the 12 months – I thought I had it but I have had to fight and had to leave \*\*\*\* and seek out another professional. Being believed is very important – very important. Because you feel like you are going mad" (Jay)*

Before her diagnosis Jay described herself as an active businesswoman who worked with her husband and built a successful family business. Unfortunately, when Jay began to suffer from chronic pain she was unable to work because she could not sit at a computer for any length of time. Managing the family business accounts became difficult. Jay became increasingly reliant on her husband and family, who after a while, began to lose sympathy because they could not see or understand her pain. Jay described how she became depressed because the pain was excruciating and her family's scepticism meant that she felt unsupported. The lack of a professional diagnosis compounded the negative experience because Jay expected to be believed, understood and treated. Conversely, Jay described how having unseen pain made her feel as though she was going mad. The extract from Jay's interview above provides one example of the significance validation had for the participants. In the interview, Jay talked passionately about having to 'fight for a diagnosis'. Table 11 details the open codes that were used from this interview and how they were combined with others through axial coding to highlight the power of validation through professional diagnosis. As a category, validation was explored for its properties and dimensions.

<b>Context – Jay</b>		<b>Open Codes</b>
<p><i>“My illness is <b>unseen</b> as well I mean on Thursday I <b>was diagnosed</b> with Lupus on top of my Adult still disease and my vasculitis. So I have already got 2 auto immune problems and now I have 3<sup>rd</sup> one and I have had to <b>fight for the diagnosis</b> of the Lupus. This has been going on the 12 months – I thought I had it but I have <b>had to fight</b> and had to leave **** and seek out another professional. <b>Being believed</b> is very important – very important. Because you <b>feel like you are going mad</b>”</i></p>		<p><i>Illness is <b>unseen</b></i></p> <p><i>Fighting for a <b>diagnosis</b></i></p> <p><i>Wanting to be <b>believed</b></i></p> <p><i>Felt like going <b>mad</b></i> <i>Diagnosis</i></p>
<b>Concept</b>	<b>Properties/ Dimensions</b>	
<b>Lower-level Concept: Visibility</b>	<i>Hidden, unnoticed, invisible, unobserved</i>	
	<i>Struggle to be believed, analysis, judgement, opinion Understood, legitimate, genuine,, Being believed</i>	
<b>Category: VALIDATION</b>		

**Table 11: Interrogating ‘Visibility’ to Develop Category of Validation.**

Similar to others, Jays expected health professional to believe in her pain and had subsequently lost faith as a result of the sceptical professional. Crucially, having unseen pain appeared to exacerbate her frustration and Jay felt increasingly isolated. Being believed was therefore significant because Jay said that she had lost her self-esteem. The semi-structured nature of the interviews allowed further probing and provided an opportunity to understand why being believed was important for Jay and other participants. Sensitivity to the participants’ need for validation developed through careful questioning facilitating a deeper understanding about the need for a professional diagnosis to legitimise their pain. This appeared to be important because being diagnosed meant they had a ‘*legitimate*’ cause for the pain and therefore was not a figment of their imagination.

Sensitivity to the need for validation was further strengthened after listening to JP’s experience of health care and her account of the impact that ‘*invisible*’ chronic back pain had on her life. JP described how a car accident had left her with severe spinal injuries

but no visible scars. Until she had an MRI scan, JP had believed that the pain was ‘*in her head*’ and she used the term ‘*social pariah*’ to explain how isolated she felt. The MRI scan results showed the damage to the spine after which JP began to believe in herself again. Using open and then axial coding highlighted the significance of validation and helped develop an understanding of JP and the other participants’ worlds.

*“It’s like I said I am glad I had the MRI scan cause people used to say that there’s nothing wrong with me and I’d say it’s my back but to them its general backache but it’s not its back pain – but I got to the stage questioning that I had a bad back and thinking that it’s all up here in your head and then when they found out – when I saw the MRI scan I thought I have got damage and then I say that you’ve got to have it to understand ...” (JP).*

The findings suggested that the participants wanted health professionals to legitimise the pain through diagnosis because it represented an objective ‘measure’ of their pain. Memo 43 was written after the interview with JP and highlights how her frustration with the lack of professional support influenced the analysis.

#### **Memo 43**

JP developed chronic painful back problems following an road traffic accident in September 2003. Since this time, she has had a range of treatments and therapies, which have been unsuccessful. She finally had an MRI scan which highlighted 5 ‘lumpy’ disks in her lumbar region. JP felt justified when the MRI scan showed the damage as she had begun to disbelieve her pain..... Similar to other participants, JP felt that no one could see her pain and therefore could not really understand it. Dr G and the team were the first to recognise her suffering and therefore provide some hope. An analgesic lifeline was thrown out with the promise of alternative treatments and realistic information and goals. But importantly, they never doubted her experience of pain.

JP was angry with the professionals who had mistreated her because they had made her doubt herself, which then meant that close friends and family began to doubt her pain. Like others, JP became more reliant on analgesics to manage her pain, which created other unwanted side effects. JP was clearly moved that the pain team had helped her. She was very tearful when describing the care she had received from Dr G and Sarah and implied that she owed her life to the team.

I remain shocked that people are left to suffer in this way – especially when being believed in the first place could help to avoid reliance on analgesics, depression and loss of self-esteem. Working in acute medicine for a number of years, hadn’t really exposed any of this, usually patients presented with a heart attack – of which they had clear signs, symptoms, which could be verified through blood tests and ECG’s – their pain was visible because it had physiological evidence. I am beginning to understand that people with chronic back pain have no such indicators!

JP was the seventh person to be interviewed and her description of the MRI scan’s ability to provide physiological proof of pain helped to confirm validation as a category.



The category of validation and the need to legitimise the pain experience was gradually developed through axial coding to cut across and saturate the concepts. Whilst not all concepts were developed into categories; some were significant in helping to shape and refine the analysis and indicated how being believed formed the first steps of their journey to recovery. Table 12 highlights how the open codes from 7 interviews became saturated and began to form the emergent concept of visibility, which eventually became the category ‘*validation*’.

Participant	Open Code	Lower-level Concepts	Axial Codes	Category
Helen	lot of people can't see the pain husband can't see it, children can't see it	Pain not visible	<i>Hidden, unnoticed, invisible, unobserved Struggle to be believed, analysis, judgement, opinion unnoticed Genuine, visible Understood, legitimate Valid, genuine Genuine valid Visibility, belief</i>	validation
Jay	Pain not being believed – having to fight for a diagnosis	Unseen, being believed, fighting		
KT	cause nobody can physically see what is wrong with you	See what's wrong		
Shona	Doctor's examination could not see anything wrong – so advised to take some paracetamol	Seeing the problem		
JP	No one understands the pain – just see JP walking	Pain not visible		
Kelly	Making a fuss about nothing	Being believed		
May	Being understood and believed	Understanding pain		

**Table 12: Axial Coding used to Develop Category of Validation.**

The findings suggested that many of the participants were upset because they felt as though they were not being taken seriously. In-vivo codes such as ‘*visibility, having to fight for a diagnosis*’ and ‘*lack of understanding*’ were later developed into higher-level concepts through axial coding. In another interview, May, shared her thoughts about her experiences of not being believed or taken seriously by health care professionals before being referred to the pain team:

*“I felt that they were taking it seriously and they were looking at pain from all different angles and.....well they had been like – well there's nothing we can do really and it sort*

*of er the condition and its complications to the doctor were the key things and the pain to them did not seem to be something that they specialised in as much as the condition”(May)*

Prior to developing chronic back pain; May described herself as an active community nurse who had aspirations to become a qualified nurse. May stated that she was an independent woman and was proud of her experience as a nurse and of her ability to care for others. May had suffered from back pain as a result of a nursing injury and, similar to others, May had experienced scepticism because the pain was unseen. May provided insight into why some many people with chronic pain had become depressed. For example, during her interview, May disclosed how the side effects from the strong opiates she used to control her pain had prevented her from physically picking up her grandchildren.

*“it became otherwise one bad day would follow another bad day and the other thing was that I felt that because I have always played a big input in my grandchildren’s lives and I could not be trusted to baby-sit because of the amount of tablets I was on for the younger ones I mean even now I could be carrying something and just drop it for no reason – so I wouldn’t be able to have the younger ones cause I wouldn’t be able to carry them” (May).*

May’s lack of pain control left her feeling frustrated and she described how the ‘system’ seemed to exacerbate this. Listening to the participants highlighted how having unseen pain had influenced their perceptions of care, but also appeared to affect their ability to cope with their pain. To develop further meaning about the impact this had on their lives, participants were asked to describe what it was like to have unseen pain and how important being validated by professionals meant for them. May’s response detailed below was one example of the effect of having unseen pain had on her life:

*“Before I went on the course I very much thought that it was only me that had the pain and I knew other people had pain, but I was very much in mind that if I had a walking stick or I was sat in a wheelchair people would know that you were ill cause you don’t sort of tell anyone and people are very harsh with their judgement – like why she not going to work – there’s nothing wrong with you – and I thought that were was only me like that – I very much thought that I was probably imagining the pain that it wasn’t really there cause I could not see anything so before the pain team I would stay in my PJs all day and I would only get dressed if I was going out and I did not want to go out so I had like 7 pairs of PJs but I hadn’t bought myself any proper clothes for a long time so I would just have a shower and then put my PJs on.....I had given up.”(May)*

Mays experience was profound because of the way in which she had quite simply stated that she had '*given up*'. May described how chronic unseen pain meant that she did not get the support she had expected from health care professionals and had become depressed about the situation she found herself in. The participants descriptions of the sceptical professional and their need to be believed provided a powerful image of how being disbelieved had damaged their self-esteem and indicated how their personhood could have been compromised.

Reflecting on the initial literature review was useful because it provided some explanation of the impact of unseen pain on the participants' ability to adopt a 'sick role' and later cope with the pain. The influence of the initial literature review helped to develop greater understanding about the frustration the participants felt, for example, Glenton's (2003) qualitative study previously highlighted in the literature review, revealed reasons why people with chronic pain strive to 'be sick' and living with unseen chronic pain exacerbates feelings of isolation and frustration due to lack of understanding by others. This concurred with the participant's experiences, which they attributed to the lack of observable signs and symptoms with 'unseen' pain. For example, KT described how two relationships had broken down as a result of being disbelieved, which she suggested had led to personal self-doubt and depression. This illustrated how unseen pain may have damaged the participant's self-esteem and highlighted how being disbelieved had undermined personhood and impacted on their ability to manage pain. Autonomy appeared to have been impeded as participants struggled to accept their pain and believed that the pain may not be real. The participants' descriptions presented a bleak picture of care that conflicted with the principles of person-centred care highlighted in the initial literature review. For example, McCormack's (2003) framework of person-centred care emphasised the need for respect and understanding, yet the participants' descriptions of care highlighted how the lack of faith signified limited understanding which may have impeded the participant's autonomy. Crucially, the need to be believed and to have their pain '*validated*' was fundamental to the relationship so that autonomy and control could be restored. However, the earlier influence of the sceptical professional coupled with the unseen

pain undermined the participants personhood. The need to be treated as a person through being believed was therefore crucial in their recovery. Being treated as a person and someone who was 'sick' first meant being believed and hence understood. The way in which the pain teams helped the participants to become a person and repair the damage of the sceptical professional is significant and is discussed next.

### **5.8. Category 3: Becoming a Person.**

The earlier findings highlighted the impact that unseen pain and the sceptical professional had on the participant's self-esteem and ability to manage their pain. Participants were also asked to describe how the teams cared for them and the analysis revealed a positive experience predicated on the way in which the teams developed a relationship through treating the participant as a person. The teams approach to care was described as '*informal*' and '*friendly*', which reassured participants and made them feel welcomed. The teams caring approaches engaged the participants in a '*family*' in which they were treated as people. The two higher-level concepts of '*family*' and '*informal caring*' were linked and used to develop the third category of 'becoming a person' and provided insight into the early processes used by the team to support care. The informal caring helped to shed the mind-set of the 'person as patient' and participants described how they were treated with respect. Ultimately, being treated as a person enabled the 'person to emerge'; hence the teams were perceived to have cared for 'the' person and hence, 'their' person re-emerged, thus, the(ir) person was restored. A key element of this process appeared to be the way in which the teams developed an equal relationship through using an easy-going and relaxed approach to care. The informal caring approach engaged the participants and enabled them to feel comfortable to ask questions and become more involved in their care. The higher-level concept of '*informal caring*' formed part of the relationship development and is discussed next.

### **5.8.1. Higher-level Concept: Informal Caring.**

Exploring for meaning about how the teams had cared for the participant enabled insight into the informal caring approach used by the team to restore self-esteem. Listening and careful questioning during the interviews revealed a rich picture of how trust was initiated through the use of first name terms. The participants described how they were encouraged to be involved in decisions about their care and felt comfortable taking part. They felt accepted and believed that the team understood their pain. Fundamental to this process was the way in which the descriptions of how the teams listened to them; which made them feel like people rather than a patient. Kelly was a retired government officer who talked fondly about the pain nurse because she made her feel valued. For Kelly, being listened to was important because her previous experience of the health professionals had led to self-doubt. Kelly had also been through a number of recent life events, which had exacerbated her vulnerability. For example, Kelly had lost her husband to cancer the previous year, following which she was hit in the ankle by a skateboard whilst shopping which immobilised her for several months. These events compounded her vulnerability and coupled with the influence of the sceptical professional, influenced her mistrust about health care. During the interview with Kelly, the significance of being treated as a person, being listened to and treated with respect by the pain team was discussed:

*“She [the pain nurse] had a look and she said that ‘I am taking you at your word’ that it’s a trapped nerve and gave me some capsules and within a day I could move a leg the capsules were to do with nerves not muscles and she helped me and I came home 2 days afterwards so she again listens to what you are saying and tries to help”.(Kelly)*

Listening to and responding to the person, rather than the patient was perceived as an important attribute. Helen in particular had suffered acute episodes of depression and was despondent that her husband had not believed her pain. Helen valued being treated as a person rather than a number and likened this to being understood.

*“All right he’s your doctor but he treats you as a person and not just a patient erm, he seems to understand when you are in pain” (Helen)*

Similarly, other participants used the metaphor of 'being a number' to explain how they had been previously cared for by healthcare professionals

*I think that specialist consultants could learn a lot from pain management teams and understand what the patient needs rather than being treated like a number (KT)*

Being treated by the team as a person rather than a 'patient' and a 'condition' was consistent between all the participants and appeared to have been influenced by a friendly rapport with the team. Many suggested the rapport was built on the team's friendly, respectful and informal approach and the next extracts taken from KT's interview illustrate how the team's informal approach helped her to feel like a person again:

*"I don't really think I don't feel that it is a doctor-patient relationship – he's my friend and a friend that I can rely on and turn to when I need help – I mean we don't just talk about my condition when I go in, when I went this time I had just split up with my partner after 2 years because he could not cope with my condition – which the same as what happened with my previous partner of 15years. Doctor G was so upset because we were getting married" (KT)*

KT had been in and out of hospital since her accident when she was 19 years old. Nearly 20 years later, during the interview KT reflected on her experience and described how she had lost two partners because of her 'flare ups' and 'their inability to understand' the full extent of her chronic back pain. KT had seen a range of health professionals over the years and described how she had been 'treated as a number' rather than as a person. KT's experiences of care appeared to be quite negative: The following excerpt illustrates this:

*I went to see the Consultant Anaesthetist and he had you standing on one leg and it was an op it was – I wasn't even told that the op could go wrong and you were a number and you were having an op and then you go. But at the pain clinic you are a person not a number and you are a patient with a name and not a Mrs or Miss or Mr – it's always first name. (KT)*

KT valued her relationship with Doctor G and Sarah the nurse, and referred to them as 'old friends'. Similar to other participants, KT had experienced being treated like a number and was also disappointed with the way in which her care had been managed prior to referral to the pain teams. The effects of the informal approach to caring were

also described by Liz who described how being on *'first name terms'* enabled her to feel like an *'individual'* and part of the care decision-making process.

*"Quite regularly they would speak to us as individual and ask us how we felt we were progressing what were we hoping to achieve was it achievable and were we being realistic and they would give their opinions and then hopefully work together to find a happy medium"(Liz).*

Talking to Liz about the significance of this revealed how she had previously felt ignored and overlooked by health professionals. The informal approach used by the team was supportive and influenced a trusting relationship in which participants felt confident enough to become involved in care planning. Being involved in decision-making is a central component of person-centred care because it indicates a level of autonomy and highlights the need to respect the participant's decisions (McCormack 2003, Kitwood 1997). Exploring this further with other participants enhanced sensitivity and highlighted how the use of first name terms and being treated as an individual helped them feel equal, accepted and part of the relationship. Elaine also described how the team treated her like a person:

*"yes, definitely you did not – I mean that old saying of the NHS – you certainly did not feel like a number – definitely not - that was in fact you almost – at much as they blurred into not being a physiotherapist and all the rest of it – you blurred out into not being a patient as well (Elaine)*

Elaine's use of the term *'being blurred out of not being a patient'* was significant because it appeared to suggest that she felt comfortable enough to be considered as part of the team and similar to Liz's experience, Elaine felt able to participate in decision-making. Equally, Elaine described how her views and experience were taken into account, and believed that she had been treated as a person because the team regularly invited her to describe her progress and suggest areas for action. These findings revealed the informal approach adopted by the teams; which some likened to the concept of the *'family'*. Being in a *'pain family'* appeared to influence the way in which they were made to feel like a person again and was developed into a higher-level concept that later established the category of becoming a person.

### **5.8.2. Higher-level Concept: The Pain Family.**

The pain family emerged as a higher-level concept during the interview with Roger in which he described how the team had embraced him into *a family*. Roger's description of his experience was helpful in determining an understanding about why being in a family was important. Although the notion of the family may be sometimes viewed as oppressive, Roger felt that being in a family meant that his pain was accepted. Prior to his car accident, Roger had managed a successful car showroom. He described himself as a confident person who was happily married. Roger adored his daughter who was born with cerebral palsy, and he had subsequently experienced health care through looking after his daughter. He was therefore familiar with some of the processes involved in referral and knew some of the roles of the professionals. After his car accident, Roger described how he was left with a limp as a result of one leg being shortened. He was unable to continue work due to the back pain he suffered from and gradually became reliant on morphine as a painkiller. Roger described how his life before being referred to the pain teams revolved around his daughter and his obsession with morphine. He became depressed because he was no longer able to physically care for his daughter due to the back pain. As Roger described, he was at the end of his tether and felt out of control and was one of the many participants who expressed the isolation that being disbelieved evoked:

*"I think that you need to feel at ease and they make you feel that you are not on your own and make you think that there is help for you cause you have got to the end of your tether and you have taken as much drugs as you like you have had all the injections, seen by everybody and misdiagnosed so the team needs to put across to the patient that they are somewhere who can help and instead of being on your own in some room with a jumped-up consultant surgeon – don't get me wrong they are not all like that but a lot came come across as being like that –(Roger)*

Similar to other participants, Roger's self-esteem was low and he had struggled to come to terms with the chronicity of the pain. Roger described the team fondly and remarked on how they made him feel at ease. Roger's description above resonated with many of the participants' experiences. Listening to Roger during the interview highlighted how the team and other people on receiving care had appeared to understand the impact



and experience of chronic back pain. Roger talked passionately about how the team and other people with chronic pain had embraced him and others into a 'family' on the first day of the PMP.

*"a PMP is the first place and to welcome then in to include you in a family of people in pain and embrace that and to have empathy with them and to respect your feelings"* (Roger)

Hence, being in a 'family' was significant because it supported the development of a relationship that helped the participants recover their self-esteem. This suggested that the family provided a supportive environment in which the trusting relationship grew. Although the term 'family' originated from an *in-vivo* code used by Roger, similar codes were identified during other interviews that related to being in a family, such as *shared experience, sharing knowledge/ information, shared goals, support, group support fitting in, acceptance, comrades compatibility, patient team, fellow & colleague*. Helen also referred to the supportive nature of the group and highlighted how they seemed to understand, and how they listened:

*"They listen to you – the listening is the most important – listening to what you say – more than one person listening and they all took .....they knew how we felt when we went in that morning, they would pick up on your mood and that and there was emotion as well, crying and things but we all supported each other we/they were really supportive and the group that attended the they all helped each other"* (Helen)

A similar picture emerged from the Fathersham participants' descriptions of the team. At Fathersham, there was not a dedicated PMP, and participants continued with invasive interventions to control pain, however, the participants also described how they were treated as part of a family:

*"He [Dr G] wanted to come to the wedding and he kept saying oh we'll have you off the tablets by the time you go down the aisle and he was so upset and he says that he treats his patient as his family and he really does"* (KT)-

Being in a family was important and was influenced by the informal approach to care. Memo 25 was written after the interview with Roger and illustrates how the concept of the *pain family* influenced the analysis.

## **Memo 25. Concept of the Family**

The concept of the pain family seems to be significant because it was frequently referred to and seems to signify a common bonding and acceptance. This may be because previously, participants had not had a voice and felt disbelieved. So to enter into a programme of care where others had experienced similar events and where they felt understood seems to fit with some of the concepts associated with person-centred care. Equally, for those participants who weren't involved in a PMP, the pain teams seemed to embrace the participants into a family through the way in which they used informal approaches to care. The pain family was also reflected on when participants were admitted to the pain wards where participants often demonstrated camaraderie through their laughter, understanding of others etc. Being in a family however, means being accepted – which prior to the pain teams, many participants felt rejected. To be in a family of other people who had similar complaints and to be cared for or even mothered. This appeared to be a nice feeling for Roger and many of the other participants, it seemed to imply that they were welcome, and supported within a group that recognised and importantly, empathised with their 'problem'.

The family atmosphere was important because it helped remove some of the professional hierarchy and maybe could minimise the power imbalance between the teams and the participants. The family, although short lived, were accessible later through support groups, and for those participants at Faversham the family continued because the care and interventions continued. *Hence why KT and others liked going back ...? Because they felt at ease with the team....or am I just referring to a group and group support?*

Individual participants provided similar descriptions of the first time they had met the pain teams and discussed how the team made them feel comfortable, and believed. Moreover many were keen to share that they felt understood and suggested the pain teams were the first professionals to take their pain seriously. These findings indicated how the participant's experience of pain had been legitimised and how this had influenced them to 'move on'. The teams helped them to understand their chronic pain and through listening to other people with chronic pain, participants realised that they weren't alone. This realisation was profound because it reassured that it 'wasn't just them'. This suggested that the informal caring approach made the participants feel part of a family that could sympathise and empathise with their pain. The concept of the 'pain family' provided insight into how the team developed a trusting relationship from with an informal 'family' atmosphere. This was significant because the informal approach to care enabled the participants to take part in their care and by being believed, they were able to come to terms with their chronic pain, regain control and recover the(ir) person.

The two higher-level concepts of *informal caring* and the *pain family* helped create meaning about how the team restored the person through the trusting relationship that evolved. Understanding the relationship helped saturate the category of '*becoming a person*' and collectively the concepts provided rich detail about the relationship that supported this process. Being seen as a person rather than a patient was significant because it implied a level of respect, trust and importantly, acceptance. Insight into this process helped generate meaning about the teams approach to care based on the participants interpretation of their experience. Crucially, the participants felt that they '*were not alone*' and were able to disclose their frustrations and experiences within a family, which felt safe. The family understood their pain and the team participated in the family through listening and engaging with the participants using informal caring approaches. The relationship emerged out of these actions and appeared to restore trust in health care. Gradually, being treated as a person; participants found new confidence to accept their pain, which later empowered them to regain control. The educative methods introduced by the teams were crucial because they helped restore autonomy. The significance of autonomy was described as '*getting back their life*' and '*being in control*'. Hence, regaining control emerged as a fourth category and is discussed next.

#### **5.9. Category 4: Regaining Control.**

Regaining control of the pain was seen as an important step in the recovery of the person. The ability to choose how to manage pain and understand the benefits enabled them to '*get their life back*' and for many, this process was '*life changing*'. The findings indicated how the team had used informal approaches to caring to instil a family atmosphere and validate pain. This appeared to restore the participant's self-esteem, which diluted the effects of the sceptical professional and restored faith in health care. Regaining control of the pain was very important and the interviews revealed how the team empowered them to take control of pain through educative strategies. For example, *in-vivo* codes originating early on in the interviews included '*toolbox*', '*getting my life back*' and confirmed that the teams helped the participants to take control of

their life. 'Getting your life back' was an ultimate goal and many believed that the tools provided by the teams helped to regain control of their lives through self-care management strategies. Jay, Elaine and Sandra used the metaphor of a 'toolbox' to illustrate this process, and Elaine elaborated on the significance of the toolbox:

*"I think that we likened it to that they were giving you tools – as you went along – you were given a toolbox and all these things that went into it were tools that I could take away at the end of the course that I could out as and when I needed them and every time I might have tried one tool and it did the job but this time I might have to try another one and so all your medication, everything... your relaxation and other things – normal things like I'll just go and have a nice bath and relax – you know everything that you can think of was put into this imaginary toolbox if you like"(Elaine)*

The metaphor was originally developed into a lower-level concept, which was then explored in greater detail. Raw data was re-visited to explicate the properties and dimensions and generate understanding. For example, Liz described the ways in which the team had given her the tools to help herself. The metaphor of the toolbox was also used by Liz to describe this process:

*"They were sort of giving us all the tools erm to help us cope with our pain but then they were aware that although we had these tools we would all use them to different levels – the exercises and the relaxation ....." (Liz).*

Having a 'toolbox' meant that they had a choice in their care and were able to use this with their own discretion, or 'at different levels' as Liz described. The toolbox contained tips for managing pain on a daily basis such as pacing or relaxing through Yoga or meditation and presented an opportunity to regain a sense of control. May described her thoughts about the toolbox as 'empowering';

*"I have that the team have given a sense of hope and therefore I had a sense of control – that it has really empowered me and given me the skills and the knowledge to make a decision – and skills to manage the pain, (May)*

The ability to choose a method was for some, the first positive experience of healthcare which appeared to include them in the care decision process. The descriptions of care indicated how the teams promoted autonomy through the self-care options provided in the toolbox. The next memo describes how this influenced the analysis and sensitivity about person-centred care:

## Memo 58

When asked about person-centred care – Sandra said that it was as though the team had given them a toolbox to help them cope with their pain. This is a similar analogy to other participants. This toolbox was empowering – and contained strategies for managing pain on a daily basis such as having realistic goals and aims about the housework walking the dog or any other ‘life’ activity. *Somehow, to Sandra having gained control over her pain meant that she felt empowered and therefore felt central to care?? Is this something, which I can surmise at this point? The choice was hers – therefore was she in control?* Sandra appeared to have regained autonomy with her pain management. Having the box was like having something to draw on when things got bad. Sandra felt involved in the decision-making because she could speak to the team as individuals and they discussed her goals and her plans. She was seen as an individual and not as a condition. I think that the chronic nature of the pain and the fact that so many professionals in their journey to the PMP have been negative essentially took away their control and the light at the end of the tunnel – so embarking on a PMP where they understand, get on with you and each other makes the participant central again. *Person-centred care = choice = positive = control. Maybe I need to map this??*

**Memo 59:** Jay and Elaine clearly indicated their need for control and the team helped them regain control. I questioned whether person-centred care meant ‘being in control’ or how participants were empowered. This prompted a number of other questions about how the team accomplished this. *Does the toolbox really empower people to cope – or is it subtly directing care? Was there a choice – what other options were there?* Significantly all the participants felt in control of their pain and lives – all were happier – *does this mean that the teams were person-centred?*

**Memo 60:** These have been the longest memos yet. I remember the interview with Jay and coming away from it feeling as though I hadn’t really identified anything new. I am getting confused with the concept of person-centred care – is it really just about control? Surely the way in which they were treated was significant? Or could I argue that they wouldn’t have regained control in any other way? Does providing a tool kit mean person-centred. *Surely it’s all about how trust is established in the first place?* This indicates why the need to be believed was so important. After listening to the interview again and re-reading the transcript – I found myself at the ‘ah ah’ moment that Corbin & Strauss (2008) so aptly describes. It is the point when ‘things’ start to come together and the data began to make sense. I have realised that there really are no absolute rules about analysis and that reading around key areas of interest are actually helpful is allowing you a greater analysis of the data. Using previous literature and theory doesn’t blind your analysis nor does it cloud judgement of the text – it helps to elaborate and add another dimension to the analysis so that picture begins to emerge. This interview has helped me realise much about my analysis and my approach to it. Certainly, I will probably look back at this and see areas which I have missed, but I accept that my analysis is not perfect – I embrace whole heartedly my own vision of reality and that it is quite distinct from others – I feel that my ontological position has been strengthened through this analysis.

The toolbox appeared to be helpful because it restored their autonomy and for some, such as Jay, this meant that she regained control of her life:

*“I felt part of the team that was the audience and as an individual it also answered questions for me and made me re-think my life really because I had gone into the programme feeling very negative about my illness and I came out the opposite – I felt that I had lost control and*

*the pain and my illness was really my life and I had lost control – whereas I had always had a positive attitude – I will be this, I will be strong this is not going to get me – I felt as though my illness had overtaken me and it had beaten me and had overtaken me and doing to course I felt as though I have got my life back again.”..... I feel like the captain of the ship again and I am at the steering wheel and I can go whatever port I want to”*

Being in control appeared to be the ultimate goal because they had suffered for so long with chronic pain. Many felt that the pain was ‘in their heads’, which had disabled the person and left them feeling hopeless. The findings suggested that the participants were empowered by the teams through a trusting relationship, which provided them with tools to manage their pain. The success of the relationship was predicated on a reciprocated trust in which the teams believed in the participants, and the participants believed in the teams. This highlighted the significance of ‘*being believed*’ and was a precursor to the ‘*patient becoming a person*’. Regaining control was important because it supported autonomy and helped restore personhood.

Eventually, the ‘discovered reality’ (Charmaz 2000) that emerged, revealed a complex process which enabled the participants to *regain control* through engendering aspects of person-centred care such as autonomy, reciprocity and trust previously reported in the initial literature review (McCormack 2003, Nolan et al 1997). The findings indicated that using the toolbox in context with an informal caring approach enabled the team to restore a sense of control and autonomy. From a constructivist’s perspective, how people respond to each other in everyday events is often directed by an analysis of the situation, which then influences emotions (Charmaz 2006). Hence, as ‘social actors’ the participants and the teams seemed to respond in an analytical way, because they acted on events and things that had meaning for them. The meanings were derived out of their interactions with each other, which was interpreted and responded to accordingly. Thus meaning was interpreted by the participants based on their previous experience of health care, and explained why being disbelieved was significant. The team appeared to understand the significance of being believed and responded by validating their pain through listening and introducing methods of self-care. Hence, the participants believed in the team because they felt empowered. The informal caring approach built a

therapeutic relationship, which re-established their faith in healthcare. These findings suggest that believing in health care was significant and crucial to person-centred care.

## 6.0. Chapter Summary

It is acknowledged that people with chronic pain need to feel supported and believed (Clarke & Iphrofen 2005); equally, people expect healthcare professionals to be competent. Public expectations of healthcare are well reported and are seen as a cornerstone of care for many professional regulatory bodies. However, at the onset of back pain, most participants described a journey through a health care '*system*' which did not seem to acknowledge or validate their pain. Moreover, an unintended consequence of the '*sceptical professional*' appeared to do little to support the participants and later undermined their confidence in health professionals. The '*system*' described during the interviews left many feeling demoralised and exacerbated depression for some. Listening to the participants' descriptions of the caring teams exposed a trusting relationship that evolved over time and gradually restored self-confidence. The analytic process helped generate understanding about the experience of care, which revealed that they felt respected and valued. The trusting relationship was described as empowering and used informal caring processes that engaged the participant. The use of educative strategies was successful because it restored their self-esteem and participants were able to accept and therefore manage their pain. Being *believed in* through caring was significant; equally, *believing in* the team was crucial to this process, hence, generating meaning about the team processes used to develop trust and restore faith appeared to be a fundamental component in person-centred care. The significance of *believing in* is explored in the next chapter.

## Chapter 6: *Believing in Health Care.*

Analysing the participant's experiences of care identified four categories that provided insight into how a trusting relationship was developed. *Being believed* and *believing in* was significant and the analytic process helped to elaborate this to generate further meaning about the trusting relationship. Findings from Chapter 5 indicated that being believed was a significant part of the relationship; however, believing in the team was crucial. The first part of the chapter discusses how the analytic process helped to understand why believing in the team was crucial to person-centred care. The second part of the chapter discusses how semi-structured interviews with the teams were used to explore the team's interpretation of team working to identify the professional and social processes involved in delivering person-centred care. The chapter then discusses how Ervin Goffman's (1957) sociological framework was used to enhance theoretical sensitivity and explicate the key processes described by the team that restored faith in health care. The final part of the chapter discusses how the category of 'co-validation' was developed using the constant comparative analysis and through theoretical sensitivity.

### 6.1. Understanding How the Teams Restored Faith.

Listening to the participants revealed that confidence and faith in the team was important and explicating this further, participants were encouraged to describe more about the teams to try to generate understanding about the processes used to restore faith. Words such as '*close knit unit*', '*knew each other well*', '*flowed*' or just '*gelled*' were used to describe the teams. These *in-vivo* codes were frequent and further probing during the interviews generated meaning about the terms. Elaine was one of many participants who described why she had faith in the team.

*"You felt as though you were in safe hands and you knew that they knew what they were doing so erm, yeh I think that I had confidence in them right from the beginning and I don't remember then thinking oh she's the physiotherapist or she's the pain nurse they – after a little while all that disappeared I think they were such a team together that you did not actually think about their individual roles – separately....." (Elaine)*



After transcription, the term ‘*all that*’ became an open code because it appeared to allude to a perceived an initial artificial divide between the team members. To explicate meaning about what Elaine meant by ‘*that*’, the interview was re-visited to further explore what she meant by the term when she described how the team had ‘*flowed*’.

R: *If you were to describe the team to your friends or family – how would you describe them?*  
 Elaine : *I think that they worked quite well together as a team*  
 R: *How did you ascertain that?*  
 Elaine; *erm, mainly by the flow of the sessions really...the sort of the way that the sessions went – they sort of flowed quite good – on to me and things like that.*

Table 13 present the open codes that were later used to explicate meaning from Elaine interview through a line-by-line analysis. These were also included in the memos, which were used to review and refine emergent concepts.

Context	Open Codes
R: <i>If you were to describe them as a team to your friends or family – how would you describe them?</i>	Team
Elaine: <i>I think that they worked quite well together as a team</i>	Worked, together
R: <i>How did you ascertain that?</i>	
Elaine; <i>erm, mainly by the flow of the sessions really...the sort of the way that the sessions went – they sort of flowed quite good – on to me and things like that.</i>	Flow (ed)
	On to me

**Table 13 Open Codes- Example from Elaine’s Interview**

**Memo 31.1**

This was the first interview and although I was keen to explore how the team worked and the participant’s experience of the care, I was surprised at Elaine’s use of the term *flow* to demote the smooth operation of a team. I tried to ascertain what she meant by flow but because this was my first interview I was quite nervous and I don’t really think that I got to the bottom of what she meant by flow. I am not really sure why I think that ‘flow’ is such a key word. I suspect that my own interpretation of this word relates to cohesiveness as an essential requirement of team working. *Do I explore this now or later?* For Elaine, the team came across as professional, which appeared to give her confidence in their ability. *Maybe this is the way in which the teams were able to restore faith in health care?* Elaine did not seem apprehensive and was looking forward to the interview. Elaine placed a lot of emphasis on her current employment role as a civil servant – she does (or used to) do quite a lot of teaching so is familiar with the concept of team working. I think that she has very set ideas about teams and what constitutes a good team. I was surprised how Elaine’s job had been used in her description of the team. In this interview, I found myself using a ‘flip-flop’ approach (i.e. my own experiences) to help shape or refine a question to help Elaine describe her experience. Corbin asserts that sharing a common culture with the participants can often facilitate meaning about their experiences. Perhaps that’s why I can share her understanding of the word ‘flow’.

The open code *'flow'* used by Elaine was initially confusing, so it was explored further in other interviews. Returning to the raw data later to explicate this helped to construct meaning about *'flow'* and provided insight into how the team worked together. The concept of *'flow'* was then developed into a lower-level concept to explicate meaning through re-visiting previous interviews and exploring this in more detail during subsequent interviews. Other participants implied that teams appeared to *'get on socially'* and *'knew each other's roles'* and often remarked that the team members were *'relaxed with each other'* and were *'confident in each other's abilities'*.

Re-emersion in the data highlighted that codes such as *'flow'*, *'and got on'*, were frequently referred to by the participants to describe the teams. The constant comparative analysis technique facilitated greater understanding of the team's processes. Eventually, the term *'flow'* was developed into a higher-level concept because it inferred that the team were effective; equally, they were also thought to be confident because they were described as professionals who *'knew their stuff'*. Interestingly, the participants described how the team's credibility and *'flow'* were influenced by the way in which they interacted with each other. This was illustrated by Lyndsay who described her observations of the teams' social interactions and in particular how this impacted on her confidence in the team's professional competence:

*"The banter between them and they knew where each of them was coming from and erm, they worked well together and it came across that they actually got on and that they enjoyed doing what they were doing together it was obvious"*(Lyndsay)

The relaxed and often informal team working observed by the participants appeared to strengthen their faith in the team. Being seen to *'get on'* and observing the teams *'banter'* was indicative of this and the team were described as being strong and competent. It became apparent that the participants were also describing how the team liaised professionally and socially, which when compared using the constant comparative approach highlighted how the team appeared to be confident in its (the teams) own abilities. Team credibility and the participants' perceptions of the teams own sense of effectiveness influenced their confidence in health care and seemed to be

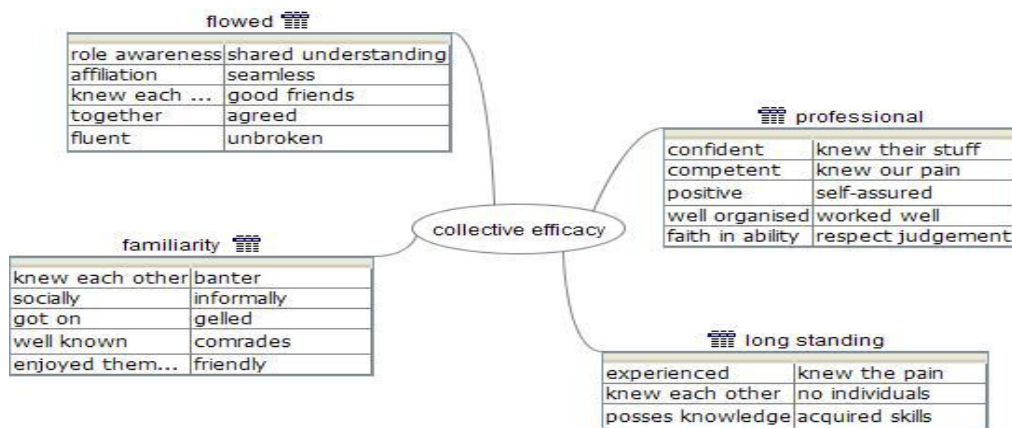
crucial in the relationship. The teams confidence and effectiveness, also known as 'collective efficacy', emerged as the fifth category and is discussed next.

## **6.2. Category 5: Collective Efficacy**

The way in which the team '*gelled*' and '*flowed*' was significant because it appeared to influence faith in health care. In seeking conceptual and theoretical clarity, the concepts were explicated further through using existing literature to develop theoretical sensitivity. Strauss and Corbin (1990) assert that theoretical sensitivity is a multidimensional concept (Strauss & Corbin 1990) that is predicated on the ability to become immersed within the data and theorised through constructing meaning. It is acknowledged that using literature can support sensitivity by enabling the researcher to explore a significant concept and use established literature or theories to give it meaning (Strauss & Corbin 1990). Hence the literature was used to develop 'theoretical sensitivity' and broaden understanding about collective efficacy and its influence on person-centred care. Enhancing the richness of the analysis through re-visiting data and micro-analysing concepts influenced the quality and transparency of the analytic process, and facilitated the development of categories. Explicating the literature that could help generate meaning about the team process revealed Banduras' (1989) theory about collective efficacy, which refers to the team's own confidence in its abilities (Bandura 1989) and became a term used to describe the category. The category of collective efficacy was therefore predicated on the lower and higher-level concepts derived from the participant's *in-vivo* codes. Albert Bandura's (1989) original work exploring self-efficacy was one of the first to explicate the concept of team efficacy. Similar concepts have been developed in the health literature, most notably by Millward & Jeffries (2001) who used the term 'team potency' to describe collective team confidence. Team confidence in itself or team potency (Millward & Jeffries 2001) builds on Albert Bandura's (1997) concept of self-efficacy, which he later developed to embrace teams and the way in which they grew a belief in the team. It is suggested that high collective efficacy will influence what people choose to do as a group and how much effort they put into it (Bandura 1997).

The participant's descriptions of care suggested that the teams appeared to believe in their ability and open codes exposed in the interviews included: 'competent', 'self-assured', 'well organised' and 'professional'. When combined using the diagram with other low level concepts such as 'flowed', 'familiarity' and 'long standing', the category of 'collective efficacy' became saturated. Once developed as a category, collective efficacy was explored further by explicating the properties and dimensions using diagramming techniques with mind map software (see figure 5). Diagramming was useful and helped visualise the key concepts whilst keeping an eye on the broader context. Flow charts in particular are advocated by Corbin & Strauss (2008) because they can aid the coding process or later category development. Using a mind map helped set out the lower-level concepts to display and visualise the analytic process that evolved in the formation of categories. The mind map was used to identify the relationship between the participant's observations and their descriptions of the team.

**Figure 5: Mind Map Category 5: Collective Efficacy:**



It is acknowledged that collective efficacy is a term frequently used in sport psychology, but it has yet to be fully explored within other professional contexts. Team collective efficacy seemed to be a fundamental element of the relationship because it re-enforced the participants' confidence and why they 'believed in' the team. The descriptions of the team enabled a deeper understanding about how 'collective efficacy' had helped restore

faith in health care. Jay described how her confidence in the team was influenced by the way in which the team displayed confidence in itself:

*"They [the team] had experience in what he were talking about – they had obviously dealt with a lot of other patients – they gelled together they all got on well together and they all had the same aim*

*R: So if they had been inexperienced would that have made you feel uncomfortable?*

*"It wouldn't have made me feel uncomfortable but it would have made me doubt their competence... the knock on effect is that you don't feel as confident in them really."(Jay)*

For others, such as Roger, having confidence in the team was important because it appeared to engender trust and respect. Roger described why having confidence was important in more detail:

*"I think that you need to have faith in the professionals that are helping you – that's the first thing you need to respect their judgment and opinions and if you don't have that respect in the first place then you're never going to think that they are going to do you any good at all". (Roger)*

Sue, who in her role as a civil servant, often taught team members about policies and practice, also raised similar comments. Sue highlighted the need for teams to know each other to enable them to understand roles and responsibilities, which she felt had underpinned effective communication:

*"I think that they just seemed to know what their role was I think- each of them seemed to know their role exactly there was never any sort of well what are we doing now – there was never any misunderstandings about what was going on er everything was definite do you know what I mean and erm, well each one of them know their own roles and the others sat back so to speak and allowed each of them their turn in whatever they were doing and it was just very well organised actually and I think that that gave you confidence in the team".*

This suggested the participants expected care to be delivered by a competent team, which was crucial factor in rebuilding faith in healthcare. May described this as reassuring because she was confident that the team were competent:

*May "I felt part of what was going on and I also felt that they all knew what they were talking about – I don't know how to word that. Cause you can tell because of my background that you have gone to lectures and you think that people are waffling that they have said what they mean and then they were just stretching it out but I felt that they all knew what they was talking about".*

These findings suggested that team collective efficacy was part of a relationship process built on informal approaches to caring which involved participants in decision-making. The team were seen as '*professional*' and therefore '*effective*', equally, they also believed the participant, which helped to restore their self-esteem. *Believing in* the team was a significant part of the person-centred relationship and collective efficacy appeared to influence faith in the team.

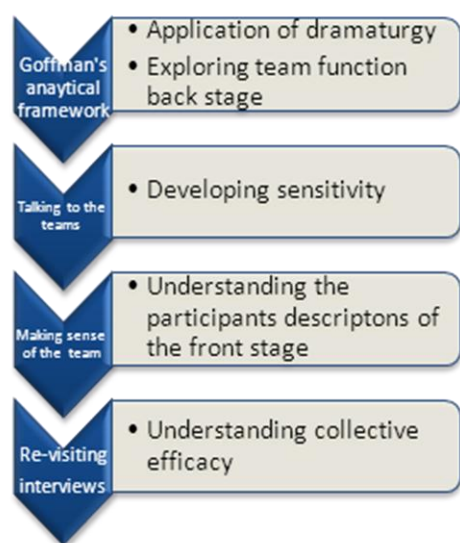
### **6.2.1. Making Sense of Collective Efficacy.**

It is acknowledged that researchers need to work with the data to generate meaning and understanding. Hence the relationship between the participants and the researcher develops throughout the interview process during which the researcher becomes the 'author' (Mills *et al* 2006) of *discovered reality* influenced by their ontological perspectives. Collective efficacy of the team was therefore co-constructed through listening to the participants, using a constant comparative approach. Moreover, Ponterotto (2005) suggested that the dynamic relationship between the researcher and the researched is responsible for the construction of social reality, hence, using a constructivist approach enabled the participant's experience to be captured and an understanding of their reality was therefore co-constructed. The relativist's ontological position of Grounded Theory helped explicate the participants' perceptions of the team and enabled a view of caring to emerge. Although the findings had indicated the need for faith in the team, the category of collective efficacy lacked depth. Whilst the observations of the participants were valuable, further analysis was undertaken to enhance sensitivity and saturate the category. Moreover, Corbin & Strauss (2008) advise that more data is selectively gathered from the field to ensure density. Based on this, engaging with the teams was important in order that meaning could be generated about the team processes used to develop collective efficacy. In seeking an emic team perspective of person-centred care, the teams from the four sites became participants in the study to ascertain their perspectives of person-centred care. Semi-structured interviews and focus groups with teams were selected because of their ability to ask pertinent questions, probe responses, enhance sensitivity and identify the social and

professional actions used by the team to develop collective efficacy. The next section briefly discusses how Erving Goffman’s sociological framework was embraced in the analysis to explicate the social processes of the team and generate meaning about collective efficacy.

### 6.6.2. Goffman’s Influence on the Analysis

**Figure 6: Goffman’s Influence**



To elaborate on the analysis and develop sensitivity, literature about the social and professional influences on team process was used. Erving Goffman’s work in particular and his seminal account ‘Presentation of Self in Everyday Life’ (1959) was appealing because it presented a sociological framework that provided an opportunity to explore social interaction, which could be used to expedite the analysis of the team’s social processes (see figure 6). Using

Goffman’s dramaturgy concept an analytic framework within a Grounded Theory approach enhanced theoretical sensitivity and helped understanding about collective efficacy. This analytic approach is not unique, indeed, Grounded Theory has a strong association with symbolic interactionism and, Goffman himself drew on the philosophical traditions of Blumer (1969) & Mead’s (1969) symbolic interactionism to fully explicate his understanding of the ‘self’ as it presented in everyday life. Using a constructivist paradigm helped generate meaning about person-centred care, but Goffman’s (1959) work in particular resonates with the methodological principles of symbolic interactionism, which interprets social actions through analysis of social intercourse. As a noteworthy architect of symbolic interactionism, Blumer (1969) described symbolic interactionism as being a:

*“peculiar and distinctive character of interaction as it takes place between human beings. The peculiarity consists in the fact that human beings interpret or “define” each other’s actions instead of merely reacting to each other’s actions. Their “response” is not made directly to the actions of one another but instead is based on the meaning, which they attach to such actions. Thus, human interaction is mediated by the use of symbols, by interpretation, or by ascertaining the meaning of one another’s actions. This mediation is equivalent to inserting a process of interpretation between stimulus and response in the case of human behaviour. (Blumer, 1969 p. 180).*

Goffman (1959) engaged with this perspective and developed Blumer’s work through his observations of social activity. Thus, Goffman asserts that the person expects that the other will take them as they are portrayed- whether what a person portrays is intentional – (given) or unintentional (gives off). It is believed that Goffman (1959) engaged in sociological research that challenged traditional empirical parameters which asserted that individuals attempt to control others through the image they ‘give’ (Manning 2008). Goffman’s views present ‘theatrical control’ or ‘dramaturgy’ as a method which a person uses to exploit a situation through presenting themselves in the front stage in an ‘agreeable light’ through careful ‘rehearsal’ in the back region. Using Goffman’s dramaturgy concept provided an opportunity to enhance theoretical sensitivity and construct meaning about the teams social and professional activity that influenced collective efficacy.

### **6.3. The Front and Back Regions of Care: Listening to the Teams.**

It is acknowledged that informal activity undertaken in the back stage by healthcare teams have received limited attention (Ellingson 2002), yet Goffman (1959) argued that it is through the backstage work that the performance is developed and where the team can rehearse the ‘single routine’. Goffman’s dramaturgical metaphor is thought to be a conceptual framework for interaction analysis (Smith 2006) and a theory that can be used to interpret social exchanges (Manning 2008). Hence it was used to generate meaning about the social actions, or performances of the teams and provided an opportunity to explicate collective efficacy. In determining how impression management is enacted, Goffman (1959) argued that there are two regions, namely the front and back from within which the act or performance is manufactured and delivered. The front region is where the performance is given and presents a ‘collective representation’ of



the actors to the audience which can give an impression of ideal standards – for example the findings from Chapter 5 suggested that the team was perceived to be credible because of the way in which they ‘flowed’ or ‘gelled’, which presented a team that appeared cohesive and confident. Conversely, the back region or back stage is where the performance is fabricated. Goffman (1959) argued that it is “*here the team can run through its performance*” to ensure a professional and seamless act. Goffman argued that performances in the back region may not be authentic as they can “knowingly contradict” (1959 p114) the front stage behaviour. A performance can be acted out by an individual or a group of people. In the context of team working, the front region therefore represented the professional exterior designed to exhibit a ‘single routine’ to participants.

It has been surmised that producing a team that collaborate effectively is in part due to the interdependence they have on each other (Goffman 1959), and because interdependence is thought to be fostered through the back stage region (Ellingson 2002). Goffman (1959) asserts that an activity is made up of compromise between the back stage and the front stage. When referring to teams, there are three premises:

1. *Team-members will want the others to think that he is loyal and well-disciplined performer – even backstage*
2. *That team mates even back stage keep each other’s morale up*
3. *There may be some parameters to backstage activity such as status, gender.*

The concept of ‘*having faith*’ that developed through the interviews with the participant were used to guide the initial team interviews and construct meaning about the team processes. This facilitated an approach that enhanced understanding through clarifying concepts with the teams and developing sensitivity. Teams from the same four sites the participant’s had attended were included, and semi-structured interviews were conducted in the clinical setting. Although this was convenient for the teams, staff availability was restricted due to workload pressures. Data were therefore collected over a two-month period, during which time Goffman’s framework was used to aid the analytic process to saturate the properties and dimensions of collective efficacy. Previous contact with the pain teams also facilitated access to the pain centres and

discussions with the leads in each of the pain teams helped advertise the study. Information sheets were left in the pain clinics and staff were asked to make contact if they were interested in participating in the study. The interview prompts included questions that encouraged the teams to discuss their thoughts about the team itself, the importance of pain validation, their views on person-centred care and what this meant and how they perceived their relationship with those they cared for. For example, the teams were asked how they felt they helped people with chronic back pain to manage, whether they felt that validation was important and their perception of the relationships they formed. Table 14 presents some of the questions used in the team interviews.

<p>Q: Please describe the team  <i>Prompts included:</i>          How do you work together?          How do you develop team confidence?          How important is team credibility to person-centred care?</p>
<p>Q: What is the significance of validating pain?  <i>Prompts included</i>          How is this achieved?          Please describe the effect you think this had on care</p>
<p>Q: Please describe what you understand to be person-centred care  <i>Prompts included</i>          How would you determine person-centred approaches?          How does the team work together to provide person-centred care?</p>
<p>Q: What do you feel are the key attributes of person-centred care?  <i>Prompts included</i>          How are these attributes influenced by the person with chronic back pain?</p>

**Table 14: Team Interview Questions.**

### **6.3.1. Sampling**

In total, 9 team members from across the four sites volunteered to take part. This enabled two focus groups and three face-to-face interviews to take place. Two of the face-to-face interviews were undertaken with the Salisbury team members; a consultant nurse and a consultant anaesthetist and the other face-to-face included a

clinical psychologist from Poulton. Some teams had experienced busy periods and struggled with staffing levels due to long term sickness so were unable to attend the interviews. Two small focus groups were held at the Faversham and Bracknell sites. At Faversham the consultant anaesthetist and senior nurse were interviewed together and at Bracknell, the physiotherapist, consultant anaesthetist and clinical psychologist attended (see table 12). The individual and focus group interview duration varied from 45 – 78 minutes and were challenged by practice and sickness. It was difficult to arrange for whole teams to attend interviews, but through negotiation it was possible to explore team working with a range of professionals. Asking the teams to describe team processes prompted detailed conversation and provided good information about the relationships, actions and philosophy of the teams. Table 15 details the teams demographics

Site	Data Collection Method	Volunteers
Poulton	Face to face interview	Clinical Psychologist
Salisbury	Face to face interview	Consultant Nurse
Salisbury	Face to face interview	Consultant Anaesthetist
Bracknell	Focus group	Consultant Anaesthetist, Physiotherapists, Clinical Psychologists
Faversham	Focus group	Consultant Anaesthetist, Senior Nurse, Pain Nurse.

**Table 15: Team Demographics.**

To ensure a transparent and auditable account of the transcription, Mergenthaler and Stinson’s (1992) stepped framework was used again to transcribe the team interviews. Once transcribed, the interviews were scrutinised through a line-by-line analysis, and, similar to the participant interviews, open codes emerged which became lower-level and then higher-level concepts. Analytic memos were recorded religiously and there was an increase in the use of ‘mind mapping’ software to support micro-analysis. The analysis thickened as the interviews progressed and the relationship between the participants and teams became more transparent. Subsequently and similar to the previous interviews with the participants, the

questions evolved, became less structured as they developed through the constant comparative approach. In addition, the semi-structured nature of the interviews enabled the team members to lead the discussion which helped strengthen the analysis.

Earlier findings in this chapter discussed the *in-vivo* codes used by the participants which described the team's performance as '*well organised*', and which '*flowed*'. Importantly, the social and professional actions of the team inspired confidence and appeared to help quell the previous effects of the sceptical professional. Jennifer the clinical psychologist from Poulton highlighted this when she talked about how the team were practiced/rehearsed and how she hoped this helped to engender a cohesive 'front'. Using terms such as '*quite well rehearsed*' and '*quite well practised*' was indicative of the team's ability to '*run smoothly*'.

*But they are quite well rehearsed, well, from my point of view in terms of the group programmes that we run here, they are quite well practiced, I should say, not rehearsed really. So I think we are quite clear about which bits we have and we know when we've finished our bit and when to hand over. So I can see – well, I would hope that that's seen from the patients' point of view to run quite smoothly (Jennifer CP Poulton).*

Similar observations made by Goffman also acknowledged that it is in the back region where "*the team can run through its performance.....here poor members of the team.....can be schooled*" (p115). Interestingly, Goffman (1959) describes the importance of the back region as a place in which communication out of character can take place and without fear of disrupting the image performed. Hence, participant's absence from the backstage, provided the teams with a space for 'shop talk'.

The 'hidden and 'invisible' work of the team was intriguing on two levels: firstly, generating an understanding of the team provided an opportunity to enhance theoretical sensitivity, the analytic process and generate insight into the reality of team work; secondly, in seeking to saturate collective efficacy, it was important that the back stage work was opened up to analysis to enable a rich picture of the team processes that influenced person-centred care. Axial coding between the participants and team descriptions was undertaken to identify commonalities between the participant's

descriptions of the team and the team’s actual perceptions. As the analysis progressed, axial coding became more sophisticated through incorporating memos, with the teams descriptions of key aspects previously identified from the participants findings. Analysing this activity involved re-visiting the data and making comparisons. For example, Anne’s (Consultant Nurse from Salisbury) statement was contrasted with the participant’s *in-vivo* codes to enhance meaning.

*“I think that we’re a very relaxed team in that we’re very relaxed personalities within the team and therefore, although there is the professional boundaries, I think that people are very natural with the patients, they’re very much themselves with the patients, you know, within that sort of setup really” (Anne Salisbury.)*

Participant Context (Elaine)	<i>In-vivo</i> Codes	Team Context (Anne)	Concept Alignment
R: If you were to describe them as a team to your friends or family – how would you describe them? Elaine: I think that they worked quite well together as a team R: How did you ascertain that? Elaine; erm, mainly by the flow of the sessions really...the sort of the way that the sessions went – they sort of flowed quite good – on to me and things like that.	Team	“I think that we’re a very relaxed team in that we’re very relaxed personalities within the team and therefore, although there is the professional boundaries, I think that people are very natural with the patients, they’re very much themselves with the patients, you know, within that sort of setup really”	Collective Efficacy
	Worked, together		
	Flow (ed)		
	On to me		

**Table 16: Side by Side In-vivo Code Comparison.**

Anne’s descriptions of the team were similar to teams social processes observed and later described by the participants, which added depth and understanding. Meaning was enhanced when this was compared with other similar *in-vivo* codes, used by the participants to describe team function, were used by the team members to describe their work. This is illustrated in tables 16 above and 17 next.

Participants In-vivo Codes	Concept Development	Teams In-vivo Codes	Concept Alignment
Flow Gelled All as one Professional Experienced Dedicated Relaxed at ease	This seems to encapsulate the perceptions that the participants had of the teams and the way in which they operated. This later began to develop into the emergent category of collective efficacy. From the outset, the participants were impressed with the level at which the team seemed to know each other and each other's roles. They felt that the team were strong and therefore had confidence in an 'authentic' team.	Respect Getting on Knowing depend on knowing each other as individuals not alone	Collective Efficacy

**Table 17: Side by Side Comparison of Concepts.**

The side-by-side comparisons were useful in visualising the front stage work as previously described by the participants and the back stage work that supported this activity as outlined by the teams. Explicating the backstage work through talking to the teams revealed two additional categories that helped generate understanding about the processes involved in collective efficacy. The categories related to the teams maturity and their physical and geographical location. Collectively, these two categories appeared to influence collective efficacy and are discussed next.

#### **6.4. Category 6: Team Maturity**

The category of team maturity was based on the teams' descriptions of their relationship. Listening to the teams provided insight into their professional and social actions, which influenced their ability to work as a team. The teams used terms such as '*experienced*', '*mature*' and the '*corporate view*' to describe how they functioned. The word '*maturity*' appeared to be significant and being a mature team was perceived to be an advantage. The following extract taken from the focus group interview with the Brecknal team illustrates their perceptions of the team and the impact of '*maturity*':

Dr G I think we have an advantage also that there's a hint of maturity to the team, people have done jobs and other things elsewhere. They're experienced in their own fields, and there's not many brand new people, I don't know really, that have not done other things.

Helen No it almost... it does need those specialists doesn't it.

Dr G Also, because of maturity you've got certain, I suppose, aspects on life, you've lived a bit, you realise it's not all squeaky clean like you thought when you were at school, and that goes right across the board, including the secretaries, they have a very similar feel. How much of that is cause or effect I don't know, because there is a corporate view, when we interview for jobs of various kinds, we know the kind of people that we are after.

Being mature was important because it was thought to support team cohesion. The *in-vivo* code of 'maturity' was initially developed as a higher-level concept, but later became a category through revisiting memos and explicating properties.

Context		Open Codes
<p>"I think we have an advantage also that there's a hint of maturity to the team, people have done jobs and other things elsewhere. They're experienced in their own fields, and there's not many brand new people, I don't know really, that have not done other things" (Dr G).</p>		<p>Maturity</p> <p>The team</p> <p>Experienced</p> <p>Brand new</p>
<p>"there's quite a lot of maturity to understand that, and it can be quite confusing for people to come in to start with, and it can be quite threatening for some of the clinicians who aren't really used to that..... So it does require a great deal of respect..... we have a long established team and we have some quite subtle working relationships and some quite sort of deep suspicions and stereotypes that are suppressed probably. We know each other quite well. I think we all respect each other, fundamentally, sometimes there's a humour about it, sometimes it can be quite edgy, sometimes there's some backroom discussions going on. So I think it can be... it is a very intimidating environment for clinicians without maturity"(Dr J).</p>		<p>Maturity</p> <p>Respect</p> <p>Long established</p> <p>Relationships</p> <p>Humour</p> <p>Backroom</p>
Category	Properties/ Dimensions	
Maturity	Committed, established, teams are long standing, new people may feel threatened. Knowing each other, successful relationships, time served team.	

**Table 18: Analysis of Maturity.**

Table 18 illustrates how *in-vivo* codes such as 'experienced', 'long established' and 'humour' used by the teams enhanced the analysis of 'maturity'. The category of maturity was also linked with experience, which appeared to influence teams' decisions to recruit new members. These comments concurred with Goffman's assumptions that team members will only select others who are loyal, dependable and trustworthy; which suggested that these characteristics were inherent within a team's selection process. Analysing the category of maturity helped explicate some of the professional actions of the team and provided insight into the actions and beliefs that supported the team's actions as observed and experienced by the participants. Equally, social activity outside of the clinical context was thought to influence team professional relationships. During

the interviews, teams described their knowledge of members' families, their nights out and other social arrangements. The team from Bracknell described how socialising through lunchtimes or nights out socialise influenced teamwork:

*Chris* I think as well, it's almost like having your *lunchtimes together* as well...

*Helen* Yes.

*Dr G* ... and knowing each *other as individuals*.

*Chris* I'm passing a room, do you want a cup of tea, Geoff, or a cup of tea, all those things...

*Helen* Yes, and should we *all go out for a night out* because it's become... we're having a tough time.

These findings suggested that maturity was also influenced by the teams social activity that extended beyond professional and clinical boundaries. Social activities, such as going out for a night, or a meal were described as being good support mechanisms and an opportunity to get to know one another. Listening to the teams enhanced sensitivity about team maturity and developed an understanding about terms used previously by participants as '*collective unit*' to describe the team. Hence, the professional and social activity was thought to be important and appeared to contribute to the participants overall impression of an effective team. Literature was also used to enhance sensitivity about social processes and the concept of team maturity in particular has been reported elsewhere. For example, Kvarnström *et al* (2006) outline the significance of team maturity and suggest that the development of maturity is predicated on temporal, professional and social constructs. Equally, the ability to coalesce outside of the clinical environment was also reported by Goffman (1959) because it enabled the teams to communicate 'out of character' and influences relationship development.

The participants also described the team as being '*familiar with each other*', interestingly, it was noted that Goffman (1959) described 'being familiar' as a key characteristic of good teams. This was emphasised in the team interviews during which the concept of '*being familiar*' was inferred by the teams to be significant in developing role awareness. For example, teams described how role awareness developed over time as individual members became familiar with responsibilities and functions within the team. The dialogue between Sarah and Doctor G at Faversham highlighted this:



*Sarah: I think this team works so well actually because the team generally do know their role, and we all have a clear and quite well defined.... We know what each other's roles are, it's not too blurred.*

*Dr G No.*

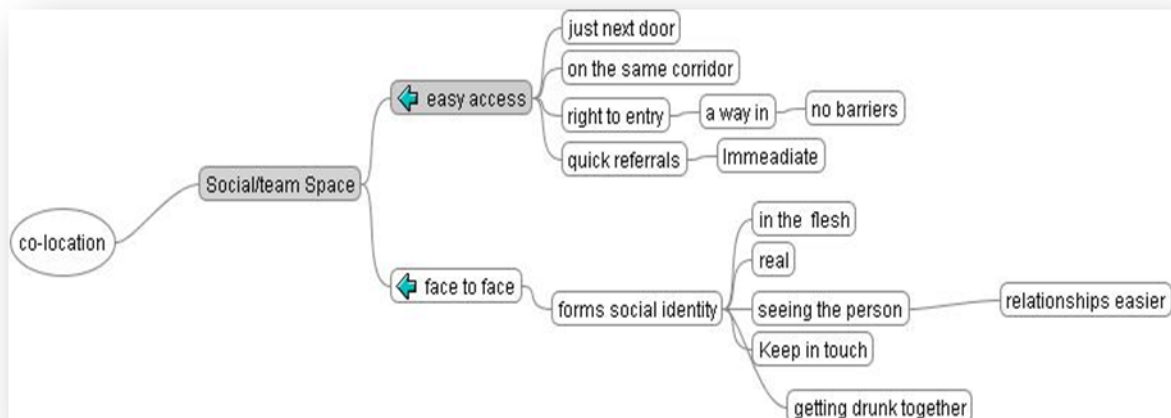
*Sarah: While we can start and finish each other's sentences off, we... it's not... we know when that's somebody else's, we will watch videos of the patients and I'll say to the patient oh you hesitated, I wondered what you were thinking, and ask them to say... you know they were a bit fearful of stepping over it because they had a thought that would actually have affected how you moved and what you did, and the physios would say what does it look like from your perspective, and I'd say he looked very tense, and guarding this area, and they'll talk about it from an anatomy perspective, so it's... everybody has their role,*

These findings suggested that team maturity developed backstage and influenced the professional and social actions in the team process. This reflected the work of Farrell *et al* (1988), which explored the influences associated with successful team working and that this encompassed a shared culture through consensually agreed expectations that were developed over time through achieving an understanding of each others' roles. Listening to the teams also revealed the significance of a 'social space' for relationship development. The social space appeared to take place in the back region and was used to support team development and needed to be geographically accessible to enable face to face contact and ease of access to colleagues. For example, the teams used terms such as 'in the same building', 'face to face' contact, 'seeing each other daily', 'physical contact' to describe methods of communication used within the social space that helped develop inter-professional relationships. The ability to coalesce in a shared space appeared to influence team maturity and emerged as a category. The significance of the shared social space is discussed next.

### **6.5. Category 7: Co-location.**

Being 'co-located' was identified as a category through earlier *in-vivo* codes such as 'easy access' and 'face to face'. The social space described by the teams was shared within a geographical environment that was co-located. Hence, the category of 'co-location' was developed because it supported team communication and development in the back stage. Working in this way enabled the teams to develop a 'negotiated order' (Allan 1997), which facilitated team effectiveness. Negotiated order refers to the way in which

social actions form interactional processes, predicated on negotiations between professional groups (Allan 1997) and as such embraces professional hierarchy as part of this process. The ability to develop a structure through ‘negotiated order’ is therefore considered by some, to be instrumental in the development and on-going evolution of multi-professional teams. Being geographically co-located provided ease of access to other team members and the ability to be able to knock on someone’s door for a quick chat or coffee provided opportunities to discuss issues ‘*face to face*’ and a more general ability to hold informal discussions. The significance of a shared geographical social space was highlighted by all the teams and suggested that communal areas were important factors associated with the development of relationships. To saturate the category of co-location, a microanalysis, using mind map diagramming helped to visualise the properties and dimensions of lower-level concepts such as ‘*social identity*’, ‘*social space*’. Figure 7 provides an illustration.



**Figure 7: Micro-analysing the Category of Co-location.**

Typically, being co-located provided ease of access to team members and facilitated a relaxed atmosphere because the team members were able to ‘communicate out of character’, which appeared to enable teams to develop informal social relationships. Team members also described how being co-located facilitated other social team activities which they believed were important for team cohesion. Codes such as ‘*having a laugh*’, ‘*going out*’, ‘*having a sense of humour*’, ‘*knowing the kids*’, ‘*being a family*’

were *in-vivo* codes used to describe the team characteristics. Jennifer, the clinical psychologist at Poulton, alluded to this when she talked about the team's clinic space:

*As you know we have a clinic space, don't we? And there's a very strong sense of belonging around that clinic space, I think. Especially from the nurses' point of view. They are quite proud of it and they do their very very best to make it as comfortable for the patients as possible. And so we have our own little private space, clinic space, so I think we can feel at ease to have conversations and not feel like we're impinging on other clinic areas or being overheard or whatever(Jennifer CP Poulton.)*

The clinic space described to by Jennifer referred to a small room within the pain clinic where the team met. This was consistent with Goffman's (1959) assertion that backstage work can take place in a number of settings and, as DiPalma (2004) suggests, happens because successful teamwork cannot be confined to mere formal structures. The offices of the team and the geographical location appeared to play an important role in the backstage work of the teams at all four sites. Being co-located on site provided opportunities to discuss care, coalesce and develop team dynamics, which ultimately appeared to influence collective efficacy. This was valued by the team members; and Anne (Consultant Nurse at Salisbury) provided insight into the influence being co-located had on care:

*"...one of the things that I think helps us to work as a team is the fact that we're all housed here together as well. So it's easy to speak to each other. So you can discuss patients, you can discuss team working and we have formal settings to do that as well, on a weekly basis, as well as being able to do it informally" (Anne Consultant Nurse at Salisbury).*

The findings suggested that being co-located helped the team to rehearse and ensured that they provided a seamless front stage image. This has been reported in the technical literature, for example, Hudson (2002) suggests that co-location is also thought to contribute to greater integration and importantly, allows space for dialogue between professional groups to share knowledge and understanding. Thus co-location of teams appeared to develop strong team dynamics through a safe environment in which the teams developed collective efficacy. This indicated greater integration, which led to the formation of the team and was an essential component of collective efficacy because it appeared to strengthen team cohesion. Coalescing in the back region enabled teams to develop knowledge about individual roles, which is understood to contribute to the

team's performance (Ellemers *et al* 2004). The familiarity between team members originated from the shared space and enabled members to challenge each other's decisions. In addition, the teams also described how they felt comfortable sharing time with colleagues away from the work environment because this helped inter-personal relationships. This point was illustrated by Sarah, the nurse at Fathersham, who suggested that knowing other team members outside of work strengthened working relationships, and helped them feel comfortable in challenging other member's decisions. In the extract below, Sarah described how knowing other team members facilitated an informal relationship:

*We can fall out. Can we then get on with what we need to do? Yes, we can. We can have a giggle. We often have a giggle..... Everybody knows how many children is in each family, we all know one another's' children's' names, all that sort of thing. We know things about one another quite personal. (Sarah Nurse at Fathersham)*

It is believed that this form of social interaction develops collegiality and improves cooperation between the team members performance (Pinto & Prescott 1993). Moreover, the findings suggest that the ability to 'get on' led to respect and confidence in team members which influenced their belief in the cohesive team. Helen, the physiotherapist and Dr G from Bracknell discuss this in more depth:

*Helen There is a team respect for each other, and for each other's personalities, and making time for each other, but I think there's a strong level of case discussion as well. You never actually feel like you are on your own with the cases in the team. If George (Dr G) has seen them I'll come to George and say discuss the case, if I'm struggling with it, or I'll discuss it with the physios or we'll see them together, so you know as a team we can rely on each other.*

The collaborative team appeared to be influenced by the interdependence developed back stage. This form of team working was also described by Ellingson (2002) whose unique research was one of the few studies that have explored back stage work of healthcare teams in any depth. Ellingson (2002) explored the way in which healthcare teams constructed meaning about their work by using Goffman's metaphor of performance and the concept of the 'backstage'. Ellingson's study revealed how back stage working can help dilute rigid divisions, establish inter-personal relationships and, 'gel' as a team. Observations of the team performance as reported by the participants

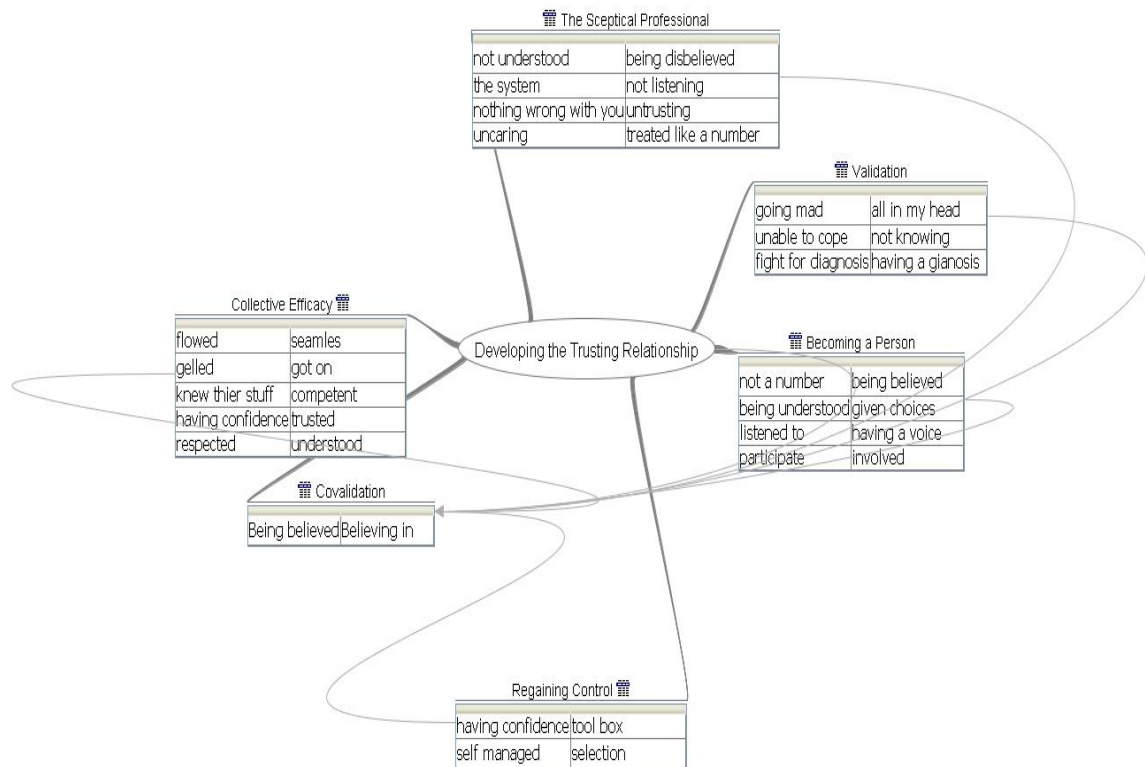
portrayed a single routine in which team's inter-personal relationship and camaraderie were described.

The findings from the team interviews suggested that co-location and team maturity influenced collective efficacy and were crucial in relationship development. Equally, the way in which the team coalesced was significant because it enabled the team to develop social and professional relationships, which influenced collective efficacy. Ultimately, this played a crucial role in restoring faith and using Goffman as a framework to analyse the teams social processes helped to explain the significance of collective efficacy. The category of '*collective efficacy*', indicated the key process involved and the analysis had revealed that *being believed* by the team and *believing in* the team was fundamental to the development of the relationship. The findings from Chapter 5 highlighted that for the participants, *being believed* and *believing in* was equally significant. Re-immersion in the interviews to support sensitivity emphasised that reciprocated belief related to all the higher-level concepts and appeared to underpin the trusting relationship. Making links with the technical literature helps to critically examine categories (Charmaz 1990) and interrogate meaning, hence, technical literature was therefore used in conjunction with analytic memos to develop theoretical sensitivity which was helpful in explicating concepts associated with team processes. The last part of this chapter discusses the significance of *being believed* and *believing in* has within the context of person-centred care.

#### **6.6. Category 8: Co-validation: Being Believed and Believing In.**

*'Being believed and believing in'* presented two conditions that influenced the person-centred relationship. Significantly, this reciprocated process appeared to underpin person-centred care and empowered the participants to regain control of their pain. Hence, the two conditions were thought to 'co-validate' each other. The process of '*co-validation*' normally relates to a "convergence to valid representations of the real-world situation" taking place (Wright & Bauers 2004 p678). In the context of person-centred care, the findings suggested that co-validation was predicated on two conditions; firstly that the pain was authenticated by more than one other person [the team] and

secondly, the person in pain had confidence in the team and expected the team to understand and legitimise their experience of pain.



**Figure 8: Mind Map of Co-validation.**

The analysis suggested that these two ‘conditions’ were fundamental in a *partnership* process, which had been influenced by a trusting relationship between the participants and teams. The co-validation process represents a key step influence of person-centred care in relation to people with chronic back pain, and in particular, co-validation explained how the participant’s recovery was supported through the restoration of self-esteem, renewed confidence which enabled the participants to regain control of their pain. Elaborating on the analysis and using a mind map (see figure 8) helped visualise how the other categories had influenced the development of co-validation. The process of co-validation incorporated all the other categories and appeared to underpin relationship development. Moreover, exploring the work of the team in the back region facilitated insight into the relationship and helped identify co-validation as one of the key concepts related to the attributes of person-centred care previously revealed in the

initial literature review, for example, Kitwood's (1997), definition of personhood. Using Goffman to explicate meaning about the social actions and subsequent relationship was helpful in establishing parallels between the literature and the emergent findings. The two conditions of *being believed* and *believing in* were fundamental to the process and relied on the team's ability to listen, react and respond accordingly. Ultimately, the co-validation process laid the foundations of a trusting relationship, as advocated in the literature review, which supported person-centred care.

The team's validation of the participants pain early on in the relationship was crucial because it helped to initiate the recovery of the(ir) person. The significance of validating pain was acknowledged by Sveilich *et al* (2005), who reported that human nature is visually orientated, thus, phenomena that are invisible are often unrecognised. Sveilich (2008) also argues that the invisibility of chronic pain in particular poses additional challenges because it does not manifest outwardly, and although it is possible to describe symptoms, there are no external physical signs. Similarly, Chapman & Gavrin (1999) point out that 'suffering' is believed to be a psychological construct, thus making chronic pain a complex phenomenon, which crucially, arises from an invisible noxious stimulus. It is the invisibility of the pain experience, which leaves many feeling isolated and stigmatised (Ware 1992) because of the perceived reactions from others. Thus, the chronicity of pain can cause suffering which if persistent can damage the integrity of self and create disparity between what is expected and what actions a person may actually take (Chapman & Gavrin 1999). This was illustrated through the participants' descriptions of 'self' demoralisation that occurred because significant others treated their pain with suspicion. A common concern disclosed by the participants was the lack of understanding of the complexity and impact of pain that was demonstrated by non-sufferers. Goffman's notion (1959 p 24) that "*society is organised on a principle that any individual who possess certain social characteristics has a moral right to expect that others will value and treat him appropriately*" echoed this perspective and provided a starting point for exploring the extent to which the team actively sought to reassure participants through confirming their pain.

The process of validating the participant's pain experience was significant because it made them feel valued, which resonated with some of the key principles associated with person-centred care such as sympathy, respect and understanding. Validating pain demonstrated understanding, and meant that the participant's pain was legitimised. This re-enforced trust and augmented confidence in the pain teams. Clarke *et al* (2005) also acknowledged that once the patient's pain is believed, an instant output is gratitude followed by the start of a rapport. This reflected the findings in Chapter 5 and suggested that listening and believing in the participant's pain was essential to the development of a trusting relationship because it accounted for and respected the person rather than the patient. This enabled the team to restore faith in healthcare and validate pain through an informal partnership approach.

The category of 'validation' was therefore instrumental in the formative stages of the relationship between the teams and patients. As the analysis thickened, there was a latent recognition that validation was a pre-requisite to person-centred ways of caring which warranted further development. Hence, its significance and priority was explored with the teams throughout the interviews using open-ended questions that invited teams to talk about the key factors they associated with relationship development. The interview with Jennifer, a clinical psychologist, based at Poulton early on, described the significance of validation which also revealed how believing the patient was prioritised.

*I think that is absolutely of paramount importance, you know, that they feel believed and that they have the opportunity to feel listened to as well. And I think that plays a big part when people actually feel that somebody's listening to them and not just going through the motions. So yeah, I think that is very important because in order to develop any kind of therapeutic relationship, the client or the patient has to have that sense of being believed and being listened to, don't they? I think for people with chronic pain, one of the key messages we hear from them all the time is how isolated they feel with the pain. Because it isn't that visible condition that people can pick up on and, 'Oh, she's got a pain condition' like you might with some kind of visible injury. People do feel very isolated with it when they're up at night in the pain and they feel like they're the only one that's up during the night with pain. Jennifer (clinical psychologist from Poulton)*



## Memo 65

Talking to Jennifer highlighted the team's awareness of the importance of validation. I realised that although the need for validation was a new concept for me, the pain teams were accustomed to their participants needs and attuned to the need to legitimise the pain early on in the relationship. Interestingly, Jennifer did not really view this as person-centred – just as an accepted norm – they recognised that the participants had 'been through the mill' and as described by others, as being 'heart sink patients'. The full extent of this did not become apparent until I had talked to the participants, which was re-enforced by the teams descriptions.

Team members later described how strategies such as '*taking the patients seriously*' were used to limit the damage of the sceptical professional. The interview with Doctor J at Salisbury was typical of the other teams and team members when describing their relationship:

*they do respect that their problem is being taken seriously, they are being taken seriously, they can see a group of people who are interested in them and their problem..... they come in here, and they do feel there's a bon ami and an interaction here that is powerful, I think it is very powerful for the patients, yes.(Doctor J Salisbury)*

Developing a relationship with the participants took place over several months, during which time the teams got to know the participants through listening to their experience and re-enforcing their belief. Helen's (clinical psychologists at Bracknell) description of how she listens to and works *with* people who have chronic pain to ensure that they are central to care were similar with some of the earlier principles of person-centred care and the individuals biography as indicated in the initial literature review.

*Yes, and respected and their needs really listened to and worked with, yes. And they are central in that respect, because we've all considered their needs and difficulties from all our perspectives, through all our research, through all our patient encounters, and their needs are very central to what we do.(Helen Bracknell)*

Stickley & Freshwater (2006) refer to the 'art' of listening, equally, using this art meant that the teams responded to and understood the participants' pain. The findings from Chapter 5 also highlighted the positive impact that simply listening and getting to know them had on the participants' self-esteem. Yet, therapeutic listening is often underestimated because of its inability to be measured (Stickley & Freshwater 2006); but, for the participants and teams, listening supported the development of

relationships and importantly, of trust in the other person. This suggests that *believing in* through listening was important because it represented the first steps in a person-centred process.

**Memo 76:**

Helen's interview highlighted the importance the team placed on listening. However, I was intrigued as to why she related this to 'our research and our perspectives'. I'm not sure what she meant by this. Helen also mentioned how identifying the patient's needs was central to the decision-making – and involved getting to know the patients. I am reminded at this point of the significance of the biography as highlighted in the literature and I now realise how this was possibly used to underpin a healthy relationship.

Equally, listening also provided a space in which the participants could open up to the teams, which helped the teams understand more about the person. Hence, the teams were described as understanding and empathic because they took the time to listen, acknowledged the person and importantly, validate their pain. Explicating the team processes that facilitated the relationship using Goffman's sociological perspective was significant and helped reveal the back stage work of the team. The collective efficacy of the team discussed earlier appeared to influence the participant's confidence and faith in health care. Significantly, as highlighted earlier, the findings revealed that the relationship was predicated on two conditions; *being believed*, and *believing in*. These concepts linked the participants and teams experiences and presented conditions inherent within the relationship that facilitated trust and person-centred care. The co-validated relationship presented insight into person-centred care, however, the teams' perceptions of the trusting relationship had not been fully analysed, and whilst Chapter 5 highlighted the participants views, the team's perspectives were needed to fully saturate the category of co-validation.

**6.7. Chapter Summary:**

Using Goffman helped identify the social actions and the hidden 'know how' of the team. For example, in explicating collective efficacy, teams remarked on their ability as a team and referred to the way in which they provided care. Goffman's sociological framework was useful in identifying the team processes used to develop trust and how the process of co-validation had supported partnership working. Using a constructivist

approach within a Grounded Theory theoretical framework (Corbin & Strauss 2008, Charmaz 1990, 2006) helped to co-create meaning about the participants' experiences of person-centred care. The analysis was influenced by an intuitive process, which provided an opportunity to move back and forth with the data as advised by Charmaz (2006). Data collection and analysis occurred contemporaneously from the first interview and supported the generation of eight categories, which informed the development of co-validation. Seeking meaning using the constant comparative analysis and theoretical sensitivity helped to understand the relevance of co-validation and highlighted the need for mutual respect, understanding and importantly a belief in the 'patient' as a person. Significantly, the way in which the teams and participants used a reciprocated belief to facilitate a partnership was important because it supported the development of trust; equally, the need to believe in was crucial in forming the trusting relationship. In seeking to saturate the category of co-validation, the teams perspective was explicated further using psychoanalytical methods. This process and subsequent impact on the emerging relationship is explored in the next chapter.

## **Chapter 7: Exploring the Teams' Experience of the Co-validated Relationship.**

The findings from Chapters 5 and 6 indicated how person-centred care was predicated on a process of co-validation which influenced and supported relationship development. This chapter builds on the analysis and explicates the relationship further to generate a substantive theory of person-centred care. The first part of this chapter discusses the analytic process used to explicate the teams' perceptions of the relationship and the emerging paradox that appeared to challenge the relationship. The second part of the chapter discusses how the dimensions and properties of the paradox were explicated using concepts derived from transactional analysis to enhance sensitivity. The chapter concludes with a discussion of the emerging theory of the conditional partnership that was developed through the analytic process.

### **7.1. Explicating Co-validation.**

The process of co-validation appeared to support a relationship that was built on the philosophical principles of personhood such as trust, respect and autonomy as highlighted in the literature review, (Lauyer *et al* 2000, Paulen & Rapps 1981, McCormack 2003, Balint 1969). However, whilst this revealed some of the processes associated with person-centred care, there was limited insight into the relationship itself, and in particular, the teams' experiences of the relationship lacked depth. Although Goffman's metaphorical account helped identify the social exchanges of the team through eliciting process and structure, Goffman's ideals were limited in assessing the human element of relationships. As the analysis deepened, Goffman's conservative subtext added little to explicating an understating the individuals agency and hence their actions within a relationship. Using a constructivist perspective to elicit meaning led to further exploration of the ontological layers that were embedded within the relationship. Developing meaning about the relationship meant thickening the analysis about the team's perspectives of care.

The interviews with the teams were also used to explicate the co-validated relationship and their perceptions of person-centred care. During the interviews, the teams appeared to describe how they controlled care and decision-making. This conflicted with the previous findings in Chapter 5 and revealed how participants may have been 'guided' into treatment options. Hence, a line by line analysis of the transcripts later revealed *in-vivo* concepts, such as 'been given information', 'they agree', 'treatment contract' and 'a two way thing' as terms used by the teams to describe the relationship. Listening to the teams and the microanalysis of the *in-vivo* codes revealed additional conditions in the relationship that appeared to be predicated on the team's expectations of the participants. The following extract from Dr J at Salisbury was one of the first interviews to reveal the conditions of care expected by teams:

*I think they've been involved in many aspects of how they get onto the programme. They've selected themselves for that sort of treatment. They've been given information that they've been asked to read, that they've been asked to comment on, so presumably they feel empowered and we've given them a lot of information, and they sign a consent form to say that they agree to come onto the programme. It's actually a two-way thing, more of a contract actually I think, it's a treatment contract that they sign. You know, they agree not to do X, Y, and Z and we agree to have them on the programme. We get them to respect... they have duties on the programme, keeping things tidy, not interrupting, respect for other members of the team, respect for other participants on the programme as well, and we do treat them as adults, and often they haven't been... hospitals tend to not treat people as adults, generally, less so now than before, but it's a very adult model of learning that we use. (Dr J Salisbury).*

Analysing this response from Dr J highlighted a discrepancy between the participants' descriptions of care and Dr J's expectations. The following memo was made during the analysis:

**Memo 58:** I find it hard to understand how the participants felt empowered and in control of their care, when the teams expectations appear to conflict with any person-centred principles. For example, how is autonomy promoted when the teams seemed to push for compliance? Using terms like, they agree, sounds coercive. Moreover, Dr J appears to be saying that they have complete control over who gets on the programme, and if the patients don't do as they have been asked, then they could be removed. The contract he talks about doesn't really appear to be 'a two-way process', and the descriptions of being empowered through 'giving lots of information' is not what I understand empowerment to be about. Was there opportunity to ask questions, seek alternative methods of treatment or were participants allowed to disagree?

The comments made by Dr J conflicted with the relationship described by the participants and therefore presented a challenge to the process of co-validation. The *in-*

*vivo* codes initially appeared to suggest that compliance with care was facilitated by the teams, and participants were expected to sign a contract. It was unclear however, how the agreement had been reached or whether the outcomes were what the participants expected and wanted. Equally, it was less clear if participants were allowed to disagree with the expected treatment. Explicating this further with other interviews revealed similar perceptions, and suggested that teams retained some control, which appeared to be influenced by additional conditions. For example, the analysis of the Bracknell team interview revealed how the teams expected participants to comply as part of the conditions within the relationship. Although the team described the relationship as a two way process, the way in which this is subtly directed was also discussed:

*Chris: It can't be unconditional, virtually everything we do is because we are very clear it's a two-way process*

*Helen: Yes*

*Dr G: We'll do our bit, you'll do your bit*

*Helen: we are only going to move you forwards...*

*Dr G: If you participate*

*Helen If you participate, and so really it is conditional because we need you to tone up, we need you to do the homework, we need you to do what we ask, and we know if you don't do that, then we are not going to be able to move you forwards, so it isn't unconditional*

**Memo 61.** The comment made by Dr G 'we'll do our bit, but you'll do your bit' seemed to imply a coercive approach. Taken in context with the other team members approach to care being 'unconditional' seemed to suggest that participants are directed through care, but essentially don't appear to have a choice. This is surprising given the participants descriptions of the team. From the participant's perspective, choice was facilitated through the informal relationship and the toolbox. The participants did not talk about an 'agreement'.

These early findings conflicted with the participant's descriptions of care and in particular the category of '*regaining control*' and '*becoming a person*'. The conflict was significant because autonomy and being a person are acknowledged by McCormack (2003), Kitwood (1997) and Nolan (1997) as being key concepts associated with personhood. The teams' descriptions seemed to highlight the control applied by the team to empower the participants. The controlling nature of the team introduced a third condition that appeared to direct care and reduce autonomy. To explicate the third condition, key concepts from Stewart & Joines' (1987) approach to transactional analysis were used to explore the properties and dimensions. The next part of this chapter

discusses transactional analysis, how it was applied and the impact on the analytic process.

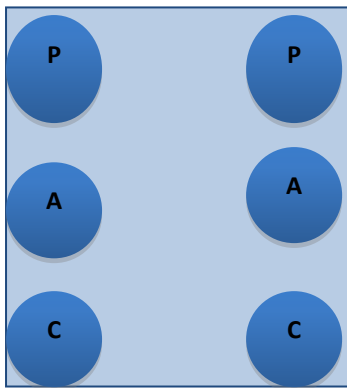
## **7.2 Understanding the 'Third Condition'.**

Generating meaning about the third condition meant returning to the data to explore the properties and dimensions of the *in-vivo* codes used by the teams to describe their relationship with the participants. According to Stewart & Joines (1987) transactional analysis (TA) is a theory of communication that can be applied within most contexts where there is a need to understand and generate meaning about individuals and relationships. The core principles of transactional analysis are similar to Charmaz's (2006) constructivist's ideals that advocate deeper reflection and analysis of the construction of another's world through developing sensitivity and meaning. Originating from Freudian theory, TA and has been adapted and interpreted in many different ways, and presented an ideal conceptual framework to use to analyse properties and dimensions of the *in-vivo* codes used by the teams to describe the relationship. TA also helps explore team processes, and in particular, the common patterns and dynamics within a team. The original version of TA was based on Berne's (1957) work, which introduced three 'ego states' as different ways of 'being in the world'. The general rubric of TA suggests that an individual's actions and responses to another are based on a life script, which is a pre-determined play of life usually developed before the age of seven. From this, ego-states emerge which form a structural analysis of the way in which individuals use their 'life script'. The ego-states refer to the Parent, Adult & Child and are described by Berne (1957) as a "*consistent pattern of feeling and experience directly related to a corresponding pattern of behaviour*" (p15) which could therefore be used to generate meaning about the third condition that had emerged from the team interview data. The key principles of the three Ego states were later used to explicate the properties and dimensions of *in-vivo* codes, which enhanced sensitivity about the third condition.

### 7.2.1. Explicating the Third Condition through the Team's Ego States.

Berne's (1957) three ego states are thought to be inhabited by the individual indiscriminately and frequently through their lifetime. The Parent Ego state refers to the actions an individual makes that have been inherited from their parents. The Child ego state relates to how a person uses their previous reactions as a child and resorts to this behaviour in 'here and now' situations. First order structural diagrams are often used in transactional analysis to help visualize the ego-states (see figure 9).

**Figure 9 First Order Structural Diagram**

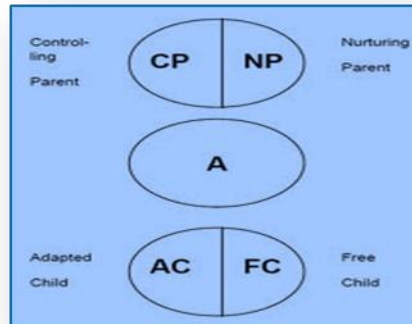


P= Parent, A = Adult, C = Child

The ego-states are further divided into the controlling and nurturing Parent, and the adapted Child and free Child. The free Child is sometimes referred to as the emotional Child whereby laughter, crying, kissing and anger are freely demonstrated. The adapted Child learns to adapt their emotional state to the given situation i.e. children should be seen and not heard. In particular, the adapted Child ego state refers to the way in which a person responds to another in Child mode to fit in with an accepted or spoken expectation or rule. The Parent ego-state is divided into the controlling Parent and the nurturing Parent and whilst both are influenced by the individual's own parent styles, they reflect the way in which parents managed behaviour. The controlling Parent provided instructions such as 'don't do this, look both ways before crossing the road, and the nurturing Parent is illustrated through the physical attention given to a child such as cuddles or reading a bedtime story, both can be positive or negative. A second



order structural diagram is normally used to sub-divide the three ego-states into a functional analysis to explore processes rather than its structure, please see figure 10 next.



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**Figure 10 Second Order Structural Diagram**

Finally, the Adult ego state suggests that the person reacts in an adult way, that is, the individual weighs up their position carefully and appraises a situation. Although analysing these ego-states can be complex, they were useful in developing understanding about the third condition and in particular, they helped determine whether the third condition was a result of a paternalistic 'controlling Parent ego state of the team, or whether they were predicated on a nurturing Parent ego state. To support the analysis, second order structural diagrams were used to identify what ego states were common in the team that signified the third condition. It is acknowledged by Stewart & Joines (1987) that ego-states are often revealed through a person's words rather than actions and although direct observation of transactions were not possible, a secondary analysis of the transcripts using the second order structural diagrams to explore the third condition was helpful in determining the relationship. Re-immersion in the data as advised by Corbin & Strauss (2008) helped refine sensitivity and exploring the nuances of the relationships using TA enabled texts between the participants and teams to be compared. In particular, the interviews were analysed to ascertain the extent to which the team were influenced by the controlling Parent ego state and/or the nurturing Parent ego state. This process was similar to open coding used at the start of the analytic process but was more sensitive because TA was being applied

specifically to explicate the third condition. Using the ego-states as a basic premise guided the analysis and revealed two further categories that related to the team dynamics. This helped to construct a picture of the teams and later uncovered how the teams '*controlling Parent Ego-state*' influenced the third condition. The first category of the nurturing team is discussed next.

### **7.3. Category 9: The Nurturing Team.**

The nurturing team emerged when TA was used to critically question how the teams enabled the participants to '*regain control*'. In particular, being empowered to take control of the pain helped the participants to regain a sense of autonomy, and appeared to be a person-centred way of caring. Using TA revealed how teams appeared to use "fundamental units of social action" referred to by Stewart & Joines (1989) as 'strokes' to enhance the participant's psychological well-being and facilitate empowerment. Strokes usually rely on some form of verbal or non-verbal recognition between two people and can be conditional or unconditional; for example, Stewart & Joines (1987) state that conditional strokes relate to what the individual does, whereas unconditional strokes refer to what the individual is; both of which can be positive and negative. Positive unconditional strokes are thought to strengthen human agency, hence it could be argued that this type of stroke would be used to support person-centred care because of an individual's need for respect, trust and involvement. For example, the participants felt like they had been cared for by the team through the way in which the team had listened, validated and empowered them to regain control. The team facilitated this through using positive strokes, such as first name terms, for example Elaine highlighted how it was nice to know who people were:

*"you knew who they all were and what their jobs were but I think that after a little while it was all first names terms..." (Elaine)*

Equally, the participants frequently described how the team helped them to relax by informal comments or other methods used to promote familiarity. Doreen's description of her relationship with Dr V illustrates how his knowledge of Doreen's 'fancy nails'

could be analysed as a positive stroke that made Doreen feel comfortable and able to take part in decision-making:

*“I always have a joke with Dr V. at one time I used to have my nails done fancy and one time I was going away and he said ‘let’s have a look at your nails’ (laughs) cause I always had designs put on them – yes I always have a laugh with Dr V and Dr S. I think that they are really, really nice men and they don’t come across as a doctor and a bit austere....”(Doreen).*

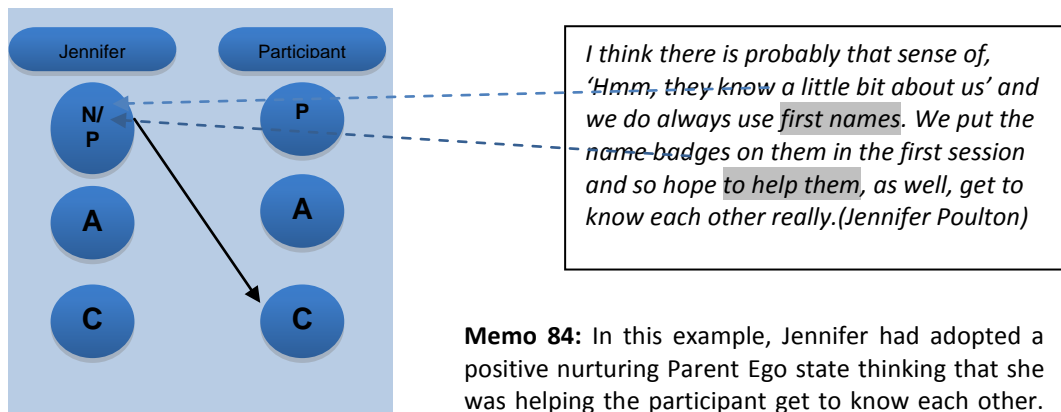
Applying TA and explicating the positive strokes highlighted a number of examples in the participant interview data. Often, positive strokes appeared to have helped create an informal and relaxed environment, which Phyllis described:

*“the first thing that they show you is where the tea and coffee is – which is always a good one and you know welcome to make a brew at any time and then they explained that there will be so many breaks and pillows, cushions and blankets were handed out to everybody – cause everyone was in various shapes – and there were comfy chairs so that part of it was very relaxed and they had aromatherapy oils and a fibre optic lamp and music playing gently in the background so as you went in the atmosphere was very relaxing and very calming” (Phyllis)*

The participants described how the teams carefully prepared the physical environment, which then appeared to have a positive effect on the participants’ psychological well-being. This enabled the participants to relax within a calming environment that later facilitated opportunities to get to know other participants and equally, the team members. For example Elaine’s description of being a person rather than a patient illustrated this effect:

*“yes, definitely you did not – I mean that old saying of the NHS – you certainly did not feel like a number – definitely not - that was in fact you almost – at much as they blurred into not being PT and all the rest of it – you blurred out into not being a patient as well (Elaine)*

The findings suggested that personalising conversation in this way supported the development of a trusting relationship and facilitated an environment that was conducive and which enabled the participants and teams to become familiar with each other. Jennifer’s description highlighted how the teams purposively use first name terms to encourage familiarity:



**FIGURE 11**

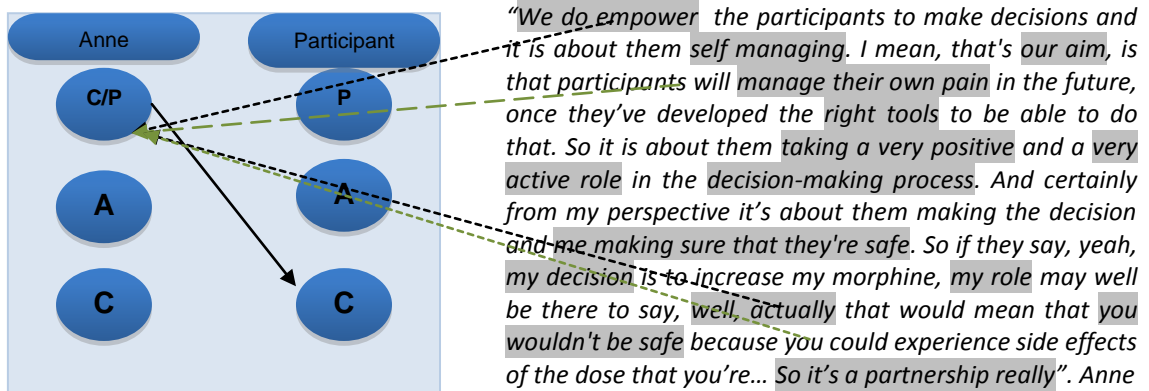
**Memo 84:** In this example, Jennifer had adopted a positive nurturing Parent Ego state thinking that she was helping the participant get to know each other. Rather than allowing participants to act as Adults and use their own initiative to initiate relationships, it was implied through the Parent Ego that this was required.

-----▶ = Promoting safety, protecting the individual  
 - - - - -▶ = Controlling

Micro-analysing the *in-vivo* codes used by Jennifer highlighted how a positive nurturing Parent Ego was adopted through the tones, words and gestures Jennifer used to promote familiarity, figure 11 illustrates this. According to Stewart & Joines (1989) the positive nurturing Parent ego state is normally provided from a position of genuine regard for the other person. Similarly, the team’s descriptions of how they cared also reflected their regard for the participants, which corresponded with the participants’ experiences as discussed in Chapter 5 and explained why the participants felt part of a family. Using transactional analysis to explicate the properties and dimensions re-enforced how the teams appeared to be influenced by a positive Nurturing Parent ego state, but did not provide any explanation of the third condition. Hence, the transactional analysis approaches used to construct meaning about the controlling Parent ego state to understand the third condition are discussed next.

#### 7.4 Category 10: The Controlling Team.

The controlling team category emerged through exploring the properties and dimensions from the team interview data. In particular, TA supported the analysis of the positive nurturing Parent role adopted by the teams, which helped generate understanding about how teams provided participants with choice, but greater understanding about the third condition was needed. Using a second order structural diagram helped visualise the way in which the team's actions appeared to be influenced by a positive controlling Parent Egos state. For example, Stewart & Joines (1989) purport that the positive controlling Parent Ego state are those, which are genuinely aimed at protecting another. This was frequently reflected in the team's descriptions of care. For example, Anne, the consultant nurse, described how she empowered participants through a 'partnership' approach. (figure 12):

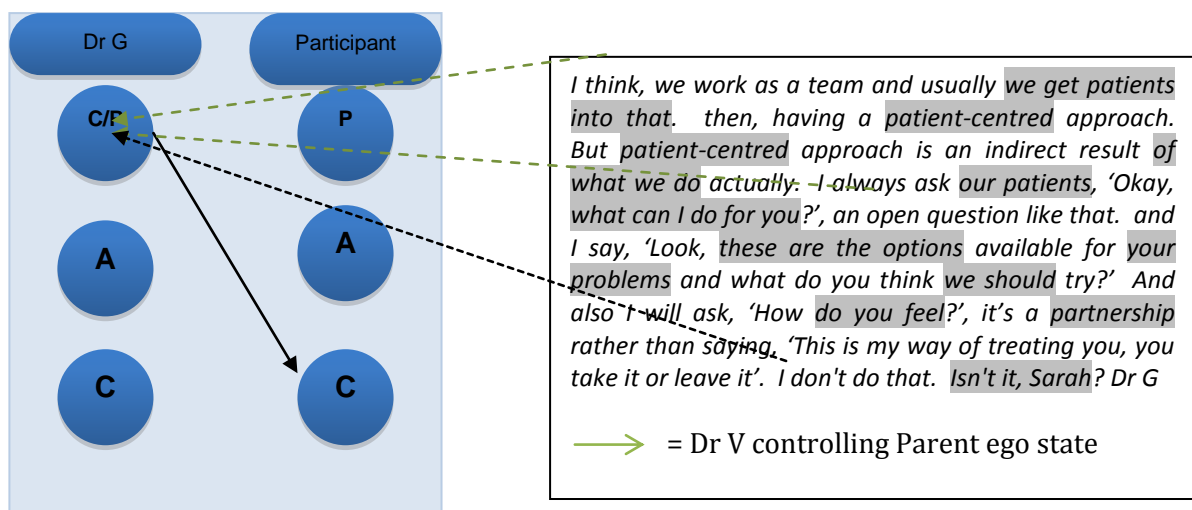


**FIGURE 12**

**Memo 90:** Anne appeared to have adopted a positive controlling Parent Ego state thinking that she was helping the participant to make their own decision about the increase in morphine, but ultimately applying some control to 'protect' the individual. Anne believes that the participants have entered into a partnership, which is confusing because Anne seems to have control over the care outcomes. For example, Anne appears to have imposed parameters on the decisions that the participant was able to make. Anne feels her role is to keep the participant 'safe'. Ultimately, this decision could have been also influenced by the professional obligation of non-maleficence – which suggests that the third condition was predicated by the positive controlling Parent Ego state.

These finding suggests that although Anne believed that she was promoting 'partnership' working, the influence of the positive controlling Parent Ego state could have directed Anne's decision to control the participant's management of the morphine

dosage. Anne's concept of the participant *taking a very positive and a very active role in the decision-making process* appeared to be constrained by her professional responsibility to safeguard the participant. Anne used the term '*partnership*' to describe the relationship she had with the participants. The partnership described by Anne appeared to be unequal and conflicted with the principle of autonomy. Other examples of the controlling team emerged as sensitivity developed. The interview with Dr V and Sarah at Faversham provided an illustration of the positive controlling Parent Ego-state when they described how they empowered the participants by providing information and asking the participant which options they preferred. Dr V also described a '*partnership*' approach in which he offers patients with a choice about a prescribed treatment: Figure 13 illustrates how the second order structural diagram helped visualise the positive controlling Parent Ego state.



**Figure 13 Dr V's Positive Controlling Parent Ego state.**

Offering options controlled by the professionals appeared to be a common method used by the teams to help the participants. Helen (physiotherapist at Poulton) described how the team 'protected' the participant from their 'unrealistic' expectations of the service and uses the concept of evidence-based practice to defend this philosophy:

*Helen ... if the patient could design this service it wouldn't look anything like we provide, and so there is a partnership in a sense, but actually because of the evidence base we know what's going to work, and actually if it was up to the participant, we would have the instant fix.*

**Memo 93:**

This denotes that Helen thinks that the participant will have unrealistic expectations. This may be due to the negative experiences the participant may have encountered or the chronicity and therefore desperation of the participant to 'get better'. Essentially, this perception that Helen has taken relates to a parent action and indicates that the nurturing but constrictive parent role has dominated and may have influenced the way in which participants are involved in their care decisions.

Yet, the teams described a '*partnership*' in which the participants had a choice about the treatment they received. However, the extent to which the partnership reflected an equal relationship was confusing because the choice was often tempered by professional obligation of non-maleficence. Often the team members believed that this was an empowering approach, equally, the participants described how they felt empowered through methods such as the '*toolbox*' previously discussed in Chapter 5. The '*toolbox*' provided by the team gave the participants confidence, control and enabled them to self-manage their chronic pain. Elaine was one of the many participants who liked the toolbox and described how it had helped her:

*"I think that we likened it to that they were giving you tools – as you went along – you were given a toolbox and all these things that went into it were tools that I could take away at the end of the course that I could out as and when I needed them and every time I might have tried one tool and it did the job but this time I might have to try another one and so all your medication, everything your relaxation and other things – normal things like I'll just go and have a nice bath and relax – you know everything that you can think of was put into this imaginary toolbox if you like"(Elaine)*

Revisiting the data revealed a number of examples where positive controlling Parent Ego-state had steered the relationship and ostensibly empowered the participants. Team members were confident that the relationship was a '*partnership*', which had empowered participants to regain control of their pain through prescribed regimen of 'safe' care. Equally, the provision of options was viewed by the participants as an empowering approach which they believed helped them regain control of their pain. The teams were seen as professional which also helped to restore faith in health care and as such, they were able to work with the participants through providing options with conditions. The findings in Chapter 5 suggested that the participants also had faith in the methods the teams had taught them to manage the pain. Ultimately, the teams appeared to be influenced by a positive controlling Parent Ego state, which supported

care predicated on the third condition. Using TA had helped explicate the third condition and visualising the relationship using the structural diagrams generated insight into how the third condition of non-maleficence was potentially influenced by the team's ego state. This influence was also consistent with the participant's descriptions of care and the findings from chapter 5. Jay's interpretation of her experience was typical of other participants' perceptions when she explained how the team had put her in charge of her destiny:

*"I felt as though I have got my life back again."..... I feel like the captain of the ship again and I am at the steering wheel and I can go whatever port I want to" (Jay).*

Yet whilst Jay was in command of the ship, undertaking a transactional analysis of the team interviews revealed that the team's positive controlling Parent Ego state retained the 'map'. This emergent paradox in the 'partnership' also presented a challenge to the concept of person-centred care because it conflicted with the principle of autonomy. However, earlier findings suggested that promoting participants autonomy was problematic because the influence exerted by professional obligations to safeguard the individual. Hence the teams' behaviour appeared to be predicated on paternalistic practices that were compounded by the positive controlling Parent Ego-state. Correspondingly, the participants followed the team's instructions by accepting the toolbox offered by 'the Parent'. This also means that the teams needed to be seen as professional to validate the participants pain hence, being seen as professional was frequently commented on by the team members and influenced the Parent Ego state. Being seen as a professional was explored in greater detail and is discussed next.

### **7.5 Category 11: Being Seen as 'Professional'.**

Being seen as professional was significant because it appeared to influence the partnership between the participants and team. It could be argued that the controlling Parent Ego state was predicated by the professionalism and professional accountability of team members. This category emerged from the team interviews but was also highlighted through additional analysis of the participant's interviews, in which the teams were described as professional because, from their observations, the teams



appeared to *'know their stuff'*. This seemed to be important for the participants and influenced their faith in the teams. The participants described the team's abilities to care for them and often based this on the team's knowledge, understanding and competence to help manage their pain. The findings from the participants' interviews suggested that being 'professional' indicated a team's authority, wisdom and credibility and also influenced collective efficacy and the development of the co-validated relationship. Exploring this category with the teams revealed how being seen as professional was also significant for the teams and explicating team processes in the back stage revealed how the teams established authority through intellectualising their knowledge base, and becoming expert in pain management.

Believing in the team was influenced by team collective efficacy based on the participants' observations of the teams' interactions and behaviours with each other. The findings from the team interviews revealed how confidence and a 'single routine' was developed in the back region and instilled participants with confidence. This resonated with Goffman's (1959) concept of 'decorum' which ostensibly meant that the teams gave off an image of professionalism which when coupled with 'professional legitimacy', helped to restore faith in healthcare. The resultant 'desired professional image' that the participants observed and described was developed by the team through inter-personal relationships that echoed Robert's (2005 p 688) identity theory analysis of professional image referred to as "personal characteristics and social identity affiliations". The teams were able to use the relationship to foster a partnership approach that enabled the participants to participate in their care and ultimately empowered them to regain control of their pain.

The relationship with the team had also been described as *'friendly'* and many participants enjoyed the relaxed and welcoming relationship they developed with the team. However, whilst the participants valued the opportunity to use first name terms with the teams, some team members, notably the medics, were reluctant to discontinue using their professional title of 'doctor' when liaising with participants and other team members. This was mainly related to the need of the medic to retain a professional

'image' and the need to sustain professional credibility, which also re-enforced the positive controlling Parent Ego state. Dr J at Salisbury explained the significance of the use of his professional title suggesting that the patients expect to call the doctor by the professional title rather than use first names. The following extract highlights Dr J's rationale for his preferred use of his professional title:

*.....usually on the programmes they [other members of the team] tend to call me Dr J, so I would refer to the psychologist and physiotherapist as Joan or Janette, or whatever, but rather than referring to me as Ted, they would refer to me as Dr J.....I've noticed that they will refer to me as Dr J and I suppose I am the senior clinician here, and they only refer to me as Ted, individually, you know directly, but in front of the patients they would say and what might Dr J think about this, so there's a sort of respect amongst us. (Dr J Salisbury).*

Interestingly, the same attitude was not reflected in the team's descriptions of their social and professional activity in the back region, where medics and other team members often used first name terms. A large percentage of the backstage work of a team is believed to be informal; hence, this activity often remains hidden from the audience (patients) because of its potential to undermine the performance, perceived professionalism and patient confidence in the team. Equally, Fordyce (1981 p51) proposed that:

*"In a multidisciplinary exercise, two or more professions may make their respective contributions, but each contribution stands on its own and could emerge without the input of the other. In an interdisciplinary effort life is not so simple. The end product requires that there be an interactive and symbiotic interplay of the contributions from different disciplines. Without that interaction, the outcome will fall short of the need . . . The essence of the matter is that each of the participating professions needs the others to accomplish what, collectively, they have agreed are their objectives".*

The use of the professional title of doctor in the front region appeared to be an accepted practice amongst the team. Anne (consultant nurse Salisbury) explained that the professional title of doctor was used in the front region because patients needed their pain to be 'professionally validated' through diagnosis, which is traditionally believed to be the role of the doctor:

*I think that's often one of the important things about patients seeing a doctor at the front door because it's a validation. If they've not seen a doctor or a consultant that validates their problem when they come along to the clinic, then I think that that can sometimes be quite difficult, (Anne CN Salisbury)*

More overt expressions of the positive controlling Parent Ego-state were described by Dr J at Salisbury when he talked about the role of the 'expert' and the need for 'massaging egos' in front of participants' to instil confidence in the team and participants:

*"it's very complicated, and to some extent we've had some... we get a lot of mileage about slapping each other on the back a little bit. And increasing other members of the team's... by respecting other members of the team, their profile is improved, I think, and so we do do that. You know I'd say I'll refer you to my colleague, so-and-so; they are really expert at this, so we do massage either's egos via the patients a little bit, because that seems to work. It's a model that does work for the patients".*

Being seen as professional, and importantly, being professional, meant that the team retained control of the care 'options' through re-asserting professional credibility and control. Ultimately, for some participants, being amongst 'professionals' made them 'feel safe', and the professional 'appearance' was also related to the professional 'title', and their perceived competence, and could also explain why the teams were perceived to be effective. The professionalism referred to by Phyllis below highlights how being 'too relaxed' could be detrimental to care:

*"My own personal point of view I like professional appearance cause I feel safe with that erm... so I don't like things being too relaxed I like a bit of professionalism erm..... (Phyllis)*

This also related to the continued use of the professional title and listening to the participant's earlier descriptions of the team highlighted the expectations of the doctor. For example, participants expected medics to have specialist knowledge, relevant competence and skills to diagnose and prescribe treatment for their pain. The title of 'doctor' was commented on by Lyndsay, who described how she became embarrassed using first names with Jennifer, the clinical psychologist, after she discovered that Jennifer was a doctor. Lyndsay suggested that being a doctor was more than just 'an ordinary' member of the team and the following extract illustrates this:

*"It took me weeks to find out that Jennifer was a doctor and then I used to call her Jennifer then I realised that she was a doctor and then I thought Oh, she's a doctor for God's sake give her respect. I just saw her as an ordinary member of the team until I found out she's a doctor – so I called her doctor after that". (Lyndsay)*

This was interesting for several reasons: firstly, previous findings from Chapter 5 highlighted that the participants valued the friendly and informal relationship with the

teams, hence, the reason why participants held such reverence for doctors was unclear. Secondly, enhancing sensitivity using the literature, helped understand this within the context of chronic back pain. For example, Glenton's (2003) qualitative work exploring the experience of chronic back pain and healthcare suggested that doctors are expected to legitimise their pain and suffering through diagnosis, which resonated with the consultant nurse, Anne's previous comments. Finally, the role of the doctor has historically been viewed as patriarchal which has influenced the relationship between patients and doctors (Freedman 2002); thus, referring to a doctor by their first name rather than their professional title could undermine the perception of the doctors credibility and power. This was referred to by Goffman (1959) as 'professional distancing', which can be used to create "a state of mystification" (p74); thus it is surmised that the professional title facilitated the mystification. It is acknowledged that professional distancing in this context can help avoid conflict with another's perceived beliefs (Laing 1965), which could have re-enforced the third condition as a result of the controlling Parent Ego state. Hence, using a doctor's Christian name could have generated conflict, and dented professional credibility.

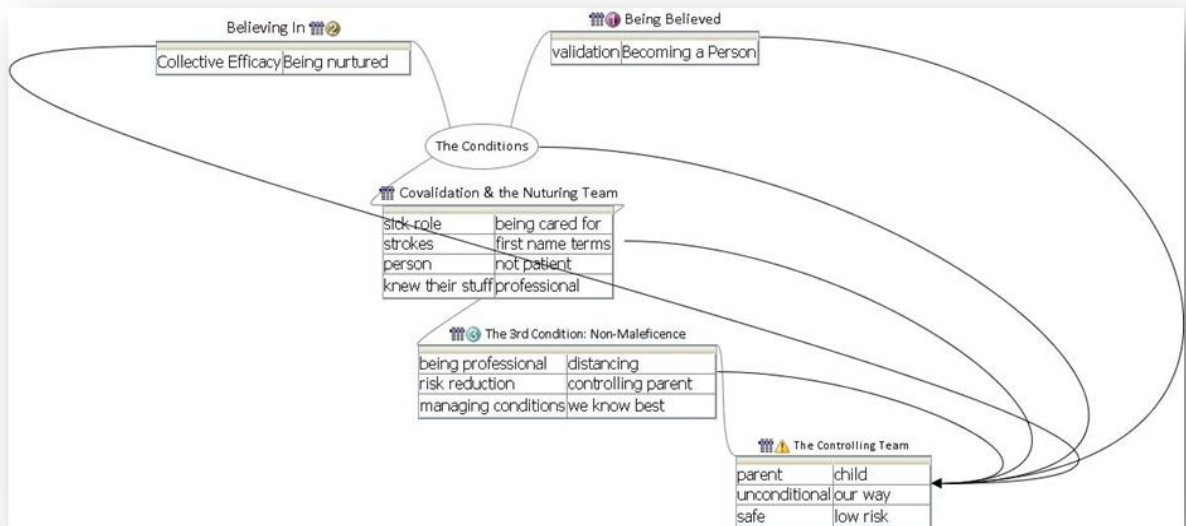
Conversely, others such as the physiotherapist, nurse and clinical psychologists used their first names to put the '*patient at ease*', which had little impact on their perceived view of the team's credibility. This appeared to be influenced by the team's expert knowledge and understanding rather than perceived professional credibility through the use of a professional title. This suggested that whilst the teams managed to develop a rapport, they were also able to maintain a professional and credible image through their expert knowledge of and belief in the participant's pain. Equally, it could be argued that this was also influenced by the controlling Parent Ego state.

Being seen as professional was important and revealed the influence that professional credibility had on the relationship. Transactional analysis of the codes was useful in highlighting the influence of the positive controlling Parent Ego state, but the extent to which this was promoted by the professional obligation of non-maleficence was unclear. The ontological clash between the team's controlling Parent Ego state and person-

centred care became apparent through the teams' descriptions of their relationship with the participants. The implied conditions appeared to suggest that treatment options were influenced by a positive controlling Parent Ego state, which meant that the teams protected the participant through guiding choice. However, this presented a challenge to the concept of autonomy and in-vivo codes used by the team such as '*we let them*', '*conditional*', '*things we do*', '*participant's unrealistic expectations*' and '*make them feel equal*' helped identify and explicate the third condition. However, the teams' descriptions also proposed that they had cared through *partnership* working, yet, the conditions presented a challenge to this, hence the partnership began to resemble a '*conditional partnership*' that appeared to constitute an accepted practice supported by the co-validation process. Significantly, the extent to which the professional obligation to do no harm influenced person-centred care was unclear and was therefore explored in greater detail within the paradox to generate meaning.

#### **7.6. The Emergence of the Partnership Paradox**

The concept of the partnership was exposed through listening to the teams' description of their perceived relationship with the participants. The term partnership was common between all the teams and was therefore significant; however the conflict between the person-centred principle of autonomy and the teams' professional obligation of non-maleficence presented a paradox. The protectionist nature of the teams meant that participants believed that they were in control of decisions, but the methods used by teams guided the participants into predetermined choices influenced by non-maleficence. The relationship appeared to be predicated on three conditions, *being believed*, *believing in* and *non-maleficence*. The findings highlighted the extent to which the three conditions of being believed, believing in and non-maleficence presented a relationship paradox, which challenged the concept of person-centred care see figure 14.



**Figure 14: The Relationship Paradox.**

Collectively, the concepts that emerged through analysis of the team and participant interviews provided an interesting but polarised account of the relationship. Despite this divergence, a common or core category began to emerge that underpinned the existing concepts and categories. The move towards 'final integration' (Corbin & Strauss 2008) was influenced by a desire to understand this paradox and how it related to person-centred care. This partnership paradox influenced the final integration of the concepts into a core category to provide a substantive theory about the relationship. Explicating this led to the final stage of analysis and the development of a theory that explained how teams provided person-centred care and what this experience was like for the participant. The findings suggested that the teams believed that they empowered participants to regain control of their pain through 'self-help' tools from which the participant was given a selection. However, in offering choice, the team included participants in the decision-making, but also maintained some control over the options provided. The level of control was subtle, and one could argue, necessary due the need to protect the participant from harm and represented a protectionist rather than paternalistic approach. Despite the non-maleficent approach to care, the teams described their approach to care as person-centred and a partnership. This dichotomy

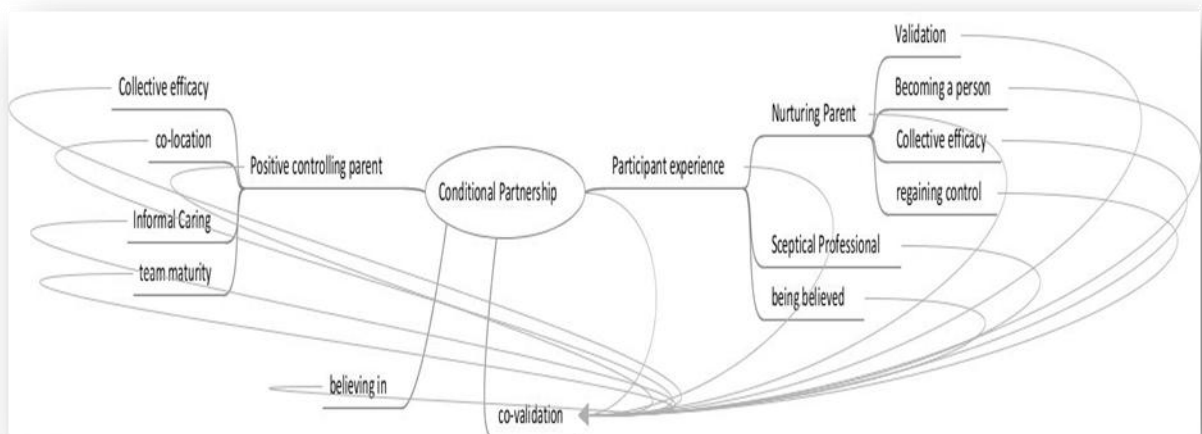
was instrumental in explicating the core, which ultimately helped to develop the conditional partnership as a theory to explain person-centred care for people with chronic back pain. The final part of the chapter discusses the core category in greater detail.

### **7.7. The Core Category: The 'Conditional Partnership'.**

It is acknowledged that the core category should help establish a substantive theory about person-centred care. However, Corbin & Strauss (2008) advised that the core concept should also embrace and saturate all other categories in order to be classified as the core. To accomplish this, means not only exploring previous categories for their relationships to the core, but re-visiting raw data to enhance sensitivity and identify any analytic gaps. The final part of the analysis therefore involved developing the conditional partnership as a core category that could support a substantive theory about person-centred care. Charmaz (1990 p1164) remarked that *"a theory explicates a phenomena, specifies concepts which categorize the relevant phenomena, explains relationships between concepts and provides a framework for making predictions"*. The research report (or thesis) represents the assembly of social constructions developed through theoretical sensitivity, and working with the data (Charmaz 1990); constructivists therefore, attempt to integrate concepts and categories in order that they can develop meaning and a greater understanding of the phenomena. Equally, constructing the conditional partnership arose out of an analytic process that relied upon developing sensitivity through theoretical memos, existing literature and revisiting data, hence, the core was constructed through listening to and re-constructing the participants experience, the team process and the subsequent relationship. Using a Grounded Theory approach within a constructivist paradigm enabled meaning about person-centred care from the perspectives of those who had managed and experienced it to be generated. To explicate theory further, Corbin & Strauss (2008) advises that the researcher re-visit the data to ensure that all the categories are fully saturated so that theoretical integration is not impeded. Hence, repeated immersion in the data during the writing of the thesis helped to ensure that the categories were fully collapsed and

supported the conditional partnership as a core category that linked all the other concepts.

Collectively, 11 categories reflected the participants' and teams' experiences of care and highlighted the conditions within a caring and person-centred relationship. The findings from Chapters 5 and 6 revealed how two conditions of being believed and believing in had formed a co-validated relationship that underpinned the conditional partnership that restored faith in the professionals and the participant's self-esteem. The emerging paradox however, challenged this and highlighted how the non-maleficent actions of the teams became an inherent part of the conditional partnership. The 11 categories were later subsumed by the core which emerged as the conditional partnership that linked all the other categories, Moreover, Strauss & Corbin (1990 p18) advise that *"in final integration, a Grounded Theory should tightly relate categories to one another and subcategories in terms of the basic paradigm features-conditions, context, actions/interactions (including strategies) and consequences. Categories should also be theoretically dense, having many properties richly dimensionalised. It is tight linkages, in terms of paradigm features and density of categories that give a theory explanatory power.* The conditional partnership that emerged was predicated on three conditions that were ultimately influenced by a co-validated relationship. Figure 15 illustrated how the categories formed the core.



**Figure 15: The Relationships between the Categories and the Core.**



The way in which the core emerged was messy and involved re-visiting data, re-writing the thesis and being critical about the analytic process; however, it is acknowledged that this process creates ideas about the data to enable deeper insight into the phenomena (Charmaz 1990). Hence, the core category presented the central phenomenon of the study and was developed through diagramming techniques and constant comparative analysis. The core category is further discussed using the three conditions of being believed, believing in and non-maleficence as points of reference.

#### **7.7.1. Condition 1: Being Believed.**

The conditional partnership represented both a process and an outcome of person-centred care, which closely followed the participant's journey through the health care system. The participants described similar experiences of health care in a system that ultimately influenced future relationship with the teams. The first interview with Elaine revealed the concept of the '*sceptical professional*' and presented an early insight into the impact that being disbelieved had on the sense of self and control of pain. It is acknowledged that a lack of symptom control may leave some feeling as though they reside in a stranger's body (Svelisch *et al* 2005). Hence, including people in decision-making can help regain control (Cartmell & Coles 2000) through empowering approaches that ensure the person's voice is heard. This concurred with Anderson (1996 pg 699) who stated "*empowerment is the outcome of more egalitarian structures that permit disenfranchised voices to be listened to*". Being believed and listening to the participant's pain was therefore significant and led to the category of validation which highlighted the participants regained self-esteem through the team's validation of their pain.

#### **7.7.2. Condition 2; Believing In**

The first condition 'being believed' was significant, however, as the relationship was a two-way reciprocated process of trust. The findings also highlighted the need for faith in the team, which was explored using Goffman as a framework to understand the team processes. Sensitivity about the team's effectiveness and processes used was enhanced

through using Bandura’s (1989) concept of collective efficacy to generate meaning about the team and how this had later influenced partnership working. Believing in the team, meant that the participants had confidence in the teams’ ability which helped to restore their faith in health care. Using Goffman to explicate the teams’ processes in the back stage revealed how team maturity and co-location influenced the development of collective efficacy. Hence, being believed and believing in emerged as two conditions of the relationship that influenced co-validation. Figure 16 illustrates the relationship between caring, empowerment and restoring belief in the team through co-validation.



**Figure 16: The Process of Co-validation.**

Explicating meaning about the co-validated relationship revealed how this had supported partnership working which helped the participants to regain control of their pain. Conditions in partnerships are rarely reported, but it is accepted that partnerships are associated with terms such as co-operation, trust, participation and collaboration; however, the concept of partnerships with participants in particular is immature (Hook 2006). Partnerships are created from many variables and have been defined as being “*an abstract that is expressed in some form with a cluster of critical attributes that are both necessary and sufficient to delineate the domain and boundaries of the concept*” (Rodgers 2000). Similarly, Gallant *et al*’s (2002) concept analysis of partnership identified three key attributes of partnerships, which included empowerment, power sharing and negotiation. Interestingly, the main consequence of partnerships was described by Gallant *et al* (2002) as ‘*the improved ability of the client to act on his/her own behalf*’ (p.

154), which was consistent with the participant's descriptions of the 'life changing' events and the toolbox. The findings from Chapter 5 indicated how the conditional partnership empowered the participants and their descriptions concurred with the key characteristics of partnership working such as shared decision-making, communication and participation (Hook 2006). However, other key principles associated with partnership working such as autonomy and shared power conflicted with later findings, which exposed the control that the teams had within the partnership. The findings suggest that the partnership conditions were predicated on pre-determined risk avoidance parameters set by the teams and led to the third condition of non-maleficence. The key attributes of partnerships are often context bound and therefore unique. Generalisations about partnerships are problematic because of the variable context in which they are formed. Hence, the first two conditions of the partnership are unique within the context of chronic back pain. The third condition, of non-maleficence, may however be commonplace in other healthcare relationships and is explored next.

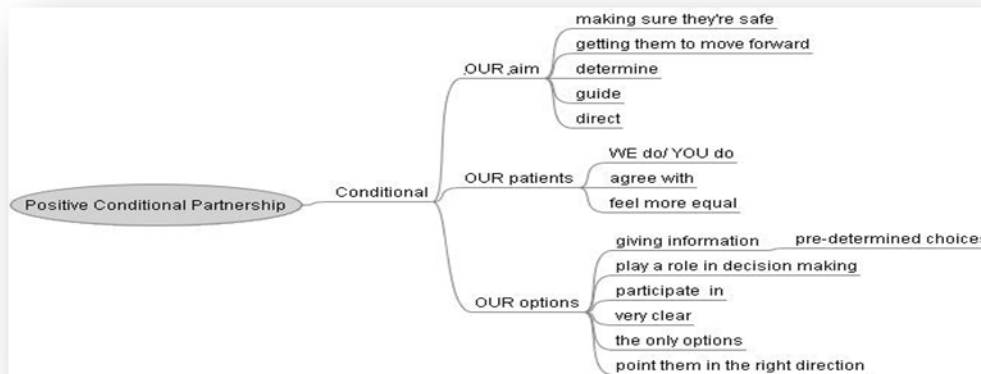
### **7.7.3. Condition 3: Non-maleficence.**

Elaborating the analysis through developing theoretical sensitivity revealed the paternalistic approaches to care and highlighted the paradox in the conditional partnership. Hence, participants felt empowered and used terms such as '*involved*', '*empowered*', '*feel more equal*' that related to partnership. However, analysis of the team interviews uncovered codes such as '*conditional*', '*provided*', '*given options*', which illustrated the teams expectations and conditions. Table 19 on the next page presents some of the open and *in-vivo* codes that were indicative of the developing paradox.

<b>Codes that illustrated 'partnership'</b>	<b>Micro-analysis of codes (revealed Parent Ego)</b>	<b>Outcome –Team (positive controlling Parent Ego)</b>
Unconditional	Conditional	Restrictions set
Involved	Informed	Part of...
Choice/options	Provided	Work within limits
Treated as adult	Asked to do ....	Given instructions
Empowered	Given options	Parameters set
First name terms	Name badge applied	Disempowered
Feel more equal	Doing my job	Not made more equal
Help them	Taking over	Disempower
Our	Us	Us & them

**Table 19: The Partnership Paradox.**

It is recognised that partnering with participants is not without its difficulties and it has been questioned as to whether it is possible to participate in healthcare without being in a partnership (Cheek 2003). Crucially, the teams regained faith through diluting the effects of the sceptical professional; ironically, the teams used terms such as *our aims*, because they had a clear idea of what *they* wanted the participants to do. In doing so, the teams referred to the participants as '*our patients*' because of their positive controlling Parent Ego-state, which, resulted in care being directed by '*our options*'. From the outset of care, the team guided participants choice based on what they believed *was best*. Believing that 'one knows best' leads to the imposition of individual values on another. Despite being predicated on ethical principles of beneficence, morally, this does not assume optimum care (Edwards, 1996). Figure 17 illustrates the key components of the third condition.



**Figure 17: Mind Map: The Properties and Dimensions of the Third Condition.**

Being believed, provided participants with an opportunity to participate in care which created a mutual relationship in which participants were empowered without being an equal partner. This philosophy reflects Naidoo & Willis' earlier work (1994) which argued that partnerships can be varied and have different levels of involvement and empowerment doesn't always feature (Naidoo & Willis 1994); equally, it is also acknowledged that some don't want to be full partners (Gallant *et al* 2002). Paradoxically, the professional is perceived as the one with the power within a relationship because they retain control through the paternalistic approaches engendered to ensure safe and ethical practice. Similarly, the findings from the team interviews were emblematic of how professionals provided choice predicated on an approach that reduced harm but retained control in which participants were seen but not treated as experts. Whilst it is recognised that the professional status was needed to ensure credibility and authenticity, it may also be argued that caring in this way fosters dependency and participants are disempowered through 'professional distancing' as previously highlighted by Goffman. Hence, caring for participants seemed to be reliant upon a non-negotiated power base in which the professional was knowledgeable and thus limited the equipoise of the relationship. Despite the third condition, the participants believed that they had been empowered; ultimately, the team helped restore their independence through a co-validated relationship that restored the(ir) person.

## 7.8. Chapter Summary.

The findings suggested that the teams worked towards rehabilitating the participants through restoring their self-esteem and sense of self. These findings therefore have implications for the way in which person-centred care is conceived by teams and experienced by participants. The conditional partnership provided an explanation of the relationship and generated meaning about the experience of person-centred care for people with chronic back pain. The paradox emerged from the third condition predicated on non-maleficence and presented challenges to assumptions about person-centred care. Autonomy is synonymous with both person-centred care and partnership working; yet, participant autonomy appeared to be compromised by the team's professional obligation to do no harm. From the outset of care, the team were clear about what the participant could expect based on what they believed *was best*. The analytic process highlighted key categories that were later developed into a core category through literature and sensitivity however; the emerging partnership paradox challenged the concept of person-centred care. The next chapter discusses the conditional partnership as a theory using Michael Bury's (1982) sociological concept of the disrupted biography to explain the significance of co-validation and the role of the conditions within the partnership.

## **Chapter 8: Discussion: Condition 1: '*Being Believed*', the Sociological Construction of Illness and Impact on the Person.**

The conditional partnership was developed as a substantive theory to explain the experience of person-centred care. The partnership conditions were influenced through co-validation which became the foundation of a relationship that facilitated participant involvement in decision-making. Regardless of the predetermined choices offered by the teams, *being believed* and *believing in* meant that participants were able to regain control of their pain. This was described as an empowering experience predicated on a conditional partnership that helped recover the(ir) person. This chapter discusses the findings and explains why co-validation was a significant influence in the partnership process and person-centred care. The significance of the third condition on person-centred care is discussed in Chapter 9.

### **8.1. The Disrupted Biography**

Consistent with symbolic interactionism, the meaning of chronic illness is derived from previous experience, discourse and social interactions (Charmaz 2006), which suggests that the way in which the individual defines the self is through others and personal experience. Hence it is acknowledged that the self is a mirrored projection and has been influenced by societal values and associated norms. This is comparable with Clarke & James (2003) assumption that the self is a sociologically derived concept often constructed through 'reflexive interaction'. Consequently, suffering can present 'existential problems of identity and continuity of self' (Charmaz 1990). Understanding sociological influences on a person's management and acceptance of pain illustrates why people with chronic pain feel impelled to have pain legitimised either through *being believed*, or through a diagnosis. Equally, Pellegrino (1976) remarked that the humanity of the ill precedes the self...hence, *believing in* the person from the outset of care, showing compassion and recognition of the 'illness' by the team was a crucial condition in the partnership that helped the participants restore self-esteem. Moreover, Charmaz (1999) later suggested that the self-concept is derived from diverse attributes, made up from an individual's sentiments and values. Chronic illness is thought to undermine

these attributes and can lead to self-doubt, hence, Charmaz (1999) suggests that suffering is a moral status which attracts moral rights and entitlements, but, interestingly, only occurs when suffering is perceived as legitimate.

It is understood that establishing the moral self is directed by portraying oneself as a person who fulfils his or her social and economic obligations. This concept was discussed by Ong *et al* (2004), who proposed that establishing a moral self enables the individual to operate with high moral standards. However, for people with unseen or invisible chronic pain, the ability to fulfil social obligations becomes problematic and can lead to stigmatisation (Ware 1992). The inability to fulfil social and economic obligations can present challenges to the moral self, and historically, people with unseen chronic back pain have had difficulty being accepted as 'sick' (Sveilich *et al* 2005). Hence, establishing oneself as moral appears to be fundamental because once the experience of pain is confirmed, the person is seen as needy and able to make moral claims. But as the findings from Chapter 5 suggested, many participants were unable to make moral claims because their suffering was not seen as legitimate by others. The lack of diagnosis and understanding exhibited by the sceptical professional meant that the participants felt compelled to legitimise their condition. This behaviour is not uncommon; and as Tishelman and Sachs (1998) report, the acceptance of chronic pain is often linked to the diagnosis. Crucially, there is a social expectation that doctors use their power and knowledge to legitimise the pain and provide some understanding for the way the person may be feeling (Clarke 2003). This is consistent with the findings from Chapter 5 and suggests that participants may have sought to legitimise their pain through a diagnosis to reclaim the moral self.

According to Hadler (1996), the reported challenges of being disbelieved faced by people with unseen chronic conditions have traditionally been blamed on the lack of a 'biological marker'. It is acknowledged that the lack of biological marker can cast doubt over a person's moral characteristics and may exacerbate a condition by eroding the integrity of the person (Asbring 2000, Bury 1982, Dickson *et al* 2007). The origins of the biological marker have been traced by Hadler (1996) to the medical paradigm, which,



predicated on a reductionist approach, has operationalised 'conditions', using algorithms to make diagnoses and to prescribe treatments. Moreover, Hadler remarked that this may have resulted in the person being overwhelmed by "*a sense of vulnerability that leads inexorably to a diagnostic contest*". The 'diagnostic contest' described by Hadler relates to the concept of the sceptical professional which indicates why so many become vulnerable through believing that their 'problem' is psychosomatic.

Hence, the social construction of illness is believed to be a significant influence on an individual's ability to react to and manage chronic illness. Sociological research related to the concept of unseen pain and societal expectations are reported in the literature for example, Wares (1992) work explored the social construction of illness from the perspective of people who had chronic fatigue syndrome and similar to Hadler (1996), found that society constructs illness as an 'observable' entity. Ware (1992) argued that the categorisation of illness as something which is observable, meant that 'being sick' involved presenting a distinguishable feature that defines illness through 'physically observable symptoms' such as looking unwell, pale or tired. Ware concluded that an absence of observable signs and symptoms could result in an individual's moral claim to 'being ill' being refuted and suggested that the lack of observable evidence and 'clinical signs' led some to question the existence of a person's chronic illness. Within the context of person-centred care, biological markers relate to sociological markers of the existence of ill health that reside within a person's biography. That is to say, the person will recognise when they are ill because they expect to have a temperature, or a broken limb or some other physical impairment. There are a number of studies that report the impact this has on an individual, for example Hadler's (1996) discursive paper provides an illustration of what it's like to be ill and be disbelieved and espoused that:

*"Viewing the world of the well as composed of those who cope blithely, those who deny; and hypochondriacs does little justice to the human predicament. Such a categorisation ignores two other groups who are well but are forced to fight against odds to feel well. One group is composed of people who manage life despite a pervasive sense of vulnerability; the other is composed of people whose sense of invincibility is buffeted by disputation"* (pg 2397)

Hadler (1996) later remarked that

*“the absence of impairment, society is not prepared to believe them. Rather, society is willing to go to great lengths and great expense to challenge their perception”.*

This perspective was consistent with the participants' descriptions of care, and it could be argued that the sceptical professional buffeted the participant's anxiety through 'disputing' their pain. Hence, it is acknowledged that the invisibility of pain can result in disconfirmation, which leads to stigma that individuals then spend time trying to conceal (Ware 1992). A lack of acceptance and/or diagnosis means that many people with chronic back pain are opened to scrutiny about their disease. This was typified in Clarke and Iphofen (2005) phenomenological study of the experience of living with chronic pain, which revealed that for many, being disbelieved was a common concern which resulted in individuals being labelled. This corresponds with studies that have reported how autonomy and individualism have been compromised through vulnerable and complex processes such as aging (Nolan et al 2004, McCormack 2004), disability or painful chronic conditions (Teh et al 2009).

The sociological influence of chronic illness are significant, in particular, one of the first sociologists to explore this concept was Michael Bury, who in 1982, published his seminal account of chronic disease trajectory within a sociological perspective. Bury used qualitative methodology to explicate how chronic 'unseen' illness affects people with rheumatoid arthritis and reported the societal rejection of people with unseen pain and the impact this had on the person's ability to cope. Bury introduced the term '*biographical disruption*' to describe how a person's biography was altered through chronic illness and believed that chronic illness was influenced by sociological structures and knowledge of life, which become disturbed in the context of chronic pain. The 'biographical disruption' therefore follows an unfolding chain of events that are influenced by three distinct processes, which mirror the trajectory of the chronic illness journey. Firstly, Bury suggests that a person will often recognise their physical health problems early on, and appraise any changes to their body. Secondly, once acknowledged, bodily changes are assessed by the individual to determine the impact on their life. Finally, the individual addresses the biographical disruption through exploring

their biography and distinguishing their 'self'. Bury concludes that accepting the biographical changes enables the individual to respond to the disruption by mobilising resources to address the challenges faced. The resources could be varied and may involve seeking medical interventions, support services and other therapies. Bury asserts that it is at this point that most individuals are able to develop ways of managing the chronicity of the illness. The way in which chronic illness is therefore recognised, accepted and managed is fundamental to the ability of the person to repair their disrupted biography.

Crucially, as Bury suggests, the person needs to question the change in their biography in order that they may later explore and find their self and mobilise resources accordingly. Repairing the biographical disruption is one of the first steps in the rehabilitation process because the individual is then able to recognise challenges and take decisive action. However, for those participants whose condition was refuted or as Klienman (1992) describes, 'delegitimised', the ability to repair the disruption becomes difficult. Delegitimation is defined as "*the experience of having ones definitions and perceptions of a condition disconfirmed*" (Klienman 1992) and is consistent with the participants' descriptions of the sceptical professional discussed in Chapter 5. Moreover, Klienman (1992) argued that absence of societal defined and observable symptoms leads to delegitimation, which can erode the individual's moral integrity. Hence, many 'unobserved' illnesses such as chronic pain, or fibromyalgia have been labelled as psychosomatic. It could be argued that the sceptical professional triggered an iatrogenic response in participants because of the impact it later had on their mental wellbeing and ability to function as their 'usual self'. This latter aspect was important because according to Bury's (1982) concept of the biographical disruption, understanding the disrupted biography can help to explain the impact of delegitimation on the person and ultimately its influence on person-centred care.

It could be surmised that delegitimation can lead to distress and uncertainty about the legitimacy and the subsequent questioning about the existence of a condition. This is comparable to the participants' descriptions of the '*system*', where biographical

disruption occurred prior to diagnosis, but their ability to respond was hindered through delegitimisation by the sceptical professional. Findings in Chapter 5 revealed the participants' anxiety and subsequent need for legitimacy, moreover, similar concerns were echoed by Bury who discovered the 'official recognition' through diagnosis and belief meant that his participants felt as though they were going to 'get things sorted out'. As Bury (1982) remarked,

*"access to medical knowledge, at least in the case of physical illness, offers an opportunity to conceptualise the disease as separate from the individual self" (pg 172). Bury later noted that "medical conceptions of chronic organic disease and its constitution are not regarded as legitimate 'reifications' from a lay point of view. They provide an objective fixed point on a terrain of uncertainty".*

The impact of this is significant and can affect an individual's ability to mobilise resources (Bury 1982). Thus, the terrain of uncertainty alluded to by Bury, also reflected Hess's work in 2003 in which she introduced terms, such as 'strange lands' to describe a place that people with chronic pain may find themselves in, more specifically, Hess asserted that:

*"Illness creates an alien world for its citizens. Maps of the person's previous homeland are useless for understanding and navigating the new worlds strange terrain and ones compass spins out of control....most devastating for the inhabitants of this strange land, perhaps, is the inability to continue to envision what is good for oneself and to determine how to achieve this end" (Hess 2003 p138).*

Both Hess (2003) and Bury's (1982, 1991) work illustrate the complexities of chronic illness and explain how people may find themselves within an unknown territory. The ability to escape from such alien worlds is influenced by the way in which the person is supported during the early stages of the chronic disease. This suggests that early legitimisation can help a person accept the chronic pain and facilitate restoration of the biographical disruption. Significantly, Bury's work highlighted the potential impact that delegitimisation could have on the individuals 'escape route' to their world and represented a cogent argument that explained why the first condition of '*being believed*' was significant. Delegitimisation of their pain caused by the sceptical professional had a profound impact on the participant's ability to mobilise resources. The impact of delegitimisation is explored in greater detail next.

## 8.2. The Impact of Delegitimisation on Recovery of the Person

Delegitimisation of the participants' pain evoked negative consequences for the participants, not least because it affected their ability to come to terms with and later manage their pain. The participants needed to *be believed*; hence the first condition in the partnership was significant. However the sceptical professional marred the integrity of the participants' sense of self, dented their faith in health care, disrupted their biography and undermined perceived self-confidence. It could be argued that the disruption caused through the sceptical professional affected the way in which the participants were therefore able to manage their pain. This is consistent with Asbrings (2000) work, which explored the experience of chronic pain from the perspectives of women with chronic fibromyalgia. Similar to Bury (1982), Asbring identified that the women's illness created a radical disruption of their biography, which later influenced their self-identity. Interestingly, Asbring (2000) used the term 'contested illnesses' to describe how people with chronic fibromyalgia were perceived by society. The delayed diagnosis described in Asbring's work was comparable with the impact of the sceptical professional from which parallels could be drawn between the 'contested illness' and the impact on the 'disrupted biography' as described by Bury. Moreover, Asbring (2000) acknowledged that the late timing of the diagnosis for people with fibromyalgia is significant because they were unable to adapt to the biographical disruption.

Similar findings were reported elsewhere, for example, in 2007, Dickson, Knussen, & Flowers explored the impact of delegitimisation on the person with chronic fatigue syndrome. The literature on the impact of delegitimisation is scarce, and Dickson's qualitative paper is one of only a few studies that described the experience from the individual's perspective. Dickson *et al* (2007) concluded that delegitimisation was seen as a 'rejection by others, and more significantly:

*"A personal attack on their sense of morality...consequently, the mutual trust, respect and communication associated with good relationships was eroded"* (pg856).

Dickson *et al* acknowledged that a diagnosis could provide credence to the person's pain and enable individuals with chronic fibromyalgia to recognise their 'genuine condition'

and stand up to delegitimisation in the wider community. The similarities between Dickson *et al's* (2007) findings and Asbring's (2000) contested illness is consistent with the descriptions of the sceptical professional presented in Chapter 5 and highlights that the experience of delegitimisation extended beyond the boundaries of chronic back pain and can cause distrust between the health professional and patient.

The reported impact of delegitimisation on an individual's integrity varies, but some studies have highlighted how delegitimisation has led to stigmatisation. One example by Borkan *et al* (1995) used a qualitative approach with interviews, focus group and participant observation to develop meaning about low back pain from the individual's perceptions. Borkan *et al* (1995) discovered that people with low back pain had been exposed or stigmatised through delegitimisation of their condition, which had a negative impact on their self-esteem and their subsequent ability to cope with their pain. Stigmatisation is a common concern reflected in the literature and illustrates the challenges faced by people with unseen chronic pain. More recently, studies have shown how people pursue meaning about their pain through seeking a diagnosis from professionals. Once 'approved' the chronic illness becomes credible and as Ong *et al's* work (2004) highlights, people who seek to legitimise pain during clinical encounters become the narrator of pain to establish themselves as credible witness to his or her own pain. It is acknowledged therefore that the unseen nature of the pain can influence a person to seek acceptance and in doing so, the need to legitimise pain becomes an integral part of a person's search for meaning (Bendelow & Williams 1995).

The literature suggests that being accepted enables a person to seek meaning about their pain, and as Bury (1982) proposed, engages the person with their disrupted biography. It is acknowledged that the ontological nature of delegitimisation influences the biography and can affect the person's image and their being and their world (Pellegrino 1976 p33). Accordingly, seeking acceptance then becomes crucial to people with chronic pain, hence Pellegrino's 1976 philosophical commentary on 'the assault of chronic illness' retains currency today because it acknowledges how being accepted through belief can influence humanity, harm the individual's physical, mental and

psychological welfare. Thus, when people with chronic pain become powerless they can also become dependent on caregivers with whom they entrust their 'self. Professional carers [healthcare staff] therefore have a hefty professional and moral responsibility to care for and empower the person to rescue the dependent self and reform them to an independent state. Conversely, the findings in Chapter 5 discussed the influence of the sceptical professional and identified an ontological crisis that damaged the participant's view of moral self and their views of health care.

### **8.2.1. Becoming Powerless.**

The disrupted biography of an individual can suspend autonomy and destabilise the person's self-identity. As a result, a person may be forced to seek the help from professionals and enter into unknown territory where those who have the knowledge to support become powerful. Being disempowered by a 'system' as described in Chapter 5 resonated with Walker *et al's* (2006) phenomenological study, which explored the experiences of 20 people with pain. Five themes were identified one of which related to the description of healthcare as 'a system' in which participants felt powerless, insignificant and mistrusted by professionals. Moreover, Walker *et al* (2006) remarked on the irony of a system that was designed "to help those who are ill, injured and disabled" (p628)...all of which are observable and open to biological markers.

From a sociological perspective therefore, chronic pain disrupts a person's biography and aggravates the position of the self through exacerbating the demarcation between the body and self. This dualist notion is further compounded because the biographical disruption mirrors the interference of self, and the person is left wandering in a strange land, seeking meaning about their pain through legitimisation from others. As Bury (1991) surmised:

*"Individuals not only wish to gain a measure of control over their condition by finding explanations that make sense in terms of their life circumstances and biographies, but they also wish to establish a proper sense of perspective about the condition and re-establish credibility in the face of the assault on self-hood which is involved.*

Bury proposed that the potential impact of the biographical disruption on the self and personhood influences relationships with other professionals and can delay the person's

ability to *mobilise resources*. Yet, people with chronic back pain are often disadvantaged because of the disrupted biography and limited control of their pain. This can leave many feeling as though their body belongs to a stranger (Sveilich 2005), which limits their ability to mobilise resources, and impacts on the capacity to participate in a partnership. This has implications for person-centred care because a deferred diagnosis, or doubt in the existence of pain can erode self-identity, which can impede an individual's ability to mobilise resources. Similarly, Ford & McCormack (2000) discussion paper argued that concept of the person's biography is embedded within the context of initial assessment because the person is determined by the past, present and future, as such, the ability to care for the individual is predicated on the inclusion of biography. The first condition of *being believed* is therefore crucial in partnership working, because it means that the person's pain is accepted and therefore credible. Importantly, once pain is legitimised, the person can make a moral claim for being ill and can begin to move towards acceptance of the disease. It could be concluded that conditional partnership helps to restore the faith in healthcare, the system and faith in the(ir) person. The two conditions are discussed in more detail next.

### **8.3. Condition 1: The Starting Point: Repairing the Biography & Mobilising Resources.**

The participants' experience of '*the system*' initially damaged the relationship, but the teams' early actions to validate the pain ensured that the participants were enabled to mobilise resources needed to repair their biography. Being believed helped to restore faith in healthcare and presented an opportunity for participants to escape the '*system*' and return to a familiar place. Participants described how they were *respected* for their insight into their own condition and were *treated as experts* in their care. From this position, participants were able to restore their disrupted biography through a relationship process predicated on trust that underpinned a partnership. Patient participation in care is not a new phenomenon and was originally championed by the World Health Organisation (WHO) in 1978 through the introduction of a social model for health in which citizens became active partners in their health care. It is believed that



advancing participants to a level of partnership implies that health providers have to give up an amount of power and recognize that their roles are evolving and changing (Kaufman 2008). This extends to the way in which participants are treated as experts in care, and as a person, not just a patient, who has knowledge of their disease, progression, prognosis and management.

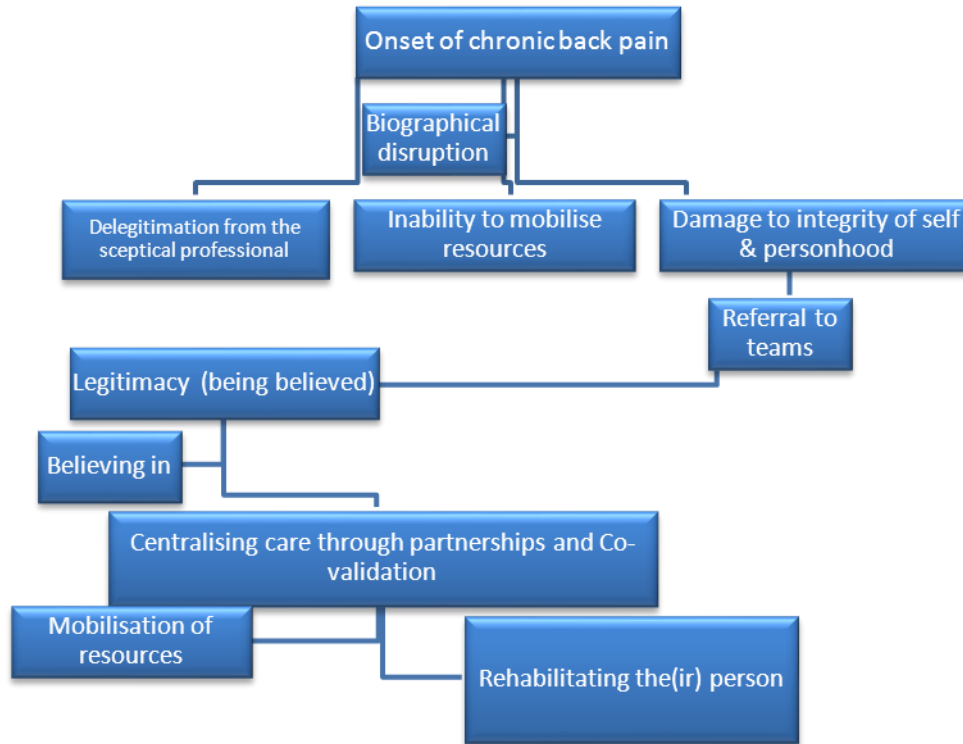
More generally, the shift from patient as 'consumer' to patient as 'expert' has evolved over the past decade and is still recognised as a central tenet of person-centred care (DH 1999, DH 2010, Wilson 2001), however, whether this reflects reality is unclear. Respect and willingness for professionals to relinquish power to embrace the individual in decision-making are essential for the expert patient, a pre-requisite of which is the need to believe in the patient. Hook (2003) also emphasised the need for partnerships to move from being an 'expert care provider' to partnering with the patient to improve their capabilities. This also reflected the paradigmatic shift in the role of 'experts' that occurred following the introduction of the Participants Charter in 1992 (Department of Health 1992) which introduced the 'expert patient' as an individual who *"feels confident and in control of their life, who would like to manage their chronic condition in partnership with health care professionals and who can use skills and knowledge to lead a full life"* (Expert Patient Programme (EPP) NHS Choices 2011).

Including participants in care through treating them as 'the expert' meant that the participants were able to undertake a more independent role in their healthcare and were able to mobilize resources to manage their pain, self-care and regain control. The 'toolbox' used by the team to support the participants to manage their pain was fundamental to this process and is acknowledged as a key method that can empower patients to make informed choice about their health to be able to self care. The toolbox presented a range of pain management strategies, which the participants could choose from and was important because it enabled the patients to be involved in care choices. The impact of similar education strategies has been reported elsewhere, for example, Ascher *et al's* (2007) exploration of the impact of educational strategies on decision-making by people with diabetes revealed that education strategies used in diabetes care

empowered individuals and their carers/relatives to self-manage their condition. In addition, Anderson & Funnell's (2010 p278) concept analysis of empowerment within the context of diabetes management concluded that "*empowerment is a process when the purpose of an educational intervention is to increase one's ability to think critically and act autonomously. Empowerment is an outcome when an enhanced sense of self-efficacy occurs as a result of the process.*" This correlates with the findings and illustrates how the toolbox enabled them to participate in decision-making through the provision of options. Similarly, it is also acknowledged that using an 'experts' advice through the provision of informed choice means that individuals can be empowered to self-care. The toolbox provided the participants with the knowledge to mobilise resources and regain control of their pain. This was described as a liberating experience, which suggested that the conditional partnership was successful in restoring autonomy.

Ultimately, the findings suggested that the teams partnered with the participants to restore the(ir) person through legitimisation, co-validation and a respect for the person. The conditional partnership engaged participants and teams in a narrative that transformed the professionals into partners, which importantly recognised the patient as expert (Holman & Lorig 2000). It is acknowledged therefore that working in partnership with patients can help the individual reassume power; ostensibly, the conditional partnership accepted the participants as an expert and is consistent with concepts associated with person-centred care such as respect, autonomy and empathy (McCormack 2003). *Being believed* was therefore, the starting point from which the participants regained a sense of self and were empowered to participate in their care, because they could mobilise their resources to restore the self. Figure 18 provides a visual representation of this process. As discussed in Chapter 5, many of the participants described being referred to the pain teams as the 'last chance saloon'. The participants had lost faith in healthcare and ironically, had become sceptical of the support offered by professionals. Hence, facilitating a trusting relationship formed an essential tenet of the conditional partnership and helped restore the disrupted biography. *Being believed* presented a starting point for the partnership that ultimately helped repair the biography. However, pain is an intensely personal experience (Sherwood *et al* 2000

p486), which makes it difficult to respond to and consequently care for. *Believing in* the participant’s pain was instrumental in the recovery process because *being believed* meant being validated as a person with pain.



**Figure 18: How The Conditional Partnership Evolved.**

Importantly, Bury (1982) suggests that the term ‘legitimation’, now refers to the process of attempting to repair disruption and establish an acceptable and legitimate place for the condition within the person’s life (Bury 1982). This correlated with the findings from chapter 5, which suggest that the participants began to understand their pain and were able to assess and re-think their biography. *Being believed and believing in* through co-validation enabled a partnership to evolve. The significance of *believing in* the team is discussed next.

#### 8.4 Condition 2: Believing In: the Significance of Co-validation

In a chronic pain context, discordance between team and patient expectations may interfere with the development of an effective collaborative relationship, which could exacerbate stigmatisation (Frantsve *et al* 2007). The importance of fostering a shared experience through the understanding of an individual's pain laid the foundations for future patient engagement. Being in a partnership provided a voice for participants who may have previously been disempowered by enabling them to initiate care. Partnering with the participants was significant and appeared to underpin the process of person-centred care, however, the ways in which partnerships evolve differ, and conflicting and ambiguous assumptions about the nature of partnership working have been reported. It is acknowledged that successful partnerships are based on trust, respect and honesty (Hardy *et al* 2000). *Believing in* is therefore significant and can influence the extent to which partnerships are egalitarian.

Through partnership working, the team were able to legitimatise the individual's pain, which laid the foundation for engagement through co-validation, listening and empathy. This helped the participants to work with their disrupted biography, mobilise resources and regain a sense of control over their lives. It could be surmised that the conditional partnership was person-centred because it empowered the participants to recover the(ir) person. This exposed a symbiotic link between empowerment and person-centred care, which was also highlighted in Holmstrom *et al's* (2010) concept analysis of the relationship between empowerment and person-centred care. Holmstrom *et al's* work proposed that a link between empowerment and 'patient-centeredness' are complimentary, but pointed out that whilst patient-centeredness can empower people, equally, people are able to empower themselves. The philosophical tradition associated with empowerment and person-centred care is diverse, yet it is clear that the processes are interlinked through partnership working. Ostensibly, partnership working is a critical component of person-centred care; empowerment therefore, is often context bound and subtly directed by the 'partners' involved. Importantly, for the participants, *believing in* the team was essential; hence co-validation became a pre-cursor of the partnership.

However, trust can be difficult to attain and relies on the ability to recognise a partners' value and ensuring an equal contribution (Hardy *et al* 2000). The need for reciprocated belief was crucial in the development of the conditional partnership – equally, the ability to compromise influenced partnership growth. For example, Holmstrom *et al* (2010) described how power sharing between participants and professionals involved being able to 'strike a balance' in the partnership to be able to respond to the participants needs for information and their part in decision-making. Ultimately, the conditions within the partnership provided an opportunity for agreement to be reached. The conditional partnership empowered the participants to self-manage their pain by re-establishing their moral self through a partnership based on co-validation. It is acknowledged that both person-centred care and empowerment involve sharing responsibility through trusting and respectful partnerships (Holmstrom *et al* 2010). Hence, *believing in* the team and *being believed* by the team through co-validation were essential rudiments of the partnership.

Having faith in a partnership is fundamental to successful partnership working. This is particularly significant for health partnerships where there is a need for professionals to ensure credibility and professionalism. Having confidence in the professional is a key attribute that can influence the way in which the partnership evolves. Hooks (2006) concept analysis of partnerships suggest that the relationship, shared power, shared decision-making and patient autonomy are key attributes. Equally, professional competence and communication are essential and provide a platform from which the partnership can flourish. Hence it could be argued that team collective efficacy was an essential attribute needed for the success of the partnership. It is difficult to ascertain whether the partnership would have been sustained without co-validation and the literature that explicitly reports on faith and professional competence in partnerships is limited. Hook (2006) outlined the key attributes of professional competence within a partnership as being; 'expertness, professional, reciprocity, empowering, coordinates and individualizes care, able to change roles, knows how to support change, educates by clarifying options, instrument of care, able to abdicate power, able to narrow the information/knowledge gap. It is acknowledged that professional competence is central

to a trusting relationship in partnerships with patients (Leisen & Hyman 2004). Equally, professional competence within a partnership is related to provision of information, openness and confidence in the professional, and technical competence. Other variables that influence partnership working and in particular, the methods used to empower patients through the partnership are important. Hence, Hook (2006) advised that partnerships support patients in having a greater voice in their care and empower them in self-management. The findings in Chapters 5 and 6 highlighted the first two conditions in the conditional partnership and suggested how the co-validated relationship influenced partnership working and empowered participants to take control. *Believing in* and *being believed* through co-validation supported a person-centred conditional partnership that was instrumental in helping restore their biography; *being believed* indicated that the teams listened to the participant's. This was consistent with the concept of personhood included in the initial literature review (Chapter 2) such as McCormack's (2003) exploration of person-centred care in gerontology, Nolan *et al's* (2004) explication of the future of person-centred care, Kitwood's (1997) seminal work on the concept of person-centred care with people who have dementia and McCance's (1997,) exploration of the concept of caring. Hence, believing in the participant meant that their suffering was morally accepted and that their moral status became significant – they were accepted as having the right to complain. Their suffering mattered. The first two conditions explained the early partnership processes needed to empower the participants.

### **8.5. Chapter Summary**

The conditional partnership generated understanding about the processes associated with person-centred care and provided insight into key attributes of partnerships in health. *Being believed and believing in* were synonymous with many of the concepts associated with person-centred care, however the third condition presented a challenge because it conflicted with the underlying philosophy of personhood. However, it is also acknowledged that partnerships are not always equal, hence the third condition appeared to present a realistic perspective of person-centred care. The third condition is therefore discussed within a professional and ethical context in the next chapter.

## **Chapter 9 Deciphering the Paradox of the Conditional Partnership:**

The conditional partnership was influenced through a co-validated partnership, which supported person-centred care. This repaired the damage caused by delegitimisation and enabled participants to mobilise resources and regain control of their lives. The first two conditions were significant in the partnership and provided the teams with an opportunity to work with participants to restore the(ir) person. The conditional partnership appeared to present a person-centred approach to care that was complex however, the third condition of 'non-maleficence' presented a challenge to the equilibrium and a paradox emerged that threatened partnership equipoise. In seeking to substantiate the theory of the conditional partnership and to understand the implication of the paradox on person-centred care, the conditions have been discussed within professional and ethical contexts. This chapter discusses the relationship between the third condition and person-centred care.

### **9.1. The Significance of the Third Condition**

Traditionally, successful partnerships are thought to be influenced by equality, respect and trust (Hardy *et al* 2000). It is understood that an equal partnership usually involves joint decision-making, hence, shared power is a key factor attributed to successful partnerships (Hardy *et al* 2000). As discussed in Chapter 7, the explication of the paradox using transactional analysis identified that the teams may have been influenced by a positive controlling Parent-Ego state. Further analysis highlighted that the third condition was predicated on the professional obligation of non-maleficence, which conflicted with the principles of person-centred care. This raised concerns about the authenticity of the conditional partnership because participants were encouraged to comply with 'choices', which seemed to be based on the teams attempts to minimise risk.

The influence of professional non-maleficence on patient autonomy and partnership working is recognised as an on-going dilemma, which has been explored in a range of ways. Generally, the relationship between patients and care providers has been a consistent subject of exploration in an attempt to understand the conflict between

autonomy and non-maleficence. For example, Freedman's (2002) ethnographic study of the encounters between physicians and breast cancer participants highlighted how autonomy was compromised through the professional and moral obligation of the health professional to do no harm. In her study, Freedman (2002) argued that non-maleficence led to prescribed forms of treatment, which the patients complied with. This conflicted with person-centred care because it disempowered individuals through limiting autonomy. Correspondingly, there is evidence to suggest that empowerment is a consequence of compliance, for example, Hook's (2006) concept analysis of partnership identified that terms such as concordance, empowerment, decision-making and interestingly, servitude were used in the literature to describe the key attributes of partnerships.

The healthcare literature frequently reports compliance as a challenge to partnership working and it has been acknowledged that compliance is the antithesis of collaboration. Holm (1993) proposed that compliance results from an unequal power base where one person retains power and directs the other, which conflicts with the principles of collaboration. Hence it is generally acknowledged that being labeled as non-compliant presents a radically paternalistic perspective that defines the health care professional as the expert with autonomous power over the individual (Holm 1993). Paternalistic practices are thought to facilitate compliance and can negatively impact on the relationship between patients and health care professionals. Hence, paternalism has become a pejorative term that has been used to describe unequal power between health professionals and patients. The significance of compliance and empowerment are discussed within the context of person-centered care next.

#### ***9.1.1. Complying to be Empowered.***

There is a body of literature, which suggests that the relationship between person-centred care and empowerment are synonymous because both are thought to promote autonomy within an equal partnership (Gallant *et al* 2002, Holm 1993, Gibson 1991). Conversely, Powers (2003 p227) reported that the concept of empowerment has been "*co-opted by health professionals and redefined as an intervention to produce*



*compliance*". Power's analysis of empowerment suggested that patients are only considered to be empowered once they reduce their 'grip on autonomy' and pay reverence to the professional 'know how'. However, as Playle & Keeley (1998 p306) argued "*the very notion of compliance implicitly requires a dependent lay person and a dominant professional one giving 'expert' advice, suggestions of orders and the other carrying them out*". This concurred with the findings from Chapter 7 which indicated that the participants may have remained passive recipients of care because of the way in which the positive controlling Parent Ego state was manifest in the non-maleficent position of the teams. This reinforced the professional's role [power] as experts [knowledge] and rather than empowering the participants, the teams encouraged them to comply with their professional advice and later justified through using the auspices of '*we know best*'.

The participants seemed content to comply because the team was perceived to have collective efficacy, which suggested that the team were knowledgeable, confident and capable of helping the participants regain control of their pain. This is not a new phenomenon; historically, the role of the health professional in partnerships has been influenced by the patients need for therapy and guidance. The reliance on professionals to guide choice and decisions is well documented in the literature as far back as 1957, when patients were using health care professionals as a form of therapy or 'drug' (Balint 1957). As highlighted in Chapter 2, Edith Balint pioneered an alternative approach to the 'consultation' based on an understanding of the patient rather than their medical diagnosis. Interestingly, critics of Balint's work and indeed the patient-centred movement amongst physicians have argued that empowerment of patients involved more than the provision of information – and should take proper consideration of the patient autonomy. In particular contexts where relationships are intense, such as chronic pain management, the professional is relied upon *as a* treatment and to *provide* treatment. Patients are involved in care, but invariably, professionals retain control of decisions because of their experience, skills, competence and professional obligation to do no harm.

Similar conclusions were drawn by Hibbard (2003) whose paper on involvement of the 'consumer' found that some patients were not willing to engage in shared decision-making because they felt intimidated by the complexity of choice and were anxious about making the right choice. Hence for many, decision-making is surrendered to the professional involved because it is assumed that they '*they know best*'. In reality, complete patient autonomy has been questioned because patients prefer to follow the advice of the professional. It is however suggested that the professional obligation to beneficence has been confused by the current allegiance to autonomy and stigma of paternalism (Woodward 1997). This concern was also highlighted by Elwyn *et al* (2000), who argued that informed choice without professional guidance though the transfer of decisional responsibility from the professional to the patient contravenes beneficence. It is acknowledged that actions which place obligation of beneficence above those to respect autonomy are paternalistic (Edwards 1996); however, empowering individuals does not permit abdication of responsibility, but is instead dependent on the intentionality of the professional which is predicated on humanist skills and the ability '*to care*'. For some, therefore, to care is to empower, but for others, such as Malin & Teasdale (1991), this also presents challenges.

In their critique of caring and empowerment, Malin & Teasdale (1991) described the tension between the concept of caring and empowerment and through discussing the micro level of caring, challenged whether caring was empowering. Malin & Teasdale (1991) proposed that at the micro level, health professionals' care for patients when they protect them from harm, hence the power base is unequal and akin to a parent child relationship which concurred with the findings in Chapter 7. Malin & Teasdale (1991) expounded concerns about the relationship and highlighted the controlling Parent state and subsequent 'control' professionals have over care. Malin & Teasdale (1991) argued that "*altruism appears to entail paternalism*" and in doing so, sways the partnership balance. Conversely, findings in Chapter 5 suggested that regaining control of pain was an outcome as a result of being empowered. Hence, the participants achieved independence, which suggests that empowerment was a goal/outcome rather than a process. This has implications when considering the context of person-centred

care and empowerment and there is a body of literature that has discussed whether empowerment is a process or an outcome. These tensions are discussed in context with the conditional partnership.

## **9.2. Challenging the Paradox of the Conditional Partnership**

The third condition highlighted a paradox within the concept of empowerment. For example, the participants described how they were empowered to regain control of their pain, which suggested that empowerment was significant as an outcome rather than a process. Conversely, the third condition also illustrated that empowerment could have been a process used to promote compliance. This ambiguity was previously noted by Bury (1991) who asserted that the term compliance was incongruent with people who have chronic conditions and is of limited use in this context. Bury justified this position and argued that neither the doctor or patient will ever have total knowledge about a condition, however, the concept of compliance suggests that the objective is clear and can be achieved if the patient follows the doctors regimen. Bury later suggested an alternative perspective of compliance as a 'pooling of expertise to facilitate shared goals' through informed choice. Self-determination through choice and education is acknowledged as an empowering approach that facilitates autonomy through educative means. However, the impact of educative methods on self-care as a person-centred approach has been questioned, for example, Feste & Anderson's (1995) review of the philosophical and theoretical foundations of empowerment in chronic disease revealed that the traditional compliance approach to health care involves some form of educative method that enables or persuades the patients to carry out (or comply with) the regimen prescribed by the health professional. In examining the differences between the compliance and empowerment approaches, Feste & Anderson (1995) argued individuals themselves generally attained empowerment, but that healthcare professionals facilitate the process. They later suggested that empowering people through health education increases choice and the freedom of the individual to make an informed choice, hence enhancing an individual's autonomy and right to choose (Feste & Anderson 1995).

However, Robinson (1988) argued that informed choice forms part of a negotiation process through which the health professional is likely to be in a stronger and more powerful persuasive position because of their expertise. Alternatively, Bury believed that negotiation is predicated on the appropriateness of therapies and interventions, which help enhance the adaptation to the disrupted biography. It is difficult to know for certain, therefore, whether patients are actually empowered, or whether they are coerced into accepting a strategy already pregnant with 'conditions'. The concept of the treatment 'strategy' is thought to conflict with person-centred caring and was illustrated by Bury who argued that the term 'strategy' suggests a need for "*a dynamic view of choice and constraint, as people attempt to weigh up the alternative forms of action*" (Bury 1992 p462).

Not surprisingly, historical and contemporary debate is littered with concerns and confusion about the rhetoric of empowerment and it is widely understood that empowerment can influence compliance. Equally, it has been reported that compliance is an ideology based on professional beliefs concerning the 'proper' roles of the patients and professionals, predicated on the principles of beneficence that promote paternalism as opposed to autonomy (Playle & Keeley 1998). The divergence in the literature presents unresolved tensions between the philosophies of empowerment and in particular the educational methods that have been used to 'empower' or 'coerce' patients into self-management. Hence, the ability of the professional to act on behalf of the patient and empowerment has been perceived as dichotomous rather than synchronous concepts. Moreover, Falk (1995) argued that empowerment becomes vulnerable to abuse because of its estrangement with its philosophical roots; which when isolated, becomes a strategy for coercion and control (Falk 1995). This presents conflicting perspectives: firstly, it could be surmised that the teams facilitated choice and autonomy, however, it could be argued that the positive controlling Parent Ego state influenced care predicated on a paternalistic rather than an empowering approach. Hence, as Falk (1995) suggested, paternalistic practices influence choice and estranges the philosophical roots of empowerment from practice. The relationship between

professional power and empowerment has influenced historical and contemporary debate in the literature and is discussed next.

### **9.2.1. Empowerment and Power.**

The issue of empowerment and power has been previously explored within the context of healthcare relationships using a range of theories and models. For example, Hess (1996) examined nurse-patient relations using Gadow's concept of relational ethics to understand power within the relationship. Hess (1996) concluded that compliance was an outcome predicated on paternalism, coercion and acquiescence to professional knowledge. The perspective that the professional 'knows best' presents a radically dogmatic and paternalistic view, which exacerbates the legitimacy of compliance and provides professionals with a rationale for retaining power (Holm 1993). Thus, as Christensen and Hewitt-Taylor (2006) reported in their analysis of empowerment versus maternalism, empowerment becomes a challenge when those who hold power are unwilling to relinquish the power in favour of the 'expert' or person with the disease. Hence, it has been established that professionals often direct patient choice predicated on non-maleficence and professional credibility.

Alternatively, it is also recognised that empowering patients enables them to access and discuss a range of information with professionals in an unbiased milieu (Christensen *et al* 2006). It is also acknowledged however, that this relies on a process of imparting power through choice, authority and permission (Rodwell 1996). Hence, the enigma of empowerment in health care has influenced contemporary debate and led some, such as Powers (2003) to argue that empowerment is a consequence of compliance and threatens autonomy. In this context, the concept of compliance assumes that patients 'accept' care and thus 'comply' with professional judgement. Compliance therefore presents a serious threat to person-centred care and is consistent with the concept of the third condition that emerged from interviews with the pain teams. The emergent paradox highlighted the control of the team and the way in which '*their options*' were used to direct the participants' decision choices which mirrored Power's (2003) theory that empowerment is predicated on patient compliance. Similar concerns have been

reported in the literature, for example, Holmström and Röing (2010) undertook a concept analysis to explore the relationship between 'patient centeredness' and patient empowerment. Their findings revealed that person-centred care originated in health care; but, the concept of empowerment was developed through societal opposition to inequality and oppression. The dichotomous origins of empowerment and person-centred care have since influenced paradigmatic challenges to person-centred care predicated on issues of power, control and manipulation.

Historically, this dichotomy has presented a dilemma for health care and has informed a plethora of literature that has explored the concept of empowerment compliance in healthcare. For example, Powers (2003) provided a logical argument for the dichotomy based on Foucault's (1982) principles of power to analyse power relationships between the patient and the professional. Powers (2003) proposed that the concept of power designates relationships between partners, or an ensemble of actions, which induce others to follow from one another. Expounding this, Powers (2003) used Foucault's paradigms and argued that empowerment is a strategy used to coerce people into believing that they have some semblance of control. Crucially, Powers suggested that those who empower others actually retain the power. Although this was consistent with Holm (1999) and Christensen and Hewitt-Taylor's (2006) views of the professional and patient relationship, Powers further contextualised the relationship using Foucault's principles through suggesting that power is not fixed, but is exercised in different ways and driven by context. This proposed that empowerment relates to a goal or outcome rather than the individual's ability to become powerful. Within the context of person-centred care, it may be considered that empowerment represents a goal or desired aim related to a personal challenge. For people with chronic back pain, being empowered means being believed and regaining control become goals, which they work towards. This is consistent with Aujoulat *et al's* (2007) systematised review which defined empowerment as a process or behaviour change that enables an individual to regain control of their bodies and treatment management.

### **9.2.2. Empowerment through Partnership.**

It is difficult to consider autonomy and subsequent empowerment as absolute because of its conflict with beneficence and professional responsibility (McFarland *et al* 2009). However, the findings from Chapter 5 revealed that participants felt empowered as a result of their relationship with the teams. Although teams appeared to use a positive controlling Parent Ego state they also engaged with the participants through co-validation, respect, empathy and understanding. This concurred with Gallant *et al's* (2002 p153) concept analysis of partnership which suggested that partnerships are “*interpersonal relationships between two or more people who work together toward a mutually defined purpose*” (Gallant *et al* 2002 p153). Typically, these styles of partnerships offer the promise of empowerment through which the patient gains ‘participatory competence’ (Kieffer 1984). Moreover, the inter-personal co-validated relationship described in Chapters 5 and 6 revealed an approach to care that was predicated on ‘person knowledge’. This is particularly significant in the context of person-centred care because, as previously noted, chronic pain influences a person’s humanity through interfering with the individual’s biography and moral identity. Using person knowledge as described by Liaschenko & Fisher (1999) therefore enabled the teams to care for the participants through the co-validated relationship they had developed. *Believing in* and *being believed* was a crucial part of the empowerment process, which suggested that the conditional partnership and person-centred care was a process that facilitated an empowering outcome.

Similarly, Price’s (1996) account of the ‘illness career’ proposed that care should begin with an understanding of the individual’s experience of pain. In his commentary, Price disclosed that health professionals often misunderstand patients with chronic pain; hence, getting ‘inside the individual’s experience’ can support long-term therapeutic relationships and help the patient manage their condition. This was consistent with Bury’s (1982) work and reinforces the need for professionals to engage with patients in a partnership approach to mobilise resources and regain control of their life. This explained why the co-validated relationship empowered participants to regain control of

their pain. Whilst this may be attributed to the original validation of the pain that had helped restore the disrupted biography, much of the care provided was seemingly driven by the team's *intentions* to support the participant through the conditional partnership. Caring for participants within a trusting relationship meant that the teams listened to and appeared to understand the participant's experience. This concurred with Price's (1996) account and suggested that the caring element of the partnership influenced the teams' approach within the partnership. Moreover, McCance (1997) proposed that caring is a nebulous concept, the dimensions of which are consistent with the principles of personhood such as listening, understanding, respect, and regard for the person. It is also acknowledged that caring is influenced by how professionals respond to and *intend* to treat other human beings (McCormack 2003), hence care is based on the *intention* of the professionals and provides a structure, which gives meaning to experience. Schoenhofer (2002) theorised that intentionality is an embodied dimension that informs an individual's capacity to have intentions. In the context of caring, the intentionality of a professional is different from *having intention* because within a caring action, intentionality refers to the inter-subjectivity of dimensions which underpin the actions of those providing care. It is understood that the objectives of practitioners who are grounded in a structure of intentionality, respond to the person rather than the system to meet the needs of the person (Schoenhofer 2002). This experience builds a bridge and understanding between the person and the professional through which the tensions between moral and professional obligations can be overcome.

It is through the context of caring and intentionality that alternative perspectives of empowerment have emerged, for example, Holm (1993) considered that through intentionality, professionals engage with patients and comply with their needs. The concept of intentionality provides an optimistic paradigm which exists in the realm of ethical know-how, where it is argued that the ways in which professionals work with patients to ensure the best care means engagement that transcends non-maleficence and re-establishes the partnership equipoise through intentionality within an engaged ethical narrative. It is acknowledged that relational ethics embraces traditional principles



but places a greater emphasis on relationships and refers to the connections that bring us into contact with others (Spren & Parker 1990). Rather than being viewed as negative, advocacy is believed to strengthen relationships and is a vehicle for relational narration. Humanising, care, listening and particularly knowing the person are seen as imperative. Predicated on humility, it requires faith in others leading to the co-creation of an ethical narrative in which professionals and patients *engage*. Overcoming paternalistic practices requires practitioners to work at the engagement level where the values of the patients and health professional are crafted. Hence, *believing in* the participants provided the teams with an opportunity to *engage* with the participants and work with them to restore the disrupted biography and ultimately the(ir) person.

A key advocate of relational ethics is Sally Gadow (1976, 1994, 1995), whose post-modern perspective resonates with the essential qualities of person-centred care; inter-subjectivity, engagement, authenticity, respect and the promotion of self-determination. Gadow believes that health professionals should engage with patients through on levels of ethical knowing. This form of ethics relates to a philosophy known as relational ethics, the core elements of which are; engagement, mutual respect, embodied knowledge, uncertainty/vulnerability and the independent environment (Aujoulat 2007). All of the above are influenced by the inter-dependent and authentic relationship between the patient and health care professionals. Hence, discussing the conditional partnership within a relational ethical paradigm presented an opportunity to explain the influence of the third condition on person-centred care and whether the intentions of the team could have been influenced by a latent ethical paradigm.

Used within a constructivist paradigm, Gadow's (1996) post-modernist perspective can help to understand *how* caring occurred and the ethical knowledge that supported the way in which health professionals operated. Post-modernism builds on the post-structuralist movement [inherent in Foucault's work] and provides a flexible context in which reality can be interpreted, shaped yet not fixed. It suggests that professional roles are socially constructed and the care provided tends to favour a power differential between the professional and the patient. In its rejection of an objective truth, post-

modernism emphasises the role of language, power relations and motivation and narrative is viewed as an epistemological mode through which the Self is configured (Hess 2003). Relationships between health professionals and patients are therefore ontological – a way of being (Hess 2003 p140), how they relate within the relationship is of importance because from a post-modern perspective this is best understood through narrative. Hence the relationship built between the participants and teams was significant because it provided an opportunity for the team to *engage* with the participant as a person and use person knowledge to underpin and direct care.

### ***9.2.3. Engaging through the Conditional Partnership.***

Hess's (2003) critique of Gadow (1996) outlined three levels of ethical knowing; immersion (ethical immediacy), detachment (ethical universalism) and engagement (ethical narrative) which are believed to influence caring. The three levels overlap, but it is the third level of ethical knowledge, which helped explain the paradox of the conditional partnership. For many, ethical immediacy occurs naturally and is based on an acceptance of the culture, professionalism and the ways in which agents [in this case health professional] work. These are accepted patterns of everyday ethical practice that health care professionals are intuitive with and socialised into. The second level of 'detachment' relates to the ethical principles used by professionals to guide and support their practice. For example, these may be principles espoused by professional regulatory bodies such as the Nursing and Midwifery Council (NMC) or equivalent. Ethical guidance inherent within policy often includes beneficence and non-maleficence as key ethical principles. On their own however, they can cause confusion and tension when they clash with professional principles or the principles of person-centred care.

It is however known that some practitioners practice at the level of ethical immediacy in which their professionalism dictates care and invades the inter-personal space. Health practitioners in this example expect that patients will comply – and assume at the level of immediacy that patients will seek advice and comply with instruction. Hence compliance becomes the thesis and autonomy the antithesis. At the level of detachment however, the patient can be non-compliant because of the principle of autonomy but

this then competes with the principle of beneficence. Autonomy should take precedence because of its deontological construct and the binding rule of health professionals that are morally obliged to comply- as the evidence and study findings suggest, the reality indicates a paradox.

The third level of ethical knowledge – engagement, however, relates to the ethical narrative and personal responsiveness. It is a relational narrative that is formed through engagement with the patient (Hess 2003) and is consistent with the conditional partnership built between the teams and patients. Referred to as ‘the homeland’, Gadow (1996) suggests that the ethical narrative creates a place where patients and health practitioners can go and is a ‘moral guide predicated on post-modern thinking’ (Hess 2003). Engagement influences the discourse between health professionals and the patient and ensures that good is mutually responsive and sought. In this way, the patient remains autonomous because they no longer inhabit an isolated autonomous position. Hence, the professional works with the patient through narrative and, as indicated in Chapters 5 and 6, related to the conditional partnership within which the teams engaged with the participants through listening, caring and believing in their pain. It is acknowledged that listening, patience; taking time to listen can replace the tensions between autonomy and beneficence through the ethical encounter (Olsen 2010). This was consistent with the participants’ descriptions of care and reflected an approach in which the teams *engaged* with the participants and believed in their pain.

“Engagement is the freedom to act as one’s own capacity for moral deliberation which emanates from dialogic stories” Hess (2003 p143). Dialogic engagement with the participants within the conditional partnership provided a shared moral space in which meaning could be co-authored and constructed. Hence, the team used person knowledge and the participants’ biographies in the partnership to gain an understanding of the patient as person and could explain why participants suggested that the teams ‘*seemed to know my pain*’. It could be surmised therefore that the conditional partnership was influenced by a relational ethical paradigm built at the level of engagement between the participants and teams. The relationship was founded on the

individuals' paradigms [team and participants] in which both the team and participant shaped the partnership. The conditional partnership meant that the participants and team were engaging as moral agents through the process of listening, respect and co-validation. Gadow (1994) advised that engaging in an ethical narrative means *"confirming or declining the meaning of health that each offers the other, until eventually, a narrative is composed that both can accept and act upon in their situation together"* (Gadow 1994 p 305). Hence the relationship developed between the team and participants predicated on co-validation (mutual trust and acceptance) resonates with Gadow's (1994) third ethical principle because it nurtured a relationship on the premise of the ethical narrative.

### **9.3. Rehabilitating the Patient to Recover The(ir) Person through The Conditional Partnership**

Chapman & Gavrin (1999) noted that chronic pain is *"a serious disruption in the psychological trajectory of a human life, .....the onset of uncontrolled pain can cause such a disparity and thereby compel changes in the sense of Self"* (Chapman & Gavrin 1999 p2234). From the onset of care, the teams had a moral obligation to understand the existential situation of the participants. Believing in the participants helped restore their biography and mobilise resources to repair the(ir) person. The findings suggested that empowerment was context bound and influenced by the individual's need to regain control. As alluded to in Chapter 5, being empowered meant that the participants were involved in the care process through a conditional partnership that engaged them in care. This is consistent with Gibson's (1991) concept analysis of empowerment which suggested that true empowerment is based on *"a social process of recognizing, promoting, and enhancing people's abilities to meet their own needs, solve their own problems, and mobilize the necessary resources in order to feel in control of their own lives"* (Gibson, 1991). The need to engage in care corresponds with the fundamental attributes of person-centred caring reported in the literature. Moreover this is consistent with theory identified in the initial literature review, for example, McCormack (2003) acknowledged the concept of person-centred care is predicated on an authentic consciousness, which advocates that the person's life as a whole should be considered

to maintain meaning in life. This involves being conscious of and engaging with another's beliefs and ensuring that decisions are orientated from the person's values, views and experiences. Facilitating this process means that a flexible, respectful approach that empowers the person's right to self-determination are essential (McCormack 2003). Fredriksson & Eriksson (2003) develop this further and posited that in moving from communication to conversation within an ethical narrative, professionals are able to place an emphasis on the meaning of the person in the conversation. This, replacing exchange of information with conversation forms part of the ethics of caring (Fredriksson & Eriksson 2003) whereby suffering is seen to strike at the root of the ill and compromises a good life...suffering therefore impedes self-esteem and autonomy which an ethical narrative can help repair. It is a 'co-constructed ethical and moral encounter' that is influenced by the paradigms of both agencies and predicated on a multidimensional context in which the conditional partnership occurred.

From the participant's perspective, this meant that the team understood them because, as Sakalys (2003) argued, narration helps make sense of the patients' alien world of chronic illness, which can restore the disrupted biography and personhood. Equally, the participant's biography was restored because as a therapeutic modality, the narrative provided space for the participant biography and their voice. Fredriksson & Eriksson (2003) also asserted that the caring conversation as viewed in an ethical context promotes the ethos of *caritas* and allows space for the patient to regain self-esteem. Hence, listening was an important skill because it meant that the teams made time to listen and later believe in the participant's pain. The ethical narrative was predicated on a co-validated relationship, which formed the conditional partnership and supported person-centred care. This form of primacy and knowing the participant created meaning and awareness that restored the person. The ethical narrative that supported the conditional partnership meant that the team believed *in* the patient as person and expert. The mutual respect and trust was reciprocated through the narrative that was bolstered through a relational ethical approach. Thus the notion of power is transcended through the relationship and accepted by the patient and teams, which provides a platform from within which person-centred care could flourish. As Gadow (1996)

remarked – the condition of the patient is abstracted through positive engagement which stops the reduction of the patient to a level of objectification so that they are able to remain at the centre of their experience. Engaging through the conditional partnership enabled participants to mobilise resources and rebuild their self. The three conditions, being believed, believing in and non-maleficence related to an ethical narrative within which participants felt supported to regain control of their pain.

#### **9.4. Concluding Thoughts**

The co-validated relationship supported a conditional partnership that engaged the participants and helped restore trust. The emerging paradox initially challenged the partnership; however, explicating the paradox further highlighted the team's intention to support participants to restore the disrupted biography. Ultimately, person-centred care engaged participants within a conditional partnership which was used to repair the disrupted biography, recover the moral self and restore the(ir) person. It is acknowledged that empowerment brings about changes in the persons behaviour, social situations and other aspects that influenced their lives (Feste & Anderson 1995). Hence, it could be surmised that the participants were empowered because they were able to physically and psychologically cope with and manage their pain. This thesis proposes that person-centred care is predicated on a conditional partnership that engaged participants within an ethical narrative through co-validation to repair the disrupted biography, recover the moral self and restore the(ir) person. This suggests that empowerment is a participant driven outcome influenced by an engaged relationship that restores the moral self.

Listening to the participants highlighted the significance of control, but more importantly, *being believed* and restoration of the 'self' took precedence. Generating meaning about the world of the person with chronic back pain meant venturing into unknown territory to understand that person-centred care was *personal*. For some, such as May, person-centred care meant being able to go out, being able to get rid of her PJ's and being empowered to take on life again.

*"I would stay in my PJs all day and I would only get dressed if I was going out and I did not want to go out so I had like 7 pairs of PJ's but I hadn't bought myself any proper clothes for a long time so I would just have a shower and then put my PJ's on."(May).*

For others, it meant very different things, but for all of them, it meant more than being empowered, person-centred care meant being believed and being treated as a person.

## **Chapter 10: Conclusions - The Implications of the Conditional Partnership for Education, Practice, Research and the Person with Chronic Back Pain.**

This thesis has presented a substantive theory, which proposed that person-centred care is predicated on a conditional partnership that engages participants within an ethical narrative through co-validation to repair the disrupted biography, recover the moral self and restore the(ir) person. There are a number of implications that this theory has on research, education and practice and importantly for people with chronic pain which are discussed later in this chapter. Fundamental to this process however, is the reflexivity of the researcher within Grounded Theory and in particular, the data collection and analysis process (Corbin & Strauss 2008, Charmaz 2006), hence, a reflection on the quality of the study has been included at the start of the chapter. This includes an appraisal of the robustness of the analysis and the measures I have taken to ensure that my role was transparent within the analytic process; equally, acknowledging the limitations of the study is crucial and are also discussed. The chapter begins with a reflection on the quality of the study and the limitations that relates to the original assumptions of qualitative research and concludes by discussing the implications of the research to education, practice, research and the person with chronic back pain.

### **10.1. Reflecting on the Analytic Process.**

Exploring the individual's experience of person-centred care has been an exciting journey, which exposed the world of the person living with chronic back pain. Using a Grounded Theory methodology within a constructivist framework was a flexible approach that enabled meaning to be generated about the participant's experience of person-centred care. Interviews with the teams and participants were a naturalistic method, which provided an opportunity for the participants and teams to describe their experiences in full. Indeed, Richardson *et al* (2005) concluded "*the nature of an invisible, subjective and contested condition such as chronic widespread pain brings the issue of the constructed nature of interviews to the fore*" (Richardson *et al* 2005 p1583). Moreover, the interviews enabled the participants to talk freely about their frustration



with healthcare, which later helped reveal how delegitimisation had challenged the participant's self-esteem. Heuristic approaches were carefully applied to hone these ideas through writing memos and developing sensitivity which led to the construction of the conditional partnership as a theory to explain the experience of person-centred care.

During the construction of this thesis, I was cognisant of the influence that the constructivist approach had on generating meaning, and a priority was placed on the context and in particular, the '*phenomena*' of unseen chronic pain. As the analytic process deepened, a number of theories and published research were used to generate an understanding about the experiences of chronic back pain and the person-centred approaches to care. The constructivist Grounded Theory approach was a unique process that enabled the experience and the world of the person with chronic pain to be understood and, through using memos and reflection, ensured that raw data was not used in isolation of the context. Listening to the teams and participants opened up their world to 'outsiders' and for the first time, revealed the processes and outcomes of a multi-professional person-centred approach to care. It was through listening to the descriptions of care that I was able to understand the influence of the sceptical professional on the participant's ability to cope with their pain. The impact of delegitimisation was further explored using sociological frameworks to understand why the damage had been profound. In developing the theory of the conditional partnership, the conditions were contextualised within a post-modern epistemological perspective using Gadow's concept of relational ethics (1980, 1994, 1995, 1996). This helped generate meaning about the intentions of the teams to provide care that was holistic, safe and seemingly person-centred. The conditional partnership became a polemic which originally appeared to challenge person-centred care, however, once exposed, the inter-professional practices of the teams and the subsequent impact on the relationship with participants were identified as being a catalyst to caring for and with participants and has made a distinct contribution to understanding the relationship involved in person-centred care. The reality of person-centred care was illustrated in the teams approach to care and whilst the empowerment of the individual was paramount, the subtle paternalistic practices that influenced this process were surprising. Explicating the

partnership within sociological, ethical and professional contexts helped to understand this and identified how the teams appeared to use person-centred approaches through their intentionality to care.

The participants felt empowered, which suggested that the approach used by the team may have been predicated on a third level of ethical immediacy which enabled the rehabilitation to take place. Although the concept of empowerment is contentious, judgement as to whether the individual was empowered resides with the participants. From a constructivist's stance therefore, the reality of person-centred care is contextualised within the participants' own world and predicated on their expected outcomes of care. From the participant's perspective; *being believed* and *believing in* empowered them to regain control of their lives. Hence, control was a person-centred goal that was achieved through the conditional partnership.

Although there are limitations to this study, I would first like to acknowledge that the strengths of the research were influenced by sensitivity, which informed the development of the theory throughout the analytic process and through writing the thesis. The constructivist approach provided a fresh lens to person-centred care and enabled an opportunity to see beyond the pragmatic approach used by teams to control care to the often hidden skills used to support relationship development through integration of a relational ethical approach.

## **10. 2. Reflections on Quality**

The issue of quality in qualitative research is contentious; hence, Corbin & Strauss (2008) advocated that quality should be considered throughout theory construction. In particular, how the findings were developed need to be explicit. The thesis findings and analysis were based on a research process, underpinned by a constructivist approach that used Grounded Theory as a method to analyse data. The findings were discussed in chapters 5-8 and were later contextualised with the literature and existing theory to enhance sensitivity and substantiate the theory of the conditional partnership. Although the conditional partnership may be viewed by some as an oxymoron and unrelated to

the accepted frameworks associated with person-centred care, in its defence, and in accepting the constructivists (and perhaps Pirsig's) account of 'truth' and quality, the conditional partnership presents a realistic explanation of the relationship between those who are vulnerable and those who have the ability to help. Having acknowledged that the power relationship cannot be ignored, the findings suggested that the reliance on the professional was fundamental in restoring faith in healthcare. Ultimately, the thesis argues that the conditional partnership engaged participants within an ethical narrative through co-validation to repair the disrupted biography, recover the moral self and restore the(ir) person. Having presented a theory it is crucial to return to the key principles of qualitative research and discuss how these have been achieved.

Explicating the quality of the thesis involved revisiting some of the original canons associated with qualitative research. In addition, Miles & Huberman (1994) asked "*How will you, or anyone else, know whether the finally emerging findings are good*" (p 277). The debate about whether qualitative research has specific criteria for what is good quality is on-going, but as Miles & Huberman (1994) point out, "*the problem of quality, trustworthiness, of authenticity of findings will not go away*" (p277). Consequently, identifying the most appropriate quality criteria meant re-appraising the methodology to evaluate how the conduct of the research had addressed and integrated the canons and procedures described by Corbin & Strauss (1990) and Charmaz (2006). On reflection, and having painstakingly re-analysed, re-visited and re-written this thesis over the past 4 years, I feel more confident to discuss these issues and have referred to Robert Pirsig's comments about quality and his reference to 'betterness' originally discussed in Chapter 3. Surprisingly, the concept of 'betterness' remains a challenge because it is difficult to define quality, or 'betterness', however, applying the principles, canons and procedures of Grounded Theory to the study has supported the analytic process and helped to discover a fresh and challenging insight into a health professionals understanding of person-centred care. Hence to explore the quality of the research, Corbin & Strauss (2008) & Charmaz's (2004) criterion for quality have been revisited to provide direction in an otherwise hectic and messy research world. The following section discusses the methods used to demonstrate (rather than prove) quality.

### **10.2.1. Canons Revisited.**

The purpose of Grounded Theory is to develop a core category that integrates all other concepts and categories, moreover a Grounded Theory should explain as well as describe the phenomena (Corbin & Strauss 1990) and in doing so, the role of the researcher must be acknowledged (Mills *et al* 2006). Strauss & Corbin (1990) advise that a researcher should use their 'gut sense' to describe the final story line, the core category therefore emerges both intuitively and through sensitivity, detailed analysis and attention to context. As highlighted in Chapter 3, Grounded Theory is predicated on a paradigm that acknowledges the significance of the researcher role in the analytic process. The researcher's role is integral to theory discovery and is steeped in the researcher's ontological and epistemological assumptions. Epistemologically therefore, constructivism uses the relationship between the researcher and the researched to explicate ontology through the co-construction of meaning. Thus, it is acknowledged that the humanness of the researcher provides a rich subjective account of the phenomena as opposed to an objective explanation of an event, and as Appleton (1995), Guba & Lincoln (1989) asserted, the values of the researcher must be considered within the analytic process. The way in which these values are made transparent is crucial in the thesis development and is described next.

### **10.2.2. Enhancing Depth & Credibility through Sensitivity**

Corbin & Strauss (2008) acknowledged that determining the quality of Grounded Theory can be problematic. As with most qualitative research, limitations are often inherent in the bias of the researcher and the researcher role in data collection and analysis (Holloway & Wheeler 1992). Ensuring the credibility of a theory is difficult and critics of Grounded Theory contest that small sample sizes and research bias have contributed to the lack of generalisability associated with qualitative research (Bowan 2008). However, it is also acknowledged that a central component of Grounded Theory is to ensure that the theory emerges from the data through robust data analysis methods that integrate research sensitivity as part of the analytic process (Corbin & Strauss 2008). This enables researchers to account for their own position within the research and through using

memos, record the analytic process. In addition, using literature to support the analytic process facilitates a deeper understanding of the phenomena and helps defend the credibility of the findings. Within this thesis, data collection and analysis were interrelated processes, which captured concepts, which were then used to develop the eleven categories and sensitivity evolved throughout the analytic process and as the memos were written, the analysis deepened and through writing the thesis.

Memos were helpful from the start of the study, especially in determining the influence of preconceived ideas about multi-professional team working. These processes, particularly using literature to develop sensitivity helped to analyse the concepts within the participant and team experience and ensure that open and axial codes were not used in isolation of the context. Explicating concepts through developing understanding of the properties and dimensions provided an opportunity to delve into the literature to enhance meaning and generate sensitivity about a concept. This became evident early on in the analysis as the sceptical professional emerged; for example, explicating meaning about delegitimisation was influenced by reading Clarke & Iprofen's (2005) phenomenological study that explored the experiences of people with chronic back pain and Klienmans (1992) anthropological perspectives of the pain experience. Equally, listening to the participants enabled sensitivity to the phenomena to develop, which later enhanced the analysis of the participants experience and highlighted the first two conditions; *being believed* and *believing in*. As such, the sampling was based on properties, dimensions and concepts that were identified through the analytic process, careful listening, re-immersion and coding of the data. Using a constant comparative analysis to analyse data helped to explore and account for variations in concepts, such as empowerment and compliance, which was later built into theory through the exploration of the emerging paradox. A later example of how literature sensitivity supported the analytic process emerged through the use of Bury's sociological framework which helped explore the significance of delegitimation; equally, using Gadow's relational ethics perspective helped to understand the third condition. Throughout the study, the process of writing theoretical memos helped the analytic process and were useful when re-visiting data or simply remembering why a concept

was coded in a certain way. Likewise, Corbin & Strauss (2006) suggest that the use of mind maps and other visual software can often help researchers delineate concepts and identify categories. During the initial analysis of the participant interviews data were coded and often presented in tables with memos to support the analysis. Visualising the concepts later through the mind map software transformed a rather messy list of concepts into a management format which provided the 'analytical handle' as espoused by Charmaz (2006). As the study progressed, there was an increased use of mind maps because when using rich description alongside tables, memos helped illustrate the analytic process and provided a transparent account for the reader about the analytic process which influenced the findings. For Corbin and Strauss (2008) and others such as Charmaz (2004), using these creative approaches help illustrate depth and ensure that concept contextualisation was not devoid of the context. To strengthen the context, the participants' own words were used and the open and *in-vivo* codes were highlighted within each interview excerpt. Adopting different creative approaches to data display and analysis helped to saturate the categories and were useful in presenting the ideas and findings back to Nadia, colleagues working within pain teams and service users and carers (see appendix 3a & 3b).

Using technical literature, such as Bandura's (1989) concept of collective efficacy helped to hone ideas, develop the analysis and generate meaning which also enhanced sensitivity and enabled conceptual depth to develop. This helped clarify the categories such as *collective efficacy*, *co-validation* and *being believed*. Embracing existing literature in this way enhanced confidence in the analysis and helped to shape the analytic process. For example, literature sensitivity enabled the category of collective efficacy to form predicated on an awareness of Bandura's (1989) original theory. Although this process was difficult to navigate at first, as the research progressed, sensitivity developed intuitively with experience and confidence which generated understanding about the phenomena. The difficulty with this level of sensitivity was knowing when to stop analysing and when to recognise that a concept was fully saturated. Chapters 6 and 7, provide examples of how literature sensitivity enhanced the analysis to engage with the concepts and form categories. Hence, sociological frameworks such as Goffman and

Bury were useful in elaborating the analysis; equally, Gadow's work helped to later substantiate and understand the third condition. The latter use of sociological and ethical frameworks in chapters 8 and 9 was fundamental to my understanding about person-centred care which underpinned the overall development and explication of the positive conditional partnership.

Equally, engaging with existing theoretical frameworks to discuss the findings helped to establish the credibility of the theory. For example, awareness of the relational ethical perspective helped to understand how the teams may have worked with the participants through ethical narrative to develop a shared understanding, mutual trust and acceptance of each other. Generally, making sense of person-centred care through the analytic process, literature sensitivity and sensitising helped establish a credible theory that emerged from the data. However, the process itself was not absent of flaws, and during the analysis and writing this thesis, limitations to the research became evident. In particular, the relationship between the teams and participants lacked depth and whilst transactional analysis was used to 'fill' the gap, (Corbin & Strauss 2008), there were inherent weaknesses to this approach. The limitations to credibility are explored next.

### ***10.2.3. Potential Limitations to the Credibility.***

It is acknowledged that real world research can be a messy and somewhat frustrating journey (Robson 1993). Limitations to a study are often identified during the data collection or analysis process, but more frequently occur during the writing up phase as the researcher reflects on the study (Corbin & Strauss 2008). Hence, identifying limitations to a study can support future research or theory development and contribute to theory development. Researchers are therefore advised to look back on the entire research project and consider approaches or decisions which may have been done differently to benefit the work (Oliver 2004). In relation to Grounded Theory, ensuring that the core is fully saturated is considered to be one of the key canons highlighted by Corbin & Strauss (2008). This inevitably means exploring whether the data collected were enough to saturate the concepts and form the core. Within the context of the

conditional partnership, whilst it could be argued that the core was saturated by the categories; limitations within the actual data collection process may have inhibited the analytic process through lack of density and member checking which could undermine the credibility of the theory.

The conditional partnership presents a theory of the relationship that evolved between the teams and participants. However, data collection was predicated on a single method and the inability to observe the relationship could raise questions about the credibility of the theory. For example, whilst the participants stated that they felt empowered, the relationship itself could have been further substantiated through traditional triangulation of data sources. It is acknowledged that triangulation of data methods can enhance the analysis by providing another perspective (Parahoo 2006); hence, using non-participant observation in conjunction with the interviews of the teams and participants may have helped explicate and substantiate the theory and may have enhanced the transactional analysis. Observing the relationship over time using a non-participant observational approach could have provide greater insight into the relationship between the participants and teams.

Observations in research are more commonly associated with ethnographic approaches and have much to offer qualitative research because of the ability to observe 'reality' (Corbin & Strauss 2008). This includes, for example, the subtleties of a relationship and the interactions that take place. Hence, observation of the conditional partnership would have provided an opportunity to challenge the theory and substantiate the core. Recording observations of a relationship and listening to the teams could have strengthened the study findings and subsequent credibility of the theory. However, as Corbin & Strauss (2008) comment, limitations associated with the analysis of interviews are also inherent within techniques used to analyse observational data and it is acknowledged that researchers may misinterpret another's actions. Hence, the triangulation of data sources has a unique advantage in validating the theory; conversely, triangulation of data sources also poses some risks, particularly when analysis resulting from the data source actually present a conflict (Thurmond 2001). I



acknowledged therefore that the study's reliance on a single data collection method may have affected the credibility and dependability, hence, rendering definite claims about the relationship itself being problematic. Future refinement of the conditional partnership as a substantive theory therefore needs to observe the relationship to determine the extent of the partnership through dialogue.

It is suggested that one of the most crucial methods in establishing the credibility of a study is the member checking technique (Cho & Trent 2006, Guba 1990). Moreover, Seale (1999) believes that triangulation could enhance the credibility of a research study through access to additional sources that may later provide evidence of the research key findings. This form of triangulation involves returning the analysis to the original participants to verify the accuracy of the findings and has implications for the credibility of a theory. Significantly, this also has implications for the conditional partnership theory because the findings were not discussed with the participants or the teams due to the length of time taken to analyse the data. This is a common problem reported in methodological literature and highlights the risks associated with member checking data that has evolved over a sustained period. Hence the challenge faced by qualitative researchers, is when and whether to undertake member checking. However as Guba & Lincoln (1989) point out, triangulation may be too heavily influenced a positivist implications that suggests that unchanging phenomena exists to facilitate logical triangulation as a 'check' (p240). Crucially, there are recognised disadvantages to member checking which relate to the researchers ontological assumptions. For example, the co-construction of theory means that an objective truth is not presented and participants may struggle with abstract synthesis (Sandelowski 1993). Certainly, in relation to this thesis, returning analysis back to participants five years after the original interviews posed problems. However Corbin & Strauss (2008) also advise that for research findings to be meaningful, they must be relevant and 'ring true' to the original research field. The 'fit' with current practice can influence the credibility of the findings and is discussed next.

One of the canons described by Corbin (1990) relates to how well the theory 'fits' with the original phenomena. To ensure that the analysis was an accurate representation of practice and other's experiences, the findings were presented to health care practitioners who work in the field of chronic back pain and to service users who received treatments for chronic back pain (please refer to appendix 3a & 3b). On the whole, the majority of people who attended the presentations were surprised by the actions of the sceptical professional and were upset that people with chronic pain were delegitimised. Based on the feedback from the participants and teams who specialise with supporting people with chronic back pain, the findings were consistent with their experiences, and hence appeared to 'fit' with practice. A similar presentation to a user and carer forum in the university highlighted the significance that 'being believed' had on others with chronic pain. For example, a number of members from the user and carer forum reported similar experiences, particularly in their 'early excursions' through the health care 'system'. From their perspectives, unseen pain and its associated stigma, remains a significant issue, which they believed was on-going. Collectively, the experiences described by colleagues within pain teams and service users and carers highlighted the sociological needs of people with chronic unseen illness, which may infer that these findings not only 'fit' with other service users and professionals, but that parallels may be drawn between all people who suffer from chronic pain, irrespective of the location of the pain stimuli.

### **10.3. Enhancing Understanding about Person-centred Care**

Ultimately, the aim of this study was to explore what the experience of person-centred care was like for people with chronic back pain and findings from this thesis suggest that study participants were empowered through a conditional partnership approach. The key findings challenge the notion of the 'unconditional' care and propose that person centred care is context bound, predicated on conditions set by both the participants and the teams. The three conditions outlined in the conditional partnership suggest that being believed and believing in are crucial from the team's and participants perspectives because it legitimises both the pain experience and the teams credibility thus enabling a

trusting and person centred partnership to grow. The third condition, expected by the teams, was predicated on their intentions to care for participants through an ethical narrative that engaged them in care. Ultimately, the conditional partnership manifest through a co-validated relationship that repaired the disrupted biography, recovered the moral self and restored the(ir) person.

These findings highlight the need for people with chronic back pain need to be trusted and believed by **any** health professional they come into contact with. The conditional partnership theory provides a bridge between the rhetoric and the reality of person-centred practice, in particular, the nuances of person-centred relationships has been under-researched. For example, partnership working between 'patients' and professionals has been frequently reported in the health literature, and patient expectations of health care professionals is not a new phenomenon. Equally, the expectation for health professionals to legitimise patient's pain has been noted by a number of authors (Glenton 2003). For many, the need for diagnosis is driven first by the patients' need to validate their experience and then by the need to understand what is happening to them to restore their biography. There is a plethora of literature that repeatedly points to the need for professionals to demonstrate greater awareness of the patient's needs, however, there have been very few studies that have explored the impact of delegitimation in any depth, particularly with those people who have chronic back pain.

Other research has focussed on validating pain through diagnosis; for example, the predominant discourse within radiography is predicated on the use of visual imagery and diagnostic tests to 'prove' the existence of pain. For example, Rhodes *et al* (1999) refer to the "concreteness of diagnostic images themselves" as a mechanism to make visible the private experience of pain. Similarly, Veerbeek *et al* (2004) explained how patients expect diagnostic imagery to confirm that their pain is real. Yet, research in healthcare professional literature that has explored the need for the patients' accounts of pain to be believed is rare, which is surprising given McCaffery's original statement in 1980 that advocated that pain is what the experiencing person says it is, existing whenever he/she

says it does. This seminal work by Margo McCaffery emphasised the need to believe the person's report of pain has been cited by authors within a range of clinical contexts and is easily transferable to other pain settings. However, the findings suggest that people with chronic pain struggle to be accepted as 'sick' and become deligitimised as a result. This presents challenges to person-centred care not least because it displaces the person and limits autonomy. The rhetoric of person-centred care therefore, does not appear to reflect the reality.

Surprisingly, although person-centred care is referred to in health policy, there has been little empirical research that has explored the reality from the patients' and professionals' perspectives. Listening to the teams and participants was instrumental in developing a theory that explained how relationships between the teams and participants fostered person-centred care. The findings suggest that the relationship provided an opportunity for participants to regain control of their pain through the 'toolbox' provided by the teams. However, there is very little published literature that has explored the impact of delegitimisation on person-centred care for people with chronic pain. Although the concept of the disrupted biography is familiar within the field of some chronic conditions such as fibromyalgia and rheumatoid arthritis, it has yet to be substantiated within the context of chronic back pain. In the main, research has focussed on pain assessment methods, of the management of pain through analgesics, and even more quantitative research has tended to focus on the signs, symptoms and management of pain without recognising the impact of chronic pain and in particular, delegitimisation has on the person's moral self and subsequent self-identity.

The participants described how being disbelieved impeded their autonomy and many struggled to cope with activities in life. This influenced their relationships, work and loved ones as their management of day-to-day issues became difficult. Recognising the person's pain earlier may have helped the participants and prevented the damage to their self-esteem. Hence, the findings have implications for future education, practice, research and importantly – the person around whom services are supposed to be designed. The implications are discussed next.

#### **10.4. The Implications of the Conditional Partnership: Being Taken Seriously through the Legitimation of Pain.**

Charmaz (1999) noted that chronic illness presents an 'assault' on the person's identity, self-esteem and self-worth; this was consistent with the participants descriptions of low self-esteem experienced prior to being referred to the pain teams. Significantly, the participant's experience of healthcare prior to being referred to the pain teams marred the integrity of the professionals and consequently, they had lost faith in health care. The findings revealed the significance of the participant's journey to the team and how their experience of the 'sceptical professional' had influenced the way in which they later developed partnerships with the pain teams. From the participants perspectives, being believed by the teams was equivalent to being diagnosed which meant that their pain was legitimised and played a pivotal role in the rehabilitation of the person. However, professional recognition of a condition through diagnosis can lead to labelling (Reid *et al* 1991) which can cause separate challenges. For example, it is acknowledged that a label can simplify the many dimensions of society (Allport 1954) and ironically, can prompt prejudice. Conversely, and as described by the participants, being diagnosed equated with receiving a label which helped make the invisible, visible, such as the need for a diagnosis to make their suffering credible. Although a diagnosis and subsequent label was useful in authenticating the pain, a secondary abuse of labels especially within the health care arena has been mooted. It is reported that applying a label to a person's condition is the same as categorisation, and in the case of people with chronic painful 'unseen' conditions the labelling can be endemic (Clarke *et al* 2003). Conversely, the 'label' or diagnosis as highlighted by Reid *et al* (1991) provided reassurance because it can legitimise an experience. These challenges represent the dual impact that being 'labelled' may have on a person previously reported in other studies such as Blomqvist *et al* (2002), and illustrates the endemic nature and impact that disbelief by others has on self. Hence, it is acknowledged that label can reinforce a sense of devalued self and a label applied to any person can result in marginalisation (Anderson 1991). Caution should be exercised to ensure that the legitimation of pain does not result in the labelling and demise of the person in favour of the patient. Hence, the conditional partnership,

presented a way in which the teams and participants worked together within a co-validated relationship that restored faith in health care and appeared to restore the(ir) self. This meant that the diagnosis of the pain experience was a supportive rather than destructive influence that enabled the participants to mobilise resources. The influence of being believed and believing in has implications for **all** health professionals, researchers and people with chronic back pain and the system described by the participants could have been avoided if health professionals had taken early steps to 'validate' the participants' pain. Given the need for 'biological markers' to determine legitimacy of illness, it is not surprising that many participants felt frustrated with the 'system'. Hence the need to use person knowledge as ascribed by Liaschenko & Fisher (1999) in conjunction with case and patients' knowledge could help ensure that individuals biography rather than the 'lack of observable symptoms' influence decision making. This could help ensure that the persons 'unseen pain' is recognised early on which could deter future delegitimisation of their pain. There is a need therefore to ensure that all health care professionals demonstrate faith in the person with chronic pain as it is crucial for and can influence a person's sense of identity, self-worth and esteem.

However, it is acknowledged that person-centred care is more than just 'seeing the individual' and involves generating a deeper understanding of the person (Ford & McCormack 2000). According to Radwin (1995), to be person or patient-centred means that one must 'know' the individual equally, Mead & Bower's (2000) review of the empirical literature, highlighted how the term 'patient-as person' was used to broaden the bio-psycho-social model to include the persons biography. Using person knowledge therefore could facilitate an approach to care that supports the restoration of the self-identify and moral self. As healthcare services move towards greater integration of professions; it is timely to introduce greater reverence towards the understanding of the impact of delegitimisation. Acknowledging the need for co-validation could improve outcomes for people with chronic back pain in the future and enable health care professionals to sustain and grow a quality, person-centred health service that meets the need of the individual rather than the professional.

However, for research to be of value, it must first consider the impact it has on practice, education and future research. There is a need to ensure that the conditional partnership theory is meaningful for the people with chronic back pain and the teams who cared for them. The next part of this chapter therefore discusses the how this work has enhanced an understanding of person-centred care and the implications of the theory on the people with chronic back pain, practice, education and research.

### **10.5. Implications for the Person with Chronic Back Pain.**

The conditional partnership presents a number of implications for people with chronic back pain. Crucially, the findings highlight a common concern amongst people with chronic back pain, which recognise the suffering that being delegitimised causes. Participants were disempowered through delegitimation; however, there is a dearth of literature that has explored the impact on the individual. Kathryn Clarke and Ron Iphoren's (2005, 2008) work remains one of the few studies that have specifically explored the impact of disbelief on the person. In her review, Clarke (2005) remarks that whilst there were no studies that looked exclusively at the impact of being disbelieved, a number of studies had signalled the need to explore this. Hence the need to legitimise a person's pain is significant because medical explanations of the condition may be supplemented by narrative reconstructions which attempt to place such information within a more meaningful biographical context. Assessing through biography first could help the professionals to partner with the person as opposed to the patient to identify their needs. This means enabling the person to participate in a way that they feel comfortable.

Having a voice first and empowered to self-care is important, and as discussed in Chapters 8 and 9, there are inherent tensions regarding the concept of empowerment and the extent to which informed choice becomes compliance. The point at which paternalism governs care is hard to determine and has been difficult to exclude because of professional non-maleficence. Earlier work by Malin & Teasdale (1991) drew on Griffin's (1983) concept of caring and suggested that the power base of the relationship between nurse and patient is not equal and was likened to that of "a parent and child".

The expert patient and patient as partner are believed to be methods which can empower people to self-care, but as Tattersall (2002 p227) cautions, the expert patient is “*more than just patient education to improve compliance. Instead there should be ‘a cultural change ... so that user-led self -management can be fully valued and understood by healthcare professionals’*”.

However, concerns reported in the literature suggest that partnering with patients may not take into account the preference of the individual. For example, Waterworth & Luker (1990) identified that patients are concerned with doing what is right rather than participating in care decisions, They are happy to be guided or led by the professional and to ‘toe the line’. A challenge therefore for professionals working in person-centred ways is to maintain a relationship that supports partnership working, yet allows flexibility for the patient to opt out. Part of this process requires the professional to hear the patient voice of dissent and act accordingly. Equally, the scope to support patients through decision-making processes without coercion was reciprocated in more recent work by Beaver *et al* (2005), who found that participation in the decision-making process was about being informed and feeling involved in the consultation process, whether patients actually made decisions or not. This would suggest therefore that patients might not want to make decisions. Greater effort therefore should be placed on seeking the person’s preference to the level of their involvement in decision-making. The conditional partnership provides an opportunity for professionals to work with the person and determine the extent to which patients want to participate in and make decisions about their care and ultimately regain control.

#### ***10.5.1. Regaining Control through the Conditional Partnership: The Journey to Self-Care.***

*Being believed and believing in* presented a partnership process predicated on co-validation. Historically, the complexity of partnership working has resulted in tenuous definitions that have exacerbated rather than clarified meaning about the concept. Since the early 1970’s an inconsistent dialogue about partnerships healthcare has emerged, yet the concept of partnership remains immature and there has been little consensus



between theorists (Gallant *et al* 2002). This ambiguity was reflected in a recent review of partnership working in which Warne & Howarth (2010) acknowledged the contextual inter-relatedness by using the term 'partnership' to encompass all types and levels of collaborations, attributes, joint ventures and activities. Similarly, Rodgers (2000) concept analysis of partnership acknowledged that partnerships are created from many variables and was described as being an abstract concept capable of many definitions that form around a cluster of critical attributes needed to determine the extent of partnership boundaries

Rodger's (2000) abstract connotation of partnership explains the complexities of partnership working and reflects the significance of the professional's expertise in person-centred care and the ability to share such expertise with the patient. Rodger's work has been widely adopted as a model to analyse partnerships and was later used by Hook (2003) to explore the key characteristics of partnerships in healthcare. Of note were Hook's findings which suggested that successful care strategies, which involved providers with expertise in person-centred approaches that supported shared decision-making through "*motivating participants towards active participation in self-management*" (p134). Hook introduced the concept of a passive model of care that promotes self-care through partnership approaches that share decision-making.

The ability to self-manage as a result of partnering is reported in the literature and is now considered to be a key outcome for person-centred care (Coulter 1999, McCormack 2003). Empowering patients through partnership working to self-care was consistent with the category of the 'toolbox' discussed in Chapter 5 and reflects a general trend of empowerment methods for people with chronic illness. The category of the toolbox and being empowered to regain control was similar to Kralik *et al*'s (2004) work, which used an autobiographical approach to understand the way in which people who lived with chronic illness constructed the notion of self-management. Kralik *et al* likened the term 'self-management' to the process used to enable people to "*create order, discipline and control in their lives*" (p260). Moreover, Kralik *et al* report that this process facilitates self-management in which people are encouraged to be involved in decision-making a

gain control over their lives. This suggests that embracing self-management as an outcome through shared decision-making could be person-centred. However, it is acknowledged that self-management is not the panacea anticipated by some, and for many people with long term conditions, shared decision-making is something they would shy away from, actively making decisions. For example, Beavers (2005) qualitative exploration of decision-making preferences of people with colorectal cancer identified that participants don't want make decisions but would like to be informed. Further, Beaver (2005) challenged the way in which participants had been previously described as 'passive' and asserted that partnerships with participants and professionals as equal partners was rather a simplistic view. Beavers (2005) study strengthened the need for greater conceptual clarity about what is meant by patient participation and its relationship with partnership.

#### **10.6. Implications for Practice.**

The implications for practice are considered within the context of current UK government policy and at an organisational level. The UK has generally supported the move from the patient voice to a more focussed empowerment strategy designed to encourage self-care. The new NHS strategy asserts that *"too often, patients are expected to fit around services, rather than services around patients.....foresee a better NHS that is genuinely centred on patients and carers....."*(DH 2010). Getting involved under the premise of "Working Together for a Stronger NHS" through a newly designed NHS Forum and a listening exercise has been operationalised and there has been a repeated emphasis placed on strategies to support people with long term conditions such as the recent *'risk prediction approach'* which aims to support the management of long term conditions by *'matching care to need'*. Part of this process includes using the Kaiser pyramid to allow a range of interventions to be implemented, which also relate to *'personalised care planning'* predicated on *"placing the person at the centre of decision-making about their care and agreeing a plan of how that care will be delivered"*.(DH 2011). Hence, Department of Health policy seems to reflect a 'patient-centred' approach through a 'self-care' philosophy. Contemporary examples within the long terms strategy

that embrace person-centred approaches include strategies such as 'Your Health, Your Say'. Self-Care is now considered to be a priority for people with long-term conditions and public health policies reflect the need to empower people to self-manage through the use of toolkits.

Similar to the study findings, the self-care philosophy advocates a stronger role for people in decision-making and there is an expectation that health care professionals embrace the person's voice more actively than previously suggested. To support this, the Department of Health (2011) published a range of tool kits that guide the person through ways in which they can 'self-care' (DH 2011). The pain toolkit repeats almost exactly the general self-care tool kit, but replaces the terms persistent health problem with persistent pain and focuses on becoming a 'can do' person. Crucially, belief in the person with chronic pain is now recognised as part of the rehabilitation process and self-help guides for people with chronic pain advise that professionals help the individual to get on with life through acceptance of their pain. However, the study participant's first hurdle in the healthcare 'system' highlighted the need for health professionals to believe in them. The importance of being seen as a person and not a disease impacted on patient satisfaction with care and is thought to influence care (Frantsve *et al* 2007). There is a need for professionals to legitimise the patient's pain through a shared perspective of the chronic pain experience between the patient and professional (Frantsve *et al* 2007). However, for the participants, sharing their experiences and subsequent legitimisation of their pain took place only when they were being cared for by the pain teams. The participants described a journey to the pain teams that was fraught with anxiety and where they became disillusioned with health care. Feeling disbelieved meant that they lost their self-esteem and referred to themselves as others would see them. Equally, when others exhibited disbelief the patients became disempowered which compromised partnerships with health care professionals. Disbelief in 'unseen pain' is not uncommon in health care and the evidence base alludes to a number of papers that have focussed on the effect of disbelief. Under the umbrella term of deligitimisation, authors such as Borkan *et al* (1995) and Klienman (1992) describe how being disbelieved is an attack on the self.

There is a need, therefore, to ensure that health professionals who come into contact with people who have chronic pain, take time to consider the impact of their actions, and in particular, be aware of the damage that delegitimisation causes to the person's self-esteem and subsequent recovery. The basic principles of trust and belief need to be established between the patient and health professionals before being able to 'move on and get on with life'. The self-care philosophy will only work for those people who have had pain 'validated' and therefore, health professionals need to be cognisant of delegitimisation and avoid destabilisation of the self.

Including people as partners in care fosters confidence and trust, which can help form therapeutic relationships that empower the individual to self-care. The need to ensure that people have faith in professionals is equally important and a substantial element of the findings suggests that the way in which teams mature has a direct influence on the patient perceptions of their credibility. This is particularly significant for those people who may have had to deal with an uncaring system in which the 'sceptical professional' resides. Importantly, the study findings revealed that the relationship was predicated on a co-validation process, which meant that the patients needed faith in the teams and vice versa. Lack of faith could lead to an unequal relationship in which trust and respect is limited. Having faith in the teams was therefore paramount, and as such, the way in which teams develop collective efficacy is important and keeping teams together was a significant factor. However, collective efficacy is an under researched area in health and whilst it has enjoyed popularity in sports psychology, the extent to which collective efficacy influences team working in a health context is ambiguous. One of the few studies that have explored teams in this context was Millward & Jeffries (2001) who identified the need for 'team potency', i.e. the extent to which the team had a belief in itself, was significant. The need to keep teams together, particularly in relation to keeping people central to care is important and could play a pivotal role in empowering patients to regain control of their pain or other chronic long-term condition. This point is increasingly significant when considering the current political agenda to reform the NHS. The findings from this PhD, particularly in relation to collective efficacy are timely given

the NHS reforms (please refer to appendix 1b). The potential impact on teams in relation to their maturity and ultimately efficacy is concerning and should be considered.

### **10.7. The Implications for Education.**

The conditional partnership highlighted the need to embrace the person and recognise their role in person-centred care. Believing in the person's pain indicates a move away from traditional assessment of symptoms, to models that embrace the person as opposed to clinical signs, or even 'activities of daily living' as advocated by Roper, Tierney & Logan (1980). Ensuring that the biography of the individual emerges first may be difficult given the models of nursing predominantly taught in pre-registration nurse education. However, there has been a latent recognition of the need to emphasise person-centred ways of caring in all fields of practice, yet, a precedence continues to be placed on 'clinical skills' rather than 'person-centred skills'. It could be argued that clinical skills encourage an assessment of physiological need based on the sociological and biological markers previously referred to in Chapter 9. There is a potential for the continued teaching of 'clinical skills' to create a void between the clinical skills and the person-centred skills. For example, case scenarios used in isolation of relational skills could exacerbate the medical model of care and promote the notion of symptom management rather than person-centred care. Increasingly however and since the new NMC (2010) standards, there is a need to ensure that essential skills are embedded into the curriculum to avoid disparity and inconsistency between skills and therapeutic relationships. This could go some way to address the NMC's (2010) call for education to ensure that nurses:

*"Make person-centred, evidence-based judgments and decisions, in partnership with others involved in the care process, to ensure high quality care".(p17).*

Conversely, the use of simulation using a variety of means within a 'clinical skills lab' has been accepted by the NMC as part of the practice hours of a student nurse programme.

*Most practice learning is required to be undertaken in direct care of clients, although under certain criteria up to 300 hours of practice learning may be undertaken through simulation, allowing the student to learn or practise skills in a safe situation that imitates reality (NMC 2010 p9)*

Although there is the suggestion that this replaces events where it is safer to use simulations (for example choking, cardiac arrest) simulation offers an opportunity to develop a pedagogic approach that could facilitate learning about the care of the person, which may not relate to emergency care situations. This presents some concerns in relation to the integration of the person into scenarios used to demonstrate the skills needed. It is becoming apparent, that skills are increasingly seen in isolation of the person in such labs, there is the potential risk that the person is returned to the status of the patient or, even worse, a mannequin. For example, in an acute situation in which calls for students to assess an individual's chest pain, the initial priority is appropriately given to the physical needs, however, the need to allay anxiety, talk to the individual and provide reassurance takes second place. It is unclear to what extent simulation training can encourage the student to carry out the systematic assessment as advocated by the NMC below (NMC 2010 p18);

*“All nurses must carry out comprehensive, systematic nursing assessments that take account of relevant physical, social, cultural, psychological, spiritual, genetic and environmental factors, in partnership with service users and others through interaction, observation and measurement”.*

Whilst it accepted that simulation as a means to develop students clinical skills within a 'safe' environment is a positive step forwards, the scenarios used in simulation need to embrace person-centred skills as well as clinical skills within scenarios. Moreover, there is also a valuable opportunity to embrace the 'patient' or 'service user' perspective within education to ensure that their voice influences students, pedagogic approaches and the curriculum. Increasingly, the move to ensure that the patients inform curricula has been eagerly embraced and the emergence of service users' forums and conferences in healthcare is developing.

Hence, there should be a greater emphasis placed on developing student nurses skills in obtaining a biography *and* a history of symptoms that will enable the person rather than the patient to be 'assessed'. Using person knowledge as suggested by Liaschenko & Fisher (1999) could support the development of person-centred skills; for example, obtaining biography through a skills based approach could be emphasised within this

pedagogic approach to enable the students to see beyond the patient/mannequin. The methods that have been used and which should be promoted to enable this include the use of therapeutic letters, art and other media that utilise and embed the relational ethical approach within education.

Embedding the ethics of caring into the nursing curriculum is one way in which person-centred skills could be integrated into education. Seeing beyond the patient to the person understanding the person through biography is an approach to learning that has been explored already, but predominantly in the field of mental health nursing. In this discipline, the focus on getting to know the person is clearly recognised and innovative techniques, such as therapeutic letter writing, have been used to encourage the student to identify with the person rather than the patient. Therapeutic letter writing as a pedagogic to support person-centred care has been evaluated recently by Smithbattle *et al* (2010), Freedman (2002), Freed *et al* (2010). Therapeutic letters are personal documents that have been frequently used in mental health nursing to promote person-centred care and are acknowledged to be meaningful for the participants (Freed *et al* 2010). They are traditionally written by health professional to patients to convey compassion, validate the person's strengths and provide recommendations (Freed *et al* 2010). Smithbattle *et al* (2010) report that they can help develop relational skills that are central to person-centred care because they can help the student learn from the person and help them connect with the individual. Although there is limited evidence as to the impact the letters have on the patient's experience, the work that has been done suggests that using therapeutic letters can provide encouragement to patients and provide tangible evidence of partnerships that the patients and with students. Therapeutic letter writing therefore provides a medium through which person-centred care takes precedence. The need for further research into the impact of disbelief on the self and person is critical if person-centred strategies for the management of pain are to be successful. Without a belief in the individual, there is no individual. Hence the study findings suggest that there is an imperative to believe in the patient as a person and the way in which this can be harnessed is diverse and has far reaching effects on policy, practice and research. Enabling the person to have a voice in care is crucial to person-

centred care. Facilitating a realistic rather than tokenistic approach means believing in the person's pain throughout the healthcare 'system' which has significant implications for research.

#### **10.8. Developing the Theory - The Implications for Future Research.**

The conditional partnership emerged as a theory to explain the experience of person-centred care from the perspectives of people with chronic back pain and the teams who cared for them. The theory highlighted the conditions essential for the partnership to succeed and therefore have implications for future research into person-centred care. The transferability to other settings is important. Person-centred care is not isolated to pain management, and as identified in the review, the work of Nolan *et al* (2004), McCormack (2003, 2006) and Kitwood (1997) have been instrumental in developing knowledge within the field of gerontology. Equally, Barker (2001) and others work in mental health context has inspired an approach to care that involved person-centred approaches. These theories and the conditional partnership need to be embraced within a wider arena such as acute and community contexts, surgical, medical and other specialities. Equally, Richardson *et al* (2005) argued that further research is needed in order to determine whether chronic pain is biographically disruptive and research in this area could help substantiate Bury's (1982) original work within a chronic pain context and identify ways in which delegitimisation could be avoided. Additionally, further research in this area could help develop meaning and understanding about the process of delegitimisation in other unseen conditions and expose ways in which to enable people with chronic back pain to mobilise their resources much earlier.

Using a sociological perspective to analyse and generate meaning about the experience of delegitimisation of the ability of the individual to repair the disrupted biography would help to further explicate the polemic of the conditional partnership and expand the theory through research specifically aimed at uncovering this experience. Ultimately, people with chronic back pain have been over-researched, but the focus has been on pain assessment and management through pharmaceutical methods as opposed to more subjective elements of chronic pain. The world of the person with pain has yet to



be fully explored. The number of people who suffer from long term chronic unseen illnesses is predicted to increase as the population ages and medicine advances. It is timely therefore to explore how people with chronic unseen pain can best benefit from a healthcare system that works with their needs and recognises the impact of the disrupted biography. Future research could enhance understanding of the disrupted biography and develop new ways of identifying this early on in the person's journey through healthcare.

### **10.9 Final Reflections.**

The research journey has been a rollercoaster of emotions: after feeling initially shocked to learn about the 'sceptical professional' through to later awareness of how teams had restored faith and helped the participants regain control. In particular, the 'paternalistic' actions of the team were at first disconcerting, because it forced me to critically analyse my understanding of care and the way in which healthcare is provided. The journey into the world of the person with chronic back pain has been revealing and rewarding. I was moved by the descriptions of care provided by the participants and relieved to discover that they had finally been helped to address their loss and pain. Generating meaning of the participant's world helped develop an understanding of person-centred care and encouraged reflection on my understanding of the concept of empowerment. However, having explicated the relationship and acknowledged the conditions that the participants and teams had about care, I now accept that person-centred care is conditional. For some, this revelation is incongruent with the principles of person-centred care, and may be perceived as contrary to the philosophical traditions of personhood such as altruism, unconditional regard and autonomy; yet, from an ethical and sociological perspective, this conclusion seems logical. I would therefore argue that this study represents a unique insight into the conditions of person-centred care that perhaps challenges the traditional and accepted norms of unconditional care.

## **10.10 Conclusion**

Grounded theorists have the opportunity to transform knowledge and push the boundaries of accepted practice. Taking the constructivist position to its logical conclusion, Grounded Theory can answer questions about phenomena, develop meaning and generate understanding. Importantly using Grounded Theory has extended the knowledge base and for people with chronic back pain, and through understanding their hidden world, has revealed person-centred ways of caring. As the key findings suggest, legitimisation of the chronic back pain experience is significant in helping an individual mobilise their resources and restore the(ir) moral self, hence, to be disbelieved or have ones experience delegitimized results in erosion of trust and eventually a negative image of self. The participants described how actions like this resulted in their disempowerment which ultimately deactivated them from the decision making process. From this position, it was easy to understand how significant the act of belief becomes when caring for people with chronic unseen and undiagnosed pain. The conditional partnership represents a relationship process that supports person-centred care through using biography to establish reciprocated faith and a healthy regard for the person as the cornerstone of care. Constructing the theory has been challenging, however, the implications of this work for teams and people with chronic back pain mean that the conditions within a partnership are transparent and acknowledged. For the person with chronic back pain, this means that from the outset of care, all professionals recognise the significance of legitimising pain and, above all, 'patients' with chronic back pain are made to feel valued, believed and cared for like a person.

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