Acquired brain injury and the emotional, behavioural and cognitive sequelae: the family experience

Mary Elizabeth Braine

Institute for Health & Social Care Research

School of Nursing, University of Salford, Salford, UK

Table of Contents

Chapter 6 Implications and Conclusions   164

Appendices

List of Tables

List of Figures

Acknowledgements

Abstract

Acquired brain injury (ABI) can be a sudden, dramatic and sometimes fatal event that instantly disrupts the lives of the patient and their families. ABI causes a variety of deficits including motor, cognitive, functional, emotional and behavioural. Whilst the extent of these deficits and their recovery may vary, and the affect of these injuries on the family has been the subject of much research over the past three decades, the specific impact that challenging behaviour has as a consequence of the ABI however, is sparse. This thesis will present the findings of a descriptive phenomenological study which set out to describe the experiences of those immediate family members of persons who have suffered acquired brain injury and present with challenging behaviours. Five carers who met the inclusion criteria participated in the study and were recruited from a regional neuroscience centre. The experiences were collected through in-depth, face-to-face semi-structured interviews with family members of persons with acquired brain injury. The interviews were recorded and transcribed verbatim to provide textual descriptions of the family members' experiences. Analysis provided rich descriptions of the family members' experiences. Seven interrelated themes emerged through data analysis: one theme described the challenging behaviours of the people with acquired brain injury and six themes describe the experiences of the family members; emotional turmoil that these behaviours engendered, a profound sense of loss, concerns for the future for themselves as well as the injured, a sense of loneliness, the affect on family functioning and finally the family members coping and adapting to the behaviours. The interview data also revealed that with time the experiences expressed were not dissipated. This study contributes to healthcare providers' understanding and knowledge of families experience of living with a person with acquired brain injured and their cognitive, emotional and behaviour sequelae, and supports the need for continued research in this area.

Glossary of definition and abbreviations

Acquired brain injury (ABI) - refers to the damage to the brain after birth; as a result of traumatic, chronic or pathological injury. It is an injury to the brain that is not hereditary, congenital or degenerative, such as Alzheimer's disease or multiple sclerosis. The term ABI includes traumatic brain injury, can be caused by some medical conditions, including strokes, encephalitis, aneurysms, anoxia (lack of oxygen during surgery, drug overdose, or near drowning), metabolic disorders, meningitis or brain tumours.

Adynamia - apathy or lacking in motivation, initiating activities or completing tasks, giving an appearance of lethargy.

Aggression - state of high agitation. Aggressive behaviour may be verbal, physical, environmental, self-directed or sexual. It includes any of the following components; behaviour damaging to individuals or property, attitudes, moods or gestures that people find threatening or intimidating, and behaviours that disrupt rehabilitation activities and social integration (Wood, 1990).

Agitation - distinguished from aggression and defined as disturbed behaviour as a result of over activity, resulting from internal discomfort (i.e. pain) or an external stimulus (i.e. excessive number of visitors). They may be uncooperative, incoherent, abusive and irritable.

Akathisia - a constant sense of inner restlessness, which may or may not be manifested in motor activity, ranging from bouncing legs and fidgeting hands to pacing behaviour. It does not require the presence of aggression (Lombard and Zafonte, 2005). Derived from the Greek word `kathisis` which translates to 'sitting'.

Alexithymia - a reduction in the tendency to think about emotions and a deficit in the ability to consciously experience, describe and identify emotions. Defined more than 30 years ago Sifneos (1973) introduced the concept of alexithymia, literally as 'a lack of words for emotions'. Features include difficulty identifying feelings and distinguishing between feelings and the bodily sensations of emotional arousal, difficulty describing and interpreting feelings of other people correctly.

Brain Injury - Damage to the soft tissue that make up the brain and which may result in significant impairments in an individual's physical, cognitive, emotional, and psychological ability.

Brief Symptom Inventory (BSI) – a 53 item self- reporting symptom inventory, widely used to assess current psychological distress and symptoms in both patient and non-patient populations. It uses a 5-point Likert scale from 0 symptom dimensions and three global indices of distress (Derogatis, 1993). The three global indices are Global Severity Index (GSI), Positive Symptom Distress Index (PSDI), and Positive Symptom Total (PST).

Burden - defined as the state of affairs that is difficult to deal with physically or emotionally (Allen *et al,* 1994), or something difficult to bear either emotionally or physically.

Caregiver burden - the extent to which caregivers perceive their emotional or physical health, social life, or financial status to be affected by caring for their impaired relative.

Caregiver Strain Index (CSI) - developed by Robinson (1983) as a brief measure of strain among informal caregivers of recently discharged medical patients. The scale consists of 13 items that reflect perceptions of care giving; care recipient characteristics, and the caregiver's emotional status.

Cognitive impairment - a loss or reduction in cognitive function usually identified via standardisation neuropsychological tests. Examples are memory, attention, spatial and perceptual function, planning, problem solving and reasoning skills etc.

Diffuse axonal injury (DAI) - Tearing and shearing of axons and insulating myelin sheath due to acceleration/deceleration/ rotation of brain within skull resulting in petechial haemorrhages and loss of consciousness.

Disinhibition - loss of inhibition, unrestrained behaviour as a result of a lessening or loss of inhibitions or a disregard of cultural constraints.

Emotional lability - Feeling up and down emotionally.

Family Assessment Device (FAD) - screening questionnaire designed to evaluate families according to the McMaster Model of family functioning. Developed by Epstein *et al* (1983) the respondents rate the 53 items on 4-point Likert scale ranging from 1 (strongly agree) to 4 (strongly disagree). These include; problem-solving, communication, roles affective responsiveness, affective involvement, behaviour control and general functioning. The scale has been used across different disability groups, including those with cognitive disturbances.

Family Environment Scale (FES) - designed to measure the social-environmental characteristics of all types of families (Moos and Moos, 1994). The 90-item inventory scale is based on a three-dimensional conceptualization of families, how the family members feel the family acts (real), how the family would act in a perfect situation (ideal), and in a new situation (expected).

Family Needs Questionnaire (FNQ) - developed by J. Kreutzer in the 1980s, a 40-item questionnaire designed to measure family members perceived needs after brain injury. It was designed to reflect the complete spectrum of family needs across the patient's recovery time.

Global Severity Index (GSI) - reliable indicator of distress.

Head Injury - injury to the brain that can result from blunt or penetrating trauma that result in direct injury at the impact site such as lacerations, contusions, abrasions and fractures. Indirect injury can also occur as a result of the brain movement within the skull, leading to contusion on the opposite side of the head from the impact, or injury to the brain tissue as a result of the sheering and rotational forces as the head accelerates and decelerates after the impact.

Head Injury Behavioural Scale (HIBS) - A 20-point scale which rates behavioural problems following traumatic brain injury using a 4-point Likert scale and generates two scores; a behaviour and distress score. There are two versions; the patient and the relative.

Hydrocephalus - comes from two Greek words: *hydros* means water and *cephalus* means head and refers to the abnormal expansion of cavities (ventricles) within the brain that is caused by the accumulation of cerebrospinal fluid (CSF), resulting in ventricular dilatation and raised intra-cranial pressure. This may be caused by subarchnoid haemorrhage blocking the return of the CSF to the circulation resulting in an accumulation of CSF.

Katz Adjustment Scale - (KAS- R) originally in two forms; Self-Report and Relative Report. The relative form KAS – R has proved to be more useful, used primarily in mental health patients to assess the follow-up rehabilitation services, and if so, how those services should be targeted. A 203-item scale composed of three parts; emotional/psychosocial, physical/intellectual and psychiatric changes. Used to obtain an assessment of the quality of life that is independent of the patient and administered to a relative or close acquaintance of the patient.

Perseveration - tendency for a memory or idea to persist or recur without any apparent stimulus for it or the act of continual or repetition of a particular behaviour.

Post-traumatic amnesia (PTA) - when patients wake up from coma, they are usually confused. This confused period is called *post-traumatic amnesia*. Generally they remember who they are but are otherwise very disoriented. They may not remember how old they are or where they lived. They often do not remember where they are, are very confused about time and may not accurately remember the year, month, day or date. This confused period is temporary and disappears after a period of days or weeks.

Psychological stress - stress caused by a psychological 'noxious' stimuli these stressors can be according to Lazarus (1993) differentiated into three kinds; harm, threat and challenge.

QRS - (Questionnaire on resources and stress for families with chronically ill or handicapped members) a self-administered 66-item questionnaire with 11 scales developed to measure the perceived stress in families caring for ill or disabled relatives.

Subarachnoid Haemorrhage - a type of stroke in which bleeding occurs into the narrow space between the arachnoid mater and the pia mater (surface of the brain). The subarachnoid space comprises the basal cisterns, the interhemispherical fissures and the Sylvian fissure. Aetiology varies, it can be caused by the following; aneurysm, hypertension/arteriosclerosis, arteriovenous malformation.

Traumatic brain injury (TBI) - is an assault to the brain, not of a degenerative or congenital nature, which is caused by an external physical force that may produce a diminished or altered state of consciousness, and which results in an impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioural or emotional functioning.

Chapter 1 Contextualising the research

1.1 Introduction

This chapter sets out to situate myself within the research study. I provide information about me and situate the research within the broader context of healthcare. The focus of the research is described along with the specific aims of the research study.

1.2 Context of the research

This study was conducted with families of persons with acquired brain injured who had challenging behaviour. The data were collected between January 2007 and July 2007.

1.3 Situating self in the research

Lincoln and Guba (1985) contend that the provision of biographical details about the researcher is a necessary element in qualitative research. Personal experiences, expertise and values all contribute to the research perspective adopted in a study. Providing such information gives the reader a more informed stance to assess the likely influence(s) of the researcher on a study and perhaps more pertinent, the inferences that are drawn. In phenomenological studies, the researcher is primarily the instrument of analysis, as she/he describes, evaluates participant responses for commonalities or essences (Giorgi, 1985, 1997; Moustakas, 1994; Creswell, 1998). In this thesis I operated from the premise that I must account for and publicly disclose my approach and decisions in all aspects of the research process, for indeed a crucial part of qualitative research is how we account for ourselves and how we reveal our secrets. Thus I need to lay down my own assumption about the experience of the phenomenon and what I believe about the projected study or the basis for the study. The rationales for the chosen methodological approach employed in this study along with personal reflections

are offered in Chapter 3. Information about me relating to this study is subsequently provided.

Who I am in this journey is informed by multiple experiences; personal, professional and academic. My personal background relates to the desire to understand the issues surrounding challenging behaviour, post acquired brain injury and to improve my research skills. Professionally the impetus for this research arose from my work in clinical practice as a neuroscience nurse. My interest in challenging behaviour grew from my earlier days as a ward manager, where in collaboration with Neuropsychology colleagues, we took several risks in the management of the patients and their families with challenging behaviour, under adverse conditions within the National Health Service; finite resources and lack of community services. On reflection I began to observe that the focus of managing challenging behaviour had been on the brain injury person with little provided for the family or carers. As a nurse I feel that my role is to support not only the injury person but the whole family unit and within the neuroscience setting this was often in my experience neglected. Although I started this programme of study working in clinical practice as a senior nurse within the speciality of neurosciences this was not my area of work when I started this thesis, as I had then moved into a full time position in higher education. However, despite this, I was driven by the inherent desire to continue to improve the quality of neuroscience practice both for patients and their families, and I perceived practice to be both clinical and educational.

In addition to my experiences as a nurse I also bring, at the beginning of this research study, personal critical reflection undertaken in the taught element of this programme of study. This engendered a sense of incompletion with regard to my work in the field of challenging behaviour and ultimately provided the inspiration for this study. In an effort to redress this, my academic studies led me to two publications centred on the management of challenging behaviour following acquired brain injury (Braine, 2005a, 2005b), and through joint leadership in clinical practice with my Neuropsychology colleague lead on the development of the policy for the Regional Neuroscience Centre, which addressed the serious issue of managing challenging behaviour within the service. This work clearly

identified for me the obvious gaps within the available literature, not least within nursing. There was clearly an inadequate evidence base as to the management and care of those patients with challenging behaviour in the neuroscience setting, and the balance of the current literature was markedly tipped in favour of quantitative studies. Perhaps even more fundamental to this research study was my growing sense of acute awareness of my own lack of knowledge I had of the experiences that those families could potentially have not just in the acute neuroscience setting but post-discharge from the Neuroscience Centre. The subject of this research study thus has been informed by the need to investigate and resolve a problem that related to my professional practice and one which is focused on professional knowledge and practice. According to Bourner *et al.* (2001) these are some of the distinct features in which a professional doctorate differs from a traditional doctorate. My ultimate aim being that I could impact on practice.

My research philosophy is grounded in several beliefs, one of transparency and reflection. Reflection for me is central to the research endeavour and professional development, and is a process that I have developed during the taught element of this Professional Doctorate. This, however, has fuelled doubt and presented me with challenges during this journey but, at the same time, helped me to gain a better understanding about myself and the complexities surrounding the issues that I grappled with. I also believe that there are several different ways of doing research to gain knowledge and understanding. A central tenet for me is one of appropriateness. At the beginning of this study I also recognized that my knowledge of the psychological theories that underpin my understanding of the phenomena was indeed limited and that I had little knowledge of family research or theories.

As a researcher using a qualitative methodology, I recognised that my own background can affect the credibility of a study. As Minichiello *et al.* (1995) argue, it matters whether a researcher has special 'inside' knowledge and insights or, on the contrary, comes to the study as an 'outsider' with no prior knowledge or prejudices about a group. There are arguments for and against each of these. The 'insider' has the advantage of gaining easy access to participants because of the

3

people they know and past associations with members of a group. These relationships can also work against a researcher and limit access to participants. Conversely, the 'outsider' may take longer to recruit their participants for the study and also to become familiar with the culture, political issues and the language of a study setting. While a researcher's gender, age, expertise or ethnic identity can limit or enhance study outcomes, the reality is that most researchers work with what they have, or with the resources they have to hand (Minichiello *et al.*, 1995). In this study I was well known to most staff members across the disciplines; this I initially thought would be an advantage, especially in the recruitment of the sample. Indeed what transpired during the recruiting of the participants for this study was that my clinical colleagues were instrumental in providing support in identifying possible participants. Being an insider also enabled me to remind the staff of my research study and thus gain a continual sense of support.

My clinical background of many years, including experience in managing acquired brain injured persons and their families within the acute setting, was viewed as a distinct advantage, in being able to communicate and develop a rapport with the participants. Without this insider experience I think the interviews would not have developed as they did and potentially not have generated such rich data. More importantly, I also believe that my insider/outsider perspective gave me the capacity to question and explore the experiences in ways that perhaps other researchers could not.

I recognise that these experiences that I have highlighted are embedded in consciousness and are not the kind that can be easily shared. However, I believe that it might be illuminated through some methodologies rather than others. Just as I am confronted with the new world of phenomenological research and the phenomena in question during this Professional Doctorate journey, so can it reinforce my beliefs and support existing theory. Thus the biases and beliefs that I bring to this research are such that they cannot be fully approximated at the beginning but, rather they are exposed as the journey progresses. The choices I have made in the subject of this thesis and descriptive phenomenological approach are indeed a reflection of many personal values and beliefs, although

the research approach adopted in this study was based on the fundamental belief that phenomenology would best answer my research question.

1.4 Situating the research

I consider that the acknowledgment and analysis of the situatedness of research in the wider social and political environment is important along with acknowledging one's theoretical assumptions and describing the research methodology. With this premise I will attempt to answer the fundamental question; why this study? I am acutely aware that the kind of research that I was contemplating; qualitative using semi-structured interviews, meets quite different objectives from quantitative research and provides a distinct kind of information, providing insights explanations and theories to social behaviour. I felt I was in a position to describe the reality of those who had suffered and who had not perhaps, been given a voice in this manner before.

1.5 Development of the research topic - motivations

This section is further sub-divided; firstly the background to the research problem is provided, followed by an exploration of the need for family caregiver research.

1.5.1 Background to the research problem

The increase in the number of surviving acquired brain injured persons in the population gives rise to the need to understand the impact this may have on the family and their carers in order that services can be planned and provided accordingly. It also became increasingly clear to me that the two most absorbing questions in the management of these patients and their carers were; do we fully understand from a nursing perspective the full implication of (1) acquired brain injury on the family and (2) the impact of the challenging behaviour that the injured

persons often exhibited following their acquired brain injury. These two important questions formed the basis for this research.

There has been extensive research from a quantitative perspective addressing the family outcomes of the acquired brain injury but few have approached this subject from a qualitative perspective. This arguably does not provide a complete picture of the phenomena in question. However, I do not reject other ways of knowing or understanding, but rather acknowledge that the positivistic, interpretive and critical paradigms need to work together so that holistic nursing care can be achieved and flourish. To my knowledge this research is unique in that it explores the experience of the family members of persons with challenging behaviour following acquired brain injury rather than the whole experience of living with a person with acquired brain injury.

1.5.2 Need for family caregiver research

More than 17 million people are living in the UK with chronic disability, of which approximately 10 million have a neurological condition (Neurological Alliance, 2003). Included in this group are the acquired brain injured. The aftermath of such chronic illness extends further than the individual with the health changes. It affects the entire family. The interactive nature of the individual family system calls for a more integrated approach to healthcare that includes the family as well as the individual patient. The importance of this is all too apparent in the National Service Framework (NSF[1]) for Long-term conditions which makes specific quality requirements (QRs 10):

> "Carers of people with long-term neurological conditions are to have access to appropriate support and service that recognise their needs both in their role as carer and in their own right" (DH, 2005a: p.5).

---

[1] The Department of Health's National Service Framework (NSF) for Long-Term Conditions was published in March 2005. Although much of the guidance applies to those with a long-term condition, the main focus was on neurological conditions.

The NSF for Long-term conditions (DH, 2005a) includes in its categories of long-term conditions, sudden-onset conditions and gives the example of acquired brain injury followed by a partial recovery. The framework also makes specific reference to the cognitive and behavioural problems that are associated with such conditions and the need to address such problems. The NSF (DH, 2005a) also specifically sets out to address the assessment of personal care and support which includes the psychological and emotional needs of the patient and this assessment needs to take into account the family's needs (QRs 8).

The residual effect of acquired brain injury can be lifelong and devastating for both the victim and their families. Symptoms can include physical, cognitive and psychological-social-behavioural impairments. These behaviours not only make treatment and management interventions problematic, resulting in physical or psychological harm to the patients, but also can have an effect on the family or carers. In recognition that the experiences are unique to each individual, but may have common characteristics, has significance for the provision of nursing and for these families. This is particularly pertinent in the current political and economical climate in which standards of care and value for money are the drivers for service initiatives and redesigns (DH, 2004, 2006a, 2006b). The Audit Commission (2006) stated that the successful management of long-term conditions is a great challenge for NHS management, but it has the potential to improve the quality of life for service users and their families and also generate significant savings. Furthermore, in order to provide holistic care, nurses have to be able to look at not only the medical aspects presented during assessment, but also the psychological, emotional, environmental, and the lived experiences that the patient and the family endure. Arguably healthcare professionals working with families of acquired brain injured patients need to consider the impact of a long-term caring role of the carer's wellbeing. For many patients the families play an important role in their rehabilitation process in promoting health and wellness (Sander *et al.*, 2002; Turner-Stokes, 2003). However, to provide families with the most appropriate long-term support to prevent carer morbidities such as anxiety, stress, and depression and alleviate any adjustive problems that they may experience, then further research is required in order to understand how best to meet these needs. Because of the important role that the family plays in the rehabilitation

process and little understanding of the effect on the family it would seem pertinent to focus on the family caregiver rather than on the victim of the acquired brain injury (ABI).

1.6 Purpose of the study – aims

Acquired brain injury can be a sudden, dramatic and sometimes fatal event and instantly disrupts the lives of the patient and their families. These events can lead to stress for the families and even lead to crisis affecting both the individual family members and the family system as a whole. Many of these patients suffer cognitive, emotional and behavioural problems post injury and it is these sequelae that the study intended to focus on, exploring the immediate family's experience of such psychological changes. The purpose of this research was to describe the family's experience of challenging behaviour following a primary diagnosis of ABI. My aim, however, was not to generate theory, nor to generate a general explanation but to 'explore and understand the lived experience of family members who have experienced challenging behaviour'. In addition, the research intended not only to re-conceptualise but to challenge how nurses view the nurse-family relationship.

In order to address this question a phenomenological approach was used, which aims, through description, to illuminate participants' experiences and to reveal their meaning. The descriptive work of the study is based on semi-structured interviews with immediate family members of patients who, following acquired brain injury, exhibited challenging behaviour. Each participant was asked to describe their experience; to 'tell their story'. The transcripts of the interviews were systematically analysed to present the phenomenon from the participant's perspective and searched for meaning units and explicate their main themes. In phenomenological research, the research questions are developed and worded carefully so that they are appropriate to the phenomenon being studied (Moustakas, 1994). Thus the specific research questions for the study were as follows:

- What are the experiences of immediate family members of persons who have suffered acquired brain injury and who present challenging behaviour?
- What is the effect of the challenging behaviour on the family member?

As the focus of this study was on the family's experiences of care it was anticipated that the data analysis and findings would add to the existing body of evidence and may be used to inform policy and enhance care delivery to an under researched group within the field of neurosciences. This practically may be facilitated through education programmes, raising the importance and need for family support in this patient group and through future guideline developments. It was also anticipated that it may provide a means of identifying and justifying future provision of high quality nursing care. Finally, the importance of the family's needs at such a difficult time may be highlighted through this research and redress the need for an integrated system of recovery that also encompasses the family and carers. The objective of the research also intends not only to re-conceptualise but to challenge how nurses view the nurse-family relationship.

1.7 Summary of the proposed study

As this thesis forms part of the submission for the professional doctorate it has been written in such a way as to represent the researcher's journey of discovery and growth, thus reflection and reflexivity are weaved throughout this thesis. The subsequent chapters will present the research study and its findings in the following way: Chapter 2 provides a detailed literature review of the current findings on acquired brain injury and its cognitive, emotional and behavioural sequelae. Chapter 3 discusses the methodology and defines the phenomenological approach used in this study, justifying its application. Chapter 4 sets out to describe and discuss the research method employed, detailing sampling, the conduct of the semi-structured interviews and issues that this raised. This chapter will also discuss the experiences of data analysis including the transcribing and development of emergent themes and concludes with a presentation of emergent themes. Chapter 5 provides a presentation and discussion on the emergent themes. Finally, the concluding Chapter 6 provides a

summary of the study, its findings and the contribution it has made to the advancement of my professional practice. This final chapter also includes a discussion on the implication for nurse education, practice and further research.

---oOo---

Chapter 2 Acquired brain injury; reviewing the evidence

2.1 Introduction to the area of study

This chapter demonstrates my understanding of the literature on acquired brain injury and the neuropsychological (cognitive, behavioural and emotional) sequelae. The purpose of this literature review is to provide a description of the context and setting for this research study, the epidemiology and consequences of acquired brain injury (ABI), the prevailing literature pertaining to the families/carers' experiences with specific reference to the cognitive, emotional and behavioural sequelae. The chapter also provides a brief review of healthcare workers' experiences of challenging behaviour. Finally a reflection is offered on the literature searching process.

The literature reviewed in this chapter was wide-ranging (but not exhaustive) and did not exclude those studies that were over 10 years old or sourced from different countries. As the topic in question is not delineated in the nursing literature or indeed very well in other bodies of literature, a broad range of search strategies was used. This strategy included electronic database searches, hand searching relevant journals and reviewing key documents (governmental, policy and practice documents and inquiry reports). A detailed account of the literature searching process is illustrated in Appendix A.

2.2 The problem of acquired brain injury

Acquired brain injury is the leading killer and cause of disability in children and young adults (House of Commons Health Committee, 2001). ABI is an inclusive category that refers to the impairment of brain function that is physically and psychologically verifiable. Common causes of ABI include the following; trauma due to head injury or post-surgical damage (e.g., following tumour removal), vascular accident (e.g., stroke or subarachnoid haemorrhage), cerebral anoxia and other toxic or metabolic insult (e.g., hypoglycaemia) and infection (e.g., meningitis, encephalitis) or other inflammation (e.g., vasculitis), with the resultant

11

impairment of cognitive ability, sensory and physical function. This may either be temporary or permanent and may result in partial or total disability or psycho-social maladjustment. However, the most common cause of ABI is a traumatic injury to the brain (TBI) a subset of ABI and refers to the cerebral assault by an external physical force that is likely to result in altered or diminished state of consciousness as a result of either a blow to the head or a violent whipping action of the neck. There is no such thing as a 'typical' ABI as similar injuries may produce different effects in different people. Whilst a large majority of brain injured patients suffer apparently minor injuries they subsequently have high levels of cognition deficits which disrupt their lives and those around them (DH, 2001a). Brain injury strikes at the very core of those fundamental structures that determine a person's humanity and self-identity (Groswasser and Stern, 1998), with the psychological, emotional and behavioural consequences initiated by ABI presenting the victims with the challenge of reconstructing and reorganising their identity. Survivors of severe TBI experience a period of post-traumatic amnesia (PTA) that may last weeks or months. During this period and often for some time afterwards, the patient may experience what Groswasser and Stern (1998) describe:

"...as having lost control over everything. They are physically, emotionally and cognitively dislocated." (p.72)

This may manifest in behaviours that are termed challenging. The term 'challenging behaviour' was introduced in North America in the 1980s to describe the problematic behaviours of people with learning difficulties. However, it is a term that is now widely used across the spectrum of health disciplines. The literature offers many definitions of challenging behaviour, but perhaps the most widely used is offered by Emerson (1995):

"...culturally abnormal behaviour of such an intensity, frequency or duration, that the physical safety of the person or others is likely to be placed in jeopardy, or behaviour that likely to seriously limit use of, or result in the person being denied access to ordinary community facilities." (pp. 4-5)

The term however, does not carry any diagnostic significance; rather it describes the behaviour of an individual. People with cognitive impairment have difficulty in processing, integrating, retaining and applying new information making

management difficult for both healthcare professionals and families/carers. Challenging behaviour is 'anti-social' which carers and services may find difficult to manage and may include self-injurious and aggressive behaviour. The more severe challenging behaviours tend to be shown by people with more severe disabilities, particularly where communication is impaired. It can take several forms, ranging from mild to severe. Challenging behaviour may take several forms these may include the following; adynamia, agitation, akathisia, disinhibition, emotional lability, denial, apathy, inertia, impulsivity, frustration, intolerance, lack of insight, poor judgement and reasoning skills, confabulation, perseveration, acts of aggression and destruction[2] (Sandel and Mysiw, 1996; Ducharme, 1999). The brain injury person may also present with depression and anxiety. These behaviours not only present many challenges to families of the injured and the multi-disciplinary team as they are only too often at the front-line of care delivery, but also to service providers. These behaviours can last for several weeks or even years and may even be permanent.

2.3 Prevalence of acquired brain injury

Traumatic brain injury is recognised as a major public health problem, affecting a significant number of young people, who, if they survive, may have significant deficits for many years, making considerable demands on health services (Jennett, 1998; DH, 2005a). Despite this, very little serious attention is devoted to brain injury, and the lay public is often unaware of both the enormity of the problem and the nature of the sequelae of TBI. Brain injury has been called the 'silent epidemic' referring to the fact that actual number of brain injuries is not known and much of the public are unaware of the impact of ABI (Langlois et al., 2004). The term 'silent epidemic' also refers to the affected families of the persons with ABI, a burden that is increasing and one which arguably is also of epidemic proportions.

---

[2] Terminology used in this thesis has been defined in the Glossary and provides an orientation and overview.

Although ABI is a well-documented reason for hospital attendance, studies on the incidence and epidemiologic features of ABI and the immediate outcomes are scant; many are out dated and not all are conducted in the UK. Furthermore whilst the literature on ABI may be prolific, the emphasis is predominantly clinical. Jennett (1998) maintains that reliable statistics are difficult to extract from routinely collected data. The best resource for this information appears to come from research data, but this seems to be variable. For the Department of Health and National Health Service organisations to be able to properly plan services that meet the real needs of people who have suffered acquired brain injury and subsequent disability, adequate epidemiologic data are undoubtedly required. Indeed this was the second recommendation of the House of Commons Health Committee's report (2001) urging the Government to address that serious deficiency in their ability to properly put in place services that match need.

The use of statistics in representing UK-wide incidence of acquired brain injury is not only many years old, but potentially erroneous. For example, the Written Answer to a Parliamentary Question on support given to survivors of acquired brain injury, quoted statistics which referred only to traumatic brain injury (head injury) (House of Commons, 2001). The designation 'acquired brain injury' however, includes not only traumatic brain injury or head injury, but also other brain injuries and progressive neurological conditions, such as stroke. The current statistics on the incidence of head injury that is often quoted by the Department of Health, is based on a 1991 study by McMillan and Greenwood (1991), estimating that approximately 186,000 people each year are admitted to hospital with a diagnosis of head injury. Furthermore it is these figures that are the origin of the statistics quoted in the 1999 Royal College of Surgeons' report into the management of head injuries (The Royal College of Surgeons, 1999). According to Brookes *et al.* (1990) the only systematic data on attenders to accident and emergency departments are from surveys carried out across Scotland in 1974 and 1985, and in one district general hospital in Glasgow in 1984. These provide a dataset of 12,000 attenders, indicating that approximately 10% of all new attenders at accident and emergency departments present with head injuries, however, these statistics are dated and thus cannot be depended on.

Jennett (1998) states that head injuries account for one quarter to one third of all accidental deaths, and for two thirds of trauma deaths in hospital and are the main cause of lifelong disability after trauma. There is an estimated 1.4 million people in the UK who will attend hospital each year as a result of a head injury (Jennett and MacMillan, 1981; Hodgkinson et al., 1994; Jennett, 1998). Of these 10,000 will suffer a moderate head injury and after five years will have physical or psychological problems, and 11,600 will suffer a severe head injury[3] with only 15% returning to work. Whereas 30 years ago 90% of all people with severe head injuries died, now the majority survive (DH, 2001b). The incidence of traumatic brain injuries is high, the annual figure for the UK has been reported at 300 per 100,000 (Barnes et al., 1998), more recent figures are frequently reported in the literature for Europe of 200-250 per 100,000 population at risk per year (Servadei et al.; 2002; Tagliaferri et al., 2006). In Maegele et al.'s (2007) Cologne (Germany) study, the authors reported much lower rates of 7.3 per 100,000 whilst in contrast the Sweden study carried out by Styrke and colleagues (2007) reported incidence rates as high as 354 per 100,000. Although the incidence may be reported to be high by some studies, the mortality rate from TBI is relatively low (6-10 per 100,000) (Kay and Teasdale, 2001). However, these data are also inconsistently reported within the literature. Tagliaferri et al. (2006) carried out a systematic review of brain injury epidemiology in Europe, 23 studies were identified and the authors reported an average higher mortality figure of 15 per 100,000. Sundstrøm et al. (2007), however, demonstrated that there are substantial disparities between the Nordic countries, with Finland reported to have about twice as high TBI mortality rate; 21.2 per 100,000 per population as other Nordic countries (mean of 12.6 per 100,000 per population). The authors make no claim as to the disparity of the figure, but comment, that although the diagnostic tools (ICD 8–10) (WHO, 2001) are similar, there may still be variations in the procedures of coding.

Despite the reported disparities in the figures, over the past 30 years, deaths following road trauma have fallen substantially, especially since the introduction of occupant-protective devices, crash helmets and alcohol limits (Rivara et al., 1999;

---

[3] The classification of mild, moderate and severe TBI (head injury) is dependent on the Glasgow Coma Scale (GCS) (Teasdale and Jennett, 1974), GCS 13-15 classified as mild TBI, GCS 9-12 moderate TBI and GCS 3-8 as severe TBI.

Cunningham *et al.*, 2000; Liu *et al.*, 2008). In spite of this, as traumatic brain injury forms a subset of acquired brain injury, the number of acquired brain injured patients who survive in the UK is likely to grow as technological advances increase the likelihood of survival, and further challenge the service provision for this patient group and their families. Furthermore as the incidence of head injury in vulnerable road users (i.e. pedestrians and cyclists) remains high and, when calculated on an exposure basis rather than a population basis, can be shown to be rising. The incidence of interpersonal violence is also a concern, with figures for England and Wales alone for violent incidences reported to be 2,164,000 for 2007/8 and with violent incidents accounting for just over a fifth (21%) of all crime in England and Wales in 2007/08 (Home Office National Statistics, 2008). As a Health Committee report on Head injury: Rehabilitation states:

> *"Head injury is the foremost cause of death and disability in young people. In an age of increased motorisation and violence, head injury is a healthcare problem which is not going to go away..."* (Health Committee, 2001: p.1)

More up to date data from the World Health Organisation postulates that, given current trends, the global burden of violence and injuries is expected to rise during the coming decades (WHO, 2008). There is increasing evidence available that links incidence and severity of head injury with violent offending. Whilst most studies have concentrated on adult offenders, demonstrating a significant association between head injury and violence (Sarapata *et al.*, 1998; Leon-Carrión and Ramos, 2003), Kenny and Lennings's (2007), Australian research on incarcerated young offenders, also reported an association with severe violent offending with previous head injuries. Although the reason why these individuals get involved in crime is multifactorial i.e. alcohol and drug misuse, cultural and social factors, this evidence clearly points to a growing problem world wide and the consequential increase in incidences of head injuries.

In Thornhill *et al.'s* (2000) study, centred on five acute Glaswegian hospitals, the authors found a high frequency of disability after mild as well as moderate and severe injuries. They estimated an annual incidence of persisting disability in young people and adults of 100-150 per 100,000 population, higher than previously thought, with seemingly mild injuries leading to high rates of long-term

disability. Although the research draws from a local population, rather then a more widespread population, the authors suggest that their findings of persisting disability in 40-50% of moderate injury is not unrepresentative of urban British populations. The authors also believe that the under appreciation of the frequency of problems after head injuries contributes to inadequate services after discharge. These estimates, however, may suffer from ascertainment bias since they are based exclusively on information about hospitalized patients and those who die before hospitalization. Whilst the codes within the International Classification of Diseases (ICD-10) (WHO, 2001) does allow some estimates of the frequency of head injuries from routine statistics on deaths and hospital discharges, Jennett (1998) contends that multiple injuries and transfers after first admission make estimates inaccurate, a view supported by Engberg and Teasdale (2001) who reported a 12% coding error whilst exploring the incidences of TBI in Denmark. Furthermore, research carried out in Wales suggests that less than 50% of all head injury admissions can be detected by this means (Debs, 1999). Bruns and Hauser (2003) contend that these figures in the USA are subject to both under numeration and over numeration depending upon where data were collected i.e. hospital admission data, emergency departments and trauma centres. Overall the researchers concluded that the TBI incidence rate in the USA is between 180-250 per 100,000 population per year. Tennant's (2005) study reported much higher head injury incidence rates in England of 229.4 per 100,000 and also commented that these incidence rates varied across health authorities and primary care trusts ranging from 91-419 per 100,000. Given that these figures were derived from hospital admissions, which are known to be an underestimation of the true figures, these rates have significant implications for service provision.

In a national survey of Health Authorities in the UK (Andrews, 1992) on services for severely brain damaged people, it was found that a considerable number of health authorities were not aware of any patients with severe brain injury. This survey has not been replicated and conclusions are difficult to draw from such as dated survey. Although according to Barnes et al. (1998) in a UK health district with a population of 250,000 it is likely to generate 44 moderate and 18 severely brain injured cases per year. Whilst estimates by the National Institute of Health Consensus Development Panel on Rehabilitation of Persons with TBI showed that

2.5-6.5 million Americans live with TBI-related disabilities (National Institute of Health, 1998). A more recent estimate of the problem is quoted in the report by the Greater Manchester Traumatic Brain Injury Audit Group (2006) in which they state that in a health district with an average population (approximately 250,000) the number of disabled survivors expected to be living in the district at any one time will be between 250 and 375.

Overall the TBI incidence rates are varied, with most studies analysing the overall population, whilst few have considered the changes in the distribution and prevalence over time. In addition, few have articulated the significance of legal initiatives such as helmet and seat belt laws, speed bumps and geography on the epidemiology of TBI; although Engberg and Teasdale (2001) felt that the decrease on TBI in Denmark between 1979 and 1996 was attributed in part to the comprehensive national programme aimed at preventing personal injury. Furthermore the epidemiological discrepancies can be attributed to the varying methodological differences between the studies particularly the inclusion criteria used, makes for comparison and conclusion drawing problematic. As most studies report the hospitalized TBI patient only part of the 'silent epidemic' is known. The number of people living with TBI-related disability is largely unknown, although according to some estimates this may be 7.8 million in Europe alone (Tagliaferri *et al.*, 2006).

Despite the discrepancies in the prevalence of TBI and ABI the demographic details of the TBI population are consistently reported within the literature. Epidemiological features of the TBI population are consistently reported to have a trimodal age-specific distribution; the first relates to school age children and pre-adolescent, the second relates to adolescent and young adults representing the highest age-specific incidence and finally the older population with an increase incidence with advancing age (Bruns and Hauser, 2003; Greenwald *et al.*, 2003). The highest incidences occur between the average age of 16-25 years and a ratio of male to female ranging from 2:1-3:1 with the most likely cases being road traffic accidents and assaults (Bruns and Hauser, 2003; Maegele *et al.*, 2007). However, it is important to point out that these figures relate to the TBI only and not inclusive of those people with acquired brain injury. Epidemiological studies in other

neurological diseases are also not so clear. For example, subarachnoid haemorrhage (SAH) epidemiological studies are variously estimated to occur in 2-22.5 per 100,000 of the population (Ingall *et al.*, 2000). Despite it being the fourth commonest cause of intracranial death, medical and surgical advances have dramatically improved the survival rates, with varying mortality and morbidity figures being reported in the literature. Although SAH is a much more infrequent illness in comparison to TBI, the consequences produce a pattern of deficits similar to that of a TBI (Leon-Carrión *et al.*, 2005).

Despite the inadequacies within the epidemiological data, Olesen and Leonardi (2003) highlight the huge burden of brain disease as defined by the World Health Organisation to include all those diseases traditionally viewed as neurological, psychiatric and neurosurgical stating that these figures are impressive, with 35% of all disease in Europe caused by brain diseases. These figures do, however; include dementia as it is included in the neuropsychiatric condition in the International Classification of Disease (ICD) codes (WHO, 2001). The authors allude to the dearth of research on the burden of brain disease in Europe but highlight that if all brain disease complications and their sequelae were included the burden would be even higher. Moreover in the first global burden disease study, Murray and Lopez (1997) predicted by the year 2020, a marked increase in the burden from brain disease.

Undoubtedly it is because of the varying conditions that make up the population of ABI, coupled with discrepancies in data collection, that enable the collating of exact figures for prevalence of ABI in adults so difficult. Despite the widespread prevalence of brain injury, services to help and support the victims are reported to be woefully inadequate (Moules and Chandler, 1999; DH, 2005a; Turner-Stokes *et al.*, 2008). Furthermore, the magnitude of the prevalence rate and the acknowledgement that this is likely to increase, suggests the importance of looking beyond the initial survival to long-term care provisions for both the brain-injured person and their families.

2.4 Prevalence of physical and behavioural, cognitive and emotional sequelae

The purely physical sequelae of severe head injuries is well documented (i.e. sensorimotor disturbance, gait disturbance, cranial nerve lesion) within the literature, but over the last 20-30 years it has been increasingly recognised that it is the psychological sequelae; the cognitive, behavioural, and emotional changes that account for the greatest share in long-term disability. Furthermore, the morbidity may persist long after injury. The cognitive, behavioural and emotional sequelae following ABI contribute more to the final outcome than the physical deficits. The psychosocial adjustment after severe TBI is a dynamic process (Tate and Broe, 1999). Moreover, this process may be a protracted one, in some cases lasting several years and presents a far more significant challenge to rehabilitation.

It is widely reported that anxiety and mood swings are common as part of the post concussional syndrome[4] found in mild traumatic brain injury, however; the studies that attempt to address the prevalence are limited. Ruff, Camenzulis and Mueller (1996) suggest that around 15% of mild TBI (MTBI) cases, display persisting cognitive weaknesses, in addition to somatic complaints, such as headache, dizziness, insomnia, and fatigue and term these the 'miserable minority'. In the USA alone it was estimated in the 1990s that 1,300,000 will suffer a MTBI per year (Kay *et al.*, 1992), given these percentages quoted by Ruff and colleagues this results in an estimated 195,000 per year that will present with persistent problems following trauma. This represents a sizable challenge to health care systems around the world. Indeed, Levin *et al.* 's (2001) research study, funded by the U.S. Centres for Disease Control and Prevention, aimed to estimate the prevalence, risk factors and effect on outcome of depression after mild to moderate TBI, found

---

[4] Post-concussional symptoms (PCS) usually include somatic problems of headache, dizziness, sleep disturbances and fatigue, cognitive problems such as information processing and attention that have an impact on memory and daily living skills and affective problems; irritability, anxiety, and depression. It usually lasts 3-6 months after minor or moderate concussional injury (Brown *et al*, 1993; Ingebrigtsen *et al.*, 1998; Mittenberg and Strauman, 2000). The ICD-10 (WHO, 2001) defines PCS as a set of three or more symptoms that appear for longer than 4 weeks after a history of head trauma injury.

that the risk of depression was significant and increased after mild-moderate TBI and may be predictable soon after injury. Similar to Langlois *et al.* (2004) defining brain injury as a silent epidemic, Gordon *et al.* (1998) characterize TBI as a 'hidden epidemic' and cite three main reasons; firstly due to the 'invisibility' of the injures as MTBI is rarely detectable via magnetic resonance imaging, secondly due to the neuropsychological sequelae not being evident immediately after impact and thus TBI remains hidden to others, and finally the person who has sustained TBI often fails to casually link the injury to their neuropsychological change. The somatic elements part of the post-concussional syndrome were formerly thought to appear only in mild TBI, however, it also reported to appear in severe TBI patients and exerts a negative influence on returning to pre-injury life (Groswasser, 2003).

ABI is characterized by moderate changes in one, or all, of an individual's level of cognitive, emotional, behavioural, or physiological functioning and these changes can take a number of forms. Exactly which of the brain's functions will be affected by an ABI depends on the location and extent of the injury. Cognitive changes may include difficulties with memory, organisational skills, concentration and attention. Emotional changes may include; an increase in irritability and a decrease in tolerance for frustration, symptoms of depression, social withdrawal, and learned helplessness and the tendency to display excessive or inaccurate emotional responses to events. Whilst behavioural problems may include, behaving inappropriately, impulsive or obsessive behaviours and lack of initiative or difficulty in following through on tasks. ABI thus can cause dramatic alterations in identity and structure of self as a result of changes in cognitive, emotional and behavioural abilities, social context and family dynamics.

Challenging behaviour has been described as a significant problem for many patients following traumatic brain injury, although the literature is inconclusive as to its prevalence. Although the prevalence of challenging behaviour within the learning disabilities population is well documented, perhaps reflecting the longer use of the term challenging behaviour in the field, in the speciality of neuroscience it is less clear. In Thornhill *et al.* (2000) study the incidence of disability following traumatic brain injury in adults was found to be higher than the researchers had

expected, with specific problems of cognition and mood consistently reported in all survivors of mild, moderate and severe head injury: 47%, 48% and 76% respectively. These results were thought to reflect the often unrecognised 'mental' sequelae of a brain injury. This was considerably higher than Masson *et al.'s* (1997) study carried out in France in which the researchers stated that 4% of head injured patients needed family support because of behavioural or cognitive problems, and this was permanent in about 20% of the most severe cases of head injury. Whilst in the much earlier Danish report, Thomsen (1974) identified 84% of survivors of severe head injury exhibited severe behavioural and emotional problems that interfered with family life. Similarly, Marsh *et al.* (1998) assessed 60 severe TBI patients and their caregivers 6 months post-injury, and reported a higher prevalence of cognitive problems (90%), and high levels of behavioural problems e.g., impatience (65%), depression (65%). Johnson & Balleny (1996), however, identified behavioural problems in about 30% of severe head injured patients whilst they were in hospital, but, interestingly once these patients had returned home their families identified symptoms in about 80% of cases. This could possibly be attributed to the increased attention required to the person with ABI, and thus increased sensitivity to the behavioural changes, once in the home environment.

In a longitudinal study of a representative sample of 157 adults with TBI compared with a control group, Hanks *et al.* (1999) explored emotional and behavioural adjustments following TBI using the Katz adjustment scale at 1-month and 12-months. The researchers reported a host of emotional and behavioural difficulties in the TBI group, with the mild or severe brain injury patients, reporting less extensive problems than the moderate brain injuries, and over a period of a year the TBI group changed in variety of ways. Although they demonstrated a decrease in some behaviours i.e. confusion, social withdrawal, other behaviours were found to increase i.e. anger, impulsivity, poor self-monitoring. This highlights the complexity of the neurobehavioural sequelae and the inherent difficulties in measuring such diverse changes.

More specifically, the prevalence of aggression following TBI is equally reported to be unclear and varied; Brooks *et al.* (1992) reported incidences of 11%, March *et*

al. (1998) reported aggressive levels of 28% in severe TBI patients 6 months post-injury and Tateno *et al.* (2003) similarly reported an aggression rate of 33.7% in their patients with TBI at 6-months follow-ups. However, Baguley *et al.* (2006) reported a lower figure of 25% of 228 patients with moderate to severe TBI, five years post-discharge from inpatient rehabilitation, were classified as being aggressive. Investigating such behaviour is arguably difficult as it is often unpredictable, transitory and overt in nature and may last for weeks or even months in some cases. It rarely occurs to order although in many cases there are predictable factors that can trigger the behaviour.

It is usual to distinguish the difference between agitation, (defined as disturbed behaviour as a result of over activity), from aggression, both verbal and physical aggression against self, objects, and other people. Agitation may occur in 10% of severe head injuries (Brooks *et al.*, 1992), although the cited incidences post injury is variable. Sandel and Mysiw (1996) maintain that the incidence of agitation after severe TBI is reported to be varied citing rates up to 50% in survivors; similarly Kadyan *et al.* (2004) reported agitation to be as common as 50% following TBI, with no difference noted in agitation with regard to gender. Whereas Nott *et al.* (2006) study which aimed to examine the nature and incidence of agitation during TBI rehabilitation in an Australian sample, found a larger proportion of patients with agitation (70%).

Only a few reports address the concept of alexithymia after TBI despite the concept being introduced over 30 years ago (Sifneos, 1973). The Finnish researchers Koponen *et al.* (2005) attempted to redress this by recruiting 210 TBI patients into their study and of the 54 that met the inclusion criteria, 31% were found to have alexithymia compared to 14% in the control group. This research highlights the importance of identifying alexithymia in the TBI population, and educating healthcare professionals as to its features.

Although the list of dysfunctional behavioural problems as a result of ABI is long, specific behavioural difficulties associated with TBI that have been identified in the literature include; anger and impulsivity (Hanks *et al.*, 1999), childish behaviour (Brooks *et al.*, 1986) agitation (Lombard and Zafonte, 2005), and aggression

(Baguley *et al.,* 2006) and alexithymia (Henry *et al.,* 2006) and lack of self-awareness. These often interact with one another, manifested by lowered frustration, tolerance and capacity to self-control mood, giving rise to the so called 'frontal syndrome'. Whilst there may be agreement on the constellations of difficulties these patients may experience, there is not such a comprehensive illumination in the literature as to the nature and affect these may have on the family and their carers.

2.5 Psychological (behavioural, emotional and cognitive) sequelae affect on family members

2.5.1 Introduction

This section reports the key literature on the family's experience of the psychological, emotional and behavioural sequelae following acquired brain injury. Rehabilitation following brain injury is expensive and time consuming and it is often the cognitive deficits (e.g., disorders of memory, perceptual, attention, concentration and planning) rather than the physical deficits (e.g., paralysis) that prevent and delays full recovery. Following ABI the family may be abruptly faced with the prospect of coping with a relative who is very different from the one that they knew before the trauma, and who may exhibit a variety of symptoms, including cognitive, emotional and behavioural problems.

Because caregivers of people with ABI are at risk of emotional maladjustment an increasing substantial body of research is emerging that attempts to understand the impact on family members. Examining the literature on the acquired brain injury family two major approaches seemed to emerge. One approach views the family as a whole system concerned with family functioning and relationships. The other utilizes an individualistic approach, concerned with individual family members (i.e. spouse, parent and sibling) and the impact the ABI family member has on them. At this juncture I consider it is important to define what is meant by a family. The definitions of family vary within the literature and may be dependent on

culture and society, and would appear to change over time. However, any definition of a family should include the widely quoted definition offered by Beutler *et al.* (1989) in which the family is characterised as a unique set of relationships, experiences and characteristics[5]. An alternative definition is offered by Hanson (2001) in which a family refers to:

> "...*two or more individuals who depend on another for emotional, physical and economical support.*" (p. 6)

The following section will present a review of the key literature on the subject, firstly exploring the impact on the family as a whole and then focusing on the affect of ABI and its psychological sequelae on individual family members. In the final section the influence of time since injury on the non-injured family member experience is also explored along with the perceived needs of family members of the ABI person.

2.5.2 Carers' distress, stress and burden

There is increasing evidence that there is a strong correlation between the behavioural and emotional problems with the extent to which family members experience pressure, anxiety and feelings of depression. However, the significance of the impact of challenging behaviour following ABI on family members has not fully been explored. Researchers have reported that behavioural problems in patients following TBI leads to an increased stress level and risk of depression and anxiety in family carers (Gillen *et al.*, 1998; Watanabe *et al.*, 2001; Connolly and O'Dowd, 2001; Harris *et al.*, 2001; Godfrey *et al.*, 2003). In a cross-cultural comparison study (UK and Japan) Watanabe *et al.* (2001) examined the impact on family members who care for an individual with TBI via face to face interviews and questionnaires with 18 British family members and 12 Japanese family members. Whilst both cultures felt a duty of care for the injured person and

---

[5] "These are a) the generational nature and permanence of family relationships, (b) concern with 'total' persons, (c) the simultaneous process of orientation that grows out of familial care giving, (d) a unique and intense emotionality, (e) an emphasis on qualitative purposes and processes, (f) an altruistic orientation, and (g) a nurturing form of governance." (Berulter *et al.*, 1989: p.806)

25

reported being tired and frustrated and anxious by the experience, the British families reported more stress than the Japanese families. However, the study did not assess the level of disability, especially the behavioural and personality changes of the patients, thus families whose TBI relative had more changes might have experience higher levels of stress than those with less.

Connolly and O'Dowd (2001) whilst investigating the effects of different disabilities on the primary caregivers' found that behavioural disabilities showed the strongest association with the carer's perceived stress scale. These findings are also consistent with earlier research carried out by Oddy *et al.* (1978) and Allen *et al.* (1994), in which cognitive and behavioural variables have tended to have a greater association to the burden outcome measures than socio-demographic or physical variables. Whilst in the early study carried out by Rosenbaum and Najenson (1976) the researchers revealed that the childish behaviour of people with TBI was the most disturbing to their partners.

Santos *et al.* (1998) examined the complaints of TBI family members 6 years post-injury (n = 48) and clearly identified behavioural problems (aggressiveness and irritability) as the most frequent complaint by close relatives. This was later substantiated by McPherson *et al.'s* (2000) research which found that the emotional and behavioural sequelae of a TBI caused distress and strain for carers. Marsh *et al.'s* (1998) research indicated that the aggression, sudden/rapid mood changes, and argumentativeness caused the greatest degree of distress for the caregivers whilst impulsivity was reported to cause the least amount of distress. Gillen *et al.* (1998) adds to this, identifying changes in emotional control and disinhibited behaviour (e.g., inappropriate sexual behaviour, use of foul language) as associated with family distress as measured by the Global Severity Index (GSI). Kao and Stuifbergen (2004) research findings were congruent with these previous studies revealing that the most stressful element of caring for the TBI survivor was dealing with the psychological and social elements. Conneeley (2002) investigated the social issues involved in social integration for those affected by TBI and conversely did not find high levels of social isolation as found in the much earlier study carried out by Lezak (1988). In an extension of their earlier study Gervasio and Kreutzer (1997) questioned a large number (n = 116) of family members of

TBI patients using the Brief Symptom Inventory (BSI) and a perceived stress measure to assess their level of psychological distress. The authors found over 40% of 116 caregivers had clinically significant elevated scores of BSI and is one of the few studies to highlight the need for further research to identify factors associated with well-functioning caregivers.

Researchers have suggested that the cognitive and behavioural disturbances in the injured individual are more important than the severity of the injury in predicting levels of burden experienced by family members (Oddy *et al.*, 1978; Allen *et al,*. 1994). More specifically Allen *et al.'s* (1994) findings indicated that aggressive behaviour as the greatest association with the experience of burden by the spouse or parent. Research conducted over the last couple of decades has resulted in an increased awareness of these consequences, commonly referred in the literature as 'caregiver burden'. Caregiver burden is defined in the literature as a multi-dimensional response to physical, psychological, emotional, social, and financial stressors associated with the care giving (Given *et al.*, 1988; Pearlin *et al.*, 1990). Research into carers stress and burden is, however, reported to be conceptually and operationally challenging, not least due to the varying definitions that are offered but also due to the differing personal appraisal of the stressful or burdensome situations. Brooks and Aughton (1979) from the University of Glasgow were amongst the first researchers to conduct studies of the 'burden' of caregivers of persons with TBI, differentiating between the objective and subjective burden. Whilst subjective burden-caregivers' complaints (Livingston and Brooks, 1988), refers the amount of psychological strain or stress felt by the family member who lives with the ABI person (Allen *et al.*, 1994), objective burden refers to the measurable effect of the stress on the caregiver (Livingston and Brooks, 1988), observable changes in the caregiver e.g., financial, change of role or employment status.

Many of the subsequent research studies that focused on the caregivers burden and stress came from the Glaswegian group of researchers (Brooks *et al.*, 1986, 1987). Brooks *et al.'s* (1986) study in which 42 male TBI patients underwent a structured interview measuring subjective burden (SB) found that the relatives were under more strain (subjective burden) 5 years after the injury than after 1

year, and that behavioural and personality disturbances were the main determinant of the level of strain. The researchers concluded that the greater the behavioural problems of the injured patient the greater the burden on the relative. In a more recent study Junqué *et al.* (1997), whilst exploring the information needs of the TBI patient's family, found that the closest correlation to the relatives needs for information were the perceptions, behavioural and affective symptoms and changes in quality of life, indicating that family relationships were most affected by behavioural and affective symptoms. The research in this area has largely been quantitative in nature, assessing responses through specifically developed outcome measures such as the Caregiver Strain Index (CSI) and Objective and Subjective Burden Scales. Few researchers have attempted to redress this balance by utilizing a qualitative approach to explore the family's experiences. Carson's (1993) grounded theory study focused on the parental experiences of living with head-injured offspring in 20 families using a variety of data collection tools; a parental demographic profile form and three cognitive assessment tools were used to examine the head-injured and interviews with the parents. Carson's research generated a three-phase theory *'Investing in the Comeback',* to describe the parental experiences of living with a brain-injured offspring. The parents' efforts are described in three phases; *Centering On, Fostering Independence and Seeking Stability.* In a later hermeneutic phenomenological study, Johnson (1995) described the experience of one family, during the acute phase of TBI, in three themes; *'helplessness and the need for hope', 'need to be informed and involved'* and *'impact of intubation/extubation'.* In contrast Duff's (2006) Canadian grounded theory study used a much larger sample (n=25) and focused on the problems that families face as a family unit following the traumatic brain injury of a family member. A number of processes were revealed that involved negotiations between family members, members of the health care team and others, in an effort to understand and deal with the TBI. Although the participants were almost equal in terms of their gender (12 males and 13 females), most were parents, children or siblings of the injured family member, none were spouses, thus raising the issue of whether the experience would be different for other family members.. Whilst Duff's themes provide some insight into the experiences of the families involved in the care of an injured individual the focus was not on the impact of challenging behaviour.

The consequences of ABI on the individual family highlighted within the published literature reviewed include; emotional distress and stress (Brooks *et al.*, 1986; Allen *et al.*, 1994; Knight *et al.*, 1998; Murray *et al.*, 2006), anxiety and psychological distress (Kreutzer *et al.*, 1994), psychosomatic disorders (Oddy *et al.*, 1978). Many researchers have conducted quantitative studies of family adaptation and copying after ABI especially TBI but few have been qualitative. Despite the high rates of ABI worldwide there appears to be little empirical research that has investigated the behavioural, emotional and cognitive sequelae effects on the family. Many studies have focused on levels of psychological distress experienced by family members based on the neurobehavioural sequelae of TBI (Brooks *et al.*, 1986; Anderson *et al.*, 2002). These studies however, are restrictive, exploring the psychological distress of the caregiver rather than exploring the whole experience of caregiving. Other studies have examined the prevalence of depression in caregivers of individuals with TBI, Gillen *et al.* (1998) for example, found depression levels that met a diagnostic level as high as 47% in caregivers of TBI individuals, and when measures were repeated 6-months later, they reported similar levels of 43%, indicating that the stress level do not dissipate with time.

Some studies have examined the relative's health following a family member's TBI. Oddy and colleagues (1978) questioned relatives about their physical and emotional health during the prior 6 months and found that they experienced more psychosomatic illness than either the emotional or physical health changes. Over 30 years ago Panting and Merry (1972) reported that 61% of relatives of head injured individuals were using tranquilizers to facilitate coping. This, however, may not be the case today as alternative supporting mechanism may be accessed and modes of prescribing tranquilizers may be different. A later study by Florian and Katz (1991) stated that ABI can result in both acute and chronic difficulties that affect both the patient and their families. Within other areas of care giving research a large proportion has focused on care giving of Alzheimer's, although these patient groups may share similar characteristics with the patient with ABI they differ in several key points. First the people with ABI are often younger in age, second the injury is often sudden and finally they often present with a multiplicity of problems post injury.

2.5.3 Family as a whole - family functioning and roles

The traumatic event of ABI may compound the already present stressors in a family. The degree to which individuals may react may be dependant upon the uniqueness of the individual's role and function within the family. Furthermore these stressors imposed on caregivers' and family members may reduce their own ability to maintain their functional roles and facilitate the patient's recovery process. Consequently the family experience following acquired brain injury has become an increasing concern for healthcare professionals. Interestingly Groom *et al.* (1998) found that the injury severity had little effect on family functioning, but what did affect the family were specific neurobehavioural impairments such as inappropriateness, depression and indifference. Similarly Ergh *et al.* (2002) found no association between the severities of the brain injury with caregiver distress or family functioning, but reported significant clinical family dysfunction in over 60% of the families investigated. Psychosocial adjustment within the family may be affected by a range of antecedent variables i.e. pre-morbid psychosocial variables, personal and environmental resources and situational factors. This highlights the complexity of families and the effect that a variety of factors may have on moderating the effects of ABI on caregivers. Some researchers have concentrated on the impact of ABI on family functioning. Lezak's (1988) early research revealed that the greatest impact on role functioning was the behavioural changes of the injured person. The impact of ABI for the family has since been shown to be profound and largely negative (Nabors *et al.*, 2002), in that the injured family member may have fulfilled a vital role in the family i.e. the main earner and then subsequently not be able to fulfil that role. Although previous studies contribute to our understanding of the impact of ABI on family functioning these are largely been quantitative. For example, a number of researchers (Livingston *et al.*, 1985; Brooks *et al.*, 1987; Kreutzer, *et al.*, 1994) have contended that ABI can lead to permanent changes not just in the person but within the family system; these have tended to utilize valid and reliable instruments for assessing family system outcome, although they are not designed specifically for families following brain injury i.e. Family Assessment Device (FAD), Family Environment Scale (FES). Research has concentrated on the changes in family role functioning with behavioural problems reported to be the greatest impact on the role functioning

(Lekak, 1988; Kreutzer et al., 1994; Douglas and Spellacy, 1996; Anderson et al., 2002). Douglas and Spellacy (1996) using the FES to explore family functioning in individuals with TBI and their primary caregivers on average 7 years post-injury, found that greater neurobehavioural problems were associated with greater family dysfunction. Similarly, Anderson et al. (2002) reported that spouses who had partners with many neurobehavioural problems were more likely to report higher levels of unhealthy functioning and more likely to experience psychological distress. More specifically the authors reported anxiety, dependency and memory as having the most significant effect on caregivers from 6 months post-injury to the time of the study. Whilst the earlier research carried out by Kreutzer et al. (1994) found over 50% of caregivers questioned in their research were suggestive of unhealthy family functioning.

Acquired brain injury affects the whole family, not just the injured person. Any change associated with ABI may disrupt the family equilibrium of roles performed within the family unit. Role changes can be defined in terms of either role gain or role loss (Hallett et al., 1984) and can be disrupted by an event such as ABI. Frosch et al. (1997) identified a trend between the number of role changes reported by caregivers and the present behavioural effects of the survivor with TBI on caregivers. As the caregivers reported higher behavioural effects of the survivor with TBI, they also reported higher number of role changes. The authors also reported an inverse proportional relationship between the number of support systems utilized and the number of role changes reported by the caregivers.

Thomsen (1974) suggested that partners of those with TBI are forced to change roles to a greater degree than parents. Leathem et al. (1996) argue that the partners experience significantly more role changes than parents, although both reported the greatest change in role was their 'relationship' with the head-injured relative especially by partners. Rosenbaum and Najenson (1976) suggested that this is because many of the parents' roles are either familiar or exaggerations of existing roles or prior roles. These studies, however, arguably are not applicable in the 21st century due to changes in society both demographically and socially since the 1970s.

Several researchers have focused on the needs of families of ABI persons. Mauss-Clum and Ryan (1981) appear to be the first to investigate the needs of family members caring for persons with TBI. These researchers sent questionnaires to wives and mothers of neurologically impaired patients' families (n = 30) and revealed in order of importance their needs with the highest ranking need being the need for clear explanations of the persons condition and realistic discussions on expectations of recovery. They also rated of importance the need for emotional support. All but three participants interviewed found changes in the patient's personality after injury the most difficult to adjust to rather than the physical disability or the financial worries. Despite the limitations of the small sample size (n=30), 24 attended a family support group indicating that the majority were already seeking support thus biasing their response, this study did highlight the importance of including the family in rehabilitation and the need for adequate and timely information. Campbell (1988) was also an early researcher who assessed the perceived needs of families of severe head injured patients and identified a number of problems from returned questionnaires that were administered to the families of head-injured people. Despite the poor response rate 19% (n = 14) all respondents expressed a need to 'feel there is hope', the need to learn about the community resources that might help them and the commonly expressed need for having their questions answered honestly and to learn the effect of brain injury. Other researchers have documented how well these needs have been met, with a number of studies using standardised measures such as the Family Needs Questionnaire (FNQ) to evaluate family needs which have contributed to our understanding of the needs of this population group (Murray et al., 2006; Stebbins and Leung, 1998; Kolakowsky-Hayner et al., 2001). Murray et al. (2006), reporting that receiving honestly, accurate information ranked the most important, whilst receiving emotional support needs were rated as less important supporting the earlier research by Campbell (1988). However, few have examined the quality of life and needs beyond 2 years. Kolakowsky-Hayner et al., (2001) whilst exploring the family needs at least 4 years post-injury using the FNQ, found that at 4 years those who were dissatisfied with their life, increasing nearly six fold, with instrumental support being the least met need at 4 years (e.g., to have help keeping house, cleaning, have a break from their problems and responsibilities). The authors also found that professional support needs were the

least met need, and concluded that family needs changed over time. In the South Carolina qualitative study Leith et al. (2004) used four focus groups with a total of 21 participants to explore the needs of TBI family members and identified that the families perceived the TBI service to be fragmented and made up of providers who were uninformed. The association between needs, satisfaction and behavioural problems in the carers of severely head-injured relatives was studied by Junqué et al. (1997). Despite the small sample size n=65 and the use of a non-standardised questionnaire, analysis showed a correlation between the patients' emotional and behavioural symptoms, and the changes in quality of life changes with the need for information concerning the consequences of TBI. Junqué et al. (1997) especially stressed the need for the provision of information specifically concerning emotional and behavioural changes post-injury.

Robust literature indicates that social support moderated the stress response to life events (Smith, 1979; Hansson et al., 1984). However, according to Wallace et al. (1998) little research exists in this area of ABI. Douglas and Spelling (1996) found that the adequacy of social support functions perceived by caregivers was the single most significant predictor of family functioning. In the later research carried out by Ergh et al. (2002) in which predictors of family dysfunction and caregiver distress was examined in 60 pairs of persons who sustained a TBI and their caregivers, found that as family functioning consistently improved, social support increased indicating that social support was a powerful moderator of caregivers' psychological distress. Conversely Ergh et al. (2002) also concluded that social support did not lessen caregiver distress associated with impaired neurobehavioural and affective function of the brain injured family member. Overall the extant literature suggests that the social support is an important mediating factor in caregiver burden and distress.

Research from other areas of healthcare indicates that the provision of social support is less than adequate for those with challenging behaviour. In a large study carried out in Wales, Lowe et al. (1998) found that families with young persons with developmental disability and challenging behaviour reported low levels of professional input even though their son or daughter had been identified as one of the most severely challenging in Wales. In a later quantitative study

carried out by McGill *et al.* (2006), in which family carers (n = 66) of children and young people with developmental disability and challenging behaviour were questioned via a postal questionnaire about their perceptions of help support and treatment received from services and professionals the authors found that they did not receive services or help that they found helpful. This raises concerns about the equality of services within the UK and has implications clinically for this client group and potentially for the ABI population group.

2.5.4 The family – marital/partner relationships

Increasingly other researchers have reported that marital relationships appear to be more readily affected by ABI than sibling or parent relationships (Brooks *et al.*, 1986; Lezak, 1988; Livingstone and Brooks, 1988; Florian and Katz, 1991; Kreutzer *et al.*, 1994). Although Kreutzer *et al.* (1994) reported no significant difference between spouse and parent in family functioning, the authors did provide evidence to support the claim that spouses show different symptomatology compared to parents of TBI survivors, and reported 56% of those questioned as having unhealthy general functioning using the Brief Symptom Inventory (BSI) and the Family Assessment Device (FAD). Kreutzer *et al.* (1994) supported the observation made earlier by Mauss-Clam and Ryan (1981) that spouses' adjustment is less optimal than parental adjustment. Parents may cope better than spouses in caring for the ABI person because there are often two parents sharing the burden rather than coping alone (Panting and Merry, 1972). Anderson *et al.'s* (2002) research discussed earlier, found high levels of unhealthy family functioning amongst spouse/carers of TBI patients. Katz *et al.'s* (2005) later study involving 45 wives of husbands with TBI found a statistically significant interaction between time since injury, coping flexibility and perceived burden of wives, only those women with little coping flexibility did the perceived burden increase with time since injury.

The cognitive, emotional and behavioural changes that occur as a result of ABI make it especially difficult for the spouse to adjust to the injury, reflected by the mounting evidence over the last 3 decades that the rate of divorce and separation

can increase following ABI. Panting and Merry (1972) reported divorce rates of 40% amongst a very small population of severely injured persons they studied; out of the 10 patients in their sample only 4 remained together 7 years post injury. In an equally small sample population Thomsen (1984) reported at the time of their study that of nine married subjects only 2 relationships survived. Oddy *et al.* (1985) found at the end of a 7 year follow-up study that along with reporting loneliness as the most difficult social adjustment, a separation rate of 40%. The Australian researchers Tate *et al.* (1989) reported a divorce rate of 54 % in a sample of 31 survivors of severe TBI. These earlier studies, however, are characterised by small samples sizes. In a much larger study Wood and Yurkadul (1997) investigated 131 adults with TBI to determine the incidence of divorce and separation found that 41% had divorced or separated from their partners during a 5-8 year period following brain injury. The authors also reported that gender, age and the presence of children were not factors that influenced relationship stability, but suggested that the risk of relationship breakdown was substantially increased by the nature of the neurobehavioural sequelae. Furthermore the authors suggested that the likelihood of divorce and separation increases inversely proportional to the length of the relationship. Kruetzer *et al.* (2007) replicated and extended Woods and Yurkadul (1997) study, using an American sample of 120 persons who had sustained mild, moderate and severe brain injury, and who were married at the time of their follow-up evaluation 3-8 years post-injury. The researchers reported that 75% of the sample remained married at the time of evaluation and an 8% separation rate and 17 % divorce rate. Both these groups of researchers make the point that divorce rate after TBI is much lower than rates in the general population, but marriages were susceptible to dissolution at around 5 years post-injury. A more pessimistic view of marital stability, however, emerged from Wood *et al.*'s (2005) study of persons with severe head injury in which 23 (48%) of 48 couples were divorced or separated within 6 years of injury. Much of this research, though, is several years old making comparison in the UK today problematic. Although the current divorce rate is at its lowest since 1981 with reported rates of 11.9 divorces per 1,000 married population (Office of National Statistics, 2008a), the proportion of men and women divorcing who had a previous marriage ending in divorce has doubled in the last 25 years and the number of marriages in England and Wales is also at a record low. The figures of how many

unmarried couples split, however, is currently unclear (Office for National Statistic, 2008b). The reported separation and divorce findings in the TBI population, however, needs to be viewed with caution, as this client group often contains a disproportionate number of individuals with pre-morbid histories of deviant behaviours, substance abuse and social maladjustment (Ducharme *et al.*, 1999). Therefore in the absence of ABI they may have a higher divorce rate than the average in a population. Early research also indicates that spouses of persons with brain injuries also have difficulty divorcing with dignity or in good conscience, and marriages are often maintained through bonds of guilt and fear of disapproval (Lezak, 1978; Rosenbaum & Najenson, 1976). Whether this is still the case today, however, is not clear.

Moore and his colleagues (1991) are among the few researchers that have studied the effect TBI has on marital relationships. They reported that at approximately 4 years post-injury, wives of severely ABI men reported lower adjustment than moderately severe ABI men and spinal cord injury patient groups. In the USA, Peters *et al.* (1990) attempted to delineate relationships between injury severity and various factors including marital adjustment, using standardised measurement and statistical methodology and concluded that the greater levels of physical injury and psychosocial dysfunction were associated with greater marital dysfunction. In the later qualitative study, Gosling and Oddy's (1999) examined the quality of marital and sexual relationships in 18 couples, 1-7 years after the male partner had sustained a TBI and reported that overall the female partners rated their relationship lower than that reported by their injured male partner and that their relationship was no longer equal sharing or providing companionship.

Although the research in this area is limited it does seem to indicate that wives of men with ABI have more trouble adapting to the impact of the ABI (Thomsen, 1974; Lezak, 1988). Much of this research however, draws on a mixed sample of parents and wives, thus failing to distinguish between the marital relationship and the parental one. These findings suggest that the psychological and marital adjustment following ABI represent a major challenge for both the ABI person and their spouses. The literature that specifically explores spouses' psychological adjustment to their injured spouse is limited. Furthermore as the majority of TBI

patients are male the majority of studies in the area have focused on the mother or wife. Few have looked at the heterosexual partners where a female is injured or indeed in same sex partnerships. It is worth pointing out also that few studies have evaluated both the ABI victim and their partners together.

2.5.5 The parent and spouse's experience of living with a person with acquired brain injury

The literature suggests that spouses and parents experience different challenges and needs following ABI, however, this evidence remains limited with few exploring the long term impact on couples. Since the family member who is most likely to shoulder the responsibility is the mother or the spouse it is no surprise that some researchers have focused on their needs and experience.

When exploring the differences between spouse and parent, the literature seems to be divergent with some researchers suggesting that the burden for wives is greater than for mothers (Panting and Merry, 1972; Thomsen, 1974: Mauss-Clum and Ryan, 1981). These researchers, however, failed to provide detailed information on the sample or the injury or injured person's.characteristics. Whilst others support the position that they are similar (Oddy et al., 1978; Livingston et al., 1985; Brooks et al., 1987; Allen et al., 1994). Although Allen et al.'s (1994) findings did indicate that the parents were more concerned about future care for the person with TBI observing that this was understandable given that the parents were older (mean age 53.5 years) than the spouses (mean age 40.8 years) in the study.

In Mauss-Clum and Ryan's (1981) study, discussed earlier, a higher proportion of wives reported negative reactions to the neurological damage, attributing this to the wives' difficulty in accepting the regressive behaviour of the injured person. The pioneering work carried out by Rosenbaum and Najenson (1976) compared 10 wives of men who had suffered a military head injury in the Yom Kippur War with 6 wives of paraplegics and 14 wives of uninjured men who fought in the war found that depression was more frequently reported in the wives of the head

injured than the wives of the paraplegic. Although this study is frequently reported in the literature, the sample size was very small. Kreutzer *et al.'s* (1994) more recent comparison, with larger numbers of spouses (wives n = 25 husbands n = 3) and parents (mothers n = 28 and fathers n = 6) concurred with Rosenbaum and Najenson study reporting that spouses experienced more distress than parents. Kreutzer *et al.* (1994) offered an explanation for their findings suggesting that it was due to the loss of the peer-based reciprocal relationship that was their primary support.

In a much later study Godfrey *et al.* (2003) examined the psychometric properties of the Head Injury Behaviour Scale (HIBS) as to its usefulness as a clinical and research measure on 242 caregivers. These researchers found that spouses reported significantly higher levels of distress for the sub-scale emotional regulation[6] than the parents. Panting and Merry (1972) argue that in the case of parents, the fact that there are often two parents, who can share the burden and help each other with problems involved with living with a son or daughter with ABI, eases the burden. The significance of this in the UK is questionable given that the number of one parent families has trebled from 1971-1998-99 (Office for National Statistics, 2000). Livingstone *et al.'s* (1985) Glaswegian study on 42 female primary caregivers of severely head injured patients three months post-injury, assessed the psychiatric and social impact, found no evidence to support the different outcomes depending on the relationship to the patient. Similarly Gillen *et al.* (1998) whilst exploring the differences in depression and distress between parents and spouses of TBI survivors found no difference between the two groups, nor did the length of time since injury predict a diagnosis of depression.

In one of the few qualitative studies, Kao and Stuifbergen (2004) explored the meaning of the experience of being a mother of a young TBI survivor. Using a phenomenological approach, the authors interviewed nine young adult TBI

---

[6] The caregivers' version of the HIBS is comprised of two sub-scales; the Emotional Regulation measures the behaviours that often impact on the caregiver in the context of interpersonal relations with the injured person (e.g., irritability, anger, aggression, depression) whilst the Behavioural Regulation assesses other aspects of the behavioural regulation (e.g., adynamia, poor decision-making, childish behaviour) that holds less emotional valence for caregivers.

survivors (18-25 years of age) and their mothers, reporting a strain on the mother-child relationship including struggles to over-protect the child versus letting him or her be more independent. They also describe the 'marital menace' that TBI caused along with the mothers' struggle of maintaining harmony both inside and outside the family. This research provides a more detailed account of the struggles that creates the stress between the person with TBI and the mother along with the impact of injury on their marital relationships. However, as the researcher was herself a TBI survivor her personal values and biases may have influenced the data collection.

Linn et al. (1994) were a few of the earlier researchers who compared directly levels of distress in people with TBI and their spouses (n = 60 of which approximately 2/3 were wives), found equivalent significantly elevated levels of depression (73%) and anxiety (55%). In the later Australian study Perlesz et al. (2000) assessed the level of satisfaction and psychological well-being for individuals with TBI and their primary, secondary and tertiary carers (n = 137) and found that the wives and spouses (primary carers) were the most distressed, reporting higher levels of distress, anxiety and depression than the secondary and tertiary carers[7]. The researchers also found that the wives were significantly angrier and less satisfied with their families than the mothers; however, the sample consisted of 38% male carers with only four married women with a head injury thus making any comparison or inferences on the impact on the husband difficult. Furthermore there is evidence that the spouses often have children to cope with as well as the injured person who may compete for the attention from the non-injured spouse (Kreutzer et al., 1994) adding to their stress.

---

[7] Primary carer met a criterion in which they were the family member deemed to bear the most responsibility in caring for the injured (mainly mothers and wives), secondary carer bore the next most responsibility (mostly fathers and eldest siblings) and the tertiary carer the next most responsibility (mainly siblings) (Perlesz et al., 2000).

2.5.6 The experience of being the sibling of the person with acquired brain injury

There are few research studies of sibling experience of living with a person with ABI despite the likelihood of siblings being among those family members that experience living with a person who has ABI. The empirical literature indicates that parents and spouses who care for a family member with ABI, experience clinically significant levels of psychological distress, depression and anxiety (Kreutzer *et al.*, 1994). For it is the sibling's relationship that endures longevity often spanning many decades and, it is this longevity that has the potential to result in long-term burden on the sibling.

Orsillo *et al.* (1993) maintain that they were the first to conduct a systematic investigation on stress associated with having a head-injured sibling. Of the 13 siblings in their study using a variety of outcome measures (83%) experienced significant psychological distress as long as 5 years post-injury. This proportion of siblings found under stress was far greater than other previous studies that employed the same methodology (Panting and Merry, 1972; Oddy *et al.*, 1978), however, these studies included spouses and mothers in the study and the researchers did not set out to specifically research siblings. In a later exploratory qualitative study examining the experiences of living with a brother or sister who has suffered TBI the authors reported that participants described the experience as having made *'their lives forever different'*, and that the cognitive, behavioural and interpersonal skills aspects of their ABI sibling were the most difficult to deal with (Gills and Wells, 2000). The authors found that participants assumed different responsibilities to compensate for the behavioural and cognitive impairments reporting feelings like either mother or big sister/brother watching out for their injured sibling. Interestingly some studies have reported increased conflict between siblings after one has a brain injury (Lezak, 1978; Rivara *et al.*, 1992). The limited research in the area would seem to indicate that siblings living with a brother or sister who has ABI, experience profound life changes and this may potentially render them potential consumers of the healthcare system.

2.5.7 The effect of time since injury on the family and carers

It would seem important not only to recognise the behavioural and emotional difficulties following acquired brain injury but the differentiated pattern of recovery and the effect that time has on these behaviours. As the ABI survivor's symptoms may change over time some research has attempted to explore the effect of time on the spouses and caregiver. An inverse relationship seems to be evident in that as physical impairment often stabilises in the first year post injury the neurobehavioural symptomotology may increase in the same time period. The literature, however, does reveal inconsistencies; some claiming that with time adjustment improves (Sander *et al*, 1997) whilst others reported that the carers' burden does not lesson with time (Douglas and Spellacy, 1996) and others report an increase in emotional and social distress over time (Brooks *et al.*, 1986; Gillen *et al.*, 1998).

Oddy *et al.* (1978) reported the results of one of the first studies of a large group of TBI caregivers. Their longitudinal study in which 54 relatives of severe TBI patients were interviewed indicated that although the levels of stress experienced by the relatives decreased between 1-6 months post-injury, but there was no significant decrease between 6-12 months post-injury. At a 10-15 year follow up from her original Dutch study, Thomsen (1984) reported that seven of the nine couples in her sample had separated. In Thomsen's (1992) third follow-up study of these patients more than 20 years post-injury, she found that aggressiveness, violence and sexual disinhibition continued to create the most negative impact on the carers. Thomsen appears to be one of the few researchers that have followed up a TBI population of patients over an extended period of time, although the impact of injury on the relative was not the original focus of her study and the relative's questions were not consistent throughout the three studies making comparison of data problematic. Livingston *et al.* (1985) reported that 30% of caregivers had significant emotional problems to warrant clinical interventions and that this proportion increased from year one to the year five post-injury. In the much later study Marsh *et al.* (1998) also found clinically significant levels of anxiety, stress and impaired social adjustment were observed 6-months post TBI in over a third of those caring for people with severe TBI. A longitudinal study by Brooks *et al.*

(1986) found at five years post-injury that relatives of severely head injured patients reported similar psychological symptoms of behaviour and emotional disturbances i.e. personality changes, mood changes and severe difficulties in the control of irritability and temper to Mc Kinley et al.'s (1981) earlier study, but the relatives reported significant higher levels of strain at five years (up to 89%) than at one year after injury. Brooks et al. (1986) indicated that the burden did not dissipate over the years but remained significant and remained at 89% up to seven years post TBI (Brooks et al., 1987). However, criticism has been levied at their research despite it initially providing an impetus for further research on caregivers of TBI. Sander et al. (1997) argue that the researchers used a 7-point subjective burden rating scale, arguing that it was too simplistic, reduces variances and lacks specificity.

Kruetzer et al. (1994) found that time since injury inversely related to caregiver distress, although a positive relationship was found between healthy family functioning and time, and Groom et al. (1998) found a significantly negative correlation between the time post-injury and perceived individual caregiver stress. Although Frosch et al.'s (1997) large sample of 155 caregivers of survivors of TBI found that as the number of years increased since the time of the injury the effects on the caregivers remained the same. As the average age since injury was reported to be 10.62 years this would suggest that the behavioural problems lasted for many post-injury. Likewise Gan and Schuller (2002) found no difference between time of injury and family system functioning, indicating that family system continues to be problematic and did not improve over time. These findings are consistent with earlier studies (Thomsen, 1984; Brooks, 1991). Furthermore, Wood and Yurdakul (1997) found that the likelihood of separation or divorce increased with time, and suggested a watershed for relationship breakdown being around 5-6 years post injury, and suggest that this was due to the burden of stress experienced by the partner reaching intolerable levels. Although caregivers and families may adjust to the changes and responsibilities associated with caring for a person with challenging behaviour the consequences of such, however, may not dissipate but increase with time. The unfolding of the problems and issues that caregivers face after discharge and with time may be attributed to a two main factors. First the increased sensitisation to the behaviours over time by the relative

and second the changing behaviours of the person with ABI may mean that a behaviour once tolerated but when intensified or increased in frequency become intolerable.

2.5.8 Formal carers experience of challenging behaviour

Brain injury rehabilitation is both challenging and complex, requiring specialist skills and knowledge. Cognitive impairment and challenging behaviour present one of many challenges to neuroscience health care practitioners, mainly because of the threat they pose on the safety of the patient, staff and other patients. There have been a number of research studies exploring healthcare workers' experiences of challenging behaviour (Moniz-Cook *et al.*, 2000; Hastings and Brown, 2002). Currid's (2008) phenomenological study aimed at exploring stressors in eight acute mental health nurses found violent and aggressive behaviours were among the stressors that gave rise to staff experiencing difficulties with switching off from work, poor support from management and fear of blame. There have been a number of descriptive and correlational studies that support the hypothesis that challenging behaviour elicits negative emotional reactions in professional carers (Bromley and Emerson, 1995; Emerson 1995; Bell and Espie, 2002), although these studies have been carried out primarily within the mental health or learning disabilities area of healthcare they do carry some important messages for those working and managing people with challenging behaviour what ever the speciality. Furthermore, Moniz-Cook *et al.* (2000) state that difficult uncooperative or aggressive patient behaviours contribute to staff distress, paralleling that of the family care giving literature. Perhaps more significant is the evidence that is emerging that suggests that those staff who are exposed to more frequent and severe challenging behaviour are not only at risk of stress but also burnout and mental health problems (Jenkins *et al.*, 1997; Hastings, 2002; Hastings and Brown, 2002; Rose *et al.*, 2004).

2.6 Reflection on the literature review

It is suggested that the literature review in phenomenological research should be delayed until after the data generation (Oiler, 1982). Arguably this is done in order to see the data in an 'uncontaminated stage'. This concurs with Husserl's view that it is not necessary just to bracket the individual consciousness but the outside world as well (Koch, 1995). Morse and Field (1996) argue that performing a literature review would then make it difficult to bracket one's preconceived ideas preconceptions, distracting the researcher. However, as articulated by Lowes and Prowse (2001) there are inherent ethical issues in carrying out unnecessary research, not establishing whether it has been carried out before renders the researcher on unethical ground. Furthermore, as a practitioner I had knowledge on the phenomenon prior to any further literature review making this already unrealistic. For it was precisely my previous work in challenging behaviour that led me to this research inquiry in the first place. Rather than attempting to avoid the bias by avoiding the literature review, Lowes and Prowse (2001) argue that a critical review of the strength and weaknesses of the literary evidence is an integral part to the phenomenological study. Furthermore I would argue that a greater grounding in the literature has militated against biases, as it exposed me to new and alternative perspectives on the phenomenon. I believe it may even have tempered my personal biases.

What I have come to realise is that this literature review took several methodological approaches as suggested by Moustakas (1994) who states that searching the literature employs multiple methods. It was evident to me that the sensitivity and precision in identifying relevant literature using electronic search engines was an issue and furthermore that searching across interdisciplinary areas of interest where interchangeable terminology are used can be problematic. What transpired as being critical in aiding me in the retrieval of relevant research literature was the use of the search technique 'Pearl Growing'[8] , a technique that I

---

[8] 'Pearl growing' a technique introduced to the researcher by the Publication and Information Office, Social Policy Research Unit, University of York, and refers to, in this context, the process of using the characteristics of a relevant and authoritative article,

had practiced for some time but had not previously attributed it to a recognised literature searching strategy. I also found throughout this thesis that literature searching was an on-going iterative process and one that I feel will never be totally complete.

2.7 Synopsis and literature limitations

The literature presented is this chapter is an attempt to contextualise the study both empirically and methodologically. The behavioural, cognitive and emotional sequelae that accompanies brain injury is well documented in the scientific literature. Whilst the literature on the family's experience of ABI has grown over the last 20-30 years, most follow a deductive quantitative scientific method that, a priori, measures explains and predicts the consequences of ABI and remains largely within the psychology and medical domain of healthcare, with little carried out from a nursing perspective. This dominance raises the issue of the need for a more nursing focused approach and one that offers a different perspective. The current emphasis on evidence based healthcare is on knowledge constructed through a particular scientific process and is more privileged than that which is constructed via those declared to be less scientific. The hierarchy of evidence as suggested by Sackett *et al.* (1996) in which systematic reviews of randomised controlled trials (RCTs) and single RCTs are to be considered the highest level of evidence and the rest to be considered as lower level evidence such as qualitative research, illustrates the case in point. Research methodologies are accorded a numerical value from systematic review of all relevant randomised trials as Level 1 through to consensus of opinion as Level V. The use of such hierarchy in nursing is the source of much debate and the significance of evidence other than Level 1 is one that is well recognised within the discipline. However, it is beyond the scope of this thesis to explore this in more detail.

Most of the research that has been reviewed appears to have been conducted in the UK, Canada, USA and Australia. Very few studies have explored the

---

called a 'pearl', to search for other relevant and authoritative materials i.e. articles and books thus growing a set of relevant documents.

experiences of the family caregiver from a qualitative perspective, and more importantly none-to-date has specifically explored their experiences of challenging behaviour following ABI. The current literature is scattered with terms such as 'family functioning' 'family effect' and 'family reactions' and concentrates on specific units of experiences such as distress, anxiety, stress using a wide variety of psychosocial measures for analysis. In addition the majority of the literature focuses on the TBI subset of ABI raising issues about the wider concept of the ABI family experience.

Those studies that explore the specific perceptions and experiences of family members according to their relationship with the person with ABI are notably the spouse, parent or sibling. What would seem to be lacking are studies that address the father, husband and same sex partner' perspectives. Moreover, most studies seem to either concentrate on the person who experienced the ABI or TBI or the impact of the injured on the primary caregiver, and although they provide a snap shot of the psychosocial outcome at a particular point post ABI, few have provided information on the long-term effects. An assimilation of the key literature studies related to the impact of ABI on families is tabulated and presented in Appendix B.

A notable limitation in the literature found and reviewed was the age of some of the research studies, although they are often quoted in the literature. Many have not been repeated, making applicability difficult as service provisions and cultures of societies have changed over time. An additional gap in this literature review is that although there were several international reports identified, which may have offered a unique perspective that has not been included in this appraisal; they were not available in the English language. It was beyond the scope of this study to compare all systems and the limited finances did not permit the translation of non-English language literature. The presenting studies were varied, although limited, in their country of origin making the ability to generalise for all populations of families of people with ABI difficult due to the differences in culture and service provisions. Finally the current studies are not all consistent in their findings. A methodological weakness in many of the studies reviewed is that that caregivers' studies were often from self-help groups and may already be identified as having

more distress than others, thus over-estimating the prevalence of experiences of families with ABI.

Recovery from impairment due to ABI is a life-long process affecting not only the survivor but also the primary caregiver and the family. Changes in personality and emotional control are common, and TBI significantly increases the risk of developing a variety of psychiatric disorders. It is evident that the neurobehavioral sequelae are a source of distress to injured individuals and their families/caregivers, and often are the most important barriers to returning to pre-injury quality of life. The evolving challenge that healthcare systems face is the awareness of this increasing burden and meeting the needs of both the injured person and their caregiver. The impact of acquired brain injury arguably remains a major unresolved public health problem. The family is often the neglected victim of the brain injury, and it is evident from the literature that the impact of ABI on the family carers is not only significant, suffering clinically significant psychiatric and psychosocial disturbances, but enduring. The severity of their stress may interfere with their ability to maintain effective coping mechanisms and has the potential to result in lifelong burden to the family.

Given that the research has suggested that behavioural, emotional and cognitive changes are the most troublesome and burdensome aspect for relatives/caregivers following ABI, and that these alterations give rise to the family's need for further information and support it would seem reasonable to stress the importance of meeting these needs to enable the relatives/caregiver to cope and alleviate their adjustment problems. This research was aimed at providing further information in this area. Finally despite advances in the early medical management of ABI, the provision of post-acute services for those living with ABI and their families in the UK is patchy, and slow to develop. In many areas it is provided by the private sector. Indeed, it was the focus of a National Co-ordinating Centre for Service Delivery & Organisation literature review and mapping exercise (NCCSDO MS128, 2005). Its mere call highlights the need to address the disparity and inadequate provision of this service. Although it is now recognised that the provision of appropriate psychological and rehabilitation

support can assist not only the patient, but the family in adjusting to ABI, further research, however, is needed to explore how best to meet this need.

This chapter has attempted to provide an introduction to the study's research problem. An overview of the magnitude of the acquired brain injury problem has been presented and the need for a better understanding of the impact on the lives of the persons with ABI, their families and carers. The purpose of this research is to explore the non-injured family member's experience of the behavioural, emotional and cognitive sequelae that follows acquired brain injury. The need to target family caregivers for future research has been presented.

---oOo—

Chapter 3 The phenomenological approach

3.1 Introduction

This chapter describes the processes and movement I went through from my original ideas and thoughts, through to narrowing the method of inquiry, and eventually arriving at a methodology that I subsequently use in this study. The first section of the chapter provides the rationale for the qualitative research approach that guides the research thesis, followed by a rationale for a phenomenological methodology. I include a discussion on the procedures that are unique to a phenomenological study and discuss the approach used to explore families' experience of challenging behaviour, discussing and rationalising how I arrived at the decision to use descriptive phenomenology in this study. Finally I conclude with a reflective account of the research approach adopted for the thesis.

3.2 Rationale for the philosophical approach of the study

The literature would indicate that nurses may be unaware of the family member's experience of challenging behaviour of their brain injured relative. The family members are the 'hidden patients'. I believe that specialist knowledge for the practice of nursing must reflect the lived experience and concerns of both patient and their families for whom nurses provide care. I also believe it is important that nursing develops this knowledge to enhance the quality of care delivered and thus make a difference. For me, nursing is based upon knowledge gained from science and understanding of patient's experiences of their illnesses, and its purpose is to relieve suffering and promote well-being. These concepts cannot be reduced to methodological paradigms that are founded only in the empirical scientific tradition of inquiry. Our experience is normally much richer in content than mere sensation that can be measured. I believe that other knowledge is needed, and is knowable only to the extent that we share experiences with each other. The premise being that we need to listen and understand individual patients and their families' stories about their journey through illness. Furthermore, as a nurse, I am concerned with the subjective experiences of individuals. I attempt to understand the patient's

experiences in order to inform my own decision-making, practice and teachings. Moreover, for nurses to provide holistic care they have to be able to look at not only the nursing/medical aspects presented during assessment, but also the psychological and emotional lived experiences that the patient's family have endured, thus making a complete picture. Thus the research approach chosen was qualitative enabling me to accommodate the complex and diverse nature of human beings.

Challenging behaviour may present in the form of violence, described as an aspect of human life that can elicit feelings of fear, alarm and concern (Chambers, 1998). It is a phenomenon that is difficult to investigate because of its transitory, often covert nature. To study such a complex phenomenon using a quantitative positivistic line of inquiry I felt would not give the range of experiences or understanding that this study seeks. In survey research, which is strictly quantitative such as those identified in the previous chapter, often large samples are recruited which are not able to capture and convey the unique characteristics and experiences of those persons who have ABI and their families. Indeed questions that often arise from nursing practice that are based on the notion of knowing that which is particular to the persons lived experience of an individual person arguably cannot be answered from a positivistic quantitative perspective. This, however, does not imply that I renounce empirical scientific methodologies, but rather I recognise that the positivist approach contributes to our knowledge and understanding of clinical practice. Objective techniques and experiences are a means of measuring and evaluating a phenomenon, but they fail to provide a holistic view of the complexity of human behaviour, human experiences or the nature of nursing practice. On the other hand, qualitative research based on naturalistic philosophy allows for a small group of people to be explored in-depth. By using a qualitative approach then it is possible to uncover the meaning of the experience and the outcomes of the experience. In this study, I have assumed that the immediate subjective experience of challenging behaviour is not fully understood. This mode of inquiry is non testable, and is characterised by description, analysis, reflection and interpretation. A qualitative mode of inquiry, I believe, can provide meaning to a human interaction and has the ability to generate knowledge of a particular experience. This offers an opportunity to

provide rich descriptions that "...*open the window into the world of others*" (Morse and Field, 1995: p.18). Since the primary purpose of this study was to understand the family's experience, a qualitative approach facilitated that goal.

3.2.1 Rationale for phenomenology

Once I had decided to focus on the lived experience of families with relatives with challenging behaviour following acquired brain injury I then looked for a suitable methodology that would answer my question. Initially phenomenology seemed to be the appropriate methodology. I had selected a topic that interested me deeply and one that concerned me, because of my clinical experience in caring for both the patients and their families as described previously. According to van Manen (1997) the starting point of phenomenological research is the turning to a phenomenon which seriously interests us. Phenomenology offers an approach to investigate a subject that is not easily measurable or observable as in the case of challenging behaviour. It was my belief that those families of acquired brain injured persons who display challenging behaviour would share common experiences. This inter-subjectivity, the belief in the existence of others who share a common world, is fundamental to the tradition of phenomenology (Cohen, 1987). Phenomenology was employed in order to gain access and describe the life world experience as opposed to explaining how and why the meanings occur. I was not seeking control and measurement but descriptions and meaning. I believe that phenomenology facilitates an understanding through description, reflection and directing our awareness of the phenomenon for the purpose of revealing its inherent meanings rather than observing and explaining. According to Spiegelberg (1969) phenomenological method is grounded in the belief that truth can be found in lived experience. The premise being, that the human person is understood to be the primary knower and that their experiences are there for others to uncover and explore, although this may not always be accessible to us. It seeks through questioning to obtain knowledge about the carers' world, validating all experiences as valid sources of knowledge. The essence of what it means to experience such behaviour can then be explained and understood. Thus the focus is upon the uncovering of the essence of how families experience and understand challenging

behaviour. Although on further exploration of phenomenology literature I realised that there are diverse approaches each holding varying opinions on philosophy.

The general philosophical underpinnings of phenomenological methodologies arguably are consistent with the values and beliefs of nursing practice; individualism, the desire to explore the meaning of an experience and interpret meanings to inform practice through reflection and dialogue. I believe that phenomenology can provide knowledge about a phenomenon that scientific objective approaches cannot do alone, and furthermore I believe it contributes to a more holistic picture. I thus deduced that a phenomenological approach was entirely appropriate to answer my research questions and I chose this focus so that I could find meaning for both myself and others.

When I wrote my research proposal for ethics approval, advocating phenomenology as the appropriate methodology for me to use given the type of inquiry, as a researcher I had little knowledge of phenomenology. I was not aware of its differing philosophical underpinnings and approaches and thus set out on a journey, in trepidation, to explore these approaches in an effort to determine what to use in my thesis.

3.2.2 Rationale for descriptive phenomenology

First described by Immanuel Kant in 1764 phenomenology was used in a scientific context to describe the study of 'phenomena', or 'things' (Cohen, 1987). It is this study of things that is the starting point of phenomenology. It is the study of the life world, the world as one experiences it, rather than as one conceptualises, categorises, or theorises about it (van Manen, 1984). Traditional phenomenology focused on subjective, practical, and social conditions of experience and seeks to free the cultural context, which was the initial premise of phenomenology as described by Husserl (1931). By 1889 Franz Brentano used the term 'phenomenology' to characterize what he called 'descriptive psychology', which paved the way for the beginnings of Edmund Husserl's phenomenology, the science of essential structures of pure consciousness (Moran, 2000). Because of

its reflective, evidential, and descriptive approach the beginning of phenomenology is often characterized as 'descriptive phenomenology'. Edmund Husserl took the phenomenological philosophy into its next stage, stating that;

"...in describing the elements of phenomena, the essence of the lived experience was revealed" (Fain, 1999: p. 221).

His goal was to present the parts and elements of the lived experience for what they were, without the presuppositions that science and culture often impose (Fain, 1999). Although Husserl's phenomenology changed over his life time, Cohen and Omery (1994) write that four constants were maintained throughout Husserl's evolving philosophy. One such constant was his study of descriptive phenomenology and universal essences.

"The phenomenology of essences seeks to secure absolute insights into the what, or essence, of whatever is given intuitively in experience. The task is to elucidate the general essence of the phenomena being investigated to yield a concrete descriptive analysis." (Cohen and Omery, 1994: p 138)

As van Manen (1997) stipulates the essence can be seen as a description of a phenomenon. I set out in this study to do just as Husserl had intended. I wanted to illuminate the essence of the carer's lived experience. As Giorgi (1985) states phenomenology is about describing, it is a rigorous, critical, systematic investigation of phenomena. Modern interpretive phenomenology, on the other hand, seeks to understand life world of the people seeking understanding. I did not want to, as Heidegger emphasises, associate the phenomena in the culture, political and social context. For Heidegger the context was a prime concern.

Many publications that apply phenomenological methodologies to nursing research refer to the Heidegger or mixed methods of Husserl and Heidegger. However, in an attempt to understand these principles I found that they did not offer me a complete account or provide me with any clarity. If anything they confused the issue. I also felt that many papers lacked transparency as to their methodological framework and this added to my confusion. Initially I felt that I lacked the evaluative insight as to my own philosophical beliefs to make any

evaluative judgement as to which phenomenological approach I would use. In an attempt to address this, I read around the work of Moustakas (1994) and Giorgi (1985, 1997, 2006) and attended two master classes on phenomenology. Although they provided me with some clarity of thought, adding to my knowledge and understanding, they also added to my dissonance and sense of anxiety. I felt I was in danger of being swamped by the complexities of phenomenology and was having difficulty seeing a pragmatic outcome. I began to realise that this would be an ongoing process of understanding and that I would have to come to terms with the dissonance I felt in trying to pragmatically weave through the quagmire.

As I attempted to understand the interpretive/hermeneutic phenomenological approach my confusion grew. Whilst exploring the underpinnings of Heidegger's hermeneutic phenomenology the notion that the person is linked with the world that they live in and the world that they construct seemed critical. Two essential notions of Heidegger's methodology are inextricably interlinked, the hermeneutic circle and historicality. From an interpretive phenomenological perspective the purpose is to take what is known about a phenomenon and consider it as fore structure to a new enquiry. This could be achieved through the concept of a perpetual motion within a 'hermeneutic circle'. It is also argued that the reduction *epoché* is not possible as the 'natural attitude' is perceived as being part of *'being-in-the-world'*. This constant movement of understanding and interpretation according to van Manen (1990) leads to endless possibilities and endless interpretations. This, however, was not my intention.

Methodologically from an interpretive perspective the process of interpretation and interaction between the participants and the researcher is critical. The aim being to gain understanding,and the reconstruction of experience and knowledge. Every interpretation has to be viewed in the context of the person's individual background and historicality. For Heidegger there is no encounter in the life world without reference to previous background understanding. We all experience various types of experiences including; perception, imagination, thought, emotion, desire, volition, and action. Thus interpretive phenomenology assumes an attitude that through insight and deliberation the researcher constructs meaning about a given phenomenon. From the very outset of this journey this was something that

was not in keeping with my fundamental belief of presenting the voice of the families. I wanted to preserve the uniqueness of each story without distorting what they said or interpreting and analyzing through my own experience and knowledge. Through my reflections that I undertook during the taught component of this programme I began to appreciate my positivistic stance. I do tend to seek similarities in human experience and aim to find solutions. I quickly realised that this is perhaps why I found myself increasingly aligning to Husserl's philosophical ideals. I thus rejected interpretive phenomenology as a methodological approach.

Merleau-Ponty developed a rich variety of phenomenology emphasizing the role of the body in human experience (Merleau-Ponty 2002) and offered up another phenomenological methodological approach. I soon appreciated from my readings that this was also not an approach that I wished to pursue. Initiated by analyzing the reported experience of amputees who felt sensations in a phantom limb Maurice Merleau-Ponty focused on the 'body image', our experience of our own body and its significance in our activities. This specific perspective, however, was not the focus of this research study. I was not setting out to explore the dynamic relationship between body-self-world as posited in Merleau-Ponty's phenomenology. Although for both Husserl and Merleau-Ponty phenomenology is one of pure description of the lived experience.

Conscious experiences have a unique feature; we experience them, we live through them or perform them. Husserl defined phenomenology as 'the science of the essence of consciousness' (Husserl, 1931). Conscious experience seems to be the starting point of phenomenology, but as Husserl (1931) stated, we are only vaguely aware of things in the margin or periphery of attention, and we are only implicitly aware of the wider horizon of things in the world around us. Moreover, as Heidegger in *Being and Time* (1962) stressed, in practical activities like walking along, or hammering a nail, or speaking our native tongue, we are not explicitly conscious of our habitual patterns of action. Furthermore, much of what we do is not conscious at all but, through exploration and questioning how we feel or think about something, it may become known. The description of the pre-reflective experiences as it was lived was the aim of this approach as a means of assessing the real descriptions of the experience. For Husserl (1970) the experience in the

life world is pre-reflective and is often taken for granted. By returning to the carers experiences then we uncover new or forgotten meanings. However, I felt that as these carers may be accessing events and experiences some time after the event then some may have reflected and interpreted the events individually. It is argued that it is not just the primordial or original form that is accessed, but one that has been moulded and changed due to time and thinking. Thus it may not be just their pre-reflective experiences that are explicated but the meaning of the experience as a whole. In order to reach reality, individuals must try to reach meaning in its original form, the 'natural world'.

What clearly was required was the adoption of a reflective stance, one which disentangled me from preconceptions, to gain a clear view of what was happening in the research process. I felt I could then gain understanding and discover more uncertainty and uncover new experiences. According to Moustakas (1990), an unbiased approach is a state of preparedness or openness of the mind that can only be achieved through a great deal of intelligent contemplation. Likewise, Giorgi (1985) states that "...a certain open mindedness is maintained so that genuine discoveries may ensue" (p.13).

3.3 'Bracketing'

Whilst I acknowledge that there are different philosophical traditions that inform phenomenological methods, for Husserl the process known as 'bracketing' is critical (Husserl, 1960). According to Cohen and Omery (1994) it can be interpreted to mean looking at the experience naively, without the preconditions, the prejudices, and the biases that one usually brings to description. It involves the deliberate examination of my beliefs about the phenomena and then temporarily suspending them. The philosophy of Husserl (1925/1977) believes that a return to the 'things themselves', requires the method of 'bracketing' as a way of suspending preconceived ideas. If we can bracket our preconceived ideas and prejudices, enabling us to look at the experience with eyes made open, it is proposed that it is possible to 'intuit' from the data (Jasper, 1994). Bracketing is purported to achieve contact with the essences by suspending one's judgements

and beliefs about the phenomenon and thus from its new standpoint one can see the essences clearly, seeing it as it really is. For Husserl this 'intuitive seeing' is careful description. Husserl's view is that the 'primordial phenomena' the maxim is stripping back the consciousness to reveal the original data of consciousness, it is purely descriptive. As this stripping away reveals the truth then it can only be described. It does not eliminate perspective, but brings the experience into clearer focus. This purging of our minds of our prejudices is self imposed and temporary and according to Moustakas (1994);

> "Husserl called the freedom from suppositions the epochē a Greek word meaning to stay away from or 'abstention'" (p.85).

In other words, as described by Kvale (1996) it involves adopting a 'deliberate naïveté', implying openness to new and unexpected phenomenon. Thus I needed to be critically conscious of my own presuppositions. This process of 'epochē' then permits us from interpreting, only describing in its true sense with the end result in this process is as described by Husserl (1977) the 'transcendental ego', the consciousness necessary for the appreciation of the phenomena. The end point of engaging in bracketing, is the absolute state of knowing, the essence of the phenomenon. According to Stewart and Mickunas (1974) Husserl's two terms; phenomenological reduction and epochē are interchangeable and refer to "...the change in attitude necessary for the philosophical inquiry" (p. 27). They are, however, all referring to the temporary suspension of all judgements, opinions and attitudes about the external world so as to focus on what is essential in the phenomena. However, Patton (2002) makes a distinction between epochē and bracketing postulating that the epochē is an attempt by the researcher to increase rigor in phenomenological studies by gaining clarity into and attempting to reduce the impact of one's preconceptions, and the process occurs throughout the entire research project. Bracketing on the other hand occurs specifically in relation to dissecting and inspecting the phenomenon closely, separating it from its contexts in order to analyze and examine it for its essential constituents (Moustakas, 1994; Patton, 2002). Whatever the interpretation of Husserl's original concept of bracketing, what seems to be important is that I should try to distance myself from my preconceptions in order to explore openly, bracketing and epochē, and thus

describe the experience. Moreover, what became evident to me was that the operationalization of 'bracketing' was particularly sparse within the literature. In an effort to grasp this concept I first referred back to Husserl's mathematical roots in which he described the *epoché* rather like the brackets in mathematical equations. I could relate to this, as a mathematician one keeps numbers and symbols in brackets until they are needed, so as a researcher I attempted to do the same, although this created considerable dissonance. On the one hand accepting the notion of bracketing, leads me to grapple with the applicability of generalizability in descriptive phenomenology, but on the other hand feeling constrained by the over arching accepted belief that qualitative research does not set out to generalise. 'Generalizability' refers to whether the insights gained in a particular investigation will hold true in contexts other that the original one. Clearly this is a goal for the phenomenologist, who aims for a general structural description based on multiple descriptions of a phenomenon. This issue of generalization is raised by Sandelowski (1997) and Giorgi (2006), both maintain that if one employs a true eidetic reduction and describes an essential finding then it is intrinsically general, a view that I increasingly found myself aligning with. Indeed Osborne (1990) argues that whilst:

> "...*natural science methodology looks for statistical generalizability, phenomenological research looks for empathic generalizability*" (p.86).

Although it is not possible to generalize this study's findings in empirical terms I believe it is possible to generalize our understanding to others in similar situations to those that I have investigated.

Interestingly researchers such as Paley (1997) criticise the nursing literature for their interpretation of Husserl's bracketing, arguing that the process involves the 'free variation' by which the chosen aspects of the concept in question is examined for the range of possible forms it may take, and by adding and subtracting the possibilities that cease to exemplify that concept then the essence is revealed. Paley (1997) also implies that it is not the researcher alone that must achieve primordial experience but the participants also, to truly engage in Husserl's methods. Caelli (2001) describes precisely her realization of this very point in her paper when explaining her experiences in engaging with phenomenology.

Although Caelli (2001) further argues that all involved in a research study should engage in phenomenological reduction including the research participants, she goes on to make the point that the process in not explicated in the literature. For Giorgi (1997) however, it is the researcher, not the participants, who should engage in bracketing. For me to ask the participants to 'bracket' their assumptions I believed was unrealistic for two reasons. Firstly by asking the participants to set aside their values beliefs and assumptions I felt was not appropriate. Secondly given the difficulties that even experienced phenomenological researchers have in bracketing, it is unrealistic to expect participants to achieve an understanding of this concept and how it might practically be applied in the research interview.. Furthermore, the participants may either intentionally or unintentionally attempted to tell me things that they thought I wanted to hear or would impress me rather than telling their story'.

In order to proceed then my assumptions need to be identified before they can be set aside. To prepare for such critical examination of what is before us and before our interpreting beliefs enter our thoughts then I believe this requires a reflexive stance. Every rational activity begins with assumptions about the nature of the activity. For example; I have made the assumption that to answer the research question that I have posed required an investigation via non-empirical means. Herein lays my dilemma, the mere fact that I have chosen a particular approach is indeed prejudging the questions that I ask and how I ask for clarification is also indeed influence. I cannot change this but I can make an attempt to bracket from this point on.

It is this freeing of the presuppositions that Husserl developed the suspension of the 'natural attitude'. For Husserl the natural world is different from the scientific world in which there is pure objectivity and removal of all scientific objectivity. In suspending certain commonly held beliefs *epochē* places it out of question for the present. Although Husserl did recognise that one cannot bracket everything; but what is left he referred to as the 'residue' the 'transcendental consciousnesses'. The process involves the knower reflecting upon him/herself and him/her knowing life by standing apart from the world '*I stand above the world'* Husserl (1975, p.152). Arguably this process of 'bracketing' is a means of achieving objectivity, as

a natural scientist would, and is perhaps a means of ensuring rigour. Furthermore it ensures that what is described is a faithful description of the carers' experience, one that others can recognise.

In summary, bracketing is an important consideration in phenomenological research. In an attempt to bracket my beliefs regarding the phenomenon, the following assumptions were set aside:

- Challenging behaviour is a stressful experience
- Caregivers may find relief from their situation in sharing their experiences with others
- Carers will find that as time passes ways of coping with the behaviours
- That the carers may find the behaviours difficult to understand and not know how to react to the behaviours
- That the experiences of the caregivers may result in a restriction in their daily lives
- Aggression may be the most difficult behaviour for the carers to cope with

3.4 Reflective Summary

Initially I have struggled with the concept of bracketing, but I am becoming increasingly aware that this is open to interpretation. I now understand that as one becomes curious and raises questions that fuel our research inquiry, then I believe we must remain open to all options. By bracketing our prior understanding, we no longer assume full understanding, with the resultant questioning of our prior knowledge.

Whilst accepting the notion of bracketing, I remain unsure as to how this might be truly achieved as Husserl described. We are not always aware of our assumptions and prejudices, as this is dependent upon our own self-awareness and reflective ability. Indeed this is a concept that was explored by Polanyi (1966) and referred to as *tacit* knowledge. Even in reflection we are not switching off our pre-supposititious, but rather acknowledging them, although Johns (2004) in his

reflective account of engaging in reflection argues that one draws away from one window perspective to view the matter in hand from a different window, a different perspective. Indeed, central to Johns' idea of reflective practice is the goal of accessing, understanding and learning through lived experiences. Perhaps our tacit hidden intuitive knowledge then is the 'true essence' of the experience. However, there may be a real possibility that the differences between the beliefs and 'truths' of the family members of the persons with ABI and the imposition of interpretation on these 'truths'. As Munhall (1994) articulates, the importance about perception in any phenomenological study is the respect for the individual's interpretation of an event as his or her own reality or truth. This was an aspect that deeply troubled me prior to my data collection and during analysis. Was I going to reveal the essence of the meaning or provide an interpretation of it? It is here that I believe that by bracketing out my presuppositions about the phenomena in question and by becoming attuned to my own assumptions and conscious beliefs, then I would be able to look at others. Through adopting a reflective approach I can at least approximate towards identifying my own pre-conceived understandings and deal with the barriers that this may create and thus be able to approach the data from new and different perspective(s). A purely descriptive approach as described by Husserl would mean a belief that one could bracket and thus only describe the phenomena without interpreting, adding or subtracting from it. The eidetic reduction only allows the analysis of the experiences in describing similarities and differences in the participant's responses. Through reflection then the phenomenologist can describe the 'pure' descriptions. In engaging in the 'eidetic' (from 'eidos', a Greek word meaning essence) the purpose is to gain insight into the essence of the experience. Through holding examples, variations of the phenomena in the mind, they are then integrated to grasp the 'essence', and the end product being the description of the phenomena.

I also questioned whether the experience can also be apprehended by observing, thus justifying the field notes and the writing of what is observed as well as what is spoken; I am not so sure. Thus it is an analysis and interpretation of the symbolic behaviour that accompanies the experience as well as the words spoken. Indeed this is in keeping with Husserl's (1977:p.85) 'metatheory' in which he indicates that

the intention of another is given to the observer through language, actions, facial expressions and artefacts.

This journey of exploration into phenomenology and its application to research has not been without its angst. I have arrived at the belief that a phenomenological methodology that is both descriptive and reflective will enable me to arrive at an understanding of the phenomenon in question. The phenomenological approach that I used was inductive, descriptive approach informed by philosophical work of Husserl. This approach allowed the investigation and description of the phenomena in question. It will address the research question by exploring the experience to discover insights, meanings and understanding of those experiences. Furthermore I believe that the inherent individualistic approach in phenomenology allows for the unique experience of individual's immediate families/carer to be explored and expressed.

3.5 Conclusion

This chapter has described the issues and challenges I confronted in determining an appropriate methodology for my research thesis. This included a discussion on the concept of bracketing. The methodological approach adopted must be defensible from both a philosophical and epistemological position (Caelli, 2001). Furthermore I now realise that I must become cognizant of the differing philosophical approaches within the phenomenological paradigm in order to make an informed choice of the methodology. Starting out on a journey of utilizing phenomenology as a methodology proved a challenge; navigating the literature for clarity and understanding on how to achieve the research was problematic. Furthermore, understanding the complexity of the underpinning philosophies proved a major challenge for me not least because I had little knowledge of the subject, although during the taught component of this programme I had explored the concept of personhood which took me down several ethical and philosophical avenues. This background reading during the taught element of the Professional Doctorate has proved invaluable. Although I have found myself swinging, hanging

on just at times, between the beliefs of suspending ones presuppositions and describe the meaning and the hermeneutic cycle of interpretation.

I understand that the philosophical ideals are crucial to research, providing coherence and the appropriateness of its methodological processes and to its data analysis. I realise that whatever method I agreed upon needed to follow and reflect the philosophy chosen throughout the study. I also understand that this process is fluid, changing as my understanding develops and evolves just as Speigelberg (1969) described the historical roots of phenomenology as a 'movement'. Initially I had thought about using an interpretive approach, viewing that if I was to interpret the texts then I would gain understanding for nursing practice. However, as I engaged in reading descriptive phenomenology as Husserl maintains, then themes and statements can be achieved that may actually provide some form of generality.

From the outset of choosing a phenomenological methodology I began a long process of self reflection so as to be aware of my own beliefs and assumptions in an effort to follow a descriptive phenomenological approach. Furthermore, it is arguably fundamental to the process of bracketing. My dilemma, as a nurse though, is that I am grounded in the belief that as a practitioner I seek understanding through description and interpretation and self-reflection which are inherent in the Heideggerian existentialist interpretive doctrine, whilst also being holding a logical and positivist view. Whilst I recognise that there are several approaches within the phenomenological movement, I am influenced by Husserl's philosophical ideals and the empirical phenomenology developed by Giorgi.

The following chapters will be informed by these concepts and will follow the structure set out in Husserl's philosophical method and Giorgi's methodology:

- Adopt the phenomenological attitude, bracketing personal past knowledge, other theoretical knowledge
- Encounter the phenomenon of challenging behaviour
- Analyse the data
- Describe the essences that were discovered

---oOo---

Chapter 4 'Doing' the research

4.1 Introduction

This chapter describes the methods employed in this study. It describes how participants were selected for the study, the ethical considerations; informed consent, confidentiality and anonymity issues are described along with how the data was collected. This section concludes by reflecting on data collection and ethical issues that arose. This is then followed by a discussion of the transcribing process and methodological issues that this created, culminating in a reflection on this process. The chapter concludes with a description of the data analysis procedure following transcription as well as a summary of checks that were employed to address the trustworthiness of the study. Finally a presentation of emergent themes is provided

4.2 The study participants

According to Hycner (1999):

> "...the phenomenon dictates the method (not vice-versa) including even the types of participants". (p.156)

As the purpose of phenomenology is to contribute to the understanding of a phenomenon, then the sampling method used needs to be able to select those who could provide some insight into the phenomenon of challenging behaviour. Thus for the purpose of this study I chose a non-probability, purposive sampling strategy, which is considered by Welman and Kruger (1999) as the most important kind of non-probability sampling, to identify the participants. Patton (1990: p.182) describes 15 strategies for purposefully selecting information-rich cases, all of which have in common the intention of selecting for the purpose of the study although different in their approach and purpose. According to Patton's strategy I chose criterion sampling. Creswell (1998) states that the 'criterion' sampling works best in phenomenological studies and it is essential that all participants experience the phenomenon being studied and according to Miles and Huberman (1994) are

those participants who met a criterion. These terms seem to be used interchangeably. All non-probability sampling techniques used in qualitative research however, involve the researcher's subjective judgement in selection. Identifying the participants to be selected was based on the premise that I was looking for those who:

"...have had experience relating to the phenomena to be researched" (Kruger, 1988: p.150).

The inherent bias involved in this process was intentional and used positively to facilitate the research process. As Morse (1991) claims, using probability sampling would violate the whole purpose of the research of obtaining data from experts. Sandelowski (1995) concurs with Patton's (1990) view that all qualitative research can be encompassed under the umbrella term purposeful, but only describes three different types; maximum variation, phenomenal variation and theoretical variation. In phenomenal variation sampling, the researcher is intending to seek maximum phenomenal variation in order to understand how diverse factors may affect the phenomena as a whole. Initially the non-probability sampling technique snowballing was also identified as a particularly suitable technique but the local ethics committee who approved this study felt that this would subject the participants to coercion and thus deemed it inappropriate.

Because the phenomenological method seeks to uncover in-depth meaning and experiences, the sample size was deliberately small. Indeed Sanders (1982) makes the point clearly by stating "...more subjects do not yield more information." (p.356) Moreover it was recognised that the given time frame of the study would not facilitate a large sample. Initially 6-10 were expected to be interviewed, guided by the following, firstly, the quest for understanding will undoubtedly be guided by the unfolding of material and secondly by the availability and accessibility of participants. Boyd (2001) regards 2-10 participants as sufficient to reach saturation of data however; this may be more pertinent in a grounded theory approach in which the generation of theory is a prime aim of the research. Whilst Creswell (1998: p.65 & p.113) recommends "long interviews with up to 10 people" for a phenomenological study, Sanders (1982) believes it is realistic to expect that 3-6

individuals will provide sufficient information and argues that "...*quality should not be confused with quantity* "(p.356). For Sandelowski (1995), researchers have to make their own judgement on size, ensuring that the numbers are enough to permit depth, richly textured understanding of experience. Indeed Marshall (1996) asserts that an appropriate sample size is one that adequately answers the research question, a view echoed by Kvale (1996). Patton's (1990) response to the question of sample size in qualitative research is that "...*there are no rules for sample size in qualitative inquiry*" (p. 184). Whereas, Giorgi (2008) recommends at least three participants, arguing that the differences between them will make it easier to determine the individual from the general experience. A purposive sample of five close family members participated in this study. The participants were volunteers recruited from a Regional Neuroscience Centre[9] and were selected based upon my experience and the purpose of this study. The research participants were selected to fit the criteria set out in Table 1

Table 1 Participants' inclusion criteria

Family members of patients with a primary diagnosis of acquired brain injury (ABI) e.g., traumatic brain injury, intra-cerebral and sub-arachnoid haemorrhage, brain tumours, anoxia, or encephalitis occurring after birth
Experience of the phenomena of challenging behaviour
Have the ability to share their experiences, give informed consent and be willing to provide insights into their experiences
Adults who speak the English language and are able to speak about their experiences

Those who were unable to speak English were excluded from the study as there was no guarantee that the meaning would remain the same during and after translation interpretation, as perception can be different. Furthermore as I was attempting to extract meaning, it was conceived that translation may contaminate the core experiences and meaning.

---

[9] The regional neuroscience centre services a population of approximately 2.5 million, although these figures have also been quoted to be over 3.2 million, acting as a tertiary centre for all the primary and secondary referral centres. Taking the modest prevalence rate for TBI alone of 250 per 100,000 this data points to the number of new cases per year of 6,250.

For the purpose of this study a family member was defined as:

- A minimum of 18 years old
- Spouse
- Close extended family i.e. mother, father, son, daughter, brother, sister or aunt, uncle
- Partner or close friend

The importance of being able to recruit sufficient and appropriate participants for the study was considered to be vital, as this may have ultimately resulted in study abandonment. Given that this study was governed by a given time frame for completion, the need for timely participants and the perceived difficulty of accessing a vulnerable population group, the issue of achieving enough participants to address the research studies aim, was a consideration. To manage this issue a multi-recruitment strategy was used to reach and recruit potential participants for the study. Initially flyers were posted in the areas frequented by families within the neuroscience centre i.e. day rooms and outside the ward areas (Appendix D). The flyer included information about the study's purpose, length of time required and potential participants (e.g., immediate adult family members). Advertising for the study including flyers was considered as the first step in the informed consent process thus these were approved by the local ethics committee prior to their use. Other recruiting strategies that were used included:

- Letters to the specialist nurses and the Neuropsychology team working in the Regional Neuroscience Centre outlining the purpose of the study, criteria for selection and requesting them to draw attention to the research study and hand the potential participants the information sheets (Appendix C)
- Flyers on notice boards in the Brain and Spinal Injuries Centre where support groups meet (Appendix D)
- Available information letters introducing the researcher, outlining the study and its purpose and inviting them to contact the researcher if they are willing to participate in the study (Appendix E)
- By word of mouth as part of the researcher role as an academic in practice practically meant being in the clinical areas regularly (at least once per week)

My status as 'an insider' within the organisation was also perceived advantageous at the time in that I could facilitate the recruitment process.

4.3 Ethical Considerations

Permission for the research study was obtained from the Local NHS Research Ethics Committee, University of Salford Research Governance and Ethics Committee and the NHS Research and Development Forum in accordance with the Department of Health's Research Governance framework (DH, 2005b) prior to commencement of the study. In addition, as a registered nurse I adhered to the Nursing and Midwifery Council Standards of conduct, performance and ethics for nurses and midwives (2008).

4.3.1 Informed Consent

It was considered that families and carers of family members who, following ABI had challenging behaviour, were potentially vulnerable because they were experiencing exposure to traumatic events. Thus research on such participants must be conducted in a humane and dignified manner. A major challenge in preparing the recruitment flyer, information sheet and informed consent form in any research study lies in constructing these materials that are both understandable to the average lay person and include the relevant information that is crucial to participants understanding of the study. This applies to spoken as well as written communication. Clarity of the research purpose, seriousness of intent, and scientific worthiness of the study must all be established for the potential participant, both in the written and verbal communications between the researcher and the participants. Thus I considered how the study would be presented and how that could affect the participants' response to requests for participation. Due consideration was given to the quality and accuracy of both verbal and written communication between myself and the potential participants. To avoid perceived coercion that could result from asking families directly to participate, staff were asked to approach potential participants only once and to be brief and draw their

attention to the information sheet. Prior to the interview, all participants were given the information sheet which introduced the researcher, outlined the general nature of the study, its purpose and invited them to be involved in the research study. Being provided with information is, however, only part of the consenting process, it is equally important that participants also understand the process, particularly the consequences of signing a consent form and taking part in the study.

Following an initial discussion about the research study, its purpose and process, its potential risks and benefits, an opportunity was provided for participants to ask any questions or queries about the research study. My willingness to answer questions in an empathetic, as well as in an informative and scientifically accurate manner is an aspect of communication that I felt would facilitate trustworthiness. During this interaction I also felt it was important to assess participants' emotional state as to their readiness to share their experience. As Munhall (1994) stressed, the need for readiness is a priority condition. This I achieved through discussion, listening and addressing any concerns about the proposed research. Furthermore any potential participant must be given sufficient information to allow them to decide whether or not they want to take part. The purpose of the information sheet was to ensure that participants understood the risks and benefits of participation (compared to non-participating) to both themselves and others. Whilst devising the form, I was aware of the need to strike a balance in deciding the amount of information to give. Too much risked limiting the spontaneity of the information to be gained whilst too little risked compromising the informed consent (Appendix F).

The informed consent form was explained to the participants at the beginning of each interview (Appendix F). A copy of both forms once signed was given to participants for their information. During this study any verbal and written communication with participants was aimed at providing adequate information to enable them to make an informed decision about participation. However, the concept of informed consent does imply that the researcher knows in advance what is going to happen, what is going to be revealed and the subsequent consequences. This, I felt, was not entirely the case as I did not know what the interviews would reveal. Ramos (1989), claims that the nature of data collection in

qualitative research makes it almost impossible to achieve informed consent, and offers the concept of:

"...ongoing consensual decision-making where emergent difficulties are discussed openly" (Ramos, 1989: p.61)

as a way forward in an attempt to address this dilemma. This concept was later referred to as 'process consent' (Munhall, 1991), suggesting that this encourages mutual participation and mutual affirmation between researcher and participant. Munhall (1994) also argues that informed consent should be an on-going process, starting with the researcher's first contact with the individual and continues throughout the research study, participant withdrawal, and beyond. This continual re-negotiation, informing and re-informing and seeking permission established trust between me and participants. I felt assured that I had proceeded in a transparent ethical manner. The participants received information about their right to discontinue participation in the study at any stage during the interview, without the need to give a reason, thus ensuring participant integrity.

4.3.2 Confidentiality

Confidentiality was assured in the reporting of the study both verbally and in writing with no actual names being included in the interview material, transcripts or notes. Although complete confidentiality cannot be assured as this implies that I will not share their information with anyone, the best I felt I could offer was a modified confidentiality. Furthermore it was recognised that disclosures could occur during the course of an interview, thus a clear explanation of the limitations of the principles of confidentiality were outlined to participants before the interview commenced, both verbally and in writing. I also recognised that I might have to refer to an appropriately trained health care professional, for further support once issues have been disclosed, which raises the issue of breaching confidentiality. Although this transpired to be unnecessary I realized that there could be no absolute safeguard against breaches of confidentiality; at best my responsibility lay with ensuring that as many processes were in place to lessen the likelihood of

such breaches. Although procedural ethics cannot provide solutions to all the dilemmas that researcher's face in the field, it can as Guillemin and Gillam (2004) articulate, provide a practical reminder of the principles that guide us.

The records of this study were kept private. In the event of any sort of report being published, then this would not include any information that will make it possible to identify the participant. Research records and mini-disc recordings were kept in a locked file; only the researcher had access to the records and the recordings and records were destroyed upon completion of the study in accordance with the Data Protection Act 1998 (1998).

4.3.3 Anonymity

In recognition of the importance of the difference between anonymity and confidentiality the research will ensure that the identity of the research subject will not be revealed. As stipulated in the Data Protection Act (1998) the mini-disc recordings were anonymized and encrypted. Although total anonymity could not be assured as both I and my supervisor could identify the participants, I could assure that anonymity outside the remit/sphere of the researcher and supervisor was preserved.

4.3.4 Assessment of risk – protecting the interest of the participants

During the preparation of the research protocol for this research I became aware of the perceived potential risk to the participants in taking part in the study. I deemed the subject of the research to be sensitive, assuming that exploring participants' experience of their family members challenging behaviour was a sensitive subject because of the perceived change in their family member's behaviour since their ABI. Potentially this was further emphasized by the difficult life situations that these families face as a result of the challenging behaviours displayed by the person with ABI. In addition, participants were going to be asked to describe these situations and their experiences. At this juncture I drew on my

71

own deep reflection that I had undertaken as part of the taught component of this programme of study. This intense personal scrutiny of my values, beliefs and dialogue had been a painful one. But as a result I had, I believe, emerged with a greater sense of conscious understanding of self and the consequential impact that this had had and can have on my professional practice. My dialectical thinking had enabled me to see things differently, be aware of my own bias and my inherent ideologies and gave me a sense of enlightenment. The family members' opportunity to express themselves during their interviews, something which perhaps had not been afforded to them before, I thus reasoned, might equally be enlightening and facilitate the construction of meaning, although I understood this would not be without risk and I could not promise any benefit for participating families or patients. Many researchers have argued that unstructured qualitative interviews can have a positive effect upon participants (Hutchinson *et al.*, 1994; Kavanaugh and Ayres, 1998; Corbin and Morse, 2003). Murray (2003) illustrated the therapeutic benefits of undertaking qualitative research interviews with a vulnerable population, with regard to a sensitive phenomenon (parental alcoholism), that of making sense of the situation and a change in their perception of their experiences. There is research evidence within the field of psychology on the benefits of sharing experiences and the effect on health and well-being (Pennebaker, 1993; Pennebaker, 1997). Whilst achieving insight is the most cited benefit, other benefits include emotional relief and the satisfaction of making a contribution to the welfare of others by serving as a research participant (Newman and Kaloupek, 2004). It was conceived that the revealing of one's emotions for the participants in this study may be helpful in understanding of their experiences of challenging behaviour and thus be a therapeutic experience, although this is not the stated purpose of the research study. These benefits are, however, actual benefits not intended benefits and will indeed vary according to the individual and may even take time to transpire. On the other hand the effect of providing a listening ear and stimulating disclosure could be construed as manipulation.

In therapeutic practice the giving of space and time for reflection gives new meaning to an experience. This undoubtedly resonates with the interviews undertaken in research that focus on experience. For it is not just us that judge the interview but the participants also, they may well judge them as therapeutic. It

perhaps is pertinent here to define therapeutic. McLeod (1997) summarises it as a particular type of 'emotional processing', an act of self-disclosure, telling about your sense of self, and all practices converge on the objective of reconstructing such narratives. In this sense the research interview and the therapeutic practice may involve self-disclosure, in the presence of a listener. However, Kvale (1996) makes a clear distinction between the two; whilst therapeutic practice is aimed at a change in the patient, in research interview it is about the acquisition of knowledge.

I acknowledged that participant harm may arise from undue stress through their participation, loss of self-esteem, or psychological injury. Levine (1979) stipulates that various factors may be important in assessing the risk-benefit ratio of a particular inquiry, such as the probability of risk, the number of people at risk, the severity of potential harm, the anticipated utility of findings, few of which are usually quantifiable. In recognition that the potential was there, I set out to try and minimise disturbance to both the participants and myself by working within an ethical framework. However, neither informed consent from participants or any legal framework can fully protect the individual against potentially harmful effects of participating. Through my searching and reading I explored and clarified potential risks and benefits. This process enumerated the issues, clarified potential risks and benefits and in doing so made it easier to manage the research study. This culminated in the production of a risk protocol to aid management of my potential risk and in the event of participants experiencing any undue stress during the interview (Appendix G). Although at the beginning of this research journey I had not conceived the potential harm that the research process might have on me as researcher; I had concentrated on the potential ethical dilemmas for the research participants at the expense of looking closer to home at my own risks. The ethics committee raised this very point, stressing the need for some protection for me as researcher, ensuring that I mitigate against my own potential psychological stress from the disclosure of sensitive painful experiences and potentially being overwhelmed by the sensitive nature of what I have heard. Indeed some go as far as arguing that safeguarding the physical, emotional and professional well-being of researchers' tends to be underdeveloped (Lee-Treweek

and Linkogle, 2000). In agreement with my supervisor, a debriefing with her after each interview was agreed.

As laid out in the protocol, if at any stage during the interview the participants were distressed or upset by the conversation during the interview, the interview would be stopped and participants offered support initially from myself. If further support was required it was sought from either the specialist neuroscience nursing or neuro-psychology clinical staff through the appropriate referral systems. In reality, during and after the interviews, participants did not require any further support. Although at times they were emotional, I observed their body language and used non-verbal cues to make a judgement about what was acceptable in recognition that any interview about one's experiences was likely to incite emotions. The issue of risk, however, raises the question as to why risk should be any greater if personal revelations and disclosures are made to a researcher than if they were made to their family members or friends. Corbin and Morse (2003) suggest that the difference between researcher and family members is that the researcher is more likely to be interested in hearing their story and empathize, whilst family members often do not want to hear the story and/or are embarrassed by the intensity of the emotional response. Indeed in the case of the first interview I did get a sense that the mother had not divulged her full story to any other family members, crucially because of family dynamics that she disclosed prior to and during the interview; her husband was an only child and had been murdered, her mother was dead and her brother and sister were now estranged due to financial wrangles. At the end of the interview she brought me her detailed diary of events surrounding her son's accident and subsequent injury, and her thoughts since her son's head injury. I spent some time with her listening to some of her entries providing a listening, empathetic ear, and I contemplated her sorrow on leaving. The impact or benefit of this mother writing down her story, I will never know, but perhaps it echoes the findings of innovative research carried out by Pennebaker (1993; 1997) who expressed the salutary therapeutic effect of journal writing about personally upsetting experiences upon one's well being and has been heralded as a major finding in understanding the impact of trauma and physical health. Indeed I will never know the true impact of the family members telling me their stories and experiences.

4.4 Data collection

4.4.1 Introduction

Many options for data collection are available to qualitative researchers, including interviewing, personal interaction, document reviews, and research notes (Denzin and Lincoln, 2000; Patton, 2002). In this study data collection included 1) interviewing and 2) research field notes. The data collection process occurred over an 8-month period in 2007. In this section the conduct and recording of interviews is discussed along with the use of field notes. Practical consideration and issues that arose are presented, followed by a reflection on the whole data collection process.

4.4.2 Interviewing

If the essence of the phenomena in question is to reflect the experiences from the subject perspective then a research method needs to embrace such underpinning philosophies and data collection so to enable authentic collection of data; it is with this premise in mind that interviews were selected. It is a purposeful data-generating activity characterized and defined by the philosophical position that I adopt. The interview as a data collection tool was chosen as it gives the information about the phenomenon that cannot be obtained by direct observation. I cannot observe feelings, thoughts or intentions nor perhaps, more pertinent to this research, previous experiences. There are many definitions of an interview offered in the literature Matarazzo (1978) defines it as:

> "...deliberate initiated conversation wherein two persons...engage in verbal and nonverbal communication towards the end of gathering information which will help one or more parties reach a better goal" (p, 47).

Moreover, interviews facilitate interactive dialogues between participants and researchers (Fasick, 1977; and Wellard and McKenna, 2001). Patton (1990) identifies three main types of qualitative interviews; each varied in their structure and format of their questions, and each with advantages and disadvantages.

These he identified as being the informal conversation, the general interview guide approach and the opened-ended interview or alternatively as Minichiello *et al.* (1990) refers to, the unstructured, semi-structured and the structured.

My initial approach was to use unstructured interviews or according to Patton (1990) the informal conversation. I rejected the notion of a structured interview on the basis of its limited flexibility in responding to the concerns and responses from the participants. I was not setting out to compare but rather to explore participants' experience without limitations and constraints imposed by structured questionnaires or interviews. According to Morse and Field (1996) unstructured interviews are to be used when the researcher knows little about the subject, whilst in semi-structured interviews the interviewer knows most of the answers, but cannot predict them and is defined by Burgess (1984) as *'conversations with a purpose'*. It is argued that unstructured interviews have potential to generate the richest of data in comparison to other types of interviews (Fontana and Frey, 2000; Tod, 2006). Parahoo (2006) contends that the initial meaning of the unstructured interview is that the researcher wishes to explore a very broad area or aspect of experience, with very few specific questions or topic areas defined in advance. However, the term 'unstructured' may be misleading, in that participants have consented to be interviewed for the intention of the study, and what's more roles and relationship between the researcher and participant do presume some structure. There is undoubtedly some structure to an interview, whether that be unstructured or semi-structured, otherwise how would we guarantee that the information collected was in relation to the research question. Whilst the advantages of unstructured interviews allows for more complex issues to be probed, answers to be clarified and a more relaxed research atmosphere may be more successful in obtaining more in-depth and sensitive information, the passivity of the interviewer may prevent the participants from sharing their experience. The local ethics committee, however, deemed this approach to be inappropriate and instructed a semi-structured approach. Descriptions of the phenomenon were thus elicited through an open-ended, semi-structured approach, which was recorded for analysis.

Arguably it may be more appropriate to call these interviews in-depth interviews with less structure that covers two or three issues that were deemed to be of importance. For as Minichiello *et al.* (1990) state both unstructured and semi-structured are two ways of doing in-depth interviewing and are reported to be the most common method of data collection in qualitative research (Silverman, 1993). Whereby in-depth interviewing according to Taylor and Bogdan (1984) is defined as the;

> "...repeated face-to-face encounters between researcher and informants directed towards understanding informants perspectives' on their lives, experiences or situations as expressed in their own words" (p.77).

This Minichiello *et al.* (1990) points out implies a more conversational style of interviewing, and as Legard *et al.* (2003) state, a key feature of in-depth interviewing is the combination of both structure and flexibility. Furthermore an important tenet of the Husserlian approach is the belief that the lived experience can only be revealed by a one-to-one transaction between the researched (the carers) and the researcher. It was for these reasons that face-to-face interviews were employed.

4.4.3 The flexible interview guide

In response to the local ethics committee request for a brief checklist of topics to be covered during the interviews I developed a flexible interview guide, one that was not too constrained but it gave me a sense of security in that I had some key questions to ask. These covered the general themes or issues that were to be explored; they were not rigid, but flexible in their order and allowed for the exploration of other issues. I was, however, mindful that by framing specific questions in a particular way might reflect my presuppositions or biases and may prevent the emergence of participant's experiences and thus generate broad answers. In deciding on the questions I attempted to be as broad as possible so as to reduce my presuppositions. I was aware through my reading that the family member may be experiencing stress, burden, and family dysfunction and relationship problems. Also I had personal experience of challenging behaviour

following acquired brain injury, but not in the hearing of personal accounts of others. The interview schedule (guide) is presented in Table 2.

Table 2 Interview schedule guide

"Please describe a time when your family member (patient) was experiencing/ exhibiting challenging behaviour"

'Describe in as much detail your thoughts and feelings associated with that.'

'Can you tell me about you experience of encountering this (challenging) behaviour?'

'Can you tell me about your experience? 'How did it affect you at first? How does it affect you now?'

'How would you describe how you felt?'

'Can you tell me more about . . . ?' 'Is there anything else . . . ?'

'What happened' 'When did it happen?' 'How was that for you?'

'What did you think about that'

'Can you give me an example of . . . ?'

'Can you share with me that first experience' 'How did it affect you at first'

'How does it affect you now?'

"Can you tell me what it is like to live with someone with challenging behaviour?"

'Describe in as much detail your thoughts and feelings associated with that'

"How does your relative make you feel as a result of their challenging behaviour?"

At the end of the interview:

'Is there anything else . . . ?' 'Is there anything you would like to ask me?'

The participants were thus invited to recall, reveal and construct aspects of their experience by the use of an open-questioning technique in an effort to elicit subjective and idiosyncratic responses from the family members. I also prompted with encouragement, such as 'Uh huh' 'Yes?' 'Go on', or asked example questions, like 'such as?' This approach was felt to facilitate the freedom of

participants to talk about their experiences in their own words and provide rich data. Put simply the researcher's job is to let participants tell their own story. However, it was conceived that participants may have more control over the conduct of the interview in that they were permitted to discuss issues as they arise and not necessarily in the structured order predetermined by the interview brief or by me.

How the questions were framed raised the importance of impartiality, and neutrality and emphasized freedom of participants to speak. Interviewing demands a high degree of skill in open questioning and probing in order to avoid leading the interviewee and to facilitate the in-depth exploration required. As Patton (1990) stated, good questions in an interview include those that are open-ended, neutral, sensitive and clear to the interviewee. To avoid bias the interview schedule/guide was shown and discussed with my supervisor for appropriateness, sensitivity of questions and to ensure that no pre-existing themes would contaminate the interviews. Providing interview questions in this manner, however, gives transparency as well as providing sufficient description thus allowing valid judgments to be made by the reader(s). However, I found this difficult to reconcile not least due to the fact that if a perquisite of phenomenological approach was to come without any pre-conceived notions about the topic, approaching the interviews in this way contravened its underpinning philosophy. It did, however, allay my anxieties about conducting unstructured interviews and my worry as to whether the interview would actually generate any meaningful data. I also took comfort from the fact that Arthur and Nazroo (2003) maintain that it is best to keep the interview guide as short as possible so as to encourage more in-depth data collection as I had attempted to do.

Mishler (1986) and Fontana and Frey (2000) both regard interviews as philosophically complex, contextually and ethically difficult. In an attempt to address this issue I followed a process of gently easing the participant into the interview or 'laddering' as suggested by Price (2002). I felt this added to the ethical framework that I was striving to work within, treating the interview with sensitivity and respect. Price (2002) argues that the use of a systematic technique such as 'laddering' in which questions are conceived as operating at one of three levels,

starting with the least invasive inviting description, progressing to the more invasive knowledge question and finally asking questions about their feelings, might provide richer data than that of an *ad hoc* approach. This of course I will never know. I do believe that honesty coupled with confidentiality helped reduce suspicion and promoted sincere responses from the participants. Moreover, questions that are structured around seeing and feeling according to Silverman (1976) uncover the participant's sense or essence of their lived experience.

At the start of my contact with participants I found that I was drawing on my experience as a nurse, my ability to build a rapport with patients quickly and under difficult situations. I found that I quickly developed a rapport, gaining trust and confidence with the participants. I also was acutely aware of the need to asses when it was appropriate to start interviewing. Rapport building I saw as an important means of reducing the perceived differences in status, knowledge and power that might have existed between me and the participant. Morse and Field (1996) suggest that developing a rapport with participants may take time and rushing the interview may not elicit 'rich data'. I started with questions that would also help alleviate any anxiety and provide assurances that I was interested in the participant's story. The relaxed atmosphere that ensued, I felt, cultivated a sense of openness and revealed participant's true inner feelings, attitudes and understandings. A structured interview approach clearly would not have elicited such rich data, nor permitted such a critical researcher/participant relationship to develop.

Although the interviews were semi-unstructured I initially set out to gather background information on the participant and the brain injured, prior to the commencement of the actual interview. This was to be gathered by means of a brief structured list of questions about the participant's socio-demographic characteristics i.e. gender, date of birth, occupation, education, ethnic status, date and place of interview (Appendix H). Characteristics of the ABI person were also documented including cause of injury, date of injury (if applicable) and time since injury. However, I soon realised the insensitivity of such a venture and abandoned it in favour of just chatting to the participants and gathering the relevant

information from clinicians and available medical notes either before the interview or at a later stage.

Audio mini-disc recorded face-to-face interviews on a one-to-one basis were undertaken, directed at understanding the participants' perspectives of their lives and experiences of challenging behaviour and cognitive impairment, expressed in their own words. Face-to-face interviews have the advantage of providing both researcher and participant with non-verbal cues which may promote the development of rapport and trust between two people involved and allows for nuances such as facial expressions, blushing gestures to be visible. Any non-verbal information that I collected during the interview would supplement the verbal information provided by participants. This sensitivity to nuances of interviews undoubtedly is a major advantage in data analysis, adding depth to the analysis and an improved 'feel' for the data (Fasick, 1977).

A good quality recorder, as well as tapes/mini-discs, was used to enhance the sound quality of the playback and minimise lost research material due to inaudibility. Given (2004) discussed the benefits of using a mini-disc recorder, citing increased fidelity, longer recording time and ability to index recordings. However, I acknowledged that the use of the mini-disc or tape recorder does not eliminate the need for field notes. A small, unidirectional, compact digital stereo microphone was used on a nearby available level surface (e.g., coffee table) between me and the participant. There was no indication during the interviews that this was unduly intrusive or a distraction. Due to the small size of the recorder and microphone it was easily forgotten. There were two occasions when the mini-disc recorder failed to record. This was not due to mechanical failure, but rather due to my own inadequacies. The first occasion happened at the beginning of the second interview in which I accidentally dislodged the microphone lead so that it would not work. On the second occasion I failed to turn the recorder on correctly at the beginning, and did not check later to see if it was working as I was so engrossed in the interviewing. Once I had realised these failings, I made handwritten notes, recalling as accurately as I could the events of the interview.

According the Streubert and Carpenter (1995), the phenomenological interview ends when "*participants believe they have exhausted their descriptions*" (p.43). I also felt that at this point it was important to ask participants if they had anything else they would like to tell me and give them the opportunity to do so, a view supported by Patton (2002). Once the interview drew to a close, although this formally was when the mini-disc recorder was switched off, I realised that this was indeed a gradual process. I endeavoured to 'gently withdraw' so as not to leave the participant's feeling as if they had been invaded. Once I had thanked the participant I moved the participants away from the mode of the interview by drawing the conversation into a more positive, congenial lighter subject of conversation, so that the interview experience could come to a pleasant conclusion. At this juncture I felt I needed to give something back to the participants, until there was an unsaid acceptance that I could leave the interview setting. This took much longer than I had originally anticipated and I soon realised that this was for my benefit as well as for the participants. This disengagement from the field, the dissolving of the collaborative relationship, however, is not explicated in the literature. Although Ortiz (2004) warns of the dangers of over rapport and makes the point that the leaving process is not without its difficulties.

4.4.4 Number of interviews

Participants were informed prior to the interviews that they may be interviewed twice depending upon the outcome of the first interview a second may be undertaken. This I thought would indicate that I was serious in considering the experiences of the participants, but also give them an opportunity to tell me more if they wished. In the follow-up telephone calls to participants, I gave them the opportunity for an additional interview. It was also considered that additional interviews may contribute to the integrity of the material obtained by substantiating what they may have already spoken about. At this juncture I was not aiming to conduct a longitudinal qualitative research study in a deliberate way in which temporality was a design feature of the research, but rather I was just giving the participants an opportunity to be re-interviewed to share further experiences with me. However, it was acknowledged that the participant may give a different

account of their experiences depending on their state of mind, for example in states of depressed mood then the participants may be biased towards recalling negative memories/ experiences or equally when feeling up beat may recall positive experiences. Although this was undoubtedly a risk I took for any one of the interviews that I carried out. There may also be an issue that the impact of repeated interviews may be greater than for those who had only given one, through the engagement of reflection or looking to the future and the potential for increased self-awareness about the impact on their lives. I also considered that once participants had consented to the take part in the study they may have reflected upon their experience(s), and that they may not have given a true reflection of their experience, in that they may have chosen to withhold certain painful feelings. This I anticipated to be overcome by displaying a safe, trusting environment to share their feelings with the researcher.

Three agreed to be followed up with a second interview; however, only one actually took place. The first participant (Carer 3) had agreed to be interviewed again after I returned from a week's leave but then changed her mind when I contacted her. The other participant (Carer 5) when I returned for a second interview at her house at the agreed date and time, she was out, and she did not answer her mobile or house telephone when I called. So I abandoned the thought that she would consent to a second interview although she had written it down in her diary.

4.4.5 Length and location of interviews

The interviews were anticipated to last approximately 60-90 minutes each, although this may vary and is not a fixed time period, rather an indication of the time frame for the participants. The literature offers differing views about how long interviews should last. As this research is qualitative, utilizing interviews for its data collection method 60-90 minutes is generally regarded as a reasonable length of time for an in-depth less directive interview. Seidman (1998) argues that if an interview is to enable participants to reconstitute their experience it would be difficult to achieve in less than 90 minutes. Moreover, Holloway and Wheeler

(1996) maintain that the participants should determine the duration. Given the subject that is being explored it may be that the provision of breaks is scheduled in making for a longer period of interaction with participants. In reality this was neither necessary nor appropriate.

Each interview was conducted individually. All were at a time that best suited the participants. The duration of the interviews varied between 39 minutes and 60 minutes. One participant was interviewed twice. A follow-up telephone call was carried out, permission permitting, after the interviews to thank them for participating and to ask if they had any undue concerns or anything further that they wished to discuss.

The comfort of the environment is essential if the interviewee is to feel comfortable, relaxed and at ease to be able to talk about their experiences, thus the family members home was considered as this may be where they feel most at ease. Morse and Field (1996) argue that to facilitate development of an intimate and trusting relationship with the researcher, the participant should choose the setting of the interview. As it was anticipated that most of the participants would be recruited from the Regional Neuroscience Centre at a time when the acquired injured person would still be receiving inpatient treatment and care thus the choice of location was likely to be within the centre. I conceived that the family members might choose the Neuroscience Centre for their interview for convenience e.g., before or after visiting their family member. In reality only one potential participant was identified whilst the ABI person was still receiving inpatient treatment. But, after meeting with her, discussing the research and leaving her with the information sheet to allow her to contemplate her participation; she declined from contacting me for an interview.

The locations were determined through mutual agreement, being reasonable and rational in an effort to redress the power differential between me as the researcher and the participants. I aimed to find a quiet location, the participant's place of residence or other designated setting of their choice with minimal distractions and where privacy could be maintained so that participants could talk confidentially. In reality the locations varied; two interviews were conducted within the neuroscience

centre whilst the others were conducted in the participant's home. The fact that the majority of the interviews were conducted in the participant's home may have been a reflection of their sense of security and feeling more in control in their own environment as they were on 'home ground'. As to whether the environment would have made a difference to their disclosure I am not sure. Environmental interruptions did occur on several instances despite efforts to prevent such an event from occurring. During the interview with participant 3 despite booking a quiet room away from the main activity in the hospital and putting up the notice 'Do Not Disturb' we were still interrupted by medical staff and the constant noise from building work outside. During participant's 4 interview the brain injured family member was the main distraction. He wandered in and out of the room requiring the attention of his wife. I watched with intrigue and found myself attentively observing with a critical neuroscience eye, assessing his presenting neurology. Quickly I had to withdraw and detach myself as I reflected-in-action. I was alarmed at how quickly I switched from a phenomenological researcher to a neuroscience nurse. I was also surprised at my lack of frustration at such events. Perhaps this was because I was aware of the unpredictable nature of these patients. But at the same time I was naïve to the practices in primary care that professionals may face in their daily work. Arguably though in this 'home ground' other family members have a right to be present and it may have augmented the carer's response. Thus in reality, avoiding interruptions I now realise is problematic especially when carrying out research in the participants' territory. As researchers we can only attempt to reduce them through careful planning, whilst being alert to the unpredictable nature of researching in the field.

4.4.6 Field notes

In order for a researcher to be aware of all of the participant's behaviour that relates to the study and thus act accordingly Kavanaugh and Ayres (1998) argue it is crucial to document participant's behaviour in the form of field notes. In recognition that mini-disc recordings do not portray the physical environment or non-verbal communications during the data collection, field notes were used to supplement the interview data collection method. Field notes according to Porter

(1996) contain descriptions of the social context and interactions that take place in the field. Patton (1990) argues that there is no single method or technique and that field notes can provide a check on what is reported in interviews. Arguably this enhances the rigour and reliability of what is being reported. Poland (1995) agrees that field notes may serve to clarify aspects of the interview context, providing that one accepts that they are themselves partial interpretive accounts. Easton, *et al.,* (2000) maintain that field notes are primarily an insurance against audiotape failure. Field notes were also used to help record data after the mini-disc recorder had been switched off. At such times, important information was often shared. For example, valuable comments were recorded when the follow-up telephone contact was made. Schatzman and Strauss (1973) emphasise that note-taking and research diary keeping are much more than a mechanical means of storing information for later retrieval, arguing that;

"*...the researcher requires recording tactics that will provide him with an ongoing, developmental dialogue*" (p. 94).

These included all contacts, interview cancellations, interview setting and the participant's behaviour before, during and after the interview on my devised field note paperwork. In accordance with the model described by Schatzman and Strauss (1973) the notes were then organised into categories (Appendix I Field Note Proforma). During the interview I intended to take discrete descriptive notes e.g., key words and phrases in order to keep an account of the topics covered as well as a back up to failed recordings (the batteries were regularly checked). However, in reality I soon abandoned the notion realising that I did not possess the confidence or experience to do so. What the field note proforma gave me was a clear strategy for storing notes for later retrieval during data analysis. This included reflective notes taken throughout the research project, recorded thoughts, feelings and ideas or questions that I thought of. This was based on the premise that I needed to make my biases transparent, and that there may be important non-verbal message communicated by participants that could supplement the taped recordings.

I realised that through analysis, the collected data and personal reflection came to life, and it is for this reason I decided to do the transcribing and the data analysis myself. 'Memoing' according to Miles and Huberman (1984) is another source of data collection for the researcher and emphasised the need to date the notes. At this juncture I realise that by recording field notes or 'memoing' that this was the first step towards data analysis. Directly after each interview, I described the interactions that took place between me and the participant. I was also becoming sensitive to the subject and the data. As noted by Minichiello *et al.* (1990) note-taking allows partial analysis. However, this can lead to prematurely forming of views, values and ideas about what is being said. Based on this belief I believe I made the right decision not to take notes during the interview, but to reserve them till after the interview when I rationally noted the key aspects of the interview according to the proforma.

4.5 The researcher - participant relationship

Glesne and Peshkin (1992) have questioned whether a non-hierarchical interview can ever be possible, arguing that at best the researcher-interviewer can seek reciprocity. But Nunkoosing (2005) states that the interviewer is always in a power relationship, his/her power rests with the methodological expertise and authority to seek knowledge, whilst the interviewee is seen as the 'knower'. The importance of trust and rapport has a fundamental bearing on what and how much participants are prepared to disclose (Booth and Booth, 1994). I realise that the researcher-participant relationship is crucial to allowing the 'telling of their story' thus attention was paid to creating trust and rapport. As I did not intend to provide information or education but, rather to provide a trusting, non-threatening environment in which the participants could tell their story, I had tried to maintain a clear boundary between me as a researcher and me as a nurse therapist and thus resist the urge to educate. For as Murray (2003) maintains the trusting researcher-participant relationship contributes not only to the therapeutic benefits of the interview to participants, but also to the richness of data. Furthermore, Corbin and Morse (2003) argue that it is this trust and intimacy that creates both the potential threats associated with unstructured interviews and, concomitantly, makes them

potentially therapeutic. Indeed being a sensitive researcher, creating an environment that grants permission for participants to voice their experiences is indeed blurring the boundary between the research interview and the therapeutic encounter. Clearly what is required to work within an ethical framework is to balance the risks to participants and indeed the researcher against the benefits of telling their story and having someone listen to them. As Morse and Field (1996) point out the resurgence of emotions is one indicator of the validity of the unstructured interview technique. The distinction, however, needs to be made between the emotions that emanate from the recall and 'telling the story' of their experiences and the intense fear, helplessness and horror from a direct trauma stressor. The participants did have considerable autonomy and freedom in making decisions about what they disclosed, and indeed the freedom to terminate the interview. Perhaps the one measure of how distressing the interviews were for the participants would be the number who requested further support. None of the interviewed participants required support in the form of a referral to a specialist professional e.g., neuropyschologist.

The relationship between me and the participants was not a distant one as it involved both verbal and non-verbal interaction. According to Ramos (1989) this can range from one of civil cooperation to one involving trust and dependency of the therapeutic alliance. However, when the boundaries between me and participants blurred or diminished then clearly we were exposing ourselves to ethical breeches. Thus it was crucial that I continually evaluated this relationship and whatever relationship evolved I recognised that the interactions would exert a permanent effect on both me and the participants. At the beginning of each interview I introduced myself to participants as a nurse by background and as a researcher wanting to explore their experiences in an effort to help others understand their experiences. This I felt was important, the giving of something about me as I was taking so much from them, but also in an effort to gain their trust. Furthermore, Chenitz and Swansion (1986) argue that the interviewer must have the relevant knowledge and skills necessary to gain the respect of participants. Thus the information about me, which I offered to participants, was a way of gaining that respect. Finally after ending the interviews, I found that leaving the field was more difficult than I had anticipated. I had, prior to the interviews,

conceived that this would be a gradual process as previously noted, but what I had not anticipated was the overwhelming feeling of wanting to stay. I had become deeply interested in their world and wanted to know more. I had invested in establishing rapport and trust at the beginning of the interview process and now found myself not wanting to let go. This may well have been due to my interview inexperience and the fear of not collecting enough data. What became clear in this disengagement process in some respects does not end, as the interview experiences will undoubtedly remain with me forever. In reality, I felt I was leaving behind a world that was never ending for the carers, one that they had not chosen to be in. I also felt the compulsion to ease their pain. But as a researcher and not a nurse I accepted that I had to leave.

4.6 Reflections on undertaking the data collection

4.6.1 Conducting the interviews

May (1991) asserts that as the study progresses, often the researcher becomes more focused and uses more topic guidance to explore areas of special interest, test preliminary findings or look for commonalities or differences in the participants stories. The issues surrounding the structure of interviews, the ethics of the relationship and the selection of interviewees were all shaped by my increasing awareness of the issues that this raised. I became acutely aware that I might be recruiting interviewees who were confident and coherent in their ability to divulge their experiences. There were ethical grounds for such selection, but it was also true that such interviewees were likely to provide more convincing accounts of their experiences. I also realised that this was indeed the reality of real research into life world. Although I had originally planned for unstructured interviews with an aide-mémoire of the points that might arise in discussion, the semi-structured interview did become more appealing and relevant after contemplations for several reasons. I was worried about how participants would react. I was more concerned if they would talk about their experiences with enough depth, rather than whether they would become too distressed to talk. I was also concerned about

differentiating my 'researcher self' from my 'therapeutic self', and how I would manage this, should it arise.

Whilst recognising that there are skills required in attempting to uncover what the participants really think and that there are techniques that can be employed, my interview experience in the field of research was limited. I was fearful that the participants might talk too inconsequentially, or off the subject, or vaguely. Using specific skills to enable the researcher to get the lived experience without contaminating the data is arguably crucial to the underpinning philosophical stance that I adopted. Whilst the subjective nature of factors such as the skill of the researcher, being sensitive to nonverbal messages, nuances and effects of the interview setting may pose considerable threats to the validity of the research, they are also recognised as being advantageous, in that the skilled, reflexive interviewer can be flexible and use insight to gain in-depth data and an understanding of participant's experiences. Undoubtedly the skills of the researcher in interview techniques are paramount to facilitate this process. With this in mind I initially set out to gain experience in the practice of interviewing in an unstructured way.

Practising the interview technique (Coward, 1990; Beck, 1992) is a means of ensuring that data collected are not contaminated and not an interpretation imposed by the researcher. However, upon reflection at this point I recognised my own transferable skills from clinical practice. As a qualified nurse with many years of experience in the field, combined with research supervision, facilitating self-reflection and previous reflective exercises carried out during the taught element of the professional doctorate, I felt this constituted adequate personal preconditions to conduct this sensitive research. These also include interview techniques gleaned from both within and outside the research environment which were also deemed transferable; although I recognised that this was open to further development. In-depth interviewing requires highly skilled interviewers, who are fully cognizant with the aim of the study. The underpinning aim was to encourage participants to talk freely and spontaneously about their feelings, experiences, attitudes and behaviour. I believed I was able to cope with alternating phases of openness, withdrawal, trust, distress and embarrassment, that I was a good

listener and had the skills to be able to encourage participants to talk in the first instance. Thus I concluded after reflection that I would proceed without any specific interview training. Rew *et al.* (1993) indeed asserts that the qualities of the skilled interviewer include; authenticity, credibility and sensitivity. These were skills that I believed I had. Jasper (1994:p.311) further contends that a phenomenological researcher requires a specific set of skills to get the lived experience and cites being reflective, use of clarification, the request for examples and descriptions and the conveyance of interest through listening techniques as being important. Active listening in an engaging, empathic way is not just crucial to the interview process but also an important skill for an expert nurse.

Seidman (1991) argues that a basic requirement of any phenomenological interview is the interest that the researcher has for the others' stories. Through intentional listening I found that I was using prompts to encourage the participants to continue. The conversation from this perspective is one of a storyteller and a curious listener who asks "*and* ", and "*could you give me an example?"* Never-the-less, I appreciate now, having conducted the interviews, the advantages of carrying out research interviews and that relevant training ultimately results in the development of expertise in interviewing skills. In addition to the procedural and technical aspects of the interview, I have become cognizant to the fact that I needed to move away from the technical aspect of interviewing and be sensitive to the experiences and perspectives of those I have interviewed. As Schön (1983) suggests it is necessary for novices in any practice field, such as qualitative research interviewing, to be prepared for the artistry of the practice; that is, to develop skills of reflexivity so that he or she is equipped to reflect on and make sense of the surprises, uncertainties, and challenges that occur in practice. Learning the techniques are only part of learning the ability; to apply those techniques in different contexts is, however, a different matter. I also realise that the efforts and disclosures of each participants, if only in part, were dependent on my interview skills in either facilitating or indeed hindering their ability to tell their story. As Kvale (1996) states interviewing is a craft and in order to master the craft of interviewing the researcher must practice. Dreyfus and Dreyfus (1986) refer to a model of skills acquisition in which the road to the mastery of a skill leads from rule-guided 'knowing that' to the experience-based 'knowing how'. This intuitive

knowledge that is required to 'know how' comes from practice experience. The art of interviewing does not come from the methodological rules but from practice and the skills of the researcher as the artist in their creativity and sensitivity. I understand now that it is not just the spoken word that I needed to be sensitive to, for it is not just the spoken word that is conveying the message. The skilled interviewer not only recognises and acknowledges the caregivers concerns but also asks them to expand on these cues that may be laden with other non-humorous emotions. Sparks *et al.* (2005) makes a strong case for the skilled researcher to follow up the humorous message that the caregiver may be sending with appropriate probes and non-verbal encouragement to gain the necessary insight into the caregiver's experiences. According to Bethea *et al.* (2000) what this requires is more education to be more aware of communicative cues such as humour when discussing care giving issues with family members. For it may be that they when they are offering information in a humorous manner, that these are obviously laden with other non-humorous emotions, which need to be picked up on. Humour may also serve to exacerbate communication breakdown during interviews by acting as a distraction (Bethea *et al.*, 2000). During my interviews I may not have always been sensitive to these cues thus missing the relevance of them; perhaps with more probing I may have provided caregivers opportunities to elaborate more. This is something which arguably comes with practice. Furthermore the carer may not have been aware of their use of humour to convey a message in the interview.

My confidence grew as the interviews progressed, along with my ability to create safe interactions. I understood the method, but was now beginning to master the craftsmanship of interviewing. As illustrated by Heidegger's analysis of craftwork:

> "...it is not the hammer the carpenter focuses on but the nail and the table" (Kvale, 1996: p.107).

The communities of practice that Lave and Wenger (1991) refer to, was another way in which I learned skilled practice. Through engaging in the dialogue and observing the practices of others then as Lave and Wenger (1991) suggest we gradually acquire the mastery of the craft. Through attending research master

classes and discussing with colleagues I assimilated facts, accepted the dissonances that I encountered, and gradually acquired a sense of understanding. The suggestion to employ a semi-structured interview by the local ethics committee meant that I had to return to my own thinking about the underpinning philosophy. The unstructured interviews may simply start by asking a person to describe their experiences or views in relation to the subject of interest. The researchers' role is then to pursue and clarify issues raised by the interviewee. Such interviews require a highly skilled interviewer, and interviewees who are articulate and comfortable with this approach. I was not in that league and thus accepted the ethical committees' decision with some relief. Furthermore one of the problems with such interviews is that they can easily lose their focus and generate what is sometimes termed 'dross' (information seemingly of no relevance to the focus of the study). I was indeed fearful of such an event happening. What might be seen initially as 'dross', data are irrelevant to the outcome of the research study, may emerge as very relevant information following analysis

As the goal of this research was to gain a clear understanding of the lived experience, biases need to be identified. My biases, judgments, and choices can and have influenced this study. My skills as an interviewer, my skills and knowledge, the type of interviews undertaken and the particular questions that I asked are all aspects of the researcher-as-instrument in this study and may have contributed to researcher bias. I recognise that my own knowledge of ethics, authenticity, and strong belief in honesty and integrity were crucial and that being emotionally in charge to prevent the interview from reverting into a therapeutic relationship required insight, intelligence and self-awareness. Mezirow (1990) reminds us that it is our emotions that alert us to issues that need attending to, and it is our emotions that provide us with the energy source to be challenging and creative (Brockbank and McGill, 1998). Thus I argue having a heightened rather than a dulled sense of what was going on brought to the fore ethical issues, which once addressed, arguably can only add to the rigour of this study. Whilst conceding that a researcher's bias cannot be ignored or eliminated but rather should be acknowledged and made explicit, I conducted the interviews with an open-mind and a heightened sense of awareness. I attempted to gain as rich and pre-suppositionless data as possible. I had to work hard at 'bracketing' my

presuppositions and the natural/scientific attitude in order to attend, genuinely and actively, to my participant's views and feelings so as to not impose my presuppositions and set aside any assumptions. I tried not to lead the conversations in any predetermined directions, although, when I read back over my transcriptions, I did on occasion's lapse into the more chatty style of conversation. I did find myself periodically checking to see how attentive I was being, how well I was listening and whether I was drawing conclusions or indeed interpreting. Kvale (1996) describes this as a critical consciousness of the interviewer's own presuppositions. Seeing my participants through the lens of a neuroscience nurse's eyes then I might not see all of what they presented. Had I been listening with neuroscience nurse's ears I might not have heard how much and how their lives have been denied. I endeavoured to adopt an attitude of open-ended presence to the participants' stories and experiences. Concentrating on the phenomenological description of the experience, I tried not to assume or predict any hierarchical order to the telling of their story. On occasion I prompted participants to offer concrete examples of particular moments: "Can you describe an example of an actual situation when that happened?" And "Can you describe to me an example of that?" I was an interested listener and sought to be non-judgemental and to promote natural, spontaneous conversation. I was conscious of what was being said and how it was said. In order to proceed the assumptions need to be identified before they can be disabled. Whilst I accept the notion of performing the epoché and the inherent difficulties it presents, I do not make the claim that I have identified all my assumptions, or even if they have been set aside fully, but rather just claim that I have made an attempt.

4.6.2 Ethical dilemmas

Guillemin and Gillam (2004) delineate two dimensions of ethics in research. The first being procedural; achieving the necessary ethical approval, and the second practical; the kind that deals with the situational unpredictable subtle ethics that arise from the field (practice). Although I had acknowledged that the ethical process was an on-going process and that achieving ethical approval was perceived as just the beginning of the process, what I had not fully appreciated

was the ethical dilemmas and issues that a researcher in the field could be faced with. Arguably not all of these can be foreseen or planned. The lack of guidance on how to gain access in the field, how to sustain it and then leave with grace were indeed striking. But I do acknowledge that no amount of reading or guidance could have fully prepared me for the challenges that field research poses. Indeed several situations which arose during the data collection took me by surprise.

One particular ethical issue, that of coercion, I faced on two separate occasions. The first occurred whilst I was attending a meeting with a colleague in clinical practice, during which a participant was conscripted by my colleague to be interviewed for my study, as she and her injured husband were present on the ward at the time. The enlisted participant then pressed me for an interview date. I felt very uncomfortable and withdrew her offer of making a date at that time for an interview. I informed the prospective participant that I would telephone her in the near future to discuss this further. I telephoned her two weeks later and we agreed an interview date and venue.

The second occasion occurred when returning to a participant's (carer 5) house for a second scheduled interview I found her to be out. After no answer from her house telephone I decided not to pursue this further in fear of being coercive and acknowledged that this was perhaps the participants' way of articulating that she had changed her mind. I, however, will never know whether that was the case or not. I respected her decision, although disappointed, but also fearful that I had not done a good enough 'job' in the first interview. Perhaps I should have given her a second chance by putting a note under the door, and in not doing so have I left her wanting to tell me more. I also felt a sense of rejection, feeling that she no longer wanted to speak to me.

These ethical situations are defined by Guillemin and Gillam (2004) as 'ethically important moments'. But perhaps the most poignant ethical moment for me occurred after entering a participant's house to undertake a scheduled interview. This was in fact a lady who I had tried to avoid coercing into agreeing to take part in the study. After introducing myself, engaging in a brief general conversation, I asked the participant to tell me about her husband, at which point she stood up

appeared quite upset about the request for information saying *'I thought you had all this information, why are you asking me this?'* I attempted to explain but she stated that she did not want to continue and could I leave. I was ushered out of the house, feeling frightened and anxious for the wife of the person with ABI who clearly was very distressed, and put out that she had been asked these questions. Rejection was a hard pill to stomach. I searched for why she had reacted in such an erratic manner but then realised through reflection I had not read the indicative sign beforehand. I was angry with myself, knowing that in practice I would probably have picked it up but out in the research field I had missed it. She clearly was not ready to divulge her experiences and the messages were there for me to read in the telephone conversation prior to the interview date, and on arrival at her house where she avoided eye contact and appeared aloof and disinterested. I immediately followed this up with a telephone call to the Neuroscience Centre's neuropsychologist, relaying the event and expressing my concern about her behaviour. I was informed that this lady was indeed having regular counselling along with meetings with the neuropsychology team.

At the centre of these ethical dilemmas, was that I had tried to balance the researcher's role with that of a nurse. Certainly during the interviews, especially those that were conducted in the participant's home, I was faced with confounding privilege, between me the researcher, and the researched. These privileges made me feel uneasy, feeling that I had to get it right. However, control is not necessarily in the hands of the interviewer or interviewee but rather it is fluid. Each interview was a personal encounter not just for the participant but for me. The participants may have gained from the interviews, it may have prompted reflection or increased their awareness of their plight, this is undoubtedly unknown but, what is certain is that each interview was an unforgettable experience and one which I relived during the process of transcriptions and analysis.

4.7 Demographic details of participants and the people with ABI

Of the five participants four were married, one was a parent, and all were female. This was no surprise given the fact that the majority of caregiver's of TBI survivors' is well known to be predominantly female (Kolakowsky-Hayner, 2001). There were no participants who were widowed or separated from their partners at the time of the interviews. All five acquired brain injured individuals were transferred to a rehabilitation unit following their injury, where they received a programme of care which included in some cases neuropsychology and specialist neurorehabilitation. Each ABI person at the time of the research interview was living in the community in their own home. The participants' demographics are presented in Table 3.

Table 3 Participant Demographics (family /carer)

Participant code	Relationship to the person with ABI	Others (family members) at home	Employment status
Feb 1 (P1)	Mother	None	Unemployed
Mar 1[10] (P2)	Wife	Son and daughter	Unemployed
Mar 2 (P3)	Wife	None	Retired
June 1 (P4)	Wife	Two adult sons	Worked 4 days per week
June 2 (P5)	Wife	None	Unemployed

The demographic details and background information about the acquired brain injured survivors associated with a family member is shown in Table 4.

---

[10] This interview was not tape recorded due to failure of the recording equipment however, field notes were documented post-interview.

Table 4 Demographic and background information about the people with acquired brain injured in relation to the carer (participant)

Family Carer	Details about the person with ABI					
Code assigned to carer	Age	Gender	Ethnicity	Time since ABI	Cause of ABI	Neurological deficits
Feb 1 (P1)	18	Male	British White	20 months	Road traffic accident -Seat belted front seat passenger. Diffuse Axonal Injury Closed head injury, Basal skull fracture	Lack of insight, impaired: - short-term memory right ptosis, aggression, new learning and speech difficulties
Mar 1 (P2)	46	Male	British White	2 years	Subarachnoid Haemorrhage Grade IV [11]	Lack of insight, impaired: - short-term memory, new learning, recognition, planning, spatial awareness. Right hemiparesis Right visual impairment
Mar 2 (P3)	70	Male	British White	12 years	Subarachnoid Haemorrhage (Grade unknown)	Short-term memory loss, aggression, slow in function personality changes - ego centric
June1 (P4)	40	Male	British Asian	3 years	Subarachnoid Haemorrhage (Grade III) Post-haemorrhage hydrocephalus	Language difficulty expressively dysphasia, left hemiparesis, poor co-ordination and sequencing, comprehension difficulties Aggression, emotional labile.
June 2 (P5)	40	Male	British Asian	16 months	Knocked off push bike Closed head injury, IV Ventricular haemorrhage Fractured mandible	Short-term memory difficulties, impaired: attention, emotional labile Excess use of profanities

---

[11] In addition to radiological tests, the overall condition of the patient is assessed using the Hunt-Hess grading scale. The Hunt-Hess scale grades the severity of the subarachnoid haemorrhage from I-V (Grade V being the most severe) (Hunt and Hess, 1968).

Table 3 and Table 4, only represents the key demographic details gleaned about the participants and their brain injured family member, as I acknowledge that providing a detailed context of each family is not congruent with the underpinning Husserlain philosophical foundation of this thesis. Nevertheless, I recognise that situating the participants, is essential to Giorgi's (2002, 2006) notion of validity and involves describing the research participants and their life circumstances. Thus to permit the readers to understand the social location of the participants, these descriptions have been included in Appendix J, and provide more detailed aspects of the families that are not represented in table 4.

4.8 Process of Transcribing

It would appear that data analysis is one of the most poorly illustrated techniques in the published literature. If the decisions are transparent on how the data were analyzed, then the reader can evaluate the reasonableness of the process and procedures that have been followed, and therefore the trustworthiness of the findings. Although verbatim transcripts may be useful in facilitating an audit trail of data analysis (Poland, 1995), the potential for error can, if only in part, be mitigated against by cross-checking from the original audiotapes, rather than from the transcripts.

In order to meet the anonymity requirements of this study, participants were identified by the use of an alphanumeric coding system e.g., Feb 1 (February 2007) Participant 1. I recorded each interview onto a different disc, each labelled with their assigned code. The interviews were listened to in their entirety, transcribed verbatim, read, and reread. Initially I had thought that transcribing would be undertaken by transcribers but, through my reading I came to realise that this part was critical for analysis. It is the interviewer that will get the richest appreciation of the descriptions rendered in the interviews. I could not make the assumption that the transcribers' will transcribe correctly or indeed accurately. Transcription errors missing or misinterpreting words or inaccurate punctuation which may change the entire meaning of the phrase and result in missing key themes or including themes that actually were non existent, led me to believe that

this process had to be undertaken by myself. The possibilities of errors or misinterpretations are particularly acute when different individuals are responsible for interviewing, transcribing, or analyzing data. As Tilley (2003) has argued, hired transcribers and anyone else who participates in the production of research documents leave 'fingerprints' that then influence the research. When researchers themselves transcribe their own tapes the numbers of hands that touch the research recordings are minimized and the transcript remains closer to the participant and the participant's experiences. This closeness increases the validity of the transcript as a research document. However, a transcript is only as precise as the person transcribing (Easton *et al*, 2000:p.707). Tilley (2003) furthermore argues that those researchers who delegate transcribing to others become distanced from their work and are often not aware of the decision made on their behalf. I realise now that it is not possible for any transcriber, regardless of experience or training, to capture all verbal, prosodic[12], paralinguistic, extralinguistic, and contextual features of an interview (O'Connell & Kowal, 1999). As Lapadat and Lindsay (1999) state it is not just the production of written words that is important but it is also the process that is valuable. Verbal interactions simply cannot be captured in their entirety in textual form. The transcripts are an artificial, incomplete construction of the oral to the written language and the transcripts should be seen as an aid for displaying features of speech or action that are to be analyzed, not as a replication of the spoken discourse during an interview (O'Connell and Kowa, 1999). Yet this basic process of transcription, integral to qualitative research, appears to have eluded the literature. It is as if the transcription process was flawless and a given that it represents the truth and reality, and that the actual interaction is captured on the audiotape. The quality of transcripts can be adversely affected by deliberate, accidental, and unavoidable alterations of the data. Poland (1995) suggests that researchers are not to bypass transcription as a step in the analysis, as Kvale (1996) has suggested, but rather for researchers to become more reflective about their transcription procedures. For Poland the primary concern is to enhance the "...*trustworthiness of transcripts as research data*" (1995: p. 294). To omit the transcription stage however, was not a matter that I had considered. I had, from the outset decided to include the

---

[12] Marking features of intonation, such as rising and falling pitch and points of stress, rhythm and any other attributes of the speech.

transcription as a step in the tape-transcribe-analysis process (TTCI). To include this process was based initially on the need to preserve the data in a more permanent manageable examinable format. Instead of leaping into what seemed a daunting task, I decided to take a step back, and attempt to understand what initially seemed to be a relatively simple process. This was based on my inherent belief, that to tackle a new task or venture, requires a degree of research and understanding first, so that I could embark on the matter in hand from an informed stance. For the decisions that I make during this process clearly will have consequences and implications, as articulated by Mishler (1991) who stated that the:

"...endless number of decisions that must be made about re-presentation of speech as text, that is, as a transcript, which, although apparently mundane, have serious implications for how we might understand the discourse." (p. 261)

Judgements were made on what and how to put it down in text. What to transcribe, how to organise the page, what paralinguistic and non-verbal information to include and how to re-present the record of the voices in text. There are clearly variations in the level of details of the transcriptions, for example, detailing every pause, umm, ah, etc. How the talk is structured and the use of direct and non-direct speech can alert the researcher to how the account is being framed (Ziebland and McPherson, 2006). Systematic transcription procedures are necessary for valid analysis and interpretation of interview data (Mishler, 1986). Deciding where to put the commas, the type of emphasis, where to locate the pauses and how or whether to use prosodic features of the speech or not. I could have transcribed a wide range of speech features but the final judgements that I made are evident in the transcripts. Editing out the pauses, 'ums' and 'ahs' I felt would exclude important emotional aspects of the speech, and that they may offer a richer description of the meaning than would be possible if attending to the words alone. I needed to record the affective nature of participants' experience somehow. This I balanced with the notion of striving for a precise, detailed comprehensive account, which detracted from the elicitation of meaning, the critical tenet of this research. I had to draw a line in the sand and accept that this was a never ending process and that it can only be a partial representation of what

actually occurred. I decided not to provide a technical comprehensive, one-to-one match between the discourse and what I re-presented in the text. Ultimately my selection and choice of an analytical method was dependent upon several factors; my epistemological view that the participants are articulating their experiences and it is not my interpretation, the type of data, the research question itself and practical considerations. The question that I attempted to answer was as Mishler (1991) asked *"what would be a useful transcription for my analysis and study?"* Thus I attempted to strike a balance between providing a convention that symbolises a positivist approach with extensive categories such as those found in conversation analysis[13] territory with the more narrative analysis. As Green *et al.* *(1997)* argue transcribing is an interpretive process and is a representational process, and central to this is the understanding that;

> *"...a transcript is a text that 're'-presents an event; it is not the event itself. Following this logic, what is re-presented is data constructed by a researcher for a particular purpose, not just talk written down."* (p. 172)

I made a number of choices, thus leaving my 'fingerprints' on the transcripts. Having searched for conventions used to symbolise paralinguistic and non-verbal information, I borrowed conventions from conversation analysis and developed a basic key for conventions that I used throughout my transcripts and one which I felt suited my methodology (Appendix K). One typing convention I decided to use was simply to indicate loud volume in speech with the use of capital letters and use of capital letter at the beginning of the word to denote emphasis. When the voice was inaudible or difficult to ascertain I decided to indicate this with the use of brackets i.e.*(indistinguishable word/phrase)* and when the obvious laughter or emotional expression occurred I described it in brackets i.e. (laughing). Pauses were indicated by the brief pause i.e. (...) and a lengthy moment of silence was indicated by (........). Clearly transcription is as Mishler (1991) demonstrated, not just a technical procedure but an interpretive practice. Thus writing down what is

---

[13] Conversation analysis (CA) an approach to transcription that empirical, explicitly aims to describe the completeness of speech. The transcription system used in CA is "...specifically designed to reveal the sequential features of talk" (ten Have 1990, p.1). "It studies the social organization of 'conversation', or 'talk-in-interaction', by a detailed inspection of tape recordings and transcriptions made from such recordings" (ten Have, 1990, p.1).

heard is the result of a range of interpretive acts and that the transcripts represent both the researcher and the participants in particular ways. Transcripts, therefore, are partial representations, and the ways in which data are represented influences the range of meanings and interpretations possible. As Tilley and Powick (2002) argue it is important to dispel the notion that:

"...the tape is equivalent to data that the transcript is equivalent to the tape, and therefore the transcripts equal data" (p.301).

What I elected to use was indeed an interpretation not just a description, which seemed contrary to Husserl's descriptive phenomenological and issue that I accept cannot be easily resolved. How to actually carry out this process, I came to the conclusion that there was not a right or wrong way, but what was clearly important was the transparency in undertaking such a process. What's more the on-going issue of rigour and trustworthiness can, if only in part, be addressed by the transparency and by the reflexive nature that the transcribing and analysis was undertaken.

It would appear then as Kvale (1996) and others have pointed out, the role of transcription is problematic both theoretically and methodologically, and not transparent as was originally assumed. Representing talk as text as an accurate representation of the events and experiences is clearly a challenge. Mishler (1991) also posits that there is no standard, ideal comprehensive mode of transcription, nor can it be theoretically tenable.

The issue of equipment and how to actually get the data from the mini-disc recording to the transcripts was something that caused me some considerable distress and anxiety. After searching and reading the various ways, I decided on a programme to aid the transcribing process, Express Scribe [14] which enabled me to play the text files at variable speeds, and the ability to control the playback features with system wide hot keys within Microsoft Word once the data files had

---

[14] Express Scribe is part of the NCH® Swift Sound dictation and typing suite Digital Transcription Audio Player Software, designed to assist the transcription of audio recordings. It also includes Express Dictate a professional dictation recorder for personal computers. Recordings that have been created using Express Dictate can be easily sent to Express Scribe for transcription.

been imported into the programme from the mini-disc recorder. This enabled me to play over and over again sections that were not clear or when the participant's speech was too fast for my typing skills. This certainly eased some of my anxieties of the manual transcribing process although it still transpired to be a long process. I did not change the grammar or correct the oral speech nor did I edit the transcripts, delete repetitive words for fear of affecting the intended meanings. I felt it was my responsibility to represent the family members' words respectfully.

To confirm that the data collected from the participants reflected what they had said, their account, involves at each stage of the data analysis returning it to the participants for confirmation or 'members check'. The process of returning the transcripts/narrative to the participants for clarification and validation, van Manen (1990) refers to as seeking to answer the question *"Is this what the experience is really like?"* (p.99). This method of 'member checking' periodically during the interview and the need to reiterate what has been said to ensure that the meaning has been correctly understood is considered one way to increase trustworthiness. However, Kvale (2006) argues strongly against such an attempt to reduce the researcher dominance over the research subjects and to obtain consensual knowledge on emotional grounds. Colaizzi (1978) asserts that the researcher must develop what he calls the *"...objectivity from the phenomenological perspective"* (p.52). This method involves going back to the transcripts for verifications of the themes and ultimately returning to the participants themselves for verification. Giorgi (2006), however, offers several reasons why this step does not survive critical scrutiny. Most notably Giorgi argues theoretically that if phenomenological attitude is performed then the eidetic results can only be checked by the phenomenological procedure, not by the participants. Giorgi goes on to articulate that despite the participants having lived through the experience they may not have thought about the issues presented. Sandelowski (1993) offers another view rejecting the reliability test of 'members checking' arguing that it is unnecessary and a threat to the trustworthiness of the research. Although Morse and Field (1996) suggest that the 'truth value' of data is determined by how much participants recognize their story in the researcher's analysis of their experience. On a more practical note, member checking is time consuming and there is the issue of parity in all participants responding. In addition there may be an ethical

issue of returning the transcripts to the participants' who may experience shock at the blunt disclosure of what they have said, perceive the transcripts differently or be offended by them and result in them refraining from further participation and withdrawal. In addition the transcripts may actually disrupt the existing family relationship and family systems that I was trying to improve by doing the research. I could not be sure that it would not negatively affect their lives. Kvale (1996) takes this one step further stating that the publicizing of incoherent and repetitive verbatim text may involve an unethical stigmatization of specific persons. This is the premise on which I decided not to return my transcripts to the participants.

4.8.1 Issues encountered when transcribing

Denzin (1997) notes that there are many understandings of the sound and meaning of voice. Thus, sound and voice include silence, just as silence is part of voice, so voice is implicated in silence. The importance of silence and repetition became evident after the second transcription. Poland and Penderson (1998) argue that what is not said may be as revealing as what is said and that silences are profoundly meaningful. However, the identification of these events, the silences/pauses is all that one can do, as we have no certainty about what it is we presume from these events. As silence has many meanings, it is open to interpretation.

Silence is not just the absence of words as we often find in everyday life, as we grapple to find the words during our conversations and thus being acutely aware of our inadequacies in the use of words to describe meaning. But rather it may represent something else. Social science literature makes clear distinctions between three main categories of silence, firstly the literal silence, the absence of words secondly the epistemological silence the unspeakable, and finally the ontological silence, the silence of being or life itself (van Manen, 1990). It is the second category that resonates with Polanyi (1966) who articulated that every human being has silent and unexpressed dimensions within themselves, which acknowledge situations where we recognise that 'we know more than we can explain', or as Polanyi himself expressed, tacit knowledge. Polanyi emphasised

that completely explicit knowledge is unthinkable. It is at this juncture that I became acutely conscious of the limitations of the verbal interview. That experiences maybe beyond the linguistic competency of the individual, and that they may need to be articulated by others or through alternative forms of expression such as poetry and art. I appreciated that language can never accurately capture all that lies within the experience, that there lies within, a silent language that cannot be expressed verbally. It only identifies the vulnerability and complexities of the interview transcript in analysis and the extrapolation of meaning.

It is not entirely clear what one is to make of the unsaid. Firstly one is faced with the task of deciding what it is that has not been said (the said in the unsaid, if you will) and, secondly, of determining the meaning and interpretive/theoretical significance of what one determines as having been left unsaid, as we can elect to be silent in self-protection or perhaps are speechless because we cannot find the words to respond. For Denzin (1997)

> "...the unsaid, the assumed and the silences in any discourse are the flesh and bone – the backdrop against which the meaning is established". (p.38)

I was aware how a participant may use silence to generate ethical dilemmas. Whilst acknowledging that silence is actively chosen by the participant, by forcing them out of silence, bringing into the consciousness and expressing painful experiences in speech raises the issue of coercion. As a nurse I am aware of how a participant could use silence as a means of expressing 'silent objection' and that by being insensitive to such cues as a researcher, would unquestionably be unethical.

4.8.2. Reflections on transcribing

The data analysis and the unremitting desire to be true to participants' perceptions of their experiences was one of the biggest challenges of this study so far. Whilst the aim of analysis is for truthfulness, accepting that it may not be possible to fully

reach another person's experience, has been difficult. However, as Munhall (2000) articulates, the aim is to reach adequate truthfulness. As a novice researcher at the beginning of this process I had no real concept of what would be involved after the taped interviews, one which has been informed, not just by literature searching and reading, but by 'doing' the research itself. I now understand that the process of data analysis including the transcriptions is descriptive, interpretive and flexible, but this in turn has increased my dissonance with the Husserlian philosophy that underpins this thesis. How to represent talk that reflects a thinking-as-speaking process is, as I now realise, difficult to represent as text.

Whilst transcribing the scripts I was forced to once again challenge my assumptions about what constituted an accurate descriptive representation of the voiced experience. The immediacy and intimacy of the interactions are lost when the voices are put into text. The closeness of hearing the voice, the intonation is lost once transcribed. I questioned if there was any value in not transcribing, but to listen, re-listen and listen again and then describe? I had not realised how hard it would be or how time consuming, and how distortions in the quality of the speech could effect my interpretation of the spoken word and introduce recognition error. I was also faced with decisions on page layout, whether to go across the page or down the page.

I have tried to represent the interviews as they appeared. However, after completing the transcriptions I realised I had made a presumption at the beginning that I was structuring and describing the interviews, a priori, the dominant voice of the interviewer. Despite wanting to give the participants a 'voice', I questioned whether I was actually doing the opposite. To readdress this I re-examined the transcripts from the participants' perspective. I questioned whether I had interrupted their flow of thinking and thus the telling of their story, and if the interview was less structured would they have told me more? This insight, however, did not come until the second listening and retyping of the transcripts. Each transcription contributed further to my understanding of the process of transcription and the crucial part it plays in data analysis. Every attempt to represent the experience has the potential to result in a new version, a new textual construction.

I began this phenomenological study not totally realising the choices that I would face. I found it difficult to identify a method of data analysis that was sufficiently clear in presentation that a novice researcher could follow. Colaizzi's (1978) and Giorgi (1985) stages did provide a framework for analysis of the data. I believe I have adhered to these principles, and when they have been modified, justified such an amendment, so as to provide a credible and transparent method of transcribing, describing and analysing the data.

The need to understand the intricacies of a mode of inquiry prior to submission for ethical approval placed me in an uncomfortable position. On the one hand I needed to understand the process to articulate a protocol, whilst on the other still grappling with the philosophical underpinnings of the study without fully understanding it. Furthermore the need to justify the method ensuring congruency with the methodology, equally presented a challenge. I was surprised by the few sources that actually explained how to conduct a phenomenological study. I have been struck by the diverse literature on phenomenology, both philosophically and methodologically. Phenomenology has been described as a philosophy, method and approach (Ray 1994). I have come to realise that there is no single school of phenomenology; rather it has been described as a movement. Given the diversity of the phenomenological approaches and their philosophical underpinnings, it is not surprising then that I was grappling with these concepts and philosophies. I have drawn comfort from the fact that van Manen (1990) stated that a real understanding of phenomenology can only be accomplished by doing it.

During the weeks of transcription, which I subconsciously kept putting off, I endured a level of stress that I had not anticipated. The writing up of the transcripts cannot be viewed as procedural but rather the beginning of the data analysis. I have realised that transcriptions are never complete or finite nor is it achievable. There is no correct method but rather as Kvale (1996) and Mishler (1991) both articulate what is a useful transcription for my research thesis. I have also begun to appreciate the tension that exists between analysis and interpretation. That representing discourse as a technical process was naïve and far from simple.

4.9 Field notes

The failure of the mini-disc recorder on the second interview of participant June 2 raised the question of whether the transcripts could be substituted for field notes. The use of written field notes either during or immediately after the interview has become the subject of debate. As Fasick (1977) asserts, although the audiotapes provide an accurate account of the interview, the difficulties inherent in verbatim transcription and coding reduce the value of the data collected. The field notes that I took after each interview were also analyzed. The process was not to look for frequency of comments or ideas but rather to consider the content in relation to the transcripts. I felt I needed to ask myself, and that of the data, several questions in order to ensure that my subjectivity was explicit and in pursuit of the objective stance I was aspiring to. These included the sorts of questions identified by Fook:

> "What assumptions are implied by my account, and how relevant are they to the situation?...What are the gaps and biases implied in my account? What perspectives are repressed, distorted or simply missing or de-emphasised?" (Fook 1996: p. 7)

4.10 Analysis

Whilst the interviews may provide high face validity and credibility, qualitative data must be true to the experience being explored and described. One potential issue in this research was my ability to analyse the data in an eidetic way and therefore ensuring methodological rigour. My analysis took place and understandings were arrived at through a process of listening and re-listening, viewing and re-viewing and data analysis undoubtedly begins during the data collection.

Whilst there may be computer packages available such as the CAQDAS software they are supportive of the code and retrieval operations of grounded theorizing (Seale, 2008), certainly the packages ETHNOGRAPH and ATLAS[15] were

---

[15] ETHNOGRAPH is a qualitative data analysis program, developed by Qualis Research, meant for use with text files and supports hierarchical coding, text annotations, and

designed with this methodology in mind. In addition computerised packages such as NUDIST[16] have been criticised for their emphasis on the grounded theory approach. This aside, computer assisted programmes are no substitute for thinking about the data. The intention was to analyse unstructured text data in an inclusive and rigorous manner, not to analyse natural discourse or conversational analysis that other forms of research may employ. The use of a coding system may even distance the researcher from the data rather than feeling immersed in it, a criticism levied by Seidel and Kelle (1995) and it may become more like a quantitative analysis, looking for occurrences and frequency of words. Webb (1999) furthermore argues that qualitative data analysis is a creative endeavour involving intuition and empathy and cannot be reduced to mechanical processes arguing that a manual method is preferable. The actual artistic conceptualising work can only be done by me. In reality analysis is an iterative process, moving from the original audio recordings, transcripts, and to the themes identified. I recognized that the additional use of a computerised tool runs the danger of being bogged down in the technicalities of the programme, rather than using them to aid in the creating and filing of data. Furthermore, the searching for frequencies of words and phrases is in keeping with a researcher who might be employed in ethnographic or grounded theory studies. Reducing the data analysis to a deductive process via deductively derived analytic techniques such as content analysis, emphasises the technical rather than the epistemological aspects of the method. It would also pre-determine what was observed. I thus rejected Miles and Huberman's (1994) recommendations to use a template approach to data analysis, in which 'a priori' categories are argued to help the data analysis process, on the basis that analyzing data with presuppositions would fragment and destroy the coherent phenomenological quality and prevent openness to the insights that can be derived. Furthermore undertaking content analysis and assigning codes then the uniqueness of the individual experiences would be lost,

---

advanced data search strategies. ATLAS similarly facilitates the categorization process of these types of data and enables you to organize the evolving categories in a (causal) network.

[16] NUDIST (Non Numerical Unstructured Data Indexing Searching & Theorizing) now replaced by NVivo 7 a package that both codes textual data and efficiently searches and navigates research material.

rather what is needed is to balance the need to categorise and preserve the uniqueness of the experience in relation to the phenomena being explored. Thus no specific coding frames were used as this was felt to unduly pre-determine what was observed.

Methods derived from Giorgi (1985) and Colaizzi (1978) have been applied to nursing research since their introduction in the seminal work by Omery (1983), and are derived from the philosophical ideals, assumptions and concepts of Edmund Husserl (1859-1938). These involve the repeated systematic reading of the transcripts. This can be achieved by first dwelling in the phenomenon (through emphatic immersion and reflection), then describing the psychological structures (i.e. recurrent themes) that are present (Finlay, 1999). This relies on a series of deeply understood summaries. This dwelling in the data was highlighted by Giorgi (1985) as an important notion in ensuring openness to the possibilities of new discoveries.

Many writers argue that data collection and data analysis should not be regarded as sequential stages. Analysis commences with data collection and continues until the end of the project (Burgess, 1984; Patton, 1990) a view also supported by Parahoo (2006). Moustakas (1994) uses a modified version of the Stevick-Colaizzi-Keen method. This is frequently used in phenomenological data analysis (Creswell, 1998, p 147). Thorne *et al.,* (1997) recommends analytic techniques such as the adaptations explicated by Giorgi (1985). For Giorgi (1985) the operative word in phenomenological research is 'describe', to describe as accurately as possible the phenomenon and resonates with the descriptive Husserlian method of phenomenology. The 'collective unity' that one observes through describing, that is to say they all experience the same object/ experience, this Husserl calls the 'synthesis' the aim is to look for universal patterns.

Colaizzi (1978), a former student of Giorgi, adds more detailed steps to the analysis. Although both of these scholars emanate from the descriptive phenomenology perspective their proposed methods differ on one fundamental point. For Giorgi the transcripts are not returned to the participants for verification as he believes that the researcher, not the subjects, should do the analysis. In

contrast, Colaizzi's (1978) method of data analysis requires the researcher in the final step of the data analysis to return them to the subjects and then to revise them in light of their comments, a step which I have argued in the previous chapter not to undertake.

van Manen (1990) comments that grasping and formulating a thematic understanding is not a rule-bound process but a free act of 'seeing' meaning. But I found applying his principle of 'describing the phenomenon through the art of writing and re-writing', too challenging as a novice researcher. I required a framework to help me see the 'meaning' within the interview data that I had collected. Both Colaizzi's (1978) and Giorgi's (1985) procedural steps provided me with a more structured approach for analysis. The techniques created by both Giorgi and Colaizzi have been criticised for their lack of congruency between the philosophical theories and their use in practical research (Paley, 1997; Rolfe, 2006). I, however, take the stance that these methods add to the practical application of the methodology rather than detract from it. I also felt this approach was appropriate as both Colaizzi (1978) and Giorgi (1985, 2006) use the steps in their method to analyse data from phenomenological research within the domain of psychology, and as the phenomena in question is routed in psychology this seemed apt. However, Colaizzi (1978) does suggest that the framework is not definitive and there is a tendency for the stages to overlap. The analysis approach used in this study involved several steps as a result of a synthesis of the methods advocated by both Colaizzi (1978) and Giorgi (1985), illustrated in Table 5.

Table 5 Analysis process (Colaizzi, 1978: pp. 59-61; Giorgi, 1985)

Step	Process
1	Transcribe verbatim. Listen to the recordings and correct any errors in the transcripts which had occurred.
2	Carefully read all of the interviewee's transcribed total descriptions of the given in order to acquire a 'feeling' for them, to get a sense of the whole.
3	Reread the transcriptions more slowly indentifying units/ themes.
4	Reflects on the given units identified in the concrete language of the participants Return again to the text and extract significant statements
5	Transforms the meaning of each unit spelling them out
6	Organize formulated meanings into clustered themes – looking for emerging themes that are common to all
7	Refer clusters of themes back to the original text to validate them
8	Integrate and synthesize the insights into a descriptive structure of the phenomena[17] using both concrete language and the researchers language

4.11 Process of describing the emerging themes

From the interview analysis training that I had attended during this doctorate programme of study I applied a couple of practical methods of data management to aid this process. Hard copies of the transcripts were read and re-read, key aspects from the transcripts were copied electronically and pasted into a separate file to aid the clustering of categories, similar to the traditional 'cut and paste' method (Lofland & Lofland, 1984). Where there were cases of ambiguity of meaning or inconsistencies, I referred back to the original audio tapes to clarify the

---

[17] Colaizzi's (1978) final validating step in which the researcher returns to the participant, and asks about the findings thus far "*how do my descriptions compare to your experiences?*" (p.62), and then any new data worked into the final analysis, this final step has been omitted in this study.

intended meaning from the original source. Fasick (1977) asserts that referring back to the original recording allows researchers to recreate the nuances of the conversation, such as voice, tone, and the specific language of participants, which may assist in a more complex analysis. These approaches are commonly used in the analysis of narrative texts. The rationale for synthesizing them was to reach a process that felt comfortable and practical for me to use. I am analytical in my thinking and I applied the analytical method suggested by Giorgi (1985). Analysis was achieved by dwelling on the phenomenon (through empathic immersion and reflection), then describing the psychological structures (i.e., constituents and recurrent themes) that were present (Finlay, 1999). By looking within the narratives, moving dialectically between them, this served to assist me in gaining a shared meaning and developed an insight into the nature of the lived experience of the family members. Units of meaning were clustered and categorised. The themed material was examined repeatedly for new themes that might emerge. Whilst 'cutting and pasting' the data into themes, I also kept a file called 'bits and bobs'; those words that did not initially fit the themes. I returned to these several times to get a sense of their meaning and then incorporated them into the final description.

In order to be transparent and clear about the themes, I have illustrated the sub-categories and how they culminated in generating the initial themes. Through re-reading and absorption, I then refined these, resulting in the final emergent themes. Morse (1994) described data analysis as a creative and logical process of gathering and arranging data so that the analytic scheme appears obvious. Smith (2004) has argued that an effective strategy for making meaning of qualitative data is to be as unconscious as possible; this allows researchers to engage more effectively with their data and to see things they might not see otherwise. This, however, makes the process of data analysis inaccessible to the novice researcher and the readers. But by making this process more visible then not only will it be more accessible to others but arguably augment the integrity and veracity of the research itself.

Qualitative research is I realise, something that can be learned only through doing it. The challenge of data analysis is not new. Morse in 1994 argued that the

process is not adequately described, with most learning occurring by doing. This process of crafting phenomenological description has not been without its pain. At times I avoided the notion of attempting to describe the meaning, fearful that I would get it wrong or interpret rather than describe. I had self-doubt about myself, whether I was capable of producing something that was intelligent and rigorous enough to withstand academic scrutiny. I did draw comfort that by not analysing immediately after the interviews allowed a more objective stance, as I felt I was looking at the data with fresh eyes. As Giorgi (2006) states by being objective then the phenomenon can be reported accurately.

I found at times I could not immerse myself in the data. I was conscious of just seeing the words, without meaning and feeling and I initially felt that this was an impossible overwhelming task. I also lived with and through literal silence, where I had no words in my head, in my consciousness, not being able to write or reflect. Initially I felt I was drowning in the data. I was overwhelmed. I made every excuse to avoid re-presenting it. During these times I created a 'space' in my head, to allow the relevant to emerge, not to rid the mind of what might seem trivial or unimportant but to let the mind work through the clutter to make sense of it. To enable the unconsciousness to come to the fore and to be able to enter the world of those that created the written texts. I eventually moved out of this incubation period to one of excitement and relief as I started to write and describe the experiences with some confidence. I did this in several ways; I walked away from it, allowing it to come to me, often when I was least expecting it, the unconscious became the conscious. As Smith (2004) posits this great, apparently involuntary rush is a wonderful description of the power of the unconscious as it bursts into awareness which is then at the disposal of the writer. This unconsciousness that then becomes apparent resonates with the theoretical offerings by the philosopher Michael Polanyi (1966) who wrote extensively about tacit knowledge, "...*more than we can say*" (p.4). He also referred to the term ineffable to mean:

"...*something that I know and can describe, even less precisely than usual, or even only very vaguely.*" (Polanyi, 1958: p.88)

However, the notion that only what is articulated is knowledge is perhaps questionable as this is based on the premise that the unconscious is by definition unknowable and unattainable.

For a period of time I also lost confidence with the data. I watched it and kept it at a distance, fearful of it. I also found myself ignoring the field notes, viewing them as separate entities. I was in danger of compartmentalising the data rather than seeing it as a whole. As Anderson (1991) argues the methods of data analysis that fragments the lived experience may distort that which it is trying to describe. The key to being able to engage with the data analysis was the realisation I needed to balance the whole of the research with the parts. Rather like the critical learning that comes from self-indulgence in self-dialogue and reflection then the process of *epoché*, phenomenological reduction, imagination variation and the synthesis of meaning and essences is akin to this. I see this now. The awareness, understanding and knowledge that I have gained in this roller coaster journey is indeed the unfolding of the phenomenal consciousness. I can see now that the process of withdrawing into myself, immersing myself in the data and reflecting, were necessary to provide a logical, systematic extraction of the description of the experiences. The evidence that I provide in the descriptions are then confirmed. Husserl (1975) emphasizes that the "...*confirmation-procedures belong to me as transcendental subjectivity*" (p.23).

Confirmation is thus achieved by the repeated looking and re-looking at the data while the phenomenon as a whole remains the same as suggested by Giorgi (1985). It is this consideration and re-consideration in the reflective process that permits the clarification of phenomenal experience. The 'results' of this process are the presented description of the emergent themes, with quotes from the original transcripts to illustrate the findings.

4.12 Developing the emergent themes

This section will present the findings of the experience of challenging behaviour which have derived from the data collected in this study.

After reading and rereading the transcripts and going back to the original Tape recordings, I began to get a sense of the general themes that were emerging. Finding the phenomenological themes led to what van Manen (1990) terms, 'protocol writing'. In phenomenological human science research, protocol writing is the term for writing the lived experience description from each participant based on the essential themes or essence of the phenomenon, although in this study I did not present each participant but rather I have described the whole experience of all five participants collectively achieving an analysis that maintained a strong orientation to the phenomenon and balances both the parts and the whole, instead of focusing on the parts at the expense of the whole. According to Giorgi (1985) these initial themes are placed in a temporal order so as to try and accurately represent the meaning. Although the categories illustrate the heterogeneity of participant experiences and their uniqueness of perspective, they also illustrate certain similarities; these are formulated into the themes. Although it has been argued that there is no such thing as descriptive analysis (Hammersley and Atkinson, 1995), whatever type of analysis is chosen, data reduction is a central task.. Each transcription and field notes were given the same treatment. I realise in this process that analysis required a degree of creativity and systematic searching along with greater visibility about how the data analysis was managed. This process was not a linear process but an iterative one, rather like climbing up and down a ladder, collecting more data as one progresses up the ladder rungs until eventually I reached the top, where I felt I had an overview of the whole experience and the themes became evident.

The following two tables illustrate the emergent process of describing the themes. Table 6 illustrates the development of the initial description of the emerging units and the decision trail in the process. In the second table, Table 7 the initial developed themes and categories are collectively illustrated. Each interview transcript for each participant was analyzed for emergent themes, which were

developed into short statements describing the essences of challenging behaviour. The participant's own words are used as much as possible so as to not to change the essence of their meanings. The presenting themes were not meant to be in any order of importance rather they are as they appeared. However, as the themes are presented in a table this may be indicative of an order of importance or significance that I might have assigned to them sub- consciously.

Table 6. Examples of the development of initial description of the emerging categories to illustrate the decision trail used in this analysis.

Participant: P 3 ABI: Subarchnoid haemorrhage 12 years ago, short-term memory loss, aggression, slow in function, personality changes - ego centric	Description	Initial Category
'...he say 'oh look at those two coco pops' but he was being Nice about them but you see ...Anyway Elizabeth had a word with him about That. Because it makes you feel so *embarrassed.*'	'**Makes you feel so embarrassed'**	**Embarrassment**
'And umm...it really is so *embarrassing* and well I usually go and say to somebody if you don't know anything I am sorry about that but he has had a brain operation and I'm afraid he does occasionally come out with things that...'	'**So embarrassing'** Need to explain to others	**Embarrassment**
'Yeah...I do *wonder* what he's going to come out with.'	'**wonder'** -uncertainty about what he will say	**Wondering**

Participant: P 1 ABI: Severe head injury- lack of insight, impaired short-term memory, right ptosis, aggression, new learning, speech difficulties	Description	Initial Themes
'So I am doing most of his care myself. So...I have to think that there will be an end to this so at the moment it's... so bad because it's... I do not get... any relief from it... at all. So...I have to tell myself it's *short-term if it was long-term...I do not know what I would do.*'	'**...if it was long-term...I do not know what I would do.'**	**Future** –the participants future
'...and it's...**going to be like that...for ever**. Umm and not getting a break'	'**...going to be like that ...for ever.'**	**Future** -will he change?
'...but he is not always going to be a young man and that is going to go at some point and I don't seem to be able to change his Behaviour, and that makes me *fearful for His future'.*	'***fearful for His future'.***	**Fear** for the injured persons **future**
'...and I suppose it's *the bigger picture* as well. I mean I am fifty. (....*) is eighteen, there's going to be a *very long time* when he's on his own' (* the acquired brain injured person's name removed to maintain anonymity and confidentiality)	Thinking about the **bigger picture** - the person with ABI being on their own	**Future** of the injured

119

Table 7 Developing themes and categories

Initial themes	Categories
1: The challenging behaviours	Forgetfulness Not eating Shouting Short-term memory loss Not getting dressed /apathy Aggressive Repetition Confusion
2: Restricted activities	Everyday life Loss of leisure time Loss of security
3: Uncertainty about future	Fear for the future of the person with ABI Lack of information Uncertainty about their future Unpredictability of the behaviour
4: Carers coping strategies to construct meaning	Humour Adaptive to change Family support Faith Control Diary writing
5: Loneliness	Alone Lonely
6: Impact – emotions responding to the challenging behaviour	Knowing what to do Fear Uncertainty Sadness, upset, embarrassment, being judged Frustration and annoyance Feeling of loss
7: Relationships	Changing roles Loss of previous relationship Family functioning
8: Support systems/activities	Support needs Perceptions of service provision in meeting the needs of the ABI and carers
9: Perception of others	Being judged by others What other people think – they don't understand

Rewriting can sometimes be seen as simplifying text. In phenomenological terms, this is not simplification at all, but the development of rigour in the text, through developing depth of description. I approached the re-reading with fresh naïvety, 'wide open' to the participants' perspectives. Several themes emerged after re-writing, these are illustrated in Table 8.

Table 8 The emergent themes

Initial themes	Categories	Further developed categories	Final emergent themes
1: The challenging behaviours	Forgetfulness Not eating Shouting Short-term memory loss Not getting dressed /apathy Aggressive Repetition Confusion	Memory loss Aggression Adynamia Attention-seeking	Emotional Behavioural & cognitive changes
3: Uncertainty about future	Fear for the future of the ABI		Experienced Emotions
6: Emotional Impact	Fear worry Unpredictability Sadness, upset, embarrassment, despair Frustration & annoyance		
9: Perception of others	Being judged by other What other people think – they don't understand		
6: Emotional Impact	Feeling of loss	ABI loss of memory	Loss
2: Restricted activities	Everyday life Loss of leisure time Loss of security	Loss of future planning	
7: Relationships	Loss of previous relationship	Loss of a son Loss of a partner	
3: Uncertainty about future	Fear for the ABI future Lack of information Uncertainty about their own future Unpredictability of the behaviour	Future concerns seemed to be threaded through all the themes Worry about the future	Future concerns
7: Relationships	Changing roles Loss of previous relationship Family functioning	Sibling impact	Family functioning
5: Loneliness	Alone Lonely		Loneliness
8: Support systems /activities	Support needs Perceptions of service provision in meeting the needs of the ABI and carers	Need for information	Adapting and coping
4: Carers coping strategies to construct meaning	Humour Adaptive to change Family support Faith Maintaining control Diary writing	Don't dwell on it Making sense – acceptance Trying to maintain normality	

4.13 Trustworthiness- Credibility- Rigour and Validity

A central concern in this study was the ability to analyse and describe the participant's essences as rigorously as possible. However, it is essential that qualitative research is not judged against the same criteria as used for quantitative research. As stated by Lincoln and Guba (1985):

> "...criteria defined by one perspective may not be the appropriate for judging actions taken from another perspective..." (p.393)

Sandelowski (1993) concurs with this view, proposing alternative criteria for judging qualitative enquiry such as audit trails. Lincoln and Guba (1985) claim that the quantitative criteria of internal and external validity, reliability and objectivity are to be replaced by more appropriate terminology such as credibility, transferability, dependability and confirmability. The discussion and application of such criteria now follows.

This study involves self-reporting and one where the genuineness of the data is not in question but rather the carers are trusted and the assumption is made that they can justify their authority to describe their experience, by the fact they have experienced the phenomena in question. Validation is thus provided by the descriptions themselves. Munhall (1994) argues that validity in phenomenology is about telling "...the unaltered faithful telling of experiences by people" (p. 84). However, to place such emphasis on the tangible and observable, and assume that these presenting facts are truthful, is problematic. But as Polkinghorne (1983) advocates that it is the vividness, richness and elegance unifying the essential description that will best help the reader judge the power and trustworthiness of phenomenological research.

Credibility can be enhanced by the use of an audit trail (Sandelowski, 1986, Rolfe, 2006) with justification for every step in the research process, although Morse (1992) suggests recording the decisions does not necessarily identify the quality of those decisions. The use of continued reflexivity throughout this study, I like others

(Finlay, 1999) argue that this augments/enhances the rigour and credibility of the study.

Data obtained from qualitative interviews are used to increase insight into social phenomena rather than assume representativeness. None the less, the issue of non-representativeness of people, and hence the limitations upon generalizability of results, is a criticism that is frequently encountered. If the study cannot be generalized as Paley (2001) argues, it cannot indicate, inform or be used as the basis for recommendations. The issue of generalizability, already discussed earlier in Chapter 3, is also discussed within the literature, Sandelowski (1986, 1993, 1995) is widely quoted in qualitative literature amongst nurses. However, as Sandelowski (1995) herself suggests, we must value the tension in qualitative research between the empirical and the aesthetic and instead of being polarized by the notion of generalizability in qualitative research it should be reclaimed. As the aim of this research is to make some link between the descriptions of the particular phenomena with what might already be uncovered by others, Morse (1992) argues, this alone facilitates generalizability in qualitative research. It is through the description of the particular that some of the most profound insight might be gained. Arguably it is the consumer of the research who will judge the generalizability of the research, not the researcher, in the end. As Osborne (1994) states the findings are valid to the extent that they resonate with the experiences of others who have experienced the phenomenon in question.

Dependability and Confirmability relate to the transparency of the methodological process and how well the findings and recommendations are supported by the data (Lincoln and Guba, 1985). Sandelowski (1986, 1993) emphasized that the rigour in qualitative studies will only be achieved by the researcher clearly describing their decisions and rationales throughout their study in the form of a decision audit trail. Throughout this study I have documented and described as explicitly as possible, my decisions, their influences and justifications, in order to assure trustworthiness.

4.14 Summary

This chapter has focused on study participants; research instruments, semi-structured interviews and field notes, and procedures that followed during data collection processes. The final sections in this chapter have discussed data analysis and provided an account of how I arrived at the six themes that describe the experience of the carers. I have attempted to provide a clear account of the transcribing process, its dilemmas and the rationales for the decisions that I took. I also have attempted to provide an account of the journey of 'seeing' the meaning of the phenomena. The resultant themes have been presented, and the following chapter will provide a detailed description of each theme, providing extracts from the transcriptions to authenticate the descriptions and appropriate discussions on each theme.

--oOo---

Chapter 5 The lived experience of caring for a family member who following ABI has challenging behaviour

5.1 Introduction

From the analysis seven interrelated themes emerged one theme describes behaviours that the carers encountered and six themes provided insight into the experiences of the family members. All were essential to the experience and although initially I had not assigned any particular order of presentation it later transpired that there was an apparent order of significance to their experiences. The emergent themes are identified by a central meaning description (i.e., a concise, short, descriptive title) in the language of the researcher, structured description (paragraph(s) describing the emergent theme in the words of the researcher, and inter woven with participants' descriptions that support that theme. At times this might mean lengthy quotes indicated in the text in italics. This serves to highlight the range and complexity of the meaning and aid in establishing credibility and increasing transferability of findings. However, whilst the use of verbatim quotes does offer some insight, there is a sense of danger of fragmenting or compartmentalising the data rather than representing the whole experience. However, as my appreciation of the centrality of crafted writing in phenomenological research developed, so did my need to represent the data in a meaningful way; one that provided me with a more comprehensive framework. Indeed the complexity of qualitative research makes the linear presentation of data inadequate and for me the use of artistry is to elicit and portray the essence of the meaning. I was also fearful of representing data in a linear format rather than as they appeared to me as fluid interrelated dynamic experiences. To lessen such dangers and capture the detail of the experiences Figure 1 depicts the emergent themes and their dynamic inter-relationships. This may be perceived as being interpretative, however I take the stance adopted by Todres (2007) that the textual and structural forms are part of communicating the aesthetic dimensions of the experience.

Figure 1 The dynamic nature of the emergent themes

The emotional, cognitive and behavioural changes in the person with ABI

| Aggression | Emotionally | Memory loss | Adynamia | Attention seeking |
| Unpredictability | Labile | Repetition | Slowness in tasks | Constant neediness |

Loss, loneliness, emotional turmoil, family upset, future, uncertainty

Coping and Continually Enduring the Experience
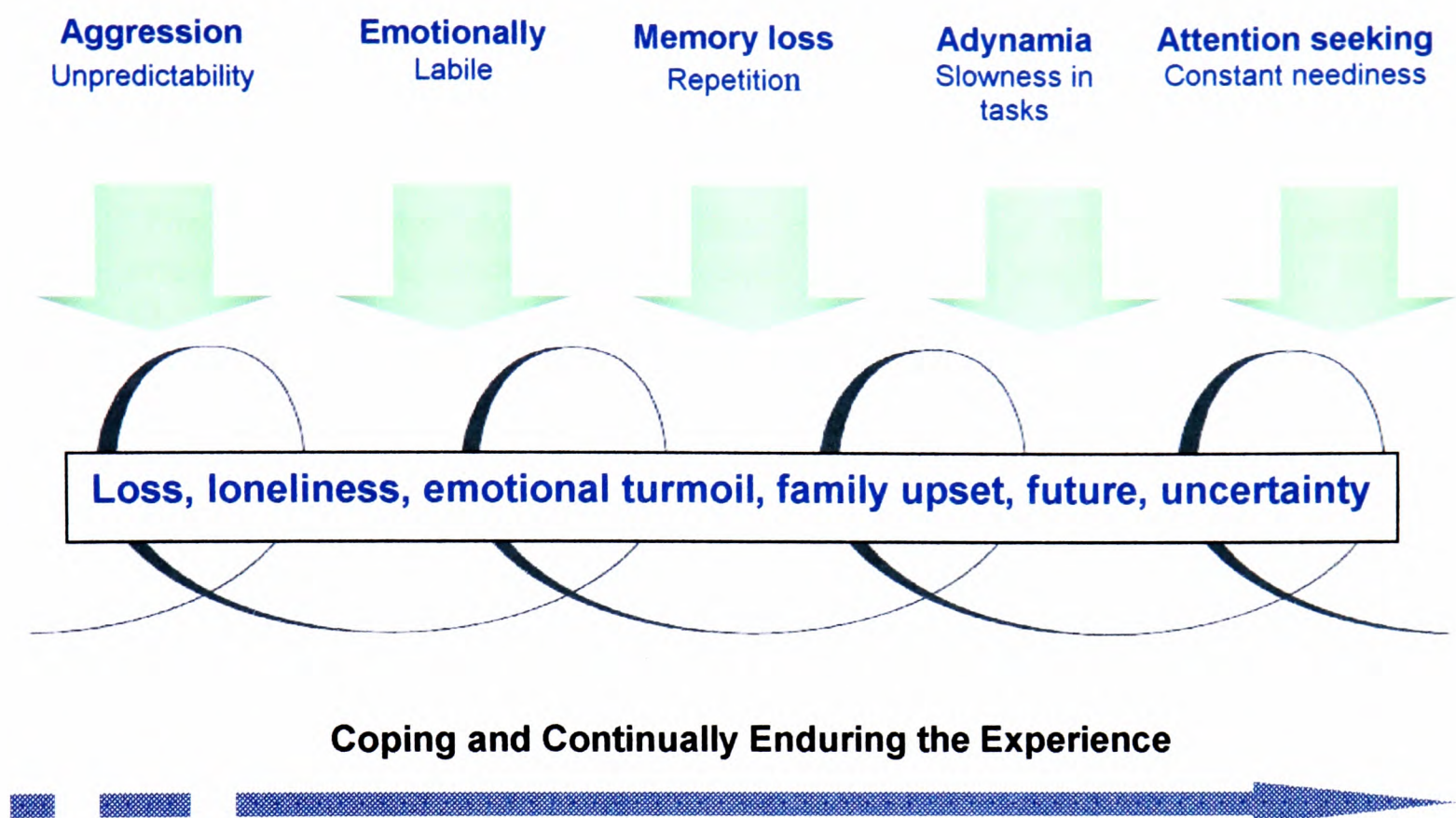
5.2 Theme 1 The emotional, cognitive and behavioural changes in the person with ABI

The family members identified an array of behavioural, emotional and cognitive changes in their family member as an aftermath of their ABI. They described behaviours of aggression, forgetfulness, repetition, slowness in carrying out tasks, apathy and constant neediness. Although the carers reported differences in their constellation of challenging behaviours, there were also striking similarities that seemed to experience, these included aggression and memory difficulties.

"...and then he was a bit aggressive on the ward....one day he just apparently smashed up all notes to the floor... then he hit one of the staff. Well that was worse, well that really was... awful." (Carer 3)

"He can... he can be very aggressive..." (Carer 4)

Memory problems were a feature that transgressed all of the carers and is encapsulated by these carers' comments:

"Because I have to... tell him things a lot of things to do and I mean he's very helpful about the house but then he'll forget... he Really couldn't remember going to church in the morning he had No idea at All. " *(Carer 3)*

"The, the biggest problem he has is memory...if he is talking and you interrupt him you know he loses track and that is very frustrating..." *(Carer 5)*

Memory loss is one of the most commonly cited cognitive sequelae features of a TBI (Oddy *et al.*, 1985; Hoofien *et al.*, 2001: Vanderploeg *et al.*, 2005). It disrupts more qualitative aspects of memory including, anterograde amnesia, the inability to learn new information i.e. short-term memory, and retrograde amnesia, the ability to recall past events. These carers reported memory deficits that involved the ability to perform an action after a short period of time, remembering to perform an action, which is conceptualized as prospective memory, and being able to retain information. According to Roche *et al.* (2002) this may be further complicated by the ABI person's poor self-awareness of their deficits.

Other changes in behaviours that the carers described include the use of explicit profanities, inappropriate remarks and being emotionally labile. Illustrated here by the following statements:

"... in front of everybody he said as we were coming out of the church 'Oh this is our little fat pastor'..." (Carer 2)

"......I find it very difficult very, very difficult I mean to 'F' ing' 'C' at people for no apparent reason err ..." (Carer 5)

The carers also highlighted their injured member's repetition of tasks i.e. playing the same video and the unpredictability of their behaviours.

5.3 Theme 2 Experienced Emotions

Family members experienced significant emotional turmoil, frustration and upset during the aftermath of their family members surviving ABI. These expressed behaviours resulted in a panoply of emotions; fear, anger, frustration, guilt and embarrassment. The devastating impact of the varying behaviours on their every day lives was one of the striking themes that emerged. The family members/carers expressed fear not just for themselves but for others:

"Does he want to hit you?" (Researcher)
"... I don't think he ever would. Umm he ....There is always that fear that, that might happen. And he is a big lad... As (....[18]) gets more mobile it's the fear of just what damage can he do at home."* (Carer 1)

"...And at that time I used to let him sit in the front seat. We were driving along and he started hitting me 'cause he didn't want to go to Oakwood, which is extremely dangerous when you're driving (whispering), so, so that, that was a bit scary" (Carer 3)

"...it's a real fear of (....) actually Really hurting someone or ...he is very aggressive when I am driving umm... he will call some one a 'dick head' or something like that umm... we would stop at the lights he's got the window open and... his fingers out... So it is always there this... fear of underlying violence if you like and aggression. "* (Carer 1)

For other carers the every day situations that they faced engendered a sense of frustration:

"I feel frustrated by it... I think it is frustrated by not being able to get around and not having the extension and not being able to travel and basically it's what's going to happen to the rest of his life and...It's...It's a whole collection of things." (Carer 1)

For this carer the repetition of her husband's behaviours was a source of frustration illustrated by the following passage:

"...he likes cowboys, cowboy videos and....I am getting rattled at the moment because...the DVD. Now, I've shown him. I've written it down. I've

---

[18] The names of the acquired brain injured or any other names from the transcripts have been deleted throughout this chapter to maintain annominity and confidentiality.

told him. EVERY, every single time he puts it on when he's opened the draw and put the DVD in he says "do I close it now?" You know I could ring his head. I really could. Now that...really does because he must have said that a hundred times. And I said "it won't play without being closed" so he closes it, "and do I press it again?" if he asks me once more I shall ...chuck something at him (laughing)..." (Carer 3)

For this carer her frustrations were caused by her husband's memory loss:

"The biggest problem he has with memory is if he is talking and you interrupt him you know he loses track and that is very frustrating." (Carer 5)

Memory/attention functioning difficulties are also cited in the research literature to be an issue that most affects the carers (Testa *et al.*, 2006). The speed by which the injured carried out every day activities or tasks also frustrated the carers in this study:

"...he takes so long...in the shower he takes ages, you have to speed him up." (Field notes Carer 2).

Also recounted here:

"....he takes SO long to do anything now..." (Carer 3)

For some the expression of anger was very apparent:

"Well... (Sigh) I don't know really...he...Sometimes I get cross."(Carer 3)

"I think there is a lot of anger that we fall foul of the legal system, the benefit system, everything else, you know, and I think that... I have been on my own, I work full time, I have paid for everything, everything that I have and it's just when I needed it. Everything... lets me down. So...I suppose there is a certain amount of ...anger." (Carer 1)

For some the perception of others and the feeling of embarrassment that the challenging behaviours made them feel:

"I feel embarrassed...and I also feel that they are going to be looking at me and thinking Oh gosh 'faffing' ... you know, because they don't understand what it's like..." (Carer 1)

For Carer 3 the embarrassment at her husband's remarks was evident:

> "*Now over the last what couple of years he has started making personal remarks about people... and he'd say 'oh look at those two coco pops' but he was being Nice about them but you see...it makes you feel so embarrassed...... it really is so embarrassing.*" (Carer 3)

For this carer this meant also being embarrassed for her husband:

> "*How does that make you feel? If he came down without any clothes on in front of his carers?*" (Researcher)
> "*I would... I would be embarrassed for him.*" (Carer 4)

Whilst others recount what others might think.

> "*...and they are looking at me I bet they think I shouldn't be here, I should be at home...I don't know whether its me judging me or perceiving that they are judging me, I don't know, but its... and then I think about when I say about the behaviour then I feel that I'm...disloyal...*" (Carer 1)

> "*...and I was remember sitting in the car we had stopped at lights at the time, these people behind us women in the car they were sort of tutting they were thinking that he was battering me an Asian women being battered (laughs) and I wanted to get out the car but I couldn't. NO you DON'T understand. It's not really. It is not as it appears.*" (Carer 4)

For most carers the emotional ups and downs were particularly difficult for them to deal with, creating uncertainty and fear. This is expressed eloquently by this carer's remark:

> "*As well as the emotional outbursts one of the hardest things to deal with was when he wouldn't get up or do anything. So he would be in bed ALL day...when you're having a good day it's manageable...and if you're not...it feels like the end of the world at times, gosh here we go again.*" (Carer 5)

In contrast to the feelings of anger, frustration, annoyance, embarrassment and fear, the carer's felt a sense of upset using words such as 'upsetting' 'saddened', 'lonely', 'bewilderment', 'despair' when describing the impact of the ABI behaviours. This added to the emotions that the carers were feeling.

For some carers though there was a lack of acceptance of some of the behaviours:

"...we had HUGE problems where he wanted to come down without any clothes on. That's TOTALLY unacceptable it's embarrassing for his children." (Carer 4)

Another carer said:

"Sometimes it does annoy me and I can't... Even now I can't really... 100% come to terms with it that he can't remember, and yet I know he can't." (Carer 3)

For this carer the frustration of her husband's apathy was all too apparent:

"Umm... days one and two I can normally cope. Day one I am very sympathetic as in 'you must be tired' or 'you mustn't be feeling quite right don't worry it will pass' that can go into day two if he needs something if he won't eat anything then I start to get very agitated and then by day three I start to loose my patience and then I will say 'you are being selfish' you know 'really this is too much.'" (Carer 5)

Notably, for some carers, the intensity of the situation they found themselves in meant a feeling of lowness in their lives:

"I have less inclination to do things..., its, little interest. And its, I suppose it's... I am not depressed but I can understand it being like a depression which I don't really have a real zest for life or any... real..." (Carer 1)

For another carer:

"Mmm... sometimes I get fed up. I think it's not fair this is not what I wanted from my life. It shouldn't be me" (Carer 4)

Depression following TBI is well reported in the literature (Levin *et al.*, 2001; Connolly and O'Dowd, 2001; Harris *et al.*, 2001; Godfrey *et al.*, 2003). In other care giving research, depression has been found to be a significant risk to caregivers of stroke victims (Grant *et al.*, 2004), subarachnoid haemorrhage survivors (Prichard *et al.*, 2004) and dementia (Adams, 2008). Several other studies have found that the behavioural and emotional changes post-brain injury are predictors of carers stress and depression as discussed in Chapter 2 (Brooks

et al., 1986; Allen *et al.,* 1994; Mitchley *et al.,* 1996). However, there would appear to be more to care giving than the negative aspects such as fear, sadness and loss that most of these carers have expressed. For Carer 3 there were positive changes in her husband after his haemorrhage, illustrated here:

> "...*he gave me this card and in it he had written 'thank you for being there'. There were some lovely words in it, you know... he would, he likes doing little nice things...more than he ever did before, really.*" (Carer 3)

Similarly for Carer 2, since her husband's haemorrhage she described how this had ironically brought them closer together, describing an improvement in family life illustrated by this comment:

> "...*we do things together now ...go to the parents evening together, he wouldn't miss it for the world now....*" (Carer 2 Field notes)

This positive aspect of care giving was also noted by the Canadian researchers Buchanan *et al.* (2000), who measured the impact of a subarachnoid haemorrhage on significant others and found along with the negative aspects i.e. burden and clinical levels of stress, that the haemorrhage made for a closer marriage for some couples. Other research has identified the positive aspects of the experience of care giving, with individuals feeling a sense of pride and competence in being able to assist the ill partner (Berg-Weger *et al.,* 2001; Veltman *et al.,* 2002). None-to-date would appear to have reported any positive effects of challenging behaviour following ABI, although parallels may be drawn from research in mental health nursing. For example, Chen and Greenberg (2004) examined family members' care giving gains when caring for their relatives with schizophrenia spectrum disorders. The researchers found that the majority of the 560 family members interviewed could identify positive gains; more confidence, awareness of inner strength and a sense of fulfilment. The emphasis on the negative aspects of care giving that has dominated the psychology and the medical literature may, however, be a consequence of the predominant use of standardised psychosocial outcome measures, which reveal degrees and levels of anxiety, stress, or burden in the quantitative literature. The complex nature of the care giving cannot be just attributed to the negative aspects, but rather needs to be viewed as a whole

experience. Victor Frankl was one of the first psychiatrists to recognise the positive effects of a traumatic situation, arguing that man can transform the traumatic situation/event into a positive meaningful one (Frankl, 1969). Researchers need to look at the pre-family relationship, as the tendency within the current literature is to dwell on the negative aspects of the experience at the expense of some of the positive effects, all be it a stressful adjustment.

Although there is replication within the literature as to the specific challenging behaviours that 'the injured' may exhibit, few have specifically identified those behaviours that cause the most upset and difficulties within the family. For the family members in this research these were identified as the passive changes in behaviour i.e. lacking in motivation and apathy, contrasting with the active changes i.e. inappropriate remarks and profanities, irritability, emotional lability and aggression and the unpredictability of the behaviours.

5.4 Theme 3 Experiencing a sense of loss

All the carers interviewed in this study had taken on the major role of primary caregiver. The result of such a change in their role was an overwhelming sense of loss. The losses experienced affected many aspects of their lives. The participants experienced a loss of a family member that once was, loss of normality in their lives, loss of freedom to carry out many activities that they once did and a loss of security.

5.4.1 Loss of family member

For some, the severe changes in the ABI person represented a loss of the family member that they once had. For Carer 1 this meant a loss of her son illustrated by the following quote:

"I thought there was nothing worse than losing a child but there actually IS. And it's THAT, that... I find it's almost like. Oh someone took that part of me

you know... there is something worse, because I lost my son that night." (Carer 1)

For others it was a loss of the relationship that they had and a fundamental change in the family functioning:

"Well it is a different relationship...In that I can't, we can't actually any more make any more joint decision." (Carer 4)

For this carer there was a sense of emptiness, and expressed her difficulty in losing a marital partner with a loss of shared responsibilities and decision making:

"...we can't actually any more, make joint decision...So I have lost that. I have lost that umm...somebody who... cares as much about the boys as I do that is going to have that input from that point of view. So that's, that's obviously gone. I miss that mostly....I miss that joint sort of thing making decision and umm...you know being able to talk things through with somebody." (Carer 4)

Carer 3 describes the changing marital relationship in the following way:

"I suppose I feel more like a mother in a way....You see...in the way you treat him a bit like a child. You try not to. Because he's not a child in a lot of ways, but in a lot of other ways he is. And it's......it's that half way..." (Carer 3)

Similarly:

"....the carer role sort of takes over it is the patient and it becomes adult child really..." (Carer 5)

This Carer then went on to say:

"In the very early days I could nurse him. I could take his breakfast up in the morning and make him eat it like a baby. " (Carer 5)

The relationship with a life partner and the prospect of a future reciprocal relationship was lost. For this carer it also meant a loss of intimacy, as she described the changes in their sleeping arrangements, due to her husband's night time shouting and incontinence; they now slept in separate bedrooms (Carer 4

Field notes). This loss of partnership is echoed in the literature that explores marital relationships following ABI (Acorn and Roberts, 1992; Gosling and Oddy, 1999). In the field of dementia care, caregivers have described a kind of bereavement as they watch the gradual loss of their family members (Light and Lebowitz, 1989). This gradual loss of the reciprocal relationship, the inability to grieve for the partial loss of the injured has been described as 'disenfranchised grief' (Doka, 1989, 2002) defined as;

> "... grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, socially sanctioned or publicly mourned." (Doka 1989: p. 4)

Doka (1989) points out several reasons why a mourner may be positioned in disenfranchised grief which included the loss that is not recognised and/or the mourner is not recognised as a legitimate griever which includes psychological death. Caregivers of ABI persons are indeed in a position where their loss may not be publicly recognised, as the victim's injuries are often hidden, as in the cognitive emotional and cognitive sequelae. For this reason they have not been afforded permission to grieve for their loss for the person that once was. This loss, however, is fundamentally different from finite loss (i.e. bereavement) related to death, as the object of their loss is still alive. Non finite loss is continuous and insidious as the person gradually discovers the impact of a diagnosis, illness, or other loss events (Bruce and Schultz, 2001). Theoretically this has been explained by Pauline Boss, who developed the theory of ambiguous loss, which asserts that if the family member is physically present but psychologically absent or conversely if the family member was physically absent but psychologically present then this is termed ambiguous loss. This ambiguous loss according to Boss (1999), "...is the most stressful loss a person can face" (p.20). Boss argues that this is due to its ambiguity, and identifies the brain injured and the unconscious as examples of being physically present but psychologically absent. The resultant confusion over the presence or absence of the family member has the potential to create a dissonance between the carers' psychological family and her physical reality, the result is stress, trauma, and weakened resilience. Boss (2006) defines this confusion over a loved one's presence or absence as boundary ambiguity. This theory posits that boundary ambiguity, confusion, frustration, depression, anxiety,

and family conflict can all exist in families who are in a constant state of uncertainty about whether or not family members are present or absent (Dupuis, 2002). Boss and Couden (2002) contend that it is boundary ambiguity, not the experience of burden, which hinders coping, and can result in depression, anxiety, hopelessness, conflict, erosion of close relationships and a loss of mastery (the extent to which individuals feel in control of their situation and choices). Furthermore, it freezes grief and defies resolution. This was plaintively conveyed here in this carer's comment:

"...because I lost my son that night. And you can't grieve for it you can't move on umm its there...every day." (Carer 1)

Similar findings of suspension of the grieving process are evident in the literature. For example, in Colling's (2007) Australian exploratory study into the grief of parent's of young ABI adults (n = 5), all participants reported experiencing grief. The researchers went on to state that this 'acute' sense of grief gradually abated into a less severe, but recurrent, form of grief. Indeed, carers of individuals with ABI may experience loss over a long time and many of these losses are not socially recognized or addressed causing a situation of disenfranchised grief as suggested by Doka (1989). Doka's theory has profound implications for these carers, they are potentially mourners shut out from the grieving process.

The carers described a variety of loses; the quality of their relationship, their role, intimacy, and social interactions. For the mother in this study this meant grieving for the loss of her son's potential for a 'normal' future and the chance to experience the events of family life that occur over a period of time i.e. raising of her children and their development into independent adults with their own lives and families. This had been put on 'hold'. But it also meant for this carer that she had lost her other son as well:

"...my friend said to me at the beginning 'you'll lose both sons, you know it's both that you're lost because of it', and its truth, I have lost that." (Carer 1)

Few researchers have attempted to clarify the grief process of immediate family members who are adjusting to change and loss following an adolescent or adult's acquired brain injury. Zinner *et al.* (1997) surveyed 102 mothers whose injured (TBI) children were aged between the ages 15-24 at time of injury, and found the grief intensity did not diminish over time (3-year post-injury period), and that the altered behaviour and personality of the TBI victims had a marked influence on the mothers' grief reactions. Likewise, Marwit and Kaye (2006) found using a standardised measurement tool developed for assessing grief in dementia population, specifically measured grief in the caregivers of persons with ABI and found high levels of grief. Despite its small sample size, and issues of reliability and construct validity, Marwit and Kaye (2006) revealed parallel results to previous larger dementia caregiver studies (Marwit and Meuser, 2002; Sanders and Corley, 2003). Also consistent with dementia care literature the neurobehavioural difficulties correlated with high levels of distress for the mothers of TBI victims.

5.4.2 Loss of normality – restrictions on activities

For most family caregivers continuation of their own activities was difficult. Their normal activity patterns and habits were seriously restricted and revolve around the ABI and their behaviours. Time to themselves was severely restricted for the carers both in the home and their ability to go out. For one carer the need to be watchful, like watching a child, meant her activities were restricted or interrupted. The following carer's quote illustrates this:

> "...if we go out you have to watch him all the time because if I go around one corner...he, he does not know that I have gone... So you are always, having to ... watch ..." (Carer 3)

For this carer the decision to leave her husband to go shopping was a difficult one:

> "I can remember going Christmas shopping in Stockport and not knowing whether I should leave him or not leave him at home... and just being in the middle of Stockport devastated..." (Carer 5)

For the mother (Carer 1) in this study, her need for time to herself was a source of frustration and an unmet need expressed here:

> "It's the constant... it's not just the aggression it's the constant neediness that (....*) has, the constant reassurance... no insight into the fact that I might... need half an hour." (Carer 1)

For most carers the behaviours of their injured family member meant they were severely restricted in what they could do. Some caregivers experienced this situation as if they were prisoners in their own homes:

> "And I suppose certain amount of ...resentment that ...my life... has been curtailed if you like now because, you know umm, a friend ...a friend of mine wants to go out more and I said 'Well I can't I have no one to leave (....*) with'." (Carer 1)

> "Why am I having to think, right I'm going out now. I have to do this then I'll do that. Why can't I just go out? You know. Why? " (Carer 4)

Carer 1 succinctly expressed her feeling of entrapment in the following quote:

> "Your experience of living with somebody who is exhibiting that behaviour on a regular basis... So what does that feel like? " (Researcher)
> "Completely trapped." (Carer 1)

For some of the carers this also meant worrying about what other people might think when they did go out, for example:

> "I suppose my world has shrunk considerably yeah. ...I went out... there is a club that we used to go to and I went there (....*) had his accident in the July and in October and some friends there knew about the accident and you know I wanted to forget the past. ...and it's they are looking at me, I bet they think I shouldn't be here, I should be at home." (Carer 1)

The carers faced many struggles and demands on their time and for most this meant restrictions on every day living. For the carer who was the only participant in this research at the time of the interview who was in employment, her leisure time was totally consumed by caring for her husband who was unable to work. This she found intense to the point that due to his incessant attention-seeking, she felt her leisure time was not her own:

"I finished off the Sunday paper. That was just absolute bliss. Can you imagine that was for the first time I went out on Sunday and bought two Sunday papers, and I sat and read them it was just gorgeous. I just sat on my bed and just read the papers. I've not being able to do that in three years." (Carer 4)

She goes on to express her need to be able read the papers:

"I should be reading the Sunday papers. So...sometimes yeah, you do think... because I can't read the papers when (...*) because he talks to me or he want... he wants my attention." (Carer 4)

This is a stark reminder that the perceived normalities of everyday life and the pleasures of such a simple private time to oneself cannot be taken for granted. This loss of freedom, inability to pursue leisure activities, restrictions in every day life has been reported elsewhere in the literature. For example, Forsberg-Wärleby, *et al.* (2002) reported after interviewing (n = 83) spouses of stroke victims that nearly half (47%) identified restrictions of valued activities as being of great significance for the perception of their future daily life. Similarly Coombs' (2007) phenomenological study in which eight spouses of stroke survivors were interviewed, identified a profound sense of loss as one of her six interrelated themes, the losses experienced included a loss of freedom, loss of leisure time and loss of a marital partner. For Carer 1 this meant not even being able to watch the television:

"...he would go to bed...he has the spare room upstairs which is directly above the living room, so I will come down and have the television on, umm you would hear him moving around and constantly calling me. So you would have to look ...you know, ask him what he wants, umm. It would be nothing." (Carer 1)

Embarrassed by the behaviours and in fear of public humiliation, this meant for some carers, restricting or curtailing of their activities in public. For example:

"We can't go out ...as a family for a meal we used to eat out quite a lot before ...." (Carer 4)

This turmoil within the family seemed to be centred on the behaviours of the ABI person, causing changes to the family routine and activities, and a need to negotiate these changes caused by the behaviour to maintain some normality in their lives despite their stress in doing so. Maintaining normality was a theme identified in Wongvatunyu and Porter's (2005) phenomenological research conducted with seven mothers of young TBI survivors. The researchers reported how the mothers scheduled the child's day and reinvented the family's life to create a new normalcy.

5.4.3 Loss of Security

In addition to the loss of the family member the carers experienced secondary loss in the form of finances and feeling secure. For Carer 1 this incited anger that the system could not help her, this was clearly indicated in this passage:

> "Umm...I think there is a lot of anger that we fall foul of the legal system, the benefit system, everything else, you know, and I think that... I have been on my own, I work full time, I have paid for everything, everything that I have and it's just when I needed it. Everything... lets me down. So...I suppose there is a certain amount of ...anger......" (Carer 1)

Insecurity about the ABI person's behaviours meant that carers did not have control over their lives any more; they were unable to plan for the future.

5.4.4 Summary

This study and past literature supports the notion that loss is a multidimensional experience. Losses of leisure time and freedom have been expressed as disruptions to the carer's leisure time and times to one's self. In addition the carers have expressed a feeling of lack of freedom and being trapped. Other researchers have also described loss as a decrease in social activities and the inability to travel (Johnson, 1998) and restrictions in time and activities (Forsberg-Wärleby et al., 2002).

5.5 Theme 4 Loneliness

Whilst enduring the behaviours that the carers have described they also described being alone in their journey. Being alone because of their loss, grieving for what once, was engendered a sense of loneliness for these carers. This loneliness is illustrated by the following statements:

> "So... lonely and upsetting I think umm.... It's a very lonely place to be. I think. There is no one else to feel... What I can feel....and it's difficult to talk to people who haven't been there. You CAN'T imagine what it is like." (Carer 1)

> "...but I means it is very difficult because for most of the time you are on your own and you try not to speak to people at times when you are upset 'cause you know you don't want to burden them with those things and also you don't just want to be telling them all the negatives." (Carer 5)

According to Peplau and Perlman (1982) "...loneliness by definition is a negative emotional state" (p.55). The subjective experience of loneliness can be described as the pain that we feel when we want, but cannot, have companionship. Loneliness is the thief of life. It consumes energy and leaves us empty. Research into the frequency of loneliness among a population based sample is largely unknown; however, what is known is the link between caregiver loneliness and the risk of depression (Beeson et al., 2000; Beeson, 2003). Few studies aim to study caregivers' loneliness and none would appear to have been conducted in the ABI population. One of the few studies that attempted to investigate the quality of life in relation to loneliness in a population-based sample of aged 75 years or older caregivers in Sweden found that loneliness was the most important factor in predicting low quality of life amongst caregivers (Ekwall et al., 2005). Equally, Beeson et al. (2003) studied Alzheimer's disease spouse caregivers, and found a significant positive relationship between loss of self and loneliness, indicating that the more the carers experienced a sense of loss of self the more they felt lonely. The perceived lack of understanding from society for some carer's in this study left them feeling alone:

> "I also feel that they are going to be looking at me and thinking Oh gosh 'faffing'...you know, because they don't understand what it's like." (Carer 1)

Loneliness is a complex phenomenon that has been studied both theoretically and clinically and involves psychological as well as social aspects. Indeed, Weiss (1973, 1982) made distinctions between the concepts, social isolation and loneliness and contended that the feeling of being socially isolated does not necessarily include the feeling of loneliness. In the related literature, findings by Mahon et al. (1998) and Asti et al. (2006) have shown that perceived social support is negatively related to loneliness, with less social support leading to greater loneliness. Peplau and Perlman (1982) assert that loneliness stems from the deficiency in the person's social relationships. Although the caregiver and the ABI person have substantial intimate contact with each other, they were in fact socially isolated. This reflects what Weiss (1982) states, that there are two main affective states likely to be characterised by loneliness, emotional and social isolation, both are distinct. However, it could be argued that according to Weiss (1982) these carers are both emotionally isolated due to their loss of partnership and sense of attachment and socially isolated due to the dramatic changes in their social life. Family isolation and a lack of social support can erode family resilience, particularly under stressful circumstances (Luthar, 1999), as in the case of challenging behaviour. In the early research carried out by Rosenbaum and Najenson (1976) social isolation was identified as a factor in the caring of the head injured.

Healthcare professionals need to be aware of the effect that challenging behaviour may have on social isolation and emotional isolation for caregivers to implement effective interventions to forestall the potential healthcare problems.

5.6 Theme 5 Future concerns

The concerns that the family members expressed were not just rooted in the past and the present but also in the future. The unpredictability of challenging behaviours undermined the carers' previous relatively safe and predictable world. Even though they may have become accustomed to their new lives, the unpredictability and uncertainly of their behaviour was enduring and difficult for them to cope with. The unbounded, unpredictable and fragile nature of the

emotional, behavioural and cognitive sequelae continually reminded the carers of the future, not only for themselves but for the injured. All of the carers expressed concern about the future of the ABI family member. Future worries were expressed as:

"...and I suppose it's the bigger picture as well. I mean I am fifty. (....*) is eighteen, there's going to be a very long time when he's on his own." (Carer1) (* ABI survivor's name removed to maintain anonymity and confidentiality)

Some of these were broader concerns about what would happen to the person with ABI, where would they end up being looked after and by whom:

"I know you have to think of the future, but, I suppose that worries me because if I died I really don't know what would happen to him." (Carer 3)

"...but he is not always going to be a young man and that is going to go at some point and I don't seem to be able to change his Behaviour, and that makes me fearful for His future." (Carer 1)

"...and even now I think what would I be like in ten, fifteen years times...I'm getting older is (....*) going to be just as difficult. " (Carer 4)

There were also expressed worries about the injured family member and how they might react in different circumstances. For example:

"I worry about his behaviour in a different circumstance... I would worry that that could be too much for him. I am nervous when I am phoning to see how things are going (laughs) and what I might hear. " (Carer 5)

The feelings that the injured behaviours incited were enough to lead Carer 3 to contemplate ending her life and her husband's. She recounted this during the follow-up telephone call (after the interview), informing me of her plans for a suicide pact soon after her husband's subarachnoid haemorrhage. However, she went on to inform me that they had not followed it through for fear that if one should survive the attempt it would leave the other alone. She particularly expressed concern for the future of her husband should he be the sole survivor and who would look after him. For Carer 1 her hopes and dreams for the future were interrupted and shattered:

"I think it is frustrated by not being able to get around and not having the extension and not being able to travel and basically it's what's going to happen to the rest of his life and...It's...It's a whole collection of things." (Carer 1)

For some carers though there was a growing acceptance of what the future might hold for them:

"As a mum you have to mop up the aftermath of something that the kids have done but this goes on forever and it's...all those sorts of things that are coming on board and the realization if you like." (Carer 1)

"...difficult because it was like umm...is this what he is always going to be like." (Carer 4)

For most, there was a level of uncertainty about what the future holds, whether they will be able to live a normal life independently. These carers have been thrown into a role that they had no warning about or preparation for. They also had little or no choice in the matter. They not only identified uncertainty about the future for themselves, but also for the ABI person. Uncertainty was also focused on the extent of the ABI recovery and the fear of what might happen if they died. Morse and Penrod (1999) maintain:

"Uncertainty paralyzes hope. The individual 'just exists,' existing in an emotional state, suffering her or his inability to move, select an option, or act. " (p.148)

These carers are stuck in the 'now' and their feeling of uncertainty has meant losing an image of the future. Morse and Penrod (1999) also articulated that this state of uncertainty is characterized by emotional instability: the person endures the present and suffers the inability to envision a way out of the predicament; the person is suspended while hope is held in abeyance. These carers have described the uncertainty and ambiguous nature of trying to achieve a sense of autonomy and continuity in their lives. This is congruent with the concept of 'liminality', in which a person in limbo is caught in an ambiguous and transitional state that is not under their control. Liminality is where all transformation happens. It is when we

are betwixt and between, and therefore by definition they are "not in control." For these carers living with uncertainty and the unpredictability of the ABI behaviours described by the carers' adds to this sense of liminality.

Previous research also has highlighted uncertainty in carers. For example, Kao and Stuifbergen's (2004) phenomenological study aimed at describing the meaning of the experiences of the relationship between the young TBI survivors and their mothers, found that the mother described a 'period of uncertainty' and how that uncertainty produced a strain on the mother-child relationship. Frustration and uncertainty of what the future holds have also been identified by people with stroke as factors which contribute to spousal strain (Blake and Lincoln, 2000).

Uncertainty was also borne out in managing the every day decisions as to how much independence to afford the ABI person. Two carers described this, but in different ways. For Carer 3 it meant working with the social worker to try and regain some of her husband's independence:

> "we decided umm to put him on the bus....And one morning she said 'I'll tell you what we will do' she said 'you put him on the bus and I'll meet him at the bus stop' so we did that a couple of times" (Carer 3)

However, for Carer 5 whose husband lacked motivation and was apathetic, she was very conscious of him perceiving her as the "big bad wolf" when encouraging him to do things. She expressed concern and uncertainty about whether to leave her husband alone in the house or not, but then went on to say:

> "The only thing that (...*) likes doing independently is...go to the Arndale centre to go shopping....he knows where he is going, he know where he is coming back there are no issues with, you know, getting lost and things like that " (Carer 5)

Families with a brain-injured member often find themselves in a reverse 'empty nest syndrome' situation, with parents having to resume a caring/parenting role. As Florian and Katz (1991) state, finding themselves back in this role means facing the reality that in the future this will not include the freedom and independence they had expected, this is aptly illustrated here:

"...I never expected I would be in position still looking after my own for ever more." (Carer 1)

For all carers a level of uncertainty existed about the future, preventing them in many instances to see beyond the immediacy of the situation that they face. Although the carers did not talk directly about maintaining hope for the future, they hoped that the situation will change. Evident in this passage:

"So I am doing most of his care myself. So...I have to think that there will be an end to this so at the moment it's... so bad because it's... I do not get... any relief from it... at all. So...I have to tell myself it's short-term if it was long-term...I do not know what I would do. " (Carer 1)

Clearly being able to plan for the future and be able to dream is important, however, most put off their plans unable to envisage planning for the future. For the mother in this study at the time of her son's accident she described how she was regaining her independence, but now was faced with the constant consideration of his care needs and a loss of independence.

5.7 Theme 6 Family functioning

Challenging behaviour of the ABI person does also have the potential to weaken and change family functioning and relationships. For the carers in this research, roles within the family changed in all of the families. For these carers they carried out a variety of new responsibilities within the family, i.e. financier, being a mother and father, housewife, and primary caregiver. The rapid unexpected role change that these carers experienced meant also the acquisition of the new role as primary caregiver. These role changes that occur were not just those demarked within the family but within the society. This is clearly articulated here:

"So has your role changed?" (Researcher)
"Completely and utterly. Absolutely. Because not only do I have to do my job I actually manage the business side of it." (Carer 3)

Similar findings of role change can be found in previous research. Acorn and Roberts (1992), whilst using the results of a larger study which surveyed Canadian

family caregivers of head injured persons to examine the needs of the family to look at the impact of the head injury on the wife of the survivor, found a strong theme of role change, with the acquisition of the carer role adding to the responsibility of being a wife.

In spite of the additional role of primary caregiver that the carers experienced there may be differences in the beliefs about the care giving responsibilities between socially binding roles of the parent-child with that of the marital relationship that can be dissolved. The research literature is suggestive that spouses of those ABI persons who exhibit challenging behaviour face increased marital difficulties, including separation and divorce (Wood and Yurdakul, 1997; Katz *et al.*, 2005). At the time of this study none spoke of their desire to leave their partner. Although Carer 5 alluded to some of her thoughts on this matter:

"*...there is no point to continuing in the way we are we need to change it if you want something to change...*" (Carer 5)

In the parent-child relationship (Carer 1 and her injured son), the burden of the socially binding relationship is all too evident by her previous comments on her expectation to look after her son "*...for ever more*". The challenging behaviours described also had a significant adverse effect on family life and function.

"*...if it wasn't for that and (....*) hadn't, you know, the other side then, it would actually have improved family life.*" (Carer 1)

Research evidence also indicates that neurobehavioural problems are related to unhealthy functioning leading to caregiver distress (Anderson *et al.*, 2002; Testa *et al.*, 2006). This raises the issue of those families at heightened risk of disruptive family functioning as a result of the neurobehavioural sequelae post ABI. Several researchers have used the Family Assessment Device (FAD) to broaden understanding of family functioning post TBI and the effects of neurobehavioural experience by the injured family member (Kreutzer *et al.*, 1994; Broom *et al.*, 1998; Anderson *et al.*, 2002), these researchers describe the adverse effect on family functioning; organisationally functional and structural. Kreutzer *et al.* (1994) found unhealthy or poorer family functioning in one half of families who included a

member with TBI whilst in a later study Testa *et al.* (2006) found about one third of all (TBI) patients' family members reported an unhealthy family functioning, and this distressed family function correlated strongly with increased rates of neurobehavioural symptoms. Groom *et al.*'s (1998) study also highlighted the effect neurobehavioural impairments had on family functioning with depression and inappropriateness being the more predicative of poor family functioning. The term family functioning is often used interchangeably in the literature with family health. Hanson (2001), however, posits that the construct of family health is not without its controversy and is constantly being redefined. However, despite this Hanson offers a definition of family health that is often quoted in the literature:

> *"A dynamic changing relative state of well-being which includes the biological, psychological, spiritual, sociological and cultural factors of the family system."* (Hanson, 2001: p.6)

Whilst this definition refers to both the individual and the family as a whole, more importantly it considers family diversity. What would seem to be important is the quality of the caring and committed relationships in the family in maintaining its healthy function.

Although neurobehavioural problems and family functioning are clearly inter-related, this is, however, generally viewed as a negative relationship. Whilst acknowledging that families are not without their difficulties, the ability of the family to rise above the challenge of problems and crises that occur has been explained within the field of family research as 'family resilience', defined as the successful coping of the family under adversity that enable them to flourish with warmth, support and cohesion (McCubbin and McCubbin, 1988, 1996). This concept has increasingly been cited in the literature as an important explanation as to why some families can only survive problems and challenges whilst others not only survive but thrive. Family resilience according to McCubbin and McCubbin (1988, 1993, 1996) can help families to be resilient to disruption and adaptive in the face of crisis situations i.e. a family member suffering ABI and their subsequent challenging behaviours. However, the family resilience concept goes beyond thriving to offering the potential for growth out of the adversity, enriching their lives and transforming the family. This resilience was clearly evident in the family of

148

Carer 2. Taken from the field notes the carer described how she had regained a family, that she felt that they had been reunited. His involvement and commitment to the family were evidence by this comment:

> "...he goes to all the parents evenings now, he won't miss them...he is at home now." (Carer 2 Field notes)

Whilst the measurement of post-injury functioning within the literature is varied, there is evidence that a substantial number of families rate their functioning unhealthy prior to their family member suffering a TBI (Sander et al., 2003). This was clearly articulated by Carer 2.

> "...they never saw their dad he was always in the pub before the haemorrhage; they did not have a father..." (Carer 2 Field notes)

Similarly Carer 1 hinted at the behaviours of her teenage son prior to his ABI in our general conversation and during the interview, stating that he 'smoked weed'. She also stated that she knew her son's friend was not insured nor did he have a licence to drive the car that resulted in the tragic crash.

5.8 Theme 7 Coping and adapting

The carers in this study adapted and attempted to cope with the challenging behaviours, enduring the experience of the familiar stranger, in a variety of ways. Although they were very much aware of their situation and the restrictions that this placed on their lives, they described the following coping strategies in an effort to maintain normality; withdrawing from public view, withdrawing into personal activities such as reading and writing down their feelings, the use of humour and spirituality and finally the belief of being in control. Coping has been described as continuous cognitive and behavioural efforts to manage particular external and internal demands which are seen as challenging or exceeding the capabilities of a person (Lazarus, 1993). Overwhelmed by the experiences, some carers could not easily express themselves illustrated by their long pauses and silences throughout the interviews.

5.8.1 Withdrawal from the public as a means of coping

For fear of encountering negative public responses and judgements to their family member's behaviours, sometimes the carers reacted in defence of the behaviours whilst at other times they withdrew back to their homes. An example of being out and having to leave to go home include:

> "...we had gone into the shop and we were just walking across into another one he kicked his shoes off started shouting and everybody was like... and I said 'come on then let's go back home' so, so you, you have to just deal with it don't you? " (Carer 4)

Similar findings can be found in the sparse qualitative research. 'Actively dodging society' was identified within the phenomenological study carried out by Kao and Stuifbergen (2004) in which the researchers explored lived experience of the relationships between young adult traumatic brain-injured survivors and their mothers. These researchers reported the mothers actively withdrawing from the public sphere because they feared encountering strangers who would react negatively to their behaviours. Other opting out strategies described by the carers included reading:

> "...well I can sit and read....I have always been able to read and I'm always glad that I could because that is my opting out." (Carer 3)

Writing memoirs or a diary was also described by two carers as an activity they regularly engaged in as a way of 'writing down' their feelings and emotions. Although Carer 3 described writing in a diary, this would seem to be a joint venture with her husband:

> "...on Sunday we do a diary on Sunday evening..." (Carer 3)

For Carer 1 though, writing the events of her son's journey and her feelings were clearly a personal venture. After the interview had finished she shared with me her weighty note book containing her memoirs over the past twenty months. She showed me how she had detailed the events of her son's journey and wrote her thoughts and feelings down along the way. She also expressed a wish that she

had wanted to share with others her experience, some of which she had already achieved:

> "The diary I ...would like to get published. I have these articles in the paper and women's magazine." (Carer 1)

This concept of 'writing down' one's emotions has been well documented in the literature, as I alluded to earlier in this thesis, most notably by James Pennebaker who found that journaling emotional experiences gave clarity and insight and reduced the cost of suppressing the emotion i.e. less stress, build an immune response to traumatic experiences (Pennebaker, 1993, 1997, 1999). Research studies offer differing explanations as to why this should be, but crucially Pennebaker (1999) makes a strong case arguing that converting emotions and images into words, changes the way the person organizes and thinks about the trauma. However, Pennebaker et al. (1997) point out that the impact on the health of the individual of writing down one's emotions is dependent on what words they use, arguing that those who used a high rate of positive-emotional words, the more likely their health improved.

5.8.2 Spirituality

One carer described how her faith had helped her to cope:

> "Where do you take comfort from?" (Researcher)
> "Well I always know that people pray for us, because we're a lot of friends... who pray for us we know that... and I find probably...me faith has helped me... a lot." (Carer 3)

As noted in this carer's comment, spiritual support can provide a source of comfort. Similar findings can be found in other research studies. For example, Kao and Stuifbergen's (2004) phenomenological study describes mothers of young acquired brain injured survivors becoming more religious and praying more to find spiritual support during their period of uncertainty.

Facing an illness, personal crises, and negative life events have often been found to predict conversion and greater religious and spiritual involvement (Spilka *et al.*, 2003). Albaugh's (2003) phenomenological study, involving a variety of people with life threatening diseases, describing how spirituality provided comfort and a sense of meaning in the participants lives (n = 7). These studies support the theoretical work of Viktor Emil Frankl (1905-1997), a neurologist and psychiatrist of Jewish origin, who described existential and developmental components to self-transcendence in people confronting their own mortality. Frankl (1969) contends that man[19] has a unique capacity to discover meaning, purpose and fulfilment, to rise above a situation, and viewed spiritual dimension as a means of empowering human beings to overcome even the most overwhelming circumstances of life. Similarly, for Boss (1999; 2006) spirituality was a factor that influenced how people gain meaning from their loss and cites her own experience with ambiguous loss, of seeing religious and spirituality beliefs promoting resilience.

5.8.3 Use of humour and laughter

Carers described having a sense of humour as one of the strategies used to cope with caring for the ABI person and their challenging behaviours and surviving in the carer role. They were able to laugh at absurdity, either at themselves or their family member. During the interviews the carers often laughed out loud about the situation they recalled:

> "You could see it happening. (....*) was stood, had got his walking frame and (....*) comes over puts his arms around him like that and the two of them have gone over. I came around by which time they are trying to pull (....*) off ... because ...he is trying to bit his ear off. " (Laughing) (Carer 1)

Another caregiver used humour to explain the difficulty she experienced trying to deal with her husband's memory loss:

> "Just...you know, and then he'd say 'did I, did I have my cap on when I came out?' and I don't know whether he had his cap on when we came or

---

[19] The word 'man' used by Victor Frankl denotes both male and female human beings.

*not (laughing) and I'd say 'I don't know I can't honestly remember."
(Laughing) (Carer 3)*

"I mean we... (laughing) some of it is so funny when we look back on it."
(Carer 5)

For Carer 5 humour provided a means of communicating her frustration:

*"...if he was going to have a go...there would only be me in the room which
is going to be very unpleasant. I did wonder if we might have CCTV
(laughs) in them (laughing), and at one stage I thought 'well (laughing) it
can work both ways (laughing) you know when I am (laughing) going to
murder him I will be found out won't I? " (Laughing)* (Carer 5)

Humour is a communication tool to convey a piece of information; it is a social phenomenon that occurs in social interactions. It is well known that humour and laughter, more than anything else in the human makeup, has the ability to rise above any situation, even if only for a few seconds. However, there is a dearth of humour research in the nursing literature. A notable feature in this research was the use of humour, the carers recounted funny stories relating to their partner or son. Humour provided a momentary release from intense situations and its accompanying frustration. Often in the most trying of times i.e. when the patient often said or did the most bizarre things. Humour may identify a unique and valuable caregiver response for coping with the care giving demands of challenging behaviour, providing an antidote in the face of adversity. For Carer 2, humour was a key feature of her husband's changed character since his subarachnoid haemorrhage:

"...he has a wicked sense of humour now" (Field notes Carer 2)

Parrish and Quinn (1999) argue that humour and laughter are the unsung heroes of coping for caregivers, helping carers survive difficult painful moments in their life. In these interviews the carers often let go for a brief moment during the interviews, removed themselves from the confines of their problems and laughed at their predicaments and themselves. As Parrish and Quinn (1999) state, carers use "... *levity in the face of darkness"* (p.204). Humour and laughter can, as Parrish and Quinn (1999) conclude in their paper, provide the caregivers with the

well-deserved, albeit temporary, peace of mind. But as Victor Frankl points out, you cannot force people to be happy or optimistic rather:

"...*if you want anyone to laugh you have to provide him with a reason, e.g., you have to tell him a joke*" (Frankl, 1984: p.163).

In certain situations humour, leading to laughter, allows an altered perspective and avoids the negative consequence of the situation. Freud (1928) regarded humour as the highest of defence mechanisms, recalling his personal experience of struggling with cancer. According to Lazarus and Folkman's theory of coping strategies, broadly speaking, humour is an emotionally-focused coping strategy. From another perspective, and perhaps linking spirituality with humour, Frankl (1984) writes that humour is "*...one of the soul's weapons in the fight for self preservation*" (p. 63).

Although the use of humour as a coping strategy has not been fully explored within the literature, some researchers have reported that humour has a positive effect on oncology patients (Bellert, 1989; Chapple and Ziebland, 2004). Few though have looked at the effectiveness of humour in mitigating caregiver stress, yet in the discipline of psychology there is an assertion that there is a link between humour and health, modulating the effect of stress (Nezlek and Derks, 2001) and the stress modulating effect has been found to be positive (Abel, 1998; Kuiper and Martin, 1998). Within the field of neuroscience, O'Connell and Baker (2004) found that humour; laughing and joking were used as a way of coping by carers of stroke survivors. Similarly, Buffum and Brod (1998), whilst exploring care giving of Alzheimer's disease patients (n=96), found that humour had a significant impact on their well-being. Bethea *et al.* (2000) furthermore argue that humour is more than 'funny stories' about caregiving, rather it serves as several communicative functions for long-term caregivers. First, humour is a comfortable way to share personal and often sensitive information, secondly humour can give caregivers a face-saving vehicle to explain how or why they thought, felt, or acted in a certain way and finally it can serve to communicate an unresolved care giving conflict or concern. It would seem that the use of appropriate humour is an important element of human well- being and it may be at the core of survival for some of these carers

and provide a means of expressing their fears and anxieties.

5.8.4 Control - Dealing with the behaviour – seeking understanding

Several of the carers felt a loss of control and identified the need to seek understanding as a means of coping with this. For example:

"...I suppose the loss of control over...so many different things." (Carer 4)

The perception of control over the behaviours of their family member for some gave them a sense of coping. Riley's (2007) research indicated that the stronger the belief in carers' own ability to control the difficult behaviour the less their stress. This highlights the notion that carers' beliefs about their injured family member's behaviour may contribute to their emotional reactions such as carers' distress. Lazarus and Folkman (1984) frequently cited work distinguished between coping strategies that are employed to confront and seek solutions to the situation, *problem-focused* strategies and *emotion-focused* strategies, which focus on ameliorating the associated level of emotional distress. Central to research into coping is the link between the use of specific coping efforts and adjustment to stress. In a large number of studies, problem-focused strategies have been found to be associated with better adjustment. Typically this has been attributed to the fact that these strategies seek to deal actively with the situation, whereas the emotional strategies are attributed to the failure to confront the problem (Lazarus and Folkman, 1984).

Conversely, Carer 2 in her appraisal of the stressfulness of the situation described the positive aspects of their personal journey, facing suffering head on, in the belief that something was to be gained from the illness experience. Lazarus and Folkman (1984) believe that enhancing the positive appraisal of the situation helps carers cope better with the situation. Whilst the distinction between problem-focused coping and emotion-focused coping may be widely acknowledged, it is conceivable that this rather simplistic distinction is not always applicable and that there may be a multitude of strategies used within these distinctions. This research

155

hinted at a number of strategies including the use of information seeking behaviours, avoidance and management seeking strategies in an attempt to manage the problem. Carver *et al.* (1989) assert that this is indeed too simplistic. Coping is far more complex as hinted at in the carers' responses, but it is beyond the scope of this thesis to explore this in detail, but what is evident is that their appraisal of the situation is variable and may even change over time.

Lazarus and DeLongis (1983) contend that personal meaning systems act to influence the manner in which individuals respond and cope with stress throughout the life-span. They argue that individual 'patterns of commitment' determine the manner in which certain events are appraised in terms of their possible impact on well-being, and influence the manner in which these events are managed. The behaviours that the carers have described; aggression, forgetfulness and apathy, do challenge important commitments and everyday life, increasing the individual's vulnerability to stress. This vulnerability, however, can also propel the individual into action, which relieves the threat and maintains coping as seen by some of the strategies described by the carers in this research such as information seeking behaviour. Lazarus & DeLongis (1983) further ague that patterns of commitment create a state of meaningfulness. In contrast, Carver *et al.* (1989) argue that there are three coping strategies that may be dysfunctional namely, venting emotions, behavioural disengagement and mental disengagement. For some carers though it would appear that they were not coping very well, illustrated here:

> "*I think what has happened is umm...you develop coping mechanisms and then you realise that they are only coping mechanisms and then one day you realise that coping is not good enough.* " (Carer 5)

Several carers attempted to seek information but described their dissatisfaction with the amount of information they had received, adding to their feeling of uncertainty and sense of loss of control. The lack of knowledge and expertise contributed to their emotional upheaval. The uncertainty about not knowing was encapsulated by the following comment:

> "*...one of the hardest things is that they don't really tell you anything.*"
> (Carer 5)

For some carers this not 'knowing' resulted in them seeking information from the Charity organisation BASIC (Brain and Spinal Injures Charity) and using the local library. Several carers commented when they did receive information, for example:

> "...'won't be the same now, in your marriage. There will be differences in his character.' Now that really did help because I suppose I had been wondering what's going with all these funny things that happened...By being told, I really appreciated that." (Carer 3)

However, the lack of information for the family also seems to be associated with the fact that the physicians and health professionals are themselves faced with many uncertainties, due to the evolving clinical condition of the ABI patient. This is summed up here with the following comment:

> "...they can't really know either with brain injury...so it's not that they are not telling you, they have no idea." (Carer 5)

5.8.5 Summary

Severe illness such as ABI disrupts and often undermines the family's understanding of the world and their selves, forcing them perhaps to rethink their own personal meaning. For some carers, spirituality, writing and seeking information and understanding were the means by which they found a sense of meaning out of the chaos that they now face.

5.9 Summary of findings

The findings described in this chapter have revealed experiences that I had not expected and arguably might not have been shown through the use of more empirical methods. The themes that have emerged are both striking and saddening. These interviews have revealed an array of emotions in the family members increasing our understanding about their individual's coping and adaptation to challenging behaviour. This resulted in a barrage of emotions: sadness, anger, uncertainty, frustration, fear and embarrassment, which gave rise

to and manifested in responses such as depression and social dysfunction. These emotions described, not only enrich our understanding but each capitulate their own meaning.

All the carers interviewed in this study had taken on the major role of primary caregiver, with the subsequent loss in the marital relationship for the spouses and the feeling of having lost a son, for the mother. They had lost an adult family member that was, and gained a child. These carers have and will continue to endue the experience of the 'familiar stranger'. The central crisis (meaning of the experience) was one of profound loss, not only for the loss of the family member that was forever, but for the life that they once had. For some this meant the loss of a companion and expectations of a reciprocal relationship. Caregiving made high demands on the caregiver's time and energy and as a consequence they were met with restrictions on their personal and social life. The non-finite loss that Bruce & Schultz (2001) described, aptly captures the carer's loss. It is continuous and denies the families their hopes, dreams, and expectations that they had for their loved ones and themselves. Overriding this loss is the sense of being alone in their coping with this loss. The carers were faced with not only readjusting to their new role in the family structure as a primary caregiver as opposed to wife in most cases but also facing the consequences of coping with the challenging behaviour. The change in the relationship in the family was a striking consequence for the carers for all this has meant a decline in social interaction which jeopardized family relationships. The devastating impact of challenging behaviours on their everyday lives was one of the striking themes that emerged, restricting their everyday activities and social network.

When a family member has survived brain injury, both the injured member and others in the family face the enormous challenge of living with the uncertainty of the disability and the challenging behaviour. The carers in this study have identified how difficult it is for them to cope with their family members' challenging behaviour. They appear to cope with an emotional roller coaster as they live with the uncertain trajectory of illness, the demands of illness and care giving, exhaustion, financial burdens and fears for the future. Family members lose their 'normal' life and are faced with learning to live with ambiguities over a long period

of time. Some appear to cope better than others. According to Boss (1999) the greater the ambiguity surrounding one's loss then the more difficult it is to master it. Indeed, Boss (1999) maintains that ambiguous loss can cause family problems not because of the flaw in their psyches but because the situation is beyond their control or outside their control, blocking their copying and grieving process. For the carers in this research, the loss of a normally functioning family member as a result of their acquired brain injury is clearly an ambiguous loss. For one carer (Carer 2) though, she had adapted, readjusted her expectations of the person who has suffered the ABI and managed to cope with the way they function as a family despite carrying the heavy 'burden' in doing so.

Whilst coping with the traumatic events such as those associated with the cognitive, behaviour and emotional sequelae following ABI these carers have described their struggle to make sense of the new world that they now face seeking understanding and meaning. Maintaining or restoring a sense of meaningfulness, optimism and control are pivotal to successful adjustment to the carers' lives. These carers attempted to cope and adapt to their changed family member with strategies such as the use of humour and laughter, withdrawing from public life and withdrawing into their own private self with activities such as reading. Some carers described strategies such as keeping a journal, expressing their feelings and thoughts in words to ease the stress of traumatic situations and helping with sense-making. This 'writing down' of emotions along with the use of humour are undoubtedly strategies that may need further exploration as an adjunct to other coping strategies and an augment to the efficacy of treatment for these carers.

Meaningful time alone was a powerful and necessary need for these carers, helping to maintain some normality to their disrupted lives. But these times of being alone, such as reading the newspaper or a book or indeed finding solace in spirituality, did not mean being lonely. As Frankl (1984) observed, difficult situations often provide a person with "...the opportunity to grow spiritually beyond himself" (p. 93). However, the feeling of being misunderstood and being alone, for the carers, engendered the feeling of loneliness.

Stress and coping theories emphasise the importance of appraising stressful events such as challenging behaviours and their capacity to address these events (Lazarus and Folkman, 1984). Identifying the factors that influence the carers' resilience can help provide a framework for better assessment and a means of helping 'at risk' families.

Although time was not a factor that had been highlighted in the interview schedule, it has had an over arching impact on the whole experience in two fundamental ways. Firstly in that carers identified that behaviours changed over time with new behaviours emerged as time progressed and secondly that with time the experiences expressed were not dissipated.

This is clearly expressed here:

> "*Has time made it better?*" (Researcher)
> "*I don't think so. Not as far as some of these he does, because... some of these are fairly new, you know, like they seem to this personal ...*" (Carer 3)

And the carer went on to state:

> "*...possibly his behaviour has changed or maybe I have become...more used to it. I don't feel any differently about challenging behaviour to...what I did three years ago...*" (Carer 3)

Several researchers have attempted to understand the impact of time on the carers experience post ABI, although these have, on the whole, been quantitative in nature and few extending beyond a couple of years as discussed in Chapter 2.

Whilst I accept the notion that within the qualitative methodologies usually the findings are presented in the form of texts (Creswell, 2003), however, I believe that additional forms of representation of the data add richness and depth. Thoughts and experiences can be understood and expressed in many different ways, not just in the spoken or written word. They can reveal insights that cannot be articulated simply as words rather like the transcripts that only represent in part the interaction that took place between the participant and the researcher in an interview. van Manen (1997) acknowledges the limitations of spoken language in the phenomenological descriptions and states that beyond the verbal language

there is the 'epistemological silence.' Equally, Dewey (1991) asserts language includes much more than the oral or spoken word, specifying the use of paintings, visual pictures and illustrations. Images are for me another way of seeing things as they are. They do not capture the whole picture rather offer a different and new way of telling the experience. For Finlay (2006), the strength of a qualitative study lies in the ability of the researcher to capture the richness of lived experience and that a study should be judged on its ability to draw the reader into the researcher's discoveries allowing the reader to see the worlds of the others in new and deeper ways. Thus both written text and visual images capture the essence of the phenomena and both require distancing from the things themselves to understand the essential feature of the experience. For Husserl the phenomenological evidence is nothing more than grasping the entity with the consciousness of it being itself there. By being open to imagination and to new possibilities for appreciating the lived experience of challenging behaviour following ABI then the true essence can be articulated. This does not draw on the linear presentation of codes and the formal processes that all too often abound in research, but it draws on new ways of knowing. I needed to find an appropriate genre which was suitable for the task of portrayal rather than the task of analysis. Thus the image presented in Figure 2 is my creative attempt to capture and communicate the rich 'voice' of the lived experience of the phenomena. Although I have not created it, in its literal sense, I had an idea that came into my consciousness just as I have attempted to uncover the pre-reflective stream of consciousness of the carers in this research. I have thus discovered it. For Husserl this seeing is a phenomenological 'seeing' not a sensual seeing and one that recapitulates certain features of the phenomena. Furthermore, I believe that the use of creativity is in itself an expression of where one is as a developed self.

Figure 2

5.10 Reflections on analysis

Several surprises were uncovered during this analysis; most notable were the use of humour and the sense of loss that these carers experienced. Whilst accepting that humour is a communication tool, what I had not expected was the use of humour by the carers in this study. During the course of this doctorate programme I had undertaken interview training, during which humour emerged as an

unexpected theme in the transcripts that we were asked to analyse[20]. Humour acts as several modes of communication, issues may have been concealed by the carers' use of humour and anecdotes. My ability to pick up on these cues, I realise now; I might not have taken full advantage of during the interviews, by using probing questions. I now understand the importance and the role that humour can play in the research interview. As Spark's *et al.* (2005) maintain it is the skilled interviewer who does not only recognise and acknowledge the caregivers concerns, but asks them to expand on their feelings.

The overwhelming sense of loss that these carers felt was not just saddening for me, but a stark reminder of its continuous and non-finite nature. I, however, was unaware of the underpinning theoretical knowledge that attempts to explain their loss, but through my readings I now appreciate the importance that this has for future research and our understanding of family care. Equally enlightening for me was the notion of resilience in the face of such adversity as challenging behaviour and the differing coping strategies that carers may employ. These unexpected findings arguably fuel the notion that through openness of the mind, then the essences reveal themselves.

--oOo---

---

[20] This finding was published by the researchers Chapple and Ziebland (2004).

Chapter 6 Implications and Conclusions

6.1 Introduction

This chapter will begin with an exploration of the impact that the research study has had on me professionally and personally, drawing on the influences of the taught component of the professional doctorate. This is followed by a discussion on implications for professional practice, implications for carers and family education and healthcare organisations. Suggestions for future research are presented followed by limitations and strengths of the study. The chapter closes with a concluding summary of the research study and reflections of the value of this study both practically and professionally.

6.2 Professional and personal impact of the research study

The Professional Doctorate has without doubt been a challenge, but it also has enabled me to 'flourish' in both personal and professional terms. As a professional it has unquestionably developed my capacity as an expert practitioner and researcher, enabling me to contribute to the neuroscience evidence base and improve patient care. Gregory (1997) eloquently captures the focus of the professional doctorate for me, describing the student as a scholarly professional', as opposed to 'professional scholar', and one whose professional competence is grounded in theoretical understanding. One of the greatest sources of learning and development has been 'doing' the research, I have grappled with ethical dilemmas, managing self and the research project.

Despite my role change during this programme, from a clinical setting to academia, I believe that my developed research skills; the ability to formulate, conduct and report on investigations in new areas, and the ability to construct coherent analysis based on data collected, along with the expert level of knowledge of current work in the field, are skills that are as important outside academia as within. I have spiralled through the turbulence of the last five years, making sense of the changed world I found myself in, and feeling as if I had fallen

off the top of the log pile and landed at the bottom. However, by creating space and reflecting, I have made sense of this turbulence, gained understanding, made connections and emerged a different person. I have developed an increased self awareness, self confidence, and have become more flexible, self reliant and independent in my approach to practice. These are arguably critical skills for the researcher in the field who may be faced with complex and unpredictable situations, but equally important in my role as a teacher and nurse. Some of my greatest surprises have occurred in that space that I have created for myself. In the doctorate programme there were times when my studies caused me a great deal of angst, self doubt and lack of confidence, but time and reflection has facilitated clarity of understanding. I have been forced to look at the world differently due to the adopted approach used in this thesis. This has undoubtedly given me a greater understanding of other forms of knowledge and perspectives.

The professional doctorate has arguably uncovered deeper issues in my practice. How I engage with self is now more reflective, artistic and critical and how I engage with others is more open and understanding. Maximising my potential, 'flourishing', is I believe, at the heart of professional practice. I also believe that I can create the conditions for others to see new ways of doing things, so they too can 'flourish'. This research has challenged my knowledge and practice of neuroscience nursing, highlighting major gaps in care delivery, and understanding and supporting the families of those family members with challenging behaviour. It has also helped me to reflect on and illuminate my own professional practice. I am certainly more family orientated and view acquired brain injury in a more holistic way not just from the acute immediate care perspective. It has strengthened my belief that I want to continue to influence neuroscience practice. I am driven by the desire to improve the quality of the patient experience, but I now understand that I can do that through several avenues not just through direct patient care. I also realise that I am intrinsically motivated by personal fulfilment and intellectual challenges.

I have also developed an understanding of my own creative ability. I believe that the use of creativity is in itself an expression of where one is as a developed self. In the past this has been hindered by my diminished confidence, and self

knowledge. In addition I realise that this may have been hindered by my positivist logical way of seeing things. I realise now that I am a risk-taker, which I alluded to in my opening chapter; I am prepared to find and try original ideas, to go beyond familiar boundaries of knowledge and explore new possibilities. I also understand that a formulaic approach to research and education is self limiting, but by combining creativity with divergent thinking then new challenges can be embraced and managed. I have, I believe, in this doctoral journey experienced different ways of accessing personal creativity and imagination. I am more amenable to a wider range of creative solutions and I have learnt to negotiate challenges through reflection and dialogue. Although I have been faced with some ups and downs in this journey it has fulfilled its original aim of personal fulfilment, for intellectual challenge and perhaps most of all to impact on patient care.

6.3 Implications for professional practice

Given the findings of the study, the following have possible implications for future professional practice. From the phenomenological approach we can derive valuable insights that can support a more comprehensive and supportive education programme for healthcare practitioners working with ABI persons and their families. This specialist knowledge of ABI for health care professionals should include the impact of the trauma, cognitive behavioural and emotional changes, and issues of loss for the family. In addition to models of family adaptation enabling families and the ABI person to manage the difficulties they may face. This however, requires a change in focus from a patient-centre rehabilitation practice to one that is family focused. This approach to managing TBI was a key recommendation in the National Service Framework for Long-term Conditions (DH, 2005). This change also requires the need for long-term input from healthcare professionals, as and when required, in recognition of the longevity of the impact of ABI on the individual and their family. The lack of focus on the impact of neurological injury and the neurobehavioural sequelae on the individual and their family needs to be addressed in both pre-registration and post qualifying nurse education in order that this vulnerable population's needs are understood and met. This lack of focus needs to be redressed given the prevalence of such

behaviours and that the need is likely to increase. Whilst nurses might be expert in care delivery in the acute sector, clearly what is required is seeing the 'bigger picture', the long-term effects highlighted in this research and previous studies the importance of support, which may take various forms including formal rehabilitation programmes and information. If professionals however, limit their ways of knowing just to their disciplinary knowledge it will limit their possibilities for responding to the uncertainties and complexities that neuroscience practice presents; thus providing existing and future nurses with opportunities to view rehabilitation through new 'eyes', further education and by increasing the focus on reflective and family practice, then these family difficulties might be addressed. Furthermore to be able to fulfil self-directed learning and critical thinking in the student I believe that the learning process is enhanced with more private in-depth reflection where students are free from the habitual ways of thinking. I understand and believe now, that not only have I developed this skill, but also it is my role to facilitate this process in others. Within the higher education institute which I work, I have already structured some of these issues into the newly developed post qualifying neuroscience modules, and plan to look at other programmes of study were they would be relevant in the future. This will include reviewing the current education provision to support healthcare professionals in specialist roles within rehabilitation. This could be supported and facilitated by providing clinical placements for pre-registration and post-qualifying students in areas that provide a family approach to care delivery for ABI individuals and their families, both within and outside the UK. Finally, as my understanding and knowledge has grown during the writing of this thesis, so has my desire to provide a voice for these families, enlightening others to the issues that these families face through the neuroscience communities that I am part of. This includes the British Association of Neuroscience Nurses, the National Neuroscience Benchmarking Group and the British Journal of Neuroscience Nurses.

In today's society families are complex and what constitutes a family is forever changing. Furthermore, their expectation from healthcare systems is also changing. As Diane Duff's (2006) paper states it is not yet established how the family evolves over time, and we are just beginning to explore the complexity of the family context, family capacity resilience and the process of adaptation. This

undoubtedly presents additional complex issues for the healthcare professionals and even more so when that family is challenged by a member surviving ABI. Nursing interventions could help the caregivers discover and make sense of their situation in a more positive way. Moreover in order to support families it is essential to understand the individual perception of the disease, the impact on their daily life in the individual context and their coping capacity.

This research found that the impact of loss was profound and multifaceted, but for some carers resilience occurs and they find ways of coping and meaning. As many of these carers experienced disenfranchised or ambiguous loss then it may be particularly important to educate nurses so that they understand what it means for the family or individual to experience ambiguous loss, so that appropriate interventions can be implemented. This research has highlighted the need to look in more detail at resilience and sense-making. If some families are able to make sense of their experience then healthcare professionals working with ABI and their families need to find and implementing strategies that may help to address and create meaning through care giving in these difficult circumstances. Moreover strategies need to support the healthcare professionals in their management of difficult behaviours in order to facilitate functioning and quality of life. How we view responses to trauma needs to include the positive transformation as well as the suffering and burden experienced by the carer.

Healthcare professionals also need to understand that some family members need to share their experiences and find ways of coping. This can be supported by working closely with the whole family especially in relation to communication skills, based on the positive aspects of coping and problem-solving skills. In addition being more responsive to the family's needs, improved partnership working with all members of the family and regular assessments will address some of these challenges.

Healthcare support workers (assistants) also need to be provided with the relevant training and education on issues such as rehabilitation, cognitive, behavioural and physical complications, social and family issues, and available support programmes related to ABI to ensure continuity of service delivery.

Rolland (1994) argues that the way that chronic illness affects the family depends on a number of factors including age, developmental stage of the ill person, family strength and coping mechanism and key family life cycle issues. The key for healthcare professionals working with ABI persons and their families is to identify those with predisposing vulnerable factors and at greatest risk. A review by Perlesz *et al.* (1999) concludes that the Family Assessment Device (FAD; Epstein *et al.*, 1983) is the most commonly used measure of family functioning in brain injury studies. They suggest that the screening instrument is a reliable and valid tool to distinguish between good and poor outcome in families following ABI. The use of early assessment and intervention of these families may help to prevent major relational and personal difficulties. Indeed established frameworks such as ambiguous loss reveal the importance of involving the family in the treatment of acquired brain injury. Furthermore accurate assessments of these families, as they move along the journey of care giving, can give a better understanding of how they are processing their experience and their anticipatory needs may be addressed more effectively. This, however, requires the introduction of reliable and valid assessment tools such as the FAD into secondary and primary care settings, facilitated by the neurorehabilitation team.

6.4 Implications for carers and patient education

Families play a crucial role in the rehabilitation process of the individual with ABI and a high portion of the family member become key carers. However, these carers experience long-term burden and stress as indicated in the literature and this research. The experiences of the caregivers in this study showed that support from informal and professional caregivers was not sufficient. Given the large number of people who have been disabled by ABI, it is important for health professionals to assist carers to adapt to their role and to develop coping strategies that will support their well-being. In addition to education provision for healthcare practitioners, there is a need for educational interventions for families following ABI that involves more then simple information giving, such as formalized programmes of service aimed at family members or group educational sessions and individual counselling. Increasingly evidence indicates the possibilities of

decreasing stress and depression in family caregivers, and increasing their belief in their care giving work by educational interventions (Hepburn *et al.*, 2001; Gerdner *et al.*, 2002). However, there must be several opportunities for educational support over the long-term and as and when needed, rather than just in the immediate post-injury period, in addition these interventions need to consider current health technologies e.g., via the web, computer, phone or TV.

Given that shorter hospital admissions and the resultant pressure that this has on primary care provision, coupled with demands on formal and informal health and social services are increasing as the population ages, families are expected to assume major responsibility of care for their family member at home. The findings of this study resemble the findings of Boland and Sims (1996), which indicated that care giving was a solitary and stressful journey. What is required is clear information coupled with specialist knowledge of ABI. Families and carers need help in understanding the cognitive, emotional and behavioural that they will experience in the ABI survivor and arguably nurses are best placed to be instrumental in providing this support. More information is required how best to recognize and meet their needs in a way that enhances the well-being of both the injured and the non-injured, and predict those carers/families who are at more risk than others.

A brain injury specialist or similar person should act as a person of contact for the carers and families of ABI persons who have concern or need help. Within the regional neuroscience centre, which was the focus for recruiting participants into this study, the neurorehabilitation specialist nurse has been kept abreast of the findings of this research and I have actively contributed to the NHS trust policy group responsible for revising and updating the policy on the management of challenging behaviour and cognitively impairment in the neuroscience patient. In recognition of the need for patient information leaflets, this group has produced several patient and carer information leaflets related to this policy.

If the passage of time fails to emolliate the sense of uncertainty and loss for these carers, then the future healthcare needs to address this issue with the appropriate strategies to support these carers in coping with the uncertainty and loss. Penrod

(2007) explored the concept of living with uncertainty amongst caregivers and asserts that a sense of confidence and control in a life situation were primary essences that determine the nature of the experience of uncertainty. Penrod (2007) further argues that strategies such as information giving were the most useful in influencing the sense of confidence in a life situation.

6.5 Implications for healthcare organisations

The provision of healthcare in the UK remains disparate as discussed in the opening chapter of this thesis. If the needs and support for family's and the ABI persons are to be met then service provision nationally needs to reflect this. In the recent review of the NHS, Lord Darzi (Darzi, 2008) advocates that all those with long-term conditions should have a personal care plan and states:

> "Personal care also considers the need of the patient within the context of their support network, including carers, family and employer." (p.21)

These plans however, are dependent on partnership working between healthcare professionals and service users and the availability of appropriate and timely services. This will however, require commissioners and healthcare policy makers to ensure that the resources are allocated so that existing inequalities are addressed and families and carers are made aware of resources and systems already in place. Ensuring that individuals whose role is to interface with the carers, provide referral advice to families and information on how families can best respond to the behaviours of the person with ABI is critical. This may be provided by a variety of professionals for example neuropsychologist or specialist nurse. Whilst some argue that healthcare professional working with ABI need to acquire additional skills and competencies others argue for the increasing integration of specialist roles such as family therapist or rehabilitation counsellors into neurorehabilitation services (Bishop *et al.*, 2006). Despite the need for family support interventions after ABI, there is no strong research evidence supporting any specific intervention method for family caregivers of individuals with ABI. Commissioning research that looks at caregiver intervention effectiveness and models of family care are a priority and prerequisite for any change.

6.6 Limitations and strengths of the study

Several methodological aspects of this study warrant consideration. Firstly as the participants were drawn primarily from a White European background this raises the issue of representation of families from different racial, ethnic and cultural backgrounds. Although ABI is not race discriminating, the exclusion of non-English speaking participants is, however, subjecting the study to a sampling bias and a limitation in this study. Other family groups who spoke English were not actively excluded from the study; they just did not present themselves at the time of data collection. Another limitation concerns the accuracy of recalling the events and feelings at the time of what happened, in some cases several months, even years after the event. Whether this would have altered the telling of the participants' stories was difficult to ascertain. I acknowledge, however, that the thoughts and feelings expressed are not just a recount of facts but are also how the carers have experienced it, and interpreted and constructed meaning in their world.

Whilst the focus of this study was on family members, the resultant participants were primary caregivers. This reflects the current focus on primary caregivers in the research literature, not only in the field of neuroscience but in other areas such as dementia care. The focus of this area of research should be expanded beyond the primary caregiver to include the effect of care giving on the whole family and their networks to provide a more holistic picture.

Other limitations of this study are those that are inherent to qualitative research methodology in general. Qualitative research, because of its focus on developing a thorough understanding of the experience of a small group of participants, does not allow researchers to make generalizations about the findings of their research (Lincoln & Guba, 1985). This may be seen as a limitation. From the outset of this thesis, the decision was made to prioritize the opportunity to gain a more detailed understanding of the carers over the importance of generalizability. It is contested that qualitative research cannot make generalizations, and indeed this may be difficult for two fundamental reasons; firstly because human nature is so deeply complex, and secondly no two family members share the same experience of challenging behaviour, however, this research has demonstrated consistency of

themes and experiences. The aim, however, of phenomenology is to reveal the specific and the concrete experiences, it is not the notion of sharing or differences in the experienced that is critical, but the essence of the meaning, that is. I believe the essences described do have specificity; it can be transferred to other contexts that are similar to the context described in this study.

Another limitation inherent in qualitative research methodologies is that of my biases and how they may have influenced the findings of the research. The searching and reviewing of the literature on the phenomena prior to the data collection may have subjected the data collection but this may have been balanced by the openness and reviewing of new literature as previously discussed in Chapter 2. I may have also influenced what and how I collected the data, thus limiting the potential to discover new data and knowledge. Furthermore the face-to-face interaction that took place during the interview is arguably not the same as what appeared in the transcription. I acknowledge that I may not have been able to achieve complete objectivity in recounting the carer's experience. But I have attempted to own my perspectives and biases by including my personal story in the introductory chapter and my personal reflections throughout this thesis to allow readers to understand my assumptions and biases. The 'bracketing' process described in Chapter 3 also fulfilled this purpose.

6.7 Suggestions for future research

This study makes a contribution to our understanding of the experience of challenging behaviour following acquired brain injury, and supports the need for continued research in this area. Some of the findings in this study may not have been replicated in previous research and thus can be used to supplement the prior construct of challenging behaviour, which is in accordance with the descriptive phenomenological approach. It opens the window into the worlds of others, and provides a different vivid glimpse of reality of the families, although this may be limited when viewed alone. This research I believe has brought us closer to the truth, revealing human frailty and vulnerability and aids in the refinement of future questions so that we can deepen our understanding of the complexities of human

nature. I believe that the positive aspects to be gained from such tragedies as ABI and the neuropsychological sequelae can help further our understanding of the coping and adaptation to these stressors. Further research studies should examine the positive impact of the care giving which may ameliorate their stresses of care giving, and help maintain their quality of life. In addition research that explores the factors that influence the level of loss and grief that these carers experience may be useful. Furthermore, longitudinal research might best illuminate the ongoing nature of the grief process for family members and provide further information regarding how best to manage it. Nearly 10 years ago Perlesz et al. (1999) argued for more family outcome research to develop a theoretical framework to understand family member's psychosocial outcome following TBI with an emphasis on family resilience. It would appear that this still needs addressing.

The challenge is for us is to listen and capture these stories and then use this knowledge to change practice. What is required is further research of this nature in the area, to refine the research in pursuit of our understanding, to explore continual themes and patterns or newly emergent trends thus providing a fuller picture of the experiences of the phenomena. Extended interviews using a variety of modalities such as the telephone and the use of carers' journaling activities could create a more complete picture of the carers' experiences. Given the evolving nature of the cognitive, emotional and behavioural sequelae following ABI these experiences may change and require constantly modified strategies, a longitudinal study following carers over a period of time may address the major gap in the literature to date on the impact of time on the carers' experiences. Furthermore this period needs to include the family's experiences from the outset of the injury thus providing insight throughout the entire trajectory.

Family care giving has clearly been identified within this study as women's work, whether the study if replicated with fathers or male partners would reveal similar lived-experience descriptions is unknown. Although there is work to suggest that there may be gender difference in their experiences. For example, a study of dementia caregivers in the UK (n = 48) showed life satisfaction was lower among the care giving wives than the care giving husbands (Collins and Jones, 1997).

Older male caregivers in Ekwall and Hallberg (2007) study were also more satisfied with their situation than older female caregivers. Despite this, fathers are under-represented and it is often assumed that mothers can represent families' views. A more complete picture of the younger ABI could be offered by interviewing parents of the injured together. This may not only increase the uptake of men as participants and be less disruptive to the family, but one parent's account may stimulate recall in the other and thus improve trustworthiness of the data. Further research is required that takes into account not only the experiences of primary caregivers, but also the experiences of siblings, fathers and husbands, extended family members, and the care recipient. The results of such research would provide a more detailed account of the preventative, therapeutic and rehabilitative interventions required to minimize the burden on the individual, their families and on society as whole.

6.8 Conclusion

The need to travel down the phenomenological path has proved to be troublesome, my reading has led be down several philosophical pathways that have created doubt, confusion and the loss of confidence in my abilities as a researcher. Over the course of this study I have considered the differing concepts within phenomenology, grappling with the idea of bracketing. This state of anguish has lessened as time has progressed in this study. I now realise that my dissonance is not going to resolve in this study, that my knowledge and understanding will evolve and develop as I develop my research capabilities.

I have attempted to understand the real world of individuals and their families in the face of challenging behaviour and heard their 'voices' through semi-structured, in-depth interviews face-to-face. The underpinning philosophical approach to inquire and capture the carers lived experiences of challenging behaviour following ABI, then phenomenological thinking was the right choice. As Boss (2006) articulates, randomised samples of distressed family members may not give us the answers on how best to provide care and interventions for a particular family. This I believe comes from a perspective that attempts to understand the meaning from

the whole family world. In this study five female carers were the source of knowing, four spouses and one mother. All were recruited from a purposeful sample from a regional neuroscience centre in the North of England. The data collected, by listening and questioning, consisted of verbatim typed transcripts, field notes and demographic information. Descriptive statements of the five participants' experiences were developed and presented. Research credibility was addressed through the use of peer debriefing, prolonged immersion in the data and reflection, thick description and an audit trail. This study was designed to elicit comprehensive descriptions of the experience of challenging behaviour using Giorgi and Colaizzi's (1978) phenomenological approach. This revealed six themes to describe the lived experience and included, experienced emotions, loss, future concerns, family functioning, loneliness and adapting and coping. These themes answer the research question and provide a rich description of challenging behaviour following acquired brain injury. Some of the findings in this study are supported in the research and literature, although not all are to be found following the experience of the phenomenon in question.

The findings from this research highlight the need for a change in nurse education that includes family assessment and family focused care along with understanding of the disease processes and pursuit of advanced treatment and management options. Meeting the needs of families and carers requires an understanding of their adjustment process. Understanding this may help healthcare practitioners to implement appropriate strategies that met their individual needs.

Educating those who are in direct contact with the injured and their families, focusing on working in partnership with the families in the planning and delivery of care, has the potential to make a real difference to the family's health and well-being. Shifting the focus of care delivery from the neurological disorders of the patient to one that includes the patient and their family requires a change. I believe the newly developed neuroscience post qualifying modules will contribute to this process. However, at the time of writing this doctorate thesis this is too early to ascertain.

This study found that the participants found the impact of challenging behaviour on families was profound and that managing this impact was complex and involved a variety of strategies. Having a family members sustain an ABI which results in cognitive, emotional and behavioural sequelae was a life-altering event for the ABI families. This unexpected tragedy was associated with changes that infiltrated every aspect if their lives and affords an extreme example of what Denzin's (1989) refers to as an 'epiphany', described as:

"...interactional moments and experiences which leave marks on people's lives" (p.70).

Denzin (1989) describes four types of 'epiphanies', the major, the cumulative, the illuminative and the relived. It would seem that the carers in this research have been confronted and experienced a major 'epiphany', the suddenness of their family members' brain injury, which has shattered their lives making it never the same again. But, then they endure the challenging behaviours subsequent to the injury, the effect of which has been both positive and negative and enduring. Arguably according to Denzin (1989) they also suffer 'cumulative' epiphanies as a result of a series of events that build up over a period of time for one carer these events were over 10 years in duration. These experiences, Denzin (1989) notes, always involve painful emotions and "they are relived and re-experienced in the stories person tell about what has happened to them" (p.71). In essence the families have experienced a profound sense of loss, challenged their sense of security and safety, and created a sense of uncertainty and unpredictability about their future, and the future of the ABI person.

Despite the limitations highlighted the findings nonetheless has generated a rich source of narratives identifying some experiences already highlighted in previous literature. I have also provided new understanding of the whole experience, enriching our understanding of how families experience challenging behaviour following acquired brain injury. Further research that deploys both quantitative and qualitative research methods would broaden our understanding and meaning.

Rather like the carers in this research I too have had, 'epiphanies', liminal moments where transformation has been sudden and dramatic. I am not the same person as when I started this doctoral journey. I also believe that a gradual transformation has also occurred in this journey from confusion, understanding emotions, to understanding 'self' and 'flourishing'. However, both kinds of transformation are neither a simple nor a smooth process of self-actualisation, but are ridden with elements of conflict, self-doubt and anxiety. For I understand now that the:

> "...act of learning can be called transformative only if it involves a fundamental questioning or reordering of how one thinks or acts..." (Brookfield, 2000: p.139).

This programme of study culminating in this thesis has been a developmental journey both professionally and personally. It has not only expanded my knowledge and understanding of acquired brain injury, its cognitive behavioural and emotional sequelae and its impact on the family, but also and perhaps more importantly facilitated my personal journey of becoming a critical, reflective and confident professional. I have developed my ability to be more divergent in my thinking looking outside the boundaries of traditional practice and those that define the problem. I understand now that to defer judgement on the value of any thoughts until enough of them have been generated is a mode of thought essential for innovative practice to thrive. My aim at the outset of this professional doctoral journal was to make an impact on practice. I hoped to achieve this via several means; through my changed thinking, developing leading edge practice and turning theory into practice, and by making it accessible to others through education and leadership. I see my journey as a commitment to reshaping neuroscience nursing, nursing as a profession and communities of practice which I am a part of, for example membership of a Guideline Development Group (GDG) for National Institute for Health and Clinical Excellence (NICE).

I also believed that challenging one's own practice is part of a nurse's professional responsibility to provide the best care one can. I am certainly more questioning. I no longer take for granted assumptions and increasingly find myself challenging

healthcare policy and decisions as my presence grows in the field of neuroscience practice.

At best, I believe I have not only brought us closer to illuminating the phenomena in question by providing a clear, accurate and vivid representation of the carer's experience but, advanced my own knowledge as a professional and researcher. As Viktor Frankl articulates, human beings not only "*enrich the world by our actions*" alone, but can also "*enrich ourselves by our experiences.*" (Frankl, 1965, p. 59) This, however, can not only be judged by me, but by other readers.

---oOo---

The literature review presented in Chapter 2 involved searching for relevant literature from the following sources and subsequent literature searching in this thesis also employed similar methods:

- Review of key documents
- Electronic Database Search
- Manual Journal searching

Key documents

The following areas were searched for key documents, these were selected for their significance internationally, nationally and locally to the area of neuroscience and the sub-speciality of acquired brain injury and traumatic brain injury and rehabilitation.

- Government reports
  - National Service Framework for Long-term conditions Department of Health (2004)
  - National Specialised Services Definition Set (2nd Edition) Department of Health (2001)
  - National Institute for Clinical Excellence (NICE) - Head injury Guidelines (2006)

- Systematic reviews
  - Cochrane Database of Systematic Reviews (CDSR)
  - Cochrane - Database for Abstracts and Reviews (DARE)
  - York Centre for Reviews and Dissemination –'Carers' experiences of providing care for people with long term conditions (2003) Social Policy Research Unit, University of York

- House of Commons Reports- Select Committee on Health- Minutes of Evidence Memorandum by Headway (H29) March 2001

- National & International Guidance & Policy
  - Royal College of Physicians and British Society of Rehabilitation Medicine *Rehabilitation following acquired brain injury: National Clinical Guidelines* (Turner-Stokes L, Eds.) London (2003)
  - Greater Manchester Traumatic Brain Injury Audit Group *Head Injury Management in Adults in Greater Manchester* (January 2006)
  - Scottish Intercollegiate Guidelines Network (SIGN) A National Clinical Guideline *Early Management of Patients with a Head Injury* No. 46 (2000)
  - New Zealand Guideline Group *Traumatic Brain Injury: Diagnosis, Acute Management and Rehabilitation* (2006)
  - U.S. Department of Health and Human Services, Center for Disease Control and Prevention, Division of Acute Care, Rehabilitation Research, and Disability Prevention- *Guidelines for Surveillance of CNS Injury* USA

- Research - National Research Register 2000-2005 Neurological research based research projects

Electronic Database Search

The data bases were selected for relevance to the subject and included the following:
- Applied Social Sciences Index & Abstracts (CSA)
- MEDLINE
- CINAHL (Allied Health and Nursing)
- Sociological abstracts (CSA)
- PsycINFO
- OVID
- BNI (British Nursing Index)
- Atypon-link
- Swetwise
- PoQUEST
- Evidence-Based Summaries: Bandolier, Clinical Evidence

General search engines on the World Wide Web i.e. Google was also used putting in key words from the text i.e. ABI, TBI, Head Injury, family experience, carers

Search strategy included the use of key words and included abstracts and full text journals. This included the following terms:

Table 1 example of the search terms used in the literature review

Acquired brain injury Traumatic brain injury Head trauma Head Injury	AND	behaviour OR challenging carers experience
Acquired brain injury Traumatic brain Injury Brain injury Head Trauma Head Injury	AND	family experience families experience

Manual searching the literature

Hand searching key journals these included the following:
> Brain Injury
> British Journal of Neuroscience Nursing
> Journal of Neuroscience Nursing
> AXONE (Canadian Journal of Neuroscience Nursing)

Grey Literature: Royal College of Nursing, London library catalogue for any relevant thesis/ dissertations

Appendix B
Relationships; marital and siblings

Research on families following acquired brain injury

Primary Investigator(s)	sample nationality	family participants	family assessment method
Panting & Merry (1972)	British (n = 30)	wives and mothers	Interviews & questionnaires
Thomsen (1974)	Danish (n = 50)	relatives	Interviews
Rosenbaum & Najenson (1976)	Israeli (n = 10)	wives	Authors questionnaire
Oddy et al (1978)	British (n = 54)	spouses, parent	Wakefield Scale & Katz Adjustment Scale
Maus-Clum & Ryan (1981)	USA (n = 54)	wives & mothers	Authors questionnaire
Livingston et al (1985)	Scottish (n = 41)	wives, mothers & daughters (female relatives)	Leeds depression scale, General health questionnaire, Social Adjustment Scale,
Brooks et al (1986)	Scottish (n = 42)	spouse, parent & others	Interviews using questionnaires
Peters et al (1990)	USA (n = 55)	wives	Dyadic adjustment scale, Personal Assessment of Intimacy In relationship, Katz adjustment scale, Eysenck adult personality questionnaire, Family crisis oriented personal evaluation scales
Orsillo et al (1993)	USA (n = 13)	siblings	McMaster Family Assessment Device, The Problem Solving Inventory Dysfunctional Attitude Scale, Rational Behaviour Inventory, Attributional Style Questionnaire, Revised Ways of Coping Checklist & Brief symptom Inventory
Carson (1993)	USA (n = 20)	parents & offspring	Interviews (Grounded theory approach)
Allen et al (1994)	USA (n = 131)	spouses and parents	Questionnaire in resources and stress
Wood & Yurdakul (1997)	England (n = 131)	spouses and partners	Clinical data & postal survey
Gosling & Oddy (1999)	England (n = 18)	female partners	Interviews; General Health Questionnaire, Golombok & Rust Inventory
Gills & Wells (2000)	Canadian (n = 9)	siblings	Interviews (descriptive qualitative design)
Anderson et al (2004)	Australian (n = 64)	spouse	Family Assessment Device, Problem Checklist of the General Health & History Questionnaire & Brief Symptom Inventory
Kao & Stuifbergen (2004)	USA (n = 11)	mothers	Interviews (Phenomenological approach)
Katz et al (2005)	Israeli (n = 44)	wives	Relative Burden Scale & Ways of Coping Questionnaire
Wongvatunyu & Porter (2005)	USA (n = 7)	parents	Interviews (phenomenological approach)

M.E. Braine 2007

Family roles and functioning

Primary Investigator(s)	sample nationality	family participants	family assessment method
Kreutzer et al (1994)	USA (n = 62)	parents, spouse	Brief Symptom Inventory, Family Assessment Device
Johnson (1995)	USA (n= 7)	parents & children	Unstructured interviews using a phenomenological approach
Leathem et al (1996)	New Zealand (n = 29)	parents & partners	Arizona Social Support Interview Schedule, Hassles & Uplifts Scale & Health Questions
Douglas & Spellacy (1996)	Australian (n = 30)	wives, mothers, husbands & fathers	a variety of standardised measures
Frosch et al (1997)	USA (n = 155)	mother & primary caregivers	Authors questionnaire, Part One & Two of the Role Checklist
Gan & Schuller (2002)	Canadian (n = 92)	spouse, parent, siblings son/daughter grandparent	Family Assessment Measure -III
Anderson et al (2004)	Australian (n = 64)	spouse	Family Assessment Device, Problem Checklist of the General Health & History Questionnaire, & Brief Symptom Inventory
Nabors et al (2002)	USA (n = 45)	parent, spouse, adult child, others	Head injury family interview, Family Needs Questionnaire, Family Assessment Device, Non-support scale of the Personality Assessment Inventory
Duff (2006)	Canadian (n = 25)	parent, son/daughter sibling, grandchild, aunt daughter-in-law	Interviews (Grounded theory approach)

Family/ carer experience

Primary Investigator(s)	sample nationality	family participants	family assessment method
Johnson (1995)	USA (n= 7)	parents & children	Unstructured interviews using a phenomenological approach
Carson (1993)	USA (n = 20)	parents & offspring	Interviews (Grounded theory approach)
Conneeley (2002)	English (n = 18)	spouse, parent	Interviews, observations & written material (qualitative exploratory approach)
Lefebvre et al (2005)	Canadian (n = 14)	parent, spouse, sibling & others	Interviews

M.E. Braine 2007

Family needs; unmet needs, information, support

Primary Investigator(s)	sample nationality	family participants	family assessment method
Acorn (1993)	Canadian (n = 42)	mothers, spouse, father and sibling	authors questionnaire (postal survey approach)
Serio et al (1995)	USA (n = 180)	spouses, partners, siblings parents, close friends, adult-children	Neurobehavioural Functioning Inventory & Family Needs Questionnaire
Junqué et al (1997)	Spanish (n = 65)	parent, spouse, sibling children, other	Authors questionnaire
Stebbins & Leung (1998)	Australian (n = 29)	parents, wives, husbands, other relatives	Family Needs Questionnaire
Moules & Chandler (1999)	England (n = 22)	spouses and parents	Schedule of Evaluation of Individual Quality of Life Golombok & Rust Inventory of Marital State, General Health Questionnaire & Family Needs Questionnaire
Morris et al (2001)	Scottish (n = 34)	parents/ partners siblings	General Health Questionnaire, Hospital Anxiety and Depression Scale Symptom Checklist & Booklet Questionnaire
Kolakowsky- Hayner et al (2001)	USA (n = 57)	parent, spouse, sibling children, other	Family Needs Questionnaire
Man (2002)	Chinese (n = 50)	wife, parent, husband child, cousin sister	Empowerment Questionnaire, General Health Questionnaire (4 participants under went long interviews)
Leith et al (2004)	USA (n = 21)	spouse & family members	Focus groups interviews (semi-structured)
Murray et al (2006)	Canadian (n = 66)	parent, spouse, other relative, children	Family Needs Questionnaire
McGill et al (2006)	English (n = 66)	parents	Postal questionnaire

M.E. Braine 2007

Health of family members/carers; stress/burden, distress, depression, anxiety

Primary Investigator(s)	sample nationality	family participants	family assessment method
Oddy et al (1978)	British (n = 54)	spouses, parent	Wakefield scale & Katz adjustment scale
Allen et al (1994)	USA (n = 131)	spouses and parents	Questionnaire in resources and stress: Short Form, Cognitive Disability & Social Aggression Scale and Functional Ability
Kreutzer et al (1994)	USA (n = 62)	parents, spouse	Brief Symptom Inventory, Family Assessment Device
Leathem et al (1996)	New Zealand (n = 29)	parents & partners	Arizona Social Support Interview Schedule, Hassles & Uplifts Scale and Health Questions
Sander et al (1997)	USA (n = 69)	parents, spouse, friends & relatives	Social Support questionnaire Disability Rating Scale, General Health Questionnaire, Ways of Coping Questionnaire & Subject Burden Measure
Gillen et al (1998)	USA (n = 59)	mother, spouses	Disability Rating Scale, Head Injury changes in functioning scale, SCL 90-R and the Global Severity Index
Knight et al (1998)	New Zealand (n = 52)	parents, spouses other relatives	Care Burden Scale, Depression Scale, Symptom distress questionnaire and Social Support questionnaire
McPherson et al (2000)	New Zealand & Scottish (n = 70)	spouse, parents, sibling and children	Office of Population and census scale of disability, Short Form 36 Questionnaire, Caregiver Strain Index, Visual analogue scale
Connelly & O'Dowd (2001)	Ireland (n = 70)	spouse/partner, parent	General Health & History Questionnaire, Caregiver Strain Index, Perceived Stress Scale
Harris et al (2001)	New Zealand (n = 58)	parents, spouse/partners friends & others	Social Behaviour Assessment Schedule & Zung Self-rating Depression Scale
Morris et al (2001)	Scottish (n= 34) and	parents/ partners siblings	General Health Questionnaire, Hospital Anxiety and Depression Scale Symptom Checklist & Booklet Questionnaire
Boyle & Haines (2002)	Australian (n = 24)	parents & spouses	Profile of Mood States, Family Environment Scale
Nabors et al (2002)	USA (n = 45)	parent, spouse, adult child, others	Head injury family interview, Family Needs Questionnaire, Family Assessment Device, Non-support scale of the Personality Assessment Inventory

Dear.....

I am writing to you to ask for your support during my research project which intends to explore the impact of patients who display challenging behaviour following acquired brain injury on their families. I am currently employed at the University of Salford as a lecturer within the School of Nursing and hold an honorary contract with the trust. I also support the clinical areas within the Neuroscience Centre by acting as the Academic in Practice (AiP), providing the link with education and training in the University and auditing and reviewing the clinical areas in support of student nurse training.

I have recently received local Research Ethical Committee approval (LREC) and Salford Royal Hospital NHS Foundation Trust Research and Development office approval, along with permission from the Neuroscience Director James Leggate for this research to be carried out within the Greater Manchester Neuroscience Centre.

Although the literature offers considerable research on the family experiences and the impact of acquired brain injury, few have explored the experiences of challenging behaviour within the field of neurosciences. The purpose of this study is to describe the meaning of the experiences of challenging behaviour following traumatic brain injury in adult family members through in-depth interviews, and by understanding their meaning healthcare professionals can provide more appropriate care. This research is hoped to report themes of their experiences which can then inform future policy and practice and enhance care delivery to a under researched group within the field of neurosciences.

I hope that you will support this research by encouraging your staff to display the flyer that has been approved for recruiting potential participants into the research project within the Neuroscience clinical areas and for you staff to hand out the information sheets to potential participants whenever they feel it is appropriate.

Thank you for your careful consideration of this request.

Yours sincerely

Mary. E. Braine
Lecturer School of Nursing
University of Salford
Tel: 0161 295 6491
e mail: m.e.braine@salford.ac.uk

University of Salford
School of Nursing Faculty of Health and Social Care

Can you help?

I am conducting a Research Study in the Greater Manchester Neuroscience Centre, Salford Royal Hospitals NHS Trust to:

Explore family's experiences of patients who display challenging behaviour following acquired brain injury (e.g., subarachnoid haemorrhage, head injury, infection, brain tumour).

Purpose of the Research Study
The aim of the study is to gain a better understanding of the family's experience of challenging behaviour and to identify common themes that can inform future care delivery for other of you and your family members.

Who is Eligible?
Participants must be:
- Aged over 18 years old
- Be a close family member i.e. mother, father, son, daughter, spouse, partner or close friend, extended family i.e. brother, sister or aunt, uncle
- Have experienced behaviour that has been challenging to you by your family member who has suffered brain injury
- Willing to share your experience and be able to participate in a verbal interview

What is involved?
If you are interested and eligible to participate in this research study, following some short questions about you, one or two face-to-face interviews by the researcher at a mutually agreed time and place will take place. Information gathered about you and during the interview is confidential and participants have the right to withdraw at any time. All risks, benefits, and requirements will be thoroughly explained prior to participation.

This study has been approved by the following: Local Research Ethics Committee (Wrightington, Wigan & Leigh), University of Salford's Research Governance and Ethics Committee and Salford Royal NHS Trust Research and Development Office.

Who do I contact?
For more information and a confidential discussion, please call
Mary Braine
School of Nursing, University of Salford
Telephone 0161 295 6491 e mail m.e.braine@salford.ac.uk

Flyer M.E.Braine 30/08/2006 Version 2

Information Sheet for Participation in a Research Study

School of Nursing, Faculty of Health and Social Care, University of Salford.

Study Title: Exploring the impact of patients who display challenging behaviour following acquired brain injury on their families.

Invitation to Participate

You have been chosen as a possible participant in this research study conducted by Mary Braine a Doctorate student at the School of Nursing, University of Salford. You are chosen because your family member has suffered an acquired brain injury and has been exhibiting challenging behaviour. This may have presented itself in a number of ways; this may include the following; being aggressive, agitated, feeling up and down emotionally, apathetic, impulsive, demonstrating frustration, lack of insight, poor judgement and reasoning skills and continually repeating themselves.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Purpose of the study

The purpose of this study is to explore your experiences as an immediate family member of a patient who has displayed challenging behaviour as a result of their acquired brain injury. This study is being carried out because there is very little evidence in this area and it is hoped that this study will inform future healthcare practice.

The study is anticipated to last approximately three years and is part of a doctorate programme of study being under taken through the University of Salford.

Confidentiality

All information, which is collected, about you during the course of the research will be kept strictly confidential and no personal identifying information will be disclosed. There will be no identifying names on the tapes, you will be identified by an Identification (ID) number and any information about you will have your name and address removed so that you cannot be recognised from it. The ID number will not be available to anyone accept the researcher. Information that is obtained from the interview(s) will be stored and secured in a locked file and only the researcher will have access to these records. The audio tapes of the interviews will be destroyed

once the study has been completed at the end of 2009. Any report that might be published will not include any information that will make it possible to identify you. A copy of the final report will be available in the University library following completion of the study.

The handling, processing, storage and destruction of your data will be compliant with the Data Protection Act (1998). The Act also gives you the right to see this information about you and have any mistakes corrected. You will be given an opportunity to review the information that you have provided during the interview.

Voluntary Participation

You do not have to be in this study if you do not want to. Your decision whether or not to participate will not influence the care that you or your family receive in the neuroscience centre. If you decide to take part you are still free to withdraw your consent and discontinue participation at any time without explanation at any point. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

If you decide later to withdraw from the study, you may also withdraw any information that has been collected about you. If you decide to withdraw the information about you will be destroyed.

What will happen to me if I take part?

Participation in the study will commence with a short series of questions to obtain demographic details, you will then be asked to take part in face-to-face interview which will be tape recorded interview(s) about your experiences of your family members' challenging behaviour. The interviews will be conducted at a mutually agreed time and venue in a confidential setting. The interviews are anticipated to last approximately 60- 90 minutes. You may be asked to participate in either one or two interviews depending upon your experiences. The interviews will be audio taped by the researcher and later transcribed for the purpose of analysing the data.

Any expenses incurred in attending the interview(s) will be reimbursed.

The risks and disadvantages of taking part

There are no risks associated with this study although you may experience discomfort associated with discussing certain aspects of your experience or when you are asked to recall your experiences. If you do experience distress during the interview then you have the right to stop the interview at any time and the researcher will make every effort to try to resolve your distress. If this is not resolved by the researcher then immediate support will be sought from the clinical staff within the Neuroscience Centre. In the event of issues arising that may need referral to appropriate staff it will be necessary to breach confidentially.

A follow-up telephone call after the interview will check that you have no lingering discomfort.

The benefits

You will receive no direct benefit from taking part in this study. There is the potential benefit of being able to share your experiences in confidence, and may be through expressing your feeling and experience it might be helpful in your understanding of the experience, although this is not the stated purpose of the research study.

The information that is collected during this study will give us a better understanding of families' experience of patients who following acquired brain injury experience challenging behaviour. It is hoped that your experience will contribute to improving the service provided to our patients and their families within the Neuroscience centre.

What if there is a problem?

If you have a compliant about your family's treatment by a member of staff (doctor, nurses etc.) then you should contact either the clinical staff concerned or the Hospital's Patient Advisory Liaison services (PALS).

If you experience any problems or you have any complaints about the way that you have been dealt with during this study then this will be addressed by the researcher who will do their best to address your concerns. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details of which can be obtained from the hospital.

If you have a concern or questions about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your queries.

What will happen to the results of the research study?

You will be given the opportunity to review your interviews transcripts (information) and you will be able to obtain results of the study upon request from the researcher. The overall result and study report will be made available to the University after completion in 2009. Results from the study are likely to be published in journals and at conferences but you will not be identifiable in any of the reports or publications.

Who has reviewed the study?

This study has been reviewed by the University of Salford's Research Governance and Ethics Committee and the Wrightington, Wigan & Leigh Local Research Ethics Committee and the Trust's Research and Development Office. This is to ensure that the research is carried out correctly.

Contact for Further Information

Take as long as you like before you make a decision. We will be happy to answer any question you have about this study. If you have further questions about this study, you can contact the researcher Mary Braine on telephone number 0161 295 6491, or the researchers' supervisor Karen Holland on telephone number 0161 295 3751.

Thank you for taking the time to read this information.

CONSENT FORM

School of Nursing Faculty of health and Social Care University of Salford

Study Title: Exploring the impact of patients who display challenging behaviour following acquired brain injury on their families.

Researcher: Mary Braine, Lecturer, School of Nursing, Faculty of Health and Social Care, University of Salford.

Before you agree to participate in this research study it is important that you read and understand the following information and ask any questions you may have before agreeing to be in the study.

Statement of Consent: **Please initial box**

I confirm that I have read and understand the information sheet dated August 2006 (Version 3) for the above study ☐

I have had the opportunity to consider the information, ask questions and I have received satisfactory answers to any questions I have asked ☐

I understand that I may withdraw my consent at any time and discontinue participation without penalty. ☐

I am willing agree to participate in the above study ☐

I am willing to have my interview recorded on tape (audio) and its contents along with any pen and paper notes taken being used for research purposes only ☐

I am willing to be contacted after the interview by the researcher by telephone ☐

....
Name of Participant   **Date**   **Signature**

....
     Researcher   **Date**   **Signature**

A copy of this Consent Form has been given to participant _____ (initialed by the researcher).

Contact Information
If you have any questions, please feel free to contact me I will be happy to answer them.
Mary Braine Telephone 0161 295 6491 email m.e.braine@salford.ac.uk
School of Nursing, Faculty of Health and Social Care, University of Salford.
Or you may contact my Supervisor Karen Holland Professorial Fellow, School of Nursing, University of Salford Telephone 0161 295 3751

Action to reduce the participants' risk

If the participant appears stressed during the interview then the, the interviewer will:

- Ensure vigilance in anticipating problems by assessing a whole range of the participants responses i.e. non-verbal and verbal (Kavanaugh and Ayres, 1998)
- Stop the interview and offer the participant the opportunity to take a breaks or postponing part or all of the interview
- Offer emotional support, such as attending listening and empathising
- If necessary, with the participants permission arrange referral(s) to the most appropriate health professional for support and help
- Debrief after the interview i.e. remain with the participant after the interview, not leaving once the interview has finished to allow the participants to gain closure

The researcher will make contact with the participants (i.e. telephone call) after the interview to determine if there are any distressing affects lingering from the interview. Referring to appropriate professionals means breaching confidentiality not only does the need for additional help need to be identified but the appropriate personal be contacted for follow-up help.

Action to reduce the researchers' risk

When visiting a participant in their home the following details will be left with a nominated colleague:

- Stating clearly the address and telephone contact for where the interview will take place
- Stating the time of the appointment, when you expect the visit to be completed and when to expect you back in the office or the time you expect to contact your nominated colleague to let them know that your visit is safely completed
- Given details of who the nominated person is to contact in the event of the researcher failing to contact them at the agreed time, ensuring that the nominated colleague is contactable by telephone for the duration of the interview
- Details of the make, model, colour and registration of the car I will be driving
- Stating the researchers contact detail i.e. mobile telephone and leaving it switched on during the interview

Appendix G: **Protocol to reduce the researcher and participant risk(s)**

General personal safety actions

- Not carrying large amounts of money or valuables on person
- Try to arrange home visits during daylight hours whenever possible
- Obtaining as much information about where you are visiting and how many people will be there before the visit.
- I will not enter someone's home if:
    - I do not feel comfortable or safe
    - If the person that I have arranged to see is not there
    - If during the interview I felt uncomfortable a prepared exit excuse will be used to facilitate departure
- The interview will not be undertaken under the following conditions:
    - If I feel uncomfortable whilst in the participants home
    - If asked to undertake the interview in the bedroom
    - If the participant is under the influence of alcohol or drug

University of Salford
School of Nursing, Faculty of Health and Social Care

Socio-Demographic Details

Interview number: Assigned code:

Date: Location of interview:

Name of participant being interviewed:

Relationship to the ABI person: Are they the primary caregiver:

Address:

Date of birth of client/patient: Ethnicity:

Gender of the person injured: Date of injury occurred:

Cause of injury:

Nature of the injury:

GP name and details:

Field Notes

Participant code:

Interview date: **Start Time:**   **Finish Time:**

Observational Notes (what was observed through watching and listening. The who, what, when, where and how)

Location of the interview:

People Present:

Description of the Environment:

Non Verbal behaviour:

Theoretical Notes (thinking about what has been experienced in an attempt to derive meaning, goes beyond the facts)

Content of the interview:

Analysis: hunches emerging patterns

Methodological notes (observational notes on the researcher themselves and upon the methodological process itself)

Researchers

Process

Technical Problems:

Analytical Memos (summary notes, progress, reviews etc)

Adapted from Morse and Field (1996) and Schatzman and Strauss (1973)

Carer -participant 1

Carer 1 is a Caucasian mother living in a semi-detached house. She is widowed, her husband was killed tragically some years ago and she has two children. In articulating her experience she described having no immediate family that she could talk to, her parents were no longer alive and since her mother's death had fallen out with her siblings. On her husband's side of the family there were no remaining family members alive.

Her eldest son lived away from home, but within the local area, with his partner. At the time of the interview they were expecting their first child. Her youngest son at the age of sixteen was a belted front seat passenger in his friend's car, when the car crashed. The circumstances of the accident are unclear due to the carer's son being found unconscious at the scene of the accident, and her son's friend was found dead. Her son's friend was uninsured to drive the car and he did not have a licence to drive. The incident (case), at the time of the interview, had yet to go to court. The carer's son was taken to the nearest intensive care unit where his severe traumatic brain injury was treated and managed. He was then later transferred to a standard care bed in the same hospital. He was eventually discharged home after receiving eight months of inpatient care. Towards the end of his inpatient care this involved being at home during the weekend. Few adaptations have been implemented to support the carers' son being managed at home; at the time of the interview she was awaiting a decision on an extension to the house to provide more room for him.

Carer-participant 2

Carer 2 is a Caucasian wife living in a semi-detached house with two children. At the time of interview both were living at home the eldest offspring was twenty years old. The carers' husband worked as a Health and Safety Officer prior to his haemorrhage and spent most of his spare time in the local public house. He drank heavily most nights. Whilst out drinking one night he suffered a subarachnoid haemorrhage. He was taken to a regional neuroscience centre were he was found to have bleed from a cerebral aneurysm; this was treated radiologically with a coiling of the aneurysm. He was treated and managed initially in the intensive care unit, and then later transferred to the neurosurgical wards. He received rehabilitation in the regional neuroscience acute rehabilitation centre and was then discharged home. The carer's husband had not worked since his haemorrhage and the carer was not working at the time of the interview.

Carer-participant 3

Carer 3 is a Caucasian wife, living in a semi-detached house with no children. The carer and her husband married late in life, and for her husband this was his second marriage, his previous wife left him. The carers' husband suffered a subarachnoid haemorrhage over ten years ago whilst they were in London. He was taken to one of London's neuroscience centres for treatment and management. His haemorrhage was found to be aneurysmal which was surgically treated with a clipping of the ruptured aneurysm via a craniotomy. After several

months he was transferred to a private neurorehabilitation unit in the North of England, near to where they now live. After nearly 12 months of inpatient care the carer's husband was discharged home.

The carer's husband was a Pastor up until his haemorrhage, but due to his neurological deficits post injury he had to relinquish this role. Despite this though, at the time of the interview, it was revealed that he still delivered a sermon on occasions from heavily scripted notes. At the time of the interview the carer was retired, but during her working life she had worked as a qualified nurse in her local district hospital. She had also worked as a district nurse for three years. The carer had only one sibling alive, a brother, but he suffers from Alzheimer's disease and was being cared for in a local nursing home. The carer's husband was one of three children but only one of his two sisters was still alive and he had lost contact with her.

Carer-participant 4

Carer 4 is an Asian wife who lived in a detached house with two children and her husband. Both children at the time of the interview were grown up men one was studying at University in the nearby vicinity the other was in full time employment. The carer's Asian husband suffered a subarchnoid haemorrhage and was taken to a regional neuroscience centre. Subsequent investigations revealed that he had bled from a ruptured cerebral aneurysm which was then treated surgically with a clipped of the aneurysm. He developed obstructive hydrocephalus post-operatively, which was treated with an insertion of a ventricular peritoneal shunt. The carer's husband following neurorehabilitation was discharged home with a package of care which involved carers during the time that she was at work and one evening a week.

The carer worked at a centre for deaf students with behavioural difficulties and has continued to work since her husband's brain injury. The carer's husband worked prior to his injury in finance, this included owning and letting a number of properties that they owned in the area.

Carer-participant 5

Carer 5 is a Caucasian wife living in a semi-detached house. The carer and her husband have been married for 10 years and have no children. The carers' Asian husband suffered a severe traumatic brain injury after being knocked off his bicycle. He was taken to a regional neuroscience centre where he was treated initially in the intensive care unit, transferred to the neurosurgical ward and then later to the neurorehabilitation unit before being discharged home after several months of treatment. The carer's mother in-law lived alone locally and spoke little English, and at the time of the interview was unwell. The carer had no nearby family and her friends lived several miles away, she was not working at the time of the interview. Her husband had one sibling, a sister but she did not live locally. Prior to his injury her husband had worked as a sales person in the cloth industry and at the time of the interview he was attempting to go back to work part-time.

Transcription Conventions

Sounds	
Thinking before someone speaks	*umm, ah*
I've never thought of that before	*hmph (huhm, ha, huh)*
Affirmative sounds	*yeah (yah, yea, ya) yup (yep)*
Listening and encouragement	*uhum, aha, uha, mmm*
Environmental sounds describe sound in brackets	*(road noise) , (knocking on door), (shouting) papers)*
Tone of speaker	
Louder	*Use CAPITAL LETTERS e.g., YES*
Stressed/emphasized word	*Use of Capital letter e.g., No*
Demonstrative expressions	
Words spoken while laughing or laughing	*(laughing)*
Laughter when both researcher and participant are laughing at something	*(laughter)*
Others	*(coughing), (sighing), etc*
Pauses short	Ellipsis ...
Pauses longer moments of silence	Ellipses ......
Self-talk or repeating what someone else has said use speech marks	"quotes"
Punctuation	
End of thought period	use of a full stop .
End of phrase / clause	use a comma ,
Thought (s) not completed	use an ellipsis ...
Thought that was not complete and ended the period	use of ellipsis and a full stop ....
Recording is unclear/ muffled and can't make out word(s) or phrase	*(indistinguishable word/ phrase) (unclear)*

References

Abel, M. H. (1998)
Interaction of humour and gender in modulating relationships between stress and outcome. *Journal of Psychology* 132, **3**: 267-276

Abel, M. H. (2002)
Humour, stress and coping strategies. *Humor: International Journal of Humor Studies* 15, **4**: 365-381

Acorn, S. and Roberts, E. (1992)
Head Injury: Impact on the Wives. *Journal of Neuroscience Nursing* 24, **6**: 324-328

Adams, K. B. (2008)
Specific effects of caring for a spouse with dementia: differences in depressive symptoms between caregiver and non-caregiver spouses. *International Psychogeriatrics* 20, **3**: 508-521

Albaugh, J. A. (2003)
Spirituality and life threatening illness: A Phenomenological Study. *Oncology Nursing Forum* 30, **4**: 592-598

Allen, K., Linn, R. T., Gutierrez, H. and Willer, B. S. (1994)
Family burden following traumatic brain injury. *Rehabilitation Psychology* 39, **1**: 29-48

Anderson, J. M. (1991)
The Phenomenological Perspective In: J.M. Morse (Eds.) *Qualitative nursing research: A contemporary dialogue.* Revised Edition, Newbury Park California: Sage. (pp. 25-39)

Anderson, M. I., Parmenter, T. R. and Mok, M. (2002)
The relationship between neurobehavioural problems of severe traumatic brain injury (TBI), family functioning and the psychological well-being of the spouse/caregiver: path model analysis. *Brain Injury* 19, **9**: 743-757

Andrews, K. (1992)
Provision of Services for severely Brain Damaged Patients in the United Kingdom. Royal Hospital & Home, Putney, London

Arthur, S. and Nazroo, J. (2003)
Designing Fieldwork Strategies and Material In: J. Ritchie and J. Lewis (Eds.) *Qualitative Research Practice: A Guide for Social Science Students and Researchers.* London: Sage Publications. (pp.109-137)

Asti, T., Kara, M., Ipek, G. and Erci, B. (2006)
The experiences of loneliness, depression, and social support of Turkish patients with continuous ambulatory peritoneal dialysis and their caregivers. *Journal of Clinical Nursing* 15: 490-497

Audit Commission (2006)
Health and social care review and studies programme. Millbank, London: Audit Commission.

Baguley, I. J., Cooper, J. and Felmingham, K. (2006)
Aggressive behaviour following traumatic brain injury: how common is common?
Journal of Head Trauma Rehabilitation 21, **1**: 45-56

Barnes, M., Eames, P., Evans, C. *et al* (1998)
Rehabilitation after traumatic brain injury: a working party report of the British Society of Rehabilitation Medicine, London, British Society of Rehabilitation Medicine.

Beck, C.T. (1992)
The lived experience of postpartum depression. *Nursing Research* **41**: 166-170

Beeson, R., Horton-Deutsch, S., Farran, C. and Neundorfer, M. (2000)
Loneliness and depression in caregivers of person with Alzheimer's disease or related disorders. *Issues in Mental Health Nursing* 21, **8**: 779-806

Beeson, R. A. (2003)
Loneliness and depression in spousal caregivers of those with Alzheimer's disease versus non-caregiving spouses. *Archives of Psychiatric Nursing* 17, **3**: 135-143

Bell, D. M. and Espie, C. A. (2002)
A preliminary investigation into staff satisfaction, and staff emotions and attitudes in a unit for men with learning difficulties and serious challenging behaviour. *British Journal of Learning Disabilities* **30**: 19-27

Bellert, J. L. (1989)
Humour: a therapeutic approach in oncology nursing. *Cancer Nursing* 12, **2**: 65-70

Berg-Weger, M., Rubio, D. M. and Tebb, S. S. (2001)
Strengths-Based Practice with Family Caregivers of the Chronically Ill: Qualitative Insights. *Families in Society: The Journal of Contemporary Humans Science* 82, **3**: 263- 272

Bethea, L. S., Travis, S. S. and Pecchioni, L. (2000)
Family Cargivers's Use of Humor in Conveying Information About Caring for Dependent Older Adults. *Health Communication* **12, 4**: 361-376

Beutler, I. F., Burr, W. R., Bahr, K. S. and Herrin, D. A. (1989)
The Family Realm: Theoretical Contributions for Understanding Its Uniqueness. *Journal of Marriage and the Family* 51, **3**: 805-816

Bishop, M., Degeneffe, C. E. and Mast, M. (2006)
Family needs after traumatic brain injury: Implications for Rehabilitation Counselling. *Australian Journal of Rehabilitation Counselling* 12, **2**: 73-87

Blake, H. and Lincoln, N. (2000)
Factors associated with strain in co-resident spouses of patients following stroke.
Clinical Rehabilitation 14, **3**: 307-314

Booth, T. and Booth, W. (1994)
The use of depth interviewing with vulnerable subjects: Lessons from a research study of parents with learning difficulties. *Social Science and Medicine* 29, **3**: 415-424

Boss, P. (1999)
Ambiguous Loss: Learning to live with unresolved grief. New York: Harvard University Press Ltd.

Boss, P. (2006)
Loss, trauma, and resilience. New York: W. W. Norton and Company.

Boss, P. and Couden, B. (2002)
Ambiguous loss from chronic physical illness: Clinical interventions with individuals, couples and families. *Journal of Clinical Psychology* 58, **11**: 1351-1360

Boland, D. L., Sims, S. L. (1996)
Family care giving at home as a solitary journey. *Image: Journal of Nursing Scholarship* 28, **1**: 55–58

Bourner, T., Bowden, R. and Laing, S. (2001)
Professional doctorates in England. *Studies in Higher Education* 26, **1**: 65-83

Boyd, C. O. (2001)
Phenomenology the method. In: Munhall, P. L. (ed.) *Nursing Research: A qualitative perspective*, 3rd Edition, Sudbury, M. A: Jones and Bartlett. (pp. 93-122)

Boyle, G. J. and Haines, S. (2002)
Severe traumatic brain injury: some effects on family caregivers` *Psychological Reports* **90**: 415-425

Braine, M. E. (2005a)
The management of challenging behaviour and cognitive impairment *British Journal of Neuroscience Nursing* 1, **2**: 67-74

Braine, M. E. (2005b)
The minimal and appropriate use of physical restraint in neuroscience nursing *British Journal of Neuroscience Nursing* 1, **4**: 177-184

Brockbank, A. and McGill, I. (1998)
Facilitating Reflective Learning in Higher Education Buckingham: Open University Press.

Bromley, J. and Emerson, E. (1995)
Beliefs and emotional reactions of care staff working with people with challenging behaviour. *European Journal of Social Psychology* **18**: 335-345

Brookfield, S. D. (2000)
Transformative Learning as Ideology Critique. In: J. Mezirow and Associates (Eds.)
Learning as transformation San Francisco: Jossey-Bass. (pp. 125-148)

Brooks, D. N. (1991)
The head-injured family. Journal of Clinical and Experimental Neuropsychology
13:155-188

Brooks, D. N. and Aughton, M. E. (1979)
Psychological consequences of blunt head injury. International Rehabilitation
Medicine 1: 160-165

Brooks, N., Campsie, L., Symington, C., Beattie, A. and McKinlay, W. (1986)
The five year outcome of severe blunt head injury. A relative` view. Journal of
Neurology, Neurosurgery, and Psychiatry 49: 764-770

Brooks, N., Campsie, L., Symington, C., Beattie, A. and McKinlay, W. (1987)
The effect of severe head injury on patient and relative within seven years of injury.
Journal of Head Trauma Rehabilitation. 2: 1-13

Brooks, N., Questad, K. A., Patterson, D. R. and Bashak, K. J. (1992)
Agitation and restlessness after closed head injury: a prospective study of 100
consecutive admissions. Archives of Physical Medicine and Rehabilitation 73: 320-
323

Brookes, M., MacMillan, R., Cully, S., Anderson, E., Murray, S., Mendelow A.D. and
Jennett, B. (1990)
Head injuries in accident and emergency departments. How different are children
from adults? Journal of Epidemiology and Community Health, 44: 147-151

Brown, S. J., Fann, J. R., and Grant, I. (1993)
Postconcussional Disorder: Time to acknowledge a common source of
neurobehavioral morbidity. Journal of Neuropsychia and Clinical Neurosciences,
6:15-22

Bruce, E. J. and Schultz, C. L. (2001)
Nonfinite Loss and Grief: A Psychoeducational Approach. Sydney: Brookes
Publishing Company.

Bruns, J. J. and Hauser, W. A. (2003)
The Epidemiology of Traumatic Brain Injury: A Review. Epilepsia 44, (Supp 10) 2-10

Buchanan, K. M., Elias, U. and Goplen, G. B. (2000)
Differing perspectives on outcome after subarachnoid haemorrhage: the patient, the
relative, the neurosurgeon. Neurosurgery 46, 4: 831-838

Buffum, M. D. and Brod, M. (1998)
Humor and Well-Being in Spouse Caregivers of Patients With Alzheimer's Disease.
Applied Nursing Research 11, 1: 12-18

Burgess, R. G. (1984)
In the field: An introduction to field research. London: Allen and Unwin.

Caelli, K. (2001)
Engaging in Phenomenology: Is It More of a Challenge Than It Needs to Be?
Qualitative Health Research 11, **2**: 273-281

Campbell, C. (1988)
Needs of relative and helpfulness of support groups in severe head injury.
Rehabilitation Nursing **13**: 320-325

Carson, P. (1993)
Investing in the comeback: Patient's experience following traumatic brain injury.
Journal of Neuroscience Nursing 25, **3**: 165-173

Carver, C. S., Scheier, M. F. and Weintraub, J. K. (1989)
Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology* 56, **2**: 267-283

Centers for Disease Control and Prevention (2001)
Traumatic Brain Injury in the United States. A Report to Congress. Atlanta, GA: Centers for Disease Control and Prevention.

Chapple, A. and Ziebland, S. (2004)
The Role of Humor for Men with Testicular Cancer. *Qualitative Health Research* 14, **8**: 1123-1137

Chambers, N. (1998)
'We have to put up with it--don't we?' The experience of being the registered nurse on duty, managing a violent incident involving an elderly patient: a phenomenological study. *Journal of Advanced Nursing* 27, **2**: 429-436

Chen, F. and Greenberg. J. S. (2004)
A Positive Aspect of Caregiving: The Influence of Social Support on Caregiving Gains for Family Members of Relatives with Schizophrenia. *Community Mental Health Journal 40*, **5**: 423-435

Chenitz, W. and Swansion, J. M. (1986)
The informal interview. In: From practice to grounded theory: Qualitative Research in Nursing Menlo Park Ca: Addison Wesley. (pp. 79-90)

Cohen, M. Z. (1987)
A historical overview of the phenomenological movement. *Image: Journal of Nursing Scholarship* 19, **1**: 31-34

Cohen, M. Z. and Omery, A. (1994)
Schools of phenomenology: Implications for research. In: J. Morse (Ed) *Critical issues in qualitative research methods* Thousand Oaks, CA: Sage. (pp. 136-156)

Colaizzi, P. (1978)
Psychological Research as the Phenomenologist Views It. In: R. S. Valle and M. King (Eds) *Existential Phenomenological Alternatives for Psychology*. Oxford: Oxford University Press. (pp. 48-71)

Colbourne, L. and Sque, M. (2005)
The culture of cancer and the therapeutic impact of qualitative interviews. *Journal of Nursing Research* 10, 5: 551-567

Collings, C. (2007)
That's Not My Child Anymore! Parental Grief after Acquired Brain Injury (ABI): Incidence, Nature and Longevity. *British Journal of Social Work*
Retrieved 25th June 2008 from the World Wide Web
http://bjsw.oxfordjournals.org/cgi/content/abstract/bcm055v1

Conneeley, A. L. (2002)
Social Integration following Traumatic Brain Injury and Rehabilitation. *The British Journal of Occupational Therapy 65*, 8: 356-362

Connolly, D. and O'Dowd, T. (2001)
The impact of the Different Disabilities arising from Head Injury on the Primary Caregiver. *British Journal of Occupational Therapy 64*, 1: 41-46

Coombs, U. E. (2007)
Spousal Caregiving for Stroke Survivors. *Journal of Neuroscience Nursing* 39, 2: 112-119

Corbin, J. and Morse, J. M. (2003)
The Unstructured Interactive Interview: Issues of Reciprocity and Risks When Dealing With Sensitive Topics. *Qualitative Inquiry* 9, 3: 335-354

Coward, D. D. (1990)
The lived experience of self- transcendence in women with advanced breast cancer *Nursing Quarterly* 3, 4:162-168

Creswell, J. W. (1998)
Qualitative Inquiry and Research Design: Choosing Among Five Traditions. Thousand Oaks CA: Sage Publications.

Cunningham, K., Brown, T. D., Gradwell, E. and Nee, P. A. (2000)
Airbag associated fatal head injury: case report and review of the literature on airbag injuries. *Journal of Emergency Medicine*. 17, 2: 139-142

Currid, T. J. (2008)
The lived experience and meaning of stress in acute mental health nurses *British Journal of Nursing* 17, 14: 880-884

Data Protection Act 1998 (1998)
The Data Protection Act 1998: protection and use of patient information. Stationary Office, London Information Commissioner, London: Stationery Office.

Darzi, A. (2008)
High Quality Healthcare for All: NHS Next Stage Review. Final Report
London: The Stationary Office

Deb, S. (1999)
ICD-10 codes detect only a proportion of all head injury admissions. *Brain Injury*, 13
5: 369-373

Denzin, N. K. (1989)
The interpretive biography. Qualitative Research Methods A Sage University Paper
Series 17. London: Thousand Oaks, Sage Publications

Denzin, N. K. (1997)
Interpretive ethnography: Ethnographic practices for the 21st century. Thousand
Oaks, CA: Sage.

Denzin, N.K. and Lincoln, Y.S. (Eds.) (2000)
Handbook of Qualitative Research 2nd Edition, Thousand Oaks, California: Sage
Publications.

Department of Health (2001a)
Neurological Condition Outline 1st January 2001 Department of Health Publication
ID=4009210 Retrieved March 2005 from the World Wide Web
www.dh.gov.uk/PublicationsAndStatistics

Department of Health (2001b)
National Specialised Services Definition Set (2nd Edition)
Complex Specialised Rehabilitation for Brain Injury and Complex Disability -
Definition No.7 (adult)

Department of Health (2004)
*Standards for Better Health –Annex A. National Standards, Local Action: Health and
Social Care Standards and Planning Framework 2005/06-2007/08* London:
Department of Health.

Department of Health (2005a)
National Service Framework for Long-term Conditions. London: Department of
Health.

Department of Health (2005b)
Research Governance for Health and Social Care. London: Department of Health

Department of Health (2006a)
Our health our care our say. Cmnd 6737. London: Department of Health.

Department of Health, (2006b)
Health reform in England: update and commissioning framework. London:

Derogatis, L. R. (1993)
BSI Brief Symptom Inventory Administration, Scoring, and Procedures Manual. 4th Edition, Minneapolis, MN: National Computer Systems.

Dewey, J. (1991)
How we think. Buffalo, New York: Promethesus Books.

Doka, K. J. (1989)
Disenfranchised grief. Recognising hidden sorrow. Lexington, MA: Lexington Books.

Doka, K. J. (2002)
Disenfranchised grief: New directions, challenges, and strategies for practice: Champaign, IL: Research Press.

Douglas, J. M. and Spellacy, F. J. (1996)
Indicators of long-term family functioning following severe traumatic brain injury in adults. *Brain Injury* 10, **11**: 819-839

Dreyfus, H. L. and Dreyfus, S. E. (1986)
Mind over machine. New York: Free Press.

Ducharme, J. M. (1999)
Subject Review: A conceptual model for treatment of externalising behaviours in acquired brain injury. *Brain Injury* 13, **9**: 645-668

Duff, D. (2006)
Family impact and influence following severe traumatic brain injury. *Axone* 27, **2**: 9-23

Dupuis, S. L. (2002)
Understanding ambiguous loss in the context of dementia care: Adult children's perspectives. *Journal of Gerontological Social Work* 37, **2**: 93-115

Easton, K. L., Fry McComish, J., and Greenberg, R. (2000)
Avoiding common pitfalls in qualitative data collection and transcription. *Qualitative Health Research.* **10**: 703-707

Ekwall, A. K., Sivberg, B. and Hallberg, I. R. (2005)
Loneliness as a predictor of quality of life among older caregivers. *Journal of Advanced Nursing* 49, **1**: 23-32l

Ekwall, A. K. and Hallberg, I. R. (2007)
The association between caregiving satisfaction, difficulties and coping among older family caregivers. *Journal of Clinical Nursing* **16**: 832-844

Emerson, E. (1995)
Challenging Behaviour. Analysis and intervention in people with learning difficulties. Cambridge: Cambridge University Press.

Engberg, A. W. and Teasdale, T. W. (2001)
Traumatic brain injury in Denmark 1979-1996. A national study of incidence and mortality. *European Journal of Epidemiology* 17, **5**: 437-442

Epstein, N. B., Baldwin, L. M. and Bishop, D. S. (1983)
The McMaster Family Assessment Device. *Journal of Marital and Family Therapy* **9**: 171-180

Ergh, T. C., Rapport, L. J., Coleman, R. D. and Hanks. R. A. (2002)
Predictors of Caregiver and Family Functioning Following Traumatic Brain Injury: Social Support Moderates Caregiver Distress. *Journal of Head Trauma Rehabilitation* 17, **2**: 155-174

Fain, J. A. (1999)
Reading, understanding, and applying nursing research. Philadelphia: F. A. Davis

Fasick, F. A. (1977-1978)
Some uses of untranscribed tape recordings in survey research. *Public Opinion Quarterly* 41, **4**: 549-552

Finlay, L. (1999)
Applying Phenomenology in Research: Problems, Principles and Practice. *British Journal of Occupational Therapy* 62, **7**: 299-306

Finlay, L. (2006)
Researching Health. Milton Keynes, Buckinghamshire: The Open University.

Florian, V. and Katz, S. (1991)
The other victims of traumatic brain injury: Consequences for family members. *Neuropsychology* **5**: 267-279

Fontana, A. and Frey, J. H. (2000)
The interview: from structured questions to negotiated text In: N. K. Denzin and Y. S Lincoln (Eds.) *Handbook of Qualitative Research* 2nd Edition, Thousand Oaks, California: Sage Publications. (pp. 645-672)

Fook, J. (1996)
The Reflective Researcher: Developing a Reflective Approach to Practice. In: *The Reflective Researcher: Social Workers' Theories of Practice Research* (Eds.) St. Leonards, Australia: Allen & Unwin. (pp. 1-8)

Forsberg-Wärleby, G., Möller, A. and Blomstrand, C. (2002)
Spouses of first-ever stroke patients: their view of the future during the first phase after stroke. *Clinical Rehabilitation* **16**: 506-514

Frankl, V. E. (1965)
The doctor and the Soul. From Psychotheraphy to Logotherapy. 2nd Edition, Harmondsworth Middlesex: Pelican Books.

Frankl, V. E. (1969)
The will to meaning: foundation and application of logotherapy. New York: World Publishing

Frankl, V. E. (1984)
Man's search for meaning. Revised and updated. New York: First Washington Square Press.

Freud, S. (1928)
Humour. *International Journal of Psychoanalysis* 9, **1**: 1-6

Frosch, S., Gruber, A., Jones, C., Myers, S., Noel. E., Westerlund. A. and Zavisin, T. (1997)
The long-term effects of traumatic brain injury on the roles of caregivers. *Brain Injury* 11, **12**: 891-906

Gan, C. and Schuller, R. (2002)
Family system outcome following acquired brain injury: clinical and research perspective. *Brain Injury* 16, **4**: 311-322

Gerdner, L., Buckwalter K. C. and Reed, D. (2002)
Impact of psychoeducational intervention on caregiver response to behavioural problems. *Nursing Research* 51, **6**: 363-374

Gervasio, A. H. and Kreutzer, J. (1997)
Kinship and Family Members' Psychological Distress after Traumatic Brain Injury: A Large Sample Study. *Journal of Head Trauma Rehabilitation.* 12, **3**: 14-26

Gillen, R., Tennen, H., Affleck, G. and Steinpreis, R. (1998)
Distress, depression symptom and depressive disorder among caregiver of patients with brain injury. *Journal of Head Trauma Rehabilitation* 13, **3**: 31-43

Gills, D. J. and Wells, D. L. (2000)
Forever different: Experiences of Living with a Sibling Who Has a Traumatic Brain Injury. *Rehabilitation Nursing* 25, **2**: 48-53

Giorgi, A. (1985)
Sketch of a psychological phenomenological method. In: A. Giorgi (Ed.) *Phenomenology and Psychological Research* Pittsburgh. PA: Duquesne University Press. (pp. 8-22)

Giorgi, A. (1997)
The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *Journal of Phenomenological Psychology,* **28**: 235-261

Giorgi, A. (2002)
The question of validity in qualitative research. *Journal of Phenomenological Psychology* **33**: 1-18

Giorgi, A. (2006)
Difficulties encountered in the application of the phenomenological method in the social sciences. *Análise Psicológica* 3, **XXIV**: 353-361

Giorgi, A. (2008)
Concerning a serious misunderstanding of the essence of the phenomenological method in psychology. *Journal of Phenomenological Psychology* 39, **1**: 35-58

Given, L. M. (2004)
Mini-disc recorder: A New Approach for Qualitative Interviewing. *International Journal of Qualitative Methods* 3, **2**: Article 5 Retrieved 3rd October 2006 from the World Wide Web http://www.ualberta.ca/~iiqm/backissues/3_2pdf/given.pdf

Given, C. W., Collins, C. E., and Given, B. A. (1988)
Sources of stress among families caring for relatives with Alzheimer's disease. *Nursing Clinics of North America* **23**: 69-82

Godfrey, H. P. D., Harnett, M. A., Knight, R .G., Marsh, N. V., Kesel, D. A., Partridge, F. M. and Robertson, R. H. (2003)
Assessing distress in caregivers of people with a traumatic brain injury (TBI): a psychometric study of the Head Injured Behaviour Scale. *Brain Injury* 17, **5**: 427-435

Gordon, W. A., Brown, M., Sliwinski, M., Hibbard, M. R. and Patti, N. (1998)
The Enigma of "Hidden" Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation* 13, **6**: 39- 56

Gosling, J. and Oddy, M. (1999)
Rearranged marriages: marital relationships after head injury. *Brain Injury* 13, **10**: 785-796

Glesne, C. and Peshkin, A. (1992)
Becoming qualitative researchers: An Introduction. New York: Longmans.

Grant, J. S., Weaver, M., Elliott, T. R., Bartolucci, A. A. and Giger, J. (2004)
Family caregivers of stroke survivors: characteristics of caregivers at risk for depression. *Rehabilitation Psychology* **49**: 172-179

Greater Manchester Traumatic Brain Injury Audit Group (2006)
Head Injury Management in Adults in Greater Manchester.

Green, J., Franquiz, M. and Dixon, C. (1997)
The myth of the objective transcript: Transcribing as a situated act. *TESOL Quarterly.* 31, **1**: 172-176

Greenwald, B. D., Burnett, D. M. and Miller, M. A. (2003)
Congenital and Acquired Brain Injury: Epidemiology and Pathophysiology. *Archives of Physical Medicine & Rehabilitation* 84. **Suppl 1**: S3-S7

Gregory, M. (1997)
Professional Scholars and Scholarly Professionals. *The New Academic Summer* **6.2**: 19-22

Groom, K. N., Shaw, T. G., O'Connor, M. E., Howard, N.I. and Pickens, A. (1998)
Neurobehavioural Symptoms and Family Functioning in Traumatically Brain-Injured Adults. *Archives of Clinical Neuropyschology* 13, **8**: 695-711

Groswasser, Z. and Stern, M. J. (1998)
'A Psychodynamic Model of Behaviour after Acute Central Nervous Damage.'
Journal of Head Trauma and Rehabilitation 13, **1**: 69-79

Groswasser, Z. (2003)
Factors determining return to work after severe traumatic brain injury.
BNPA abstracts. *Journal of Neurology, Neurosurgery and Psychiatry* **74**: 830-836

Guillemin, M. and Gillam, L. (2004)
Ethics and reflexivity, and "ethically important moments" in research. *Qualitative Inquiry* 10, **2**: 261-280

Hallett, J. D., Zasler, N. D., Maurer, P. and Cash, S. (1984)
Role change after traumatic brain injury in adults. *The American Journal of Occupational Therapy* **48**: 241-245

Hammersley, M. and Atkinson, P. (1995)
Ethnography: Principles in Practice. London: Routledge

Hanks, R. A., Temkin, N. R., Machamer, J. and Dikmen, S. S. (1999)
Emotional and behavioural adjustment following traumatic brain injury. *Archives of Physical Medicine and Rehabilitation* **80**: 991-997

Hanson, S. M. (2001)
Family Heath Nursing: An Introduction. In: S. M. Hanson (Eds.) *Family health care nursing: Theory, practice and research.* 2nd edition, Philadelphia: F.A. Davies. (pp 3-33)

Hansson, R. O., Jones, W. H. and Carpenter, B. N. (1984)
Relational competence and social support. In: P. Shaver *Review of Personality and Social Psychology: Emotions, Relationships and Health.* Beverly Hills: Sage. (pp. 265-284)

Harris, J. K. J., Godfrey, H. P. D., Partridge, F. M. and Knight, R. G. (2001)
Caregiver depression following traumatic brain injury (TBI): a consequence of adverse effect on family members? *Brain Injury* 15, **3**: 223-238

Hastings, R. P. (2002)
Do challenging behaviours affect staff responses to psychological well-being? Issues of causality and mechanisms. *American Journal of Mental Retardation* **107**: 455-467

Hastings, R. P. and Brown, T. (2002)
Coping strategies and the impact of challenging behaviour on special educators' burnout. *Mental Retardation* **40**: 148-156

Heidegger, M. (1962)
Being and Time. Trans. by John Macquarrie and Edward Robinson. New York: Harper & Row. (From the German original of 1927)

Henry, J. D., Philips, L. H., Crawford, J. R., Theodorou, G. and Summers, F. (2006)
Cognitive and psychological correlates of alexithymia following traumatic brain injury. *Neuropsychologia* **44**: 62-72

Hepburn, K.W., Tornatore, J., Center B. and Ostwald, S. (2001)
Dementia family caregiver training: affecting beliefs about caregiving and caregiver outcomes. *Journal of the American Geriatrics Society* 49, **4**: 450-457

Hodgkinson, D. W., Berry, E. and Yates, D. (1994)
Mild head injury: a positive approach to management. *European Journal of Emergency Medicine* **1**: 9-12

Holloway, I. and Wheeler, S. (1996)
Qualitative Research for Nurses. Oxford: Blackwell Science.

Home Office National Statistics (2008)
Crime in England and Wales 2007/08 Home Office Statistical Bulletin. London: Office National Statistics.

Hoofien, D., Gilboa, A., Vakil, E. and Donovick, P. L. (2001)
Traumatic brain injury (TBI) 10-20 years later: a comprehensive outcome study of psychiatric symptomatology. Cognitive abilities and psychosocial functioning. *Brain Injury* 15, **3**: 189-209

House of Commons Health Committee (2001)
Third Report- Head Injury: Rehabilitation 2000-2001 (28th March 2001) House of Commons Select Committee on Health. United Kingdom Parliament, London: Health Committee Publications.Retrieved 10th March 2005 from the World Wide Web http://www.publications.parliament.uk/pa/cm200001/cmselect/cmhealth/307/30702.htm

House of Commons (2001)
House of Commons Hansard Written Answers (House of Commons Daily Debates) 5th February 2001, column 393W
Retrieved 3rd October 2005 from the World Wide Web http://www.parliament.the-stationery-office.co.uk/pa/cm200001/cmhansrd/vo010205/text/10205w10.htm

Hunt, W. E. and Hess, R. M. (1968)
Surgical risk as related to time of intervention in the repair of intracranial aneurysms. *Journal of Neurosurgery* 28, **1**: 14-20

Husserl, E. (1931)
Ideas: General introduction to pure phenomenology. Evanston IL, Northwestern University Press.

Husserl, E. (1960)
Cartesian meditations (Trans. D. Cairns). The Hague: Martineus Nijhoff

Husserl, E. (1970)
Logical Investigations. Vol 1 Translated J.N. Finley New York: Humanities Press.

Husserl, E. (1975)
Paris Lectures. The Hague, Martinus Nijhoff.

Husserl, E. (1977)
Phenomenological Psychology (J Scanlon Trans) The Hague Martinus Nijhoff (Original work published 1962)

Hutchinson, S. A., Wilson, M. E. and Wilson, H. S. (1994)
Benefits of participating in research interviews. *IMAGE: Journal of Nursing Scholarship* 26, **2**: 161-164

Hycner, R. H. (1999)
Some guidelines for the phenomenological analysis of interview data In: A. Bryman and R. G. Burgess (Eds.) *Qualitative Research* (Vol. 3 pp.143-164), London: Sage.

Ingebrigtsen, T., Waterloo, K., Marup-Jensen, S., Attner, E. and Romner, B. (1998)
Quantification of post-concussion symptoms 3 months after minor head injury in 100 consecutive patients. *Neurology* 245, **9**: 609-612

Ingall, T., Asplund, K., Mähönen, M. and Bonita, R. (2000)
A multinational comparison of subarachnoid haemorrhage in the WHO MONICA stroke study. *Stroke* **31**: 1054-1061

Jasper, M. (1994)
Issues in phenomenology for researchers of nursing. *Journal of Advanced Nursing* 19, **2**: 976-986

Jennett, B. and MacMillan, R. (1981)
Epidemiology of head injury. *British Medical Journal (Clinical Research Edition)* 282, **6258**: 101-104

Jennett, B. (1998)
Epidemiology of head injury *Archives of Disease in Childhood* **78**: 403-406

Jenkins, R., Rose, J. and Lovell, C. (1997)
Psychological well-being of staff working with people who have challenging behaviour. *Journal of Applied Research in Intellectual Disabilities* **41**: 502-511

Johns, C. (2004)
Becoming a Reflective Practitioner. 2nd Edition, Oxford: Blackwell Publishing.

Johnson, B. P. (1995)
One Family's Experience With Head Injury: A Phenomenological study. *Journal of Neuroscience Nursing* 27, 2: 113-118

Johnson, P. D. (1998)
Rural stroke caregivers: A qualitative study of the positive and negative response to the caregiver's role. *Topics in Stroke Rehabilitation* 5: 51-68

Johnson, R. and Balleny, H. (1996)
Behavioural problems after head injury: incidence and need for treatment.
Clinical Rehabilitation 10, 2: 173-181

Junqué, C., Bruna, O. and Mataró, M. (1997)
Information needs of the traumatic brain injured patients family member regarding the consequences of the injury and associated perceptions of physical, cognitive, emotional and quality of life changes. *Brain Injury* 11, 4: 251-258

Kadyan, V., Mysiw, W. J., Bogner, J. A., Corrigan, J. D., Fugate, L. P. and Clinchot, D. M. (2004)
Gender differences in agitation after traumatic brain injury. *American Journal of Physical Medicine and Rehabilitation* 83, 10: 747-752

Kao, HF. S. and Stuifbergen, A. K. (2004)
Love and Load: The Lived experience of the Mother-Child Relationship Amongst Young Adult Traumatic Brain-Injured Survivors. *Journal of Neuroscience Nursing* 36, 2: 73-81

Katz, S., Kravetz, S. and Grynbaum, F. (2005)
Wives' coping flexibility, time since husbands' injury and the perceived burden of wives of men with traumatic brain injury. *Brain Injury* 19, 1: 59-66

Kavanaugh, K. and Ayres, L. (1998)
"Not AS Bad As It Could Have Been": Assessing and Mitigating Harm During Research Interviews on Sensitive Topics. *Research in Nursing and Health* 21: 91-97

Kay, T., Newman, B., Cavallo, M., Ezrachi, D., and Resnick, M. (1992)
Toward a neuropsychological model of functional disability after mild traumatic brain injury. *NeuroPsychology* 6: 371-384

Kay, A. and Teasdale, G. (2001)
Head injury in the United Kingdom. *World Journal of Surgery* 25: 1210-1220

Kenny, D. T. and Lennings, C. J. (2007)
The relationship between head injury and violent offending in juvenile detainees.
Crime and Justice Bulletin, NWS Bureau of Crime and Statistics and Research Sydney. No. 107

Koch, T. (1995)
Interpretive approaches in nursing research: the influence of Husserl and Heidegger.
Journal of Advanced Nursing 21, 5: 827-836

Kolakowsky-Hayner, S. A., Miner, D. K. and Kreutzer, J. S. (2001)
Long-term life quality and family needs after traumatic brain injury. *Journal of Head Trauma Rehabilitation* 16, 4: 374-385

Koponen, S., Taiminen, T., Honkalampi, K., Joukamaa, M., Viinamäki, H., Kurki, T., Portin, R., Himanen, L., Isoniemi, H., Hinkka, S. and Tenovuo, O. (2005)
Alexithymia After Traumatic Brain Injury: It's Relation to Magnetic Resonance Imaging Findings and Psychiatric Disorders. *Psychosomatic Medicine* 67: 807-812

Knight, R. G., Devereux, R. and Godfrey, H. P. D. (1998)
Caring for a family member with traumatic brain injury. *Brain Injury* 12, 6: 467-481

Kreutzer, J. S., Gervasio, A. H. and Camplair, P. S. (1994)
Primary caregivers' psychological status and family after traumatic brain injury. *Brain Injury* 8, 3: 197-210

Kreutzer, J. S., Marwitz. J.H., Hsu, N., Williams, K. and Riddick, A. (2007)
Martial stability after brain injury: An investigation and analysis. *Neurorehabilitation* 22: 53-59

Kuiper, N. A. Martin, R. A. (1998)
Laughter and Stress in Daily Life: Relation to Positive and Negative Affect. *Motivation and Emotion* 22, 2: 133-153

Kvale, S. (1996)
Inter Views: An Introduction to Qualitative Research Interviewing. Thousand Oaks CA: Sage Publications.

Kvale, S. (2006)
Dominance through Interviews and Dialogue. *Qualitative Inquiry* 12, 3: 480-500

Langlois, J. A., Rutland-Brown, W. and Thomas, K.E. (2004)
Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations, and Deaths. National Center for Injury Prevention and Control USA: Centers for Disease Control and Prevention.

Lapadat, J. C. and Lindsay, A. C. (1999)
Transcription in Research and Practice: From Standardization of Technique to Interpretive Positionings. *Qualitative Inquiry* 5, 1: 64-86

Lave, J. and Wenger, E. (1991)
Situated learning: legitimate peripheral participation. Cambridge: Cambridge University Press.

Lazarus, R. S. (1993)
From Psychological Stress to the Emotions: A History of Changing Outlooks. *Annual Review of Psychology* 44: 1-22

Lazarus R. S. and DeLongis, A. (1983)
Psychological stress and coping in aging. *American Psychologist* 38: 245-254

Lazarus R. S. and Folkman, S. (1984)
Stress, Appraisal and Coping. New York: Springer Publishing Company.

Leathem, J., Heath, E. and Woolley, C. (1996)
Relatives' perceptions of role change, social support and stress after traumatic brain injury. *Brain Injury* 10, 1: 27-38

Lee-Treweek, G. and Linkogle, S. (Eds.) (2000)
Danger in the Field: Risk and Ethics in Social Research. London: Routledge.

Legard, R., Keegan, J. and Ward, K. (2003)
In-depth Interviews. In: J. Ritchie and J. Lewis (Eds.) *Qualitative Research Practice: a guide for social science students and researchers.* London: Sage Publications. (pp. 138-169)

Leith, K. H., Phillips, L. and Sample, P. L. (2004)
Exploring the service needs and experiences of persons with TBI and their families: the South Carolina experience. *Brain Injury* 18, 12: 1191-1208

Leon-Carrión, J. and Ramos, F. J. C. (2003)
'Blows to the head during development can predispose to violent crime behaviour'. Rehabilitation of consequences of head injury is a measure of crime prevention. *Brain Injury* 17: 207-216

Leon-Carrión, J., del Rosario, M., Morales, D., Martin, J.M.B., Murillo-Cabezas, F. (2005)
Epidemiology of Traumatic Brain Injury and Subarachnoid Hemorrhage.*Pituitary* 8: 197-202

Levin, H. S., Brown, S. A., Song, J. X., McCauley, S. R., Boake, C., Contant, C. F., Goodman, H., and Kotrla, K. J. (2001)
Depression and post-traumatic stress disorder at three months after mild to moderate traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology* 23, 6: 754-769

Levine, R. J. (1979)
Clarifying the concepts of research ethics. *The Hastings Center Report* 9, 3: 21-26

Lezak, M. D. (1978)
Living with the Characterologically Altered Brain Injured Patient. *Journal of Clinical Psychiatry* 39, 7: 592-598

Lezak, M. D. (1988)
Brain Damage is a Family Affair. *Journal of Clinical Experimental Neuropsychology* 10, 1: 111-123

Light, E. and Lebowitz, B. D. (1989)
Alzheimer's disease treatment and family stress: Direction for research. (Eds.) Rockville, MD: National Institute for Mental Health.

Lincoln, S. and Guba, E. G. (1985)
Naturalistic Inquiry. Newbury Park, CA: Sage Publications.

Linn, R. A., Allen, K. and Willer, B. S. (1994)
Affective symptoms in the chronic stages of traumatic brain Injury: A study of married couples. *Brain Injury* 8, 2: 135-147

Liu, B. C., Ivers, R., Norton, R., Boufous, S., Blows, S. and Lo, S. K. (2008)
Helmets for preventing injury in motorcycle riders (Review). The Cochrane Database of Systematic Reviews. Issue 1. Art. No.: CD004333. DOI: 10.1002/14651858.CD004333.pub3.

Livingston, M. G., Brooks, D. N. and Bond, M. R. (1985)
Three months after severe head injury: psychiatric and social impact on relatives. *Journal of Neurology, Neurosurgery, and Psychiatry* 48: 870- 875

Livingston, M. G. and Brooks, D. N. (1988)
The burden on families of the brain injured: a review. *Journal of Head Trauma Rehabilitation* 3: 6-15

Lofland, J. and. Lofland, L.H. (1984)
Analyzing social settings: A guide to qualitative observation and analysis. 2nd Edition, Belmont, CA: Wadsworth.

Lombard, L. A. and Zafonte, R. D. (2005)
Agitation After Traumatic Brain Injury; Considerations and Treatment Options. *American Journal of Physical Medicine and Rehabilitation* 84, 10: 797-812

Lowe, K., Felce, D., Perry, J., Baxter, H. and Jones, E. (1998)
The characteristics and residential situation of people with severely intellectual disability and the most severe challenging behaviour in Wales. *Journal of Intellectual Disability Research* 42: 375-389

Lowes, L. and Prowse, M. A. (2001)
Standing outside the interview process? The illusion of objectivity in phenomenological data generation. *International Journal of Nursing Studies* 38: 471-480

Maegele, M., Engel, D., Bouillon, B., Lefering, R., Fach, H., Raum, M., Buchheister, B., Schaefer, U., Klug, N. and Neugebauer, E. (2007)
Incidence and Outcome of Traumatic Brain Injury in an Urban Area in Western Europe over 10 Years. *European Surgical Research* 39: 372-279

Mahon, N. E., Yarcheski,,A..and Yarcheski, T. J. (1998)
Social support and positive health practices in young adults; loneliness as a mediating variable. *Clinical Nursing Research* 7, 3: 292-308

Man, D. W. K. (2002)
Family caregivers' reaction and coping for persons with brain injury. *Brain Injury* 16, 12: 1025-1037

Marsh, N. V., Kersel, D. A., Havill, J. H. and Sleigh, J. W. (1998)
Caregiver burden at 6 months following severe traumatic brain injury. *Brain Injury* 12, 3: 225-238

Marshall, M. N. (1996)
Sampling for qualitative research. *Family Practice* 13, 6: 522-525

Marwit, S. J. and Kaye, P. N. (2006)
Measuring grief in caregivers of persons with acquired brain injury. *Brain Injury* 20, 13/14:1419-1429

Marwit, S. J. and Meuser, T. M. (2002)
Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *The Gerontologist* 42: 751-767

Masson, F. Vecsey, J., Salmi, L. R., Dartigues, J. F., Erny, P. H. and Maurette, P. (1997)
Disability and handicap 5 years after a head injury: a population-based study.
Journal of Clinical Epidemiology. 50, 5: 595-601

Matarazzo, J. D. (1978)
The interview: Its reliability and validity in psychiatric diagnosis; In: Wolman, B. J. (Eds.) *Clinical diagnosis of mental disorders: A Handbook.* New York: Plenum Press. (pp. 47-96)

Mauss-Clum, N. and Ryan, M. (1981)
Brain Injury and the family *Journal of Neuroscience Nursing* 13: 165-169

May, K. A. (1991)
Interview technique in qualitative research: Concerns and Challenges In: J. M. Morse (Eds.) *Qualitative nursing research: A contemporary dialogue.* Revised Edition Newbury Park, California: Sage. (pp. 188-201)

McCubbin, H. L. and McCubbin, M. A. (1988)
Typologies of family resilience: Emerging roles of social class and ethnicity. *Family Relations* 51, 2: 103-111

McCubbin, H. L. and McCubbin, M. A. (1993)
Families coping with illness: The resiliency model of family stress, adjustment and adaptation. In: C. B. Danielson, B. Hamel-Bissell and P. Winstead-Fry (Eds.) *Families, health and illness: Perspectives on coping and intervention* St. Louis: Mosby. (pp. 21-61)

McCubbin, H. L. and McCubbin, M. A. (1996)
Resiliency in families: A conceptual model of family adjustment and adaptation in response to stress and crisis. In: H. McCubbin, A. Thompson, and M. McCubbin (Eds.) *Family assessment: Resiliency, coping and adaptation: Inventories for research and practice.* Madison: University of Winconsin. (pp.1-64)

McGill, P., Papachristoforou, E. and Cooper, V. (2006)
Support for family carers of children and young people with developmental disability and challenging behaviour. *Child: Care, Health and Development* 32, 2: 159-165

McLeod, J. (1997)
Narrative and Psychotherapy London: Sage.

McMillan, T. and Greenwood, R. (1991)
Rehabilitation programmes for the brain-injured adult: current practice and future options in the UK. London: Department of Health.

McPherson, K. M., Pentland, B. and McNaughton, H. K. (2000)
Brain Injury – perceived health of carers. *Disability and Rehabilitation* 22, 15: 683-689

Merleau-Ponty, M. (2002)
Phenomenology of Perception, London: Routledge.

Mezirow, J. (1990)
Fostering critical reflection in adulthood: a guide to informative and emancipatory learning (Eds.) San Francisco: Jossey-Bass.

Miles, M. B. and Huberman, A. M. (1994)
An Expanded Sourcebook Qualitative Data Analysis: A sourcebook of new methods 2nd edition. Thousand Oaks CA: Sage.

Minichiello, V., Aroni, R., Timewell, E. and Alexander, L. (1990)
In-depth interviewing: researching. Melbourne: Longman Cheshire.

Minichiello, V., Aroni, R., Timewell, E. and Alexander, L. (1995)
In-depth interviewing:.principles, techniques, analysis.. 2nd edition Melbourne: Longman.

Mishler, E. G. (1986)
Research Interviewing - Context and Narratives. Cambridge Massachusetts: Harvard University Press.

Mishler, E. G. (1991)
Representing discourse: The Rhetoric of Transcription. *Journal of Narrative and Life History* 1, 4: 255-280

Mitchley, N., Gray, J. M. and Pentland, B. (1996)
Burden and coping among the relatives and carers of brain -injured survivors. *Clinical Rehabilitation* 10: 3-8

Mittenberg, W. and Strauman, S. (2000)
Diagnosis of mild head injury and the post concussion syndrome. *Journal of Head Trauma Rehabilitation.* 15, 2: 783-791

Moniz-Cook, E., Woods, R. and Gardiner, E. (2000)
Staff factors associated with perception of behaviours as 'challenging' in residential homes. *Ageing and Mental Health* 4, 1: 49-55

Moore, A. D., Stambrook, M., Peters, L. and Lubusko, A. A. (1991)
Family coping and marital adjustment after traumatic brain injury. *Journal of Head Trauma Rehabilitation* 6, 1: 83-89

Moos, R. and Moos, B. (1994)
Family Environment Scale Manual: Development, Applications, Research. 3rd Edition, Palo Alto, CA: Consulting Psychologist Press.

Moran, D. (2000)
Introduction to Phenomenology. London and New York: Routledge.

Morse, J. M. (1991)
Strategies for sampling In: J. M Morse (Eds) *Qualitative nursing research: A contemporary dialogue* Revised Edition Newbury Park California: Sage. (pp.127-145)

Morse, J. M. (1992)
The power of induction. *Qualitative Health Research* 2: 3-6

Morse, J. M. (1994)
"Emerging from the data": The Cognitive Processes of Analysis in Qualitative Inquiry. In: J. M. Morse (Eds.) *Critical issues in qualitative research methods.* Thousand Oaks CA: Sage. (pp. 23-43)

Morse, J. M. and Field, P. A. (1995)
Qualitative Research Methods for Healthcare Professionals. 2nd Edition, Thousand Oaks CA: Sage

Morse, J. M. and Field, P. A. (1996)
Nursing Research: The application of qualitative approaches. 2nd Edition, London: Chapman and Hall.

Morse, J. M. and Penrod, M. (1999)
Linking Concepts of Enduring, Uncertainty, Suffering, and Hope. *Image: Journal of Nursing Scholarship* 31, 2: 145-150

Moules, S. and Chandler, B. (1999)
A study of the health and social needs of carers of traumatically brain injured individuals served by one community rehabilitation team. *Brain Injury* 13, 12: 983-993

Moustakas, C. (1994)
Phenomenological Research Methods. Thousand Oaks California: Sage.

Munhall P. L. (1991)
Institutional review of qualitative research proposals: a task of no small consequence. In: J. M. Morse (Eds.) *Qualitative Nursing Research: A Contemporary Dialogue.* Newbury Park: California Sage. (pp. 258-271)

Munhall. P. L. (1994)
Revisioning Phenomenology: Nursing and Health Science Research. New York:
National League for Nursing Press.

Munhall. P. L. (2000)
Ethical Considerations in qualitative research. In: P. L. Munhall and C. O. Boyd
Nursing Research. A Qualitative Perspective. 2nd Edition, Sudbury MA: Jones and
Bartlett. (pp. 537-550)

Murray, B. L. (2003)
Qualitative research interviews: therapeutic benefits for the participants. *Journal of
Psychiatric and Mental Health Nursing* 10: 231-238

Murray, C. J. L. and Lopez, A. D. (1997)
Alternative projections of mortality and disability by cause 1990-2020: Global Burden
of Disease Study. *Lancet* 349, **9063**: 1436-1442

Murray, H. M., Maslany, G. W. and Jeffery, B. (2006)
Assessment of family needs following acquired brain injury in Saskatchawen. *Brain
injury* 20, **6**: 575-585

Nabors, N., Seacat, J. and Rosenthal, M. (2002)
Predictors of caregiver burden following traumatic brain injury. *Brain Injury* **16**: 1039-
1050

National Institute of Health (1998)
Rehabilitation of Persons With Traumatic Brain Injury. National Institute of Health
Consensus Development Conference Statement. Oct 26-28; 16, **1**: 1-41 Retrieved 5th
June 2007 from the World Wide Web
http://consensus.nih.gov/1998/1998TraumaticBrainInjury109html.htm

Neurological Alliance (2003)
*Neuro numbers; a Brief Review of the Numbers of People in the UK with
Neurological Conditions.* London: Neurological Alliance.

Newman, E. and Kaloupek, D. G. (2004)
The Risks and Benefits of Participating in Trauma-Focused Research Studies.
Journal of Traumatic Stress 17, **5**: 383-394

Nezlek, J. B. and Derks, P. (2001)
Use of humour as a copying mechanism psychological adjustment and social
interactions. *Humor* 14, **4**: 395-413

Nott, M.T., Chapparo, C. and Baguley, I. J. (2006)
Agitation following traumatic brain injury: An Australian sample. *Brain Injury* 20, **11**:
1175-1182

Nunkoosing, K. (2005)
Problems with interviews *Qualitative Health Research* 15, **5**: 698-706

Nursing and Midwifery Council (2008)
The Code Standards of conduct, performance and ethics for nurses and midwives
London: Nursing & Midwifery Council.

O'Connell, D. C. and Kowal, S. (1999)
Transcription and the issue of standardization. *Journal of Psycholinguistic Research* 28, **2**: 103-120

O`Connell, B. and Baker, L. (2004)
Managing as carers of stroke survivors. *International Journal of Nursing Practice* 10, **3**: 121-126

Oddy, M., Humphrey. M. and Utley, D. (1978)
Stresses upon the relatives of head-injured patients. *British Journal of Psychiatry* **133**: 507-513

Oddy, M., Coughlan, T., Tyerman, A. and Jenkins, D. (1985)
Social adjustment after closed head injury: a further follow-up seven years after injury. *Journal of Neurology Neurosurgery and Psychiatry* 48, **6**: 564-580

Office for National Statistics (2000)
Families headed by lone parents as a percentage of all families with dependent children: by marital status, 1971 to 1998-99: Social Trends 30. Office for National Statistics. London: The Stationary Office.
Retrieved 5th July 2008 from the World Wide Web
http://www.statistics.gov.uk/pdfdir/div0808.pdf

Office for National Statistics (2008a)
Divorce rate lowest for 26 years News Release
Office for National Statistics. London: The Stationary Office.
Retrieved 5th June 2008 from the World Wide Web
http://www.statistics.gov.uk/downloads/theme_population/FM2no33/FM2_no_33.pdf

Office for National Statistics (2008b)
Marriage, divorce and adoption statistics. Series FM2 no.33. Office for National Statistics. London: The Stationary Office.
Retrieved 5th June 2008 from the World Wide Web
http://www.statistics.gov.uk/downloads/theme_population/FM2no33/FM2_no_33.pdf

Oiler, C. J. (1982)
The phenomenological approach in nursing research. *Nursing Research* 31, **3**: 178-181

Olesen. J, and Leonardi, M. (2003)
The burden of brain diseases in Europe. *European Journal of Neurology* 10, **5**: 471-477

Omery, A. (1983)
Phenomenology, a method for nursing research. *Advances in Nursing Science* 5, **2**: 49-63

Orsillo, S. M., McCaffrey, R. J. and Fisher, J. M. (1993) Siblings of head-injured individuals: A population at risk. *Journal of Head Trauma Rehabilitation* 8, 1: 102-115

Osborne, J. W. (1990)
Some basic existential- phenomenological research methodology for counsellors. *Canadian Journal of Counselling* 24: 79-91

Osborne, J. W. (1994)
"Some similarities and differences among phenomenological and other methods of psychological qualitative research", *Canadian Psychology* 35, 2: 167-189

Ortiz, S. M. (2004)
Leaving the Private World of Wives of Professional Athletes: A Male Sociologist's Reflections. *Journal of Contemporary Ethnography* 33, 4: 466-487

Paley, J. (1997)
Husserl, phenomenology and nursing. *Journal of Advanced Nursing* 26: 187-193

Paley, J. (2001)
Phenomenology as rhetoric. *Nursing Inquiry* 12, 2:106-116

Panting, A. and Merry, P. (1972)
The long term rehabilitation of severe head injuries with particular reference to the need for social and medical support for the patient's family. *Rehabilitation* 82: 33-37

Parahoo, K. (2006)
Nursing Research Principles, Process and Issues 2nd edition, Basingstoke Hampshire: Palgrave Macmillian.

Parrish, M. M. and Quinn, P. (1999)
Laughing your way to peace of mind: How a little humor helps caregivers survive. *Clinical Social Work Journal* 27, 2: 203-212

Patton, M. Q. (1990)
Qualitative Evaluation and Research Methods 2nd edition, Newbury Park CA: Sage Publications.

Patton, M. Q. (2002)
Qualitative Research and Evaluation Methods. 3rd edition, Thousand Oaks, CA: Sage.

Pearlin, L. I., Mullan, J. T., Semple, S. J. and Skaff, M. M. (1990)
Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist* 30: 583-594

Pennebaker, J. W. (1993)
Putting stress into words: health, linguistic, and therapeutic implications. *Behaviour Research Therapy* 31, 6: 539-548

Pennebaker, J. W. (1997)
Writing about emotional experiences as a therapeutic process *Psychological Science* 8, **3**: 162-166

Pennebaker, J. W., Mayne, T. and Francis, M. (1997)
Linguistic predictors of adaptive bereavement *Journal of Personality and Social Psychology* **72**: 528-37

Pennebaker, J. W. (1999)
Forming a Story: The Health Benefits of Narrative. *Journal of Clinical Psychology* 55, **10**:1243-1254

Penrod, J. (2007)
Living with uncertainty: concept advancement. *Journal of Advanced Nursing* 57, **6**: 658-667

Peplau, L. A. and Perlman, D. (1982)
Loneliness: a Sourcebook of Current Theory, Research and Therapy. New York: John Wiley and Sons

Perlesz, A., Kinsella, G. and Crowe, S. (1999)
Impact of traumatic brain injury in the family: A critical review. *Rehabilitation Psychology* 44, **1**: 6-35

Perlesz, A., Kinsella, G., and Crowe, S. (2000)
Psychological Distress and Family Satisfaction Following Traumatic Brain Injury: Injured Individuals and their Primary, Secondary and Tertiary Carers. *Journal of Head Trauma Rehabilitation* 15, **3**: 909-929

Peters, L. C., Stambrook, M., Moores, A. D. and Esses, L. (1990)
Psychosocial sequelae of closed head injury effects on martial relationships. *Brain Injury* 4, **1**: 39-47

Poland, B. D. (1995)
Transcription quality as an aspect of rigor in qualitative research. *Qualitative Inquiry* 1, **3**: 290-310

Poland, B. D. and Pederson, A. (1998)
Reading between the lines: interpreting silences in qualitative research. *Qualitative Inquiry* 4, **2**: 293-313

Polanyi, M. (1958)
Personal Knowledge: Towards a post critical philosophy. London: Routledge and Kegan Paul.

Polanyi, M. (1966)
The Tacit Dimension. Gloucester Mass: Peter Smith.

Polkinghorne, D. (1983)
Methodology for the human sciences. Systems of inquiry. Albany: University of New York Press.

Porter, S. (1996)
Qualitative research. In: Cormack, D.F.S. (Ed) *The Research Process in Nursing* 3rd Edition, Oxford: Blackwell Science.

Price, B. (2002)
Laddered questions and qualitative data research interviews. *Journal of Advanced Nursing*, 37, **3**: 273-281

Pritchard, C. Clapham, L., Foulkes, L., Lang D. A., Neil-Dwyer, G. (2004)
Comparison of cohorts of elective and emergency neurosurgical patients: psychological outcomes of acoustic neuroma and aneurismal sub archanoid haemorrhage patients and carers. *Surgical Neurosurgery* 62, **1**: 7-16

Ramos, M. C. (1989)
Some Ethical Implications of Qualitative Research. *Research in Nursing and Health* **12**: 57-63

Ray, M. A. (1994)
The richness of phenomenology: philosophic, theoretic and methodologic concerns. In: Morse, J. M. (Ed) *Critical Issues in Qualitative Methodology.* Thousand Oaks, CA Sage. (pp. 117-135)

Rew, L., Bechtel, D. and Sapp, A. (1993)
Self-as-instrument in qualitative research *Nursing Research* **42**: 300-301

Riley, G. A. (2007)
Stress and depression in family carers following traumatic brain injury: influences of belief about difficult behaviours. *Clinical Rehabilitation* **21**: 82-88

Rivara, J. M.B., Fay, G. C., Jaffe, K. M., Polissar, N. L., Shurtleff, H. A. and Martin, K. M. (1992)
Predictors of family functioning one year following traumatic brain injury in children. *Archives of Physical Medicine and Rehabilitation* **73**: 899-910

Robinson, B. C. (1983)
Validation of a caregiver strain index. *Journal of Gerontology* 38, **3**: 344-348

Roche, N., Fleming, J. M. and Shum, D. H. (2002)
Self-awareness of prospective memory failure in adults with traumatic brain injury *Brain Injury* 16, **11**: 931- 945

Rolfe, G. (2006)
Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing* 55, **3**: 304-310

Rolland, J. R. (1994)
Families, Illness & Disability: An integrative treatment model. New York: Basic Books.

Rose, D., Horne, S., Rose, J. L. and Hastings, R. P. (2004)
Negative Emotional Reactions to Challenging Behaviour and Staff Burnout: Two Replication Studies. *Journal of Applied Research in Intellectual Disabilities* **17**: 219-223

Rosenbaum, M. and Najenson, T. (1976)
Changes in life patterns and symptoms of low mood as reported by wives of severely brain injured soldiers. *Journal of Consult Clinical Psychology* 44, **6**: 881-885

Ruff, R. M., Camenzuli, L. and Mueller, J. (1996)
Miserable minority: emotional risk factors that influence the outcome of a mild traumatic brain injury. *Brain Injury* 10, **8**: 551-565

Sackett, D. L., Rosenberg, W. M., Gray, J. A., Hayes, R. B. and Sheehan, J. (1996)
Evidence based medicine; what it is and what it is not. *British Medical Journal* **312**: 71-72

Sandel, E. and Mysiw, J. (1996)
The agitated brain injured patient. Part 1: Definition, differential diagnosis and assessment. *Archives of Physical Medicine and Rehabilitation* **77**: 617-623

Sandelowski, M. (1986)
Rigor and rigor mortis: The problem of rigor in qualitative research. *Advances in Nursing Science* 8, **3**: 27-37

Sandelowski, M. (1993)
Rigor and rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science* 16, **2**: 1-8

Sandelowski, M. (1995)
Focus on qualitative methods: Sample size in qualitative research. *Research in Nursing and Health* **18**: 179-183

Sandelowski, M. (1996)
Focus on qualitative methods: One is the Liveliest Number: The Case Orientation of Qualitative Research. *Research in Nursing and Health* **19**: 525- 529

Sander, A. M., High, Jr. W. M., Hannay, H. J. and Sherer, W, M. (1997)
Predictors of psychological health in caregivers of people with closed head injury. *Brain Injury* 11, **4**: 235-249

Sander, A. M., Caroselli, J. S., High, Jr. W. M., Becker, C., Neese, L. and Scheibel, R. (2002)
Relationship of family functioning to progress in a post-acute rehabilitation programme following traumatic brain injury. *Brain Injury* 16, **8**: 649-657

Sander, A. M., Sherer, M., Malec, J. F., High, W. M. Jr., Thompson, R. N., Moessner, A. M. and Josey, J. (2003)
Preinjury emotional and family functioning in caregivers of persons with traumatic brain injury. *Archives Physical Medicine Rehabilitation* 84, **2**: 197-203

Sanders, P. (1982)
Phenomenology: A New Way of Viewing Organizational Research. *Academy of Management Review* 7, **3**: 353-360

Sanders, S. and Corley, C. S. (2003)
Are they grieving? A qualitative analysis examining grief in caregivers of individuals with Alzheimer's disease. *Social Work and Health Care* **37**: 35-53

Santos, M. E., Castro-Caldas, A. and De Sousa, L. (1998)
Spontaneous complaints of long-term traumatic brain injured subjects and their close relatives *Brain Injury* 12, **9**: 756-767

Sarapata, M., Hermann, D., Johnson, T. and Aycock, R. (1998)
The role in head injury in cognitive functioning, emotional adjustment and criminal behaviour. *Brain Injury* 12, **10**: 821-842

Schatzman, L. and Strauss, A. L. (1973)
Field Research: Strategies for a Natural Sociology. Englewood Cliffs: Prentice-Hall.

Schön, D. (1983)
The Reflective Practitioner. How Professionals Think in Action. San Francisco, Jossey- Bass.

Seale, C. (2008)
Using Computers to Analyze Qualitative Data In: D. Silverman and Marvasti, A. *Doing Qualitative Research: A Comprehensive Guide.* London: Sage Publications. (pp. 233-256)

Seidel, J. and Kelle, U. (1995)
Different functions of coding the analysis of textual data. In: *Computer-Aided Qualitative Data Analysis: Theory, Methods and Practice* (Kelle, U. Ed) London: Sage.

Seidman, I. E. (1991)
Interviewing as Qualitative Research; A Guide for Researchers in Education and the Social Sciences. New York: Teachers College Press.

Seidman, I. E. (1998)
Interviewing as Qualitative Research: a Guide for Researchers in Education and the Social Sciences. 2nd edition, New York: Teacher College Press.

Serio, C. D., Kreutzer, J. S. and Gervasio, A. H. (1995)
Predicting family needs after brain injury: Implications for interventions *Journal of Head Trauma and Rehabilitation* 10, **2**: 32-45

Servadei, F., Antonelli, V., Betti, L., Chieregato, A., Fainardi, E. Gardini, E., Giuliani, G., Salizzato, L. and Kraus, J. F. (2002)
Regional brain injury epidemiology as the bais of planning brain injury treatment. *Journal of Neurosurgical Science* 46, 3/4: 111-119

Sifneos, P. E. (1973)
The prevalence of "alexithymic" characteristics in psychosomatic patients. *Psychotherapy Psychosomatics* 22, 2: 255-262

Silverman, D. (1976)
Interview talk: Bringing off a research instrument. In: D. Silverman and J. Jones (Eds.) *Organizational work: The language of grading, the grading of language.* London: Collier Macmillan. (pp. 133 -150)

Silverman, D. (1993)
Interpreting Qualitative Data, Methods of Analysing Talk, Text and Interaction. London: Sage Publication.

Smith, R. T. (1979)
Rehabilitation of the disabled: the role of social networks in the recovery process. *International Rehabilitation Medicine* 1, 2: 63-72

Smith, M. (2004)
'Killing the angel in a room of one's own. Being as unconscious as possible when writing up qualitative research'. *Journal of Social Work Practice* 18, 2: 255-265

Sparks, L., Travis, S. S. and Thompson, S. R. (2005)
Listening for the Communicative Signals of Humor, Narratives and Self-Disclosure in the Family Caregiving Interview. *Health & Social Work* 30, 4: 340-344

Spiegelberg, H. (1969)
The phenomenological movement: a historical introduction. 2nd Edition, The Hague: Martinus Nijhoff.

Spilka, B., Hood, R. W., Hunsberger, B. and Gorsuch, R. (2003)
The psychology of religion: An empirical approach. 3rd Edition, New York: Guilford Press.

Stebbins, P. and Leung, P. (1998)
Changing family needs after brain injury. *Journal of Rehabilitation* Oct/Nov/ Dec 64, 4: 15-22

Stewart, D. and Mickunas, A. (1974)
Exploring Phenomenology: A guide to the field and its literature. Chicago: American Library Association.

Streubert, H. J. and Carpenter, D. R. (1995)
Qualitative Research in Nursing: advancing the humanistic imperative. 2nd Edition Philadelphia: Lippincott.

Styrke, J., Stålnacke, B., Sojka, P. and Björnstig, U. (2007)
Traumatic brain injuries in a Well-Defined Population: Epidemiological Aspects and
Severity. *Journal of Neurotrauma* **24**: 1425-1436

Sundstrøm, T., Sollid, S., Wentzel-Larsen, T. and Wester, K. (2007)
Head injury mortality in the Nordic countries. *Journal of Neurotrauma* 24, **1**: 147-153

Tagliaferri, F., Compagnone, C., Korsic, M., Servadei, F. and Kraus. J. (2006)
A systematic review of brain injury epidemiology in Europe. *Acta Neurochirurgia
(Wien)* 148, **3**: 255-268

Tate, R. L. and Broe, G. A. (1999)
Psychosocial adjustment after traumatic brain injury: what are the important
variables? *Psychological Medicine* 29, **3**: 713-725

Tate, R. L., Lulham, J. M., Broe, G. A., Strettles, B. and Pfaff, A. (1989)
Psychosocial outcome for the survivors of severe blunt head injury: the results from a
consecutive series of 100 patients *Journal of Neurology, Neurosurgery, and
Psychiatry* 52, **10**: 1128-1134

Tateno, A., Jorge, R. E. and Robinson, R. G. (2003)
Clinical correlates of aggressive behaviour after traumatic brain injury. *Journal of
Neuropsychiatry Clinical Neurosciences* **15**: 155-160

Taylor, S. J. and Bogdan, R. (1984)
Introduction to Qualitative Research Methods: searching for meaning. 2nd Edition,
New York: John Wiley and Sons.

Teasdale, G. and Jennett, B. (1974)
Assessment of the coma and impaired consciousness A Practical scale. *Lancet* 2:
81-84

ten Have, P. (1997)
Methodological issues in conversation analysis. Ethno/CA News
Article Retrieved 1st November 2007 from the World Wide Web assessed via
http://www.pscw.uva.nl/emca/mica.htm   [ten Have (1990) Methodological Issues
in Conversation Analysis *Bulletin de Méthodologie Sociologique* **27**: 23-51]

Testa, J. A., Malec, J. F., Moessner, A. M. and Brown, A. W. (2006)
Predicting family functioning after TBI: Impact of neurobehavioral factors. *Journal of
Head Trauma Rehabilitation* 21, **3**: 236-247

Tennant, A. (2005)
Admission to hospital following head injury in England: Incidence and socio-
economic associations. *BMC Public Health* **5**: 21
Article Retrieved 1st July 2008 from the World Wide Web assessed via
http://www.biomedcentral.com/1471-2458/5/21

The Royal College of Surgeons (1999)
Report of the Working Party on the Management of Patients with Head Injuries.
London: The Royal College of Surgeons

Thomsen, I. V. (1974)
Patients with severe head injury and his family: follow-up study 50 patients.
Scandinavian Journal of Rehabilitation and Medicine 6, **4**: 180-183

Thomsen, I. V. (1984)
Late outcome of very severe blunt head injury trauma. A 10-15 year second follow-up. *Journal of Neurology, Neurosurgery, and Psychiatry* 47, **3**: 260-268

Thomsen I. V. (1992)
Late psychosocial outcome in severe traumatic brain injury. *Scandinavian Journal of Rehabilitation and Medicine* Supplement **26**: 142-152

Thorne, S., Kirkhan, S. R. and MacDonald-Emes, J. (1997)
Focus on Qualitative Methods Interpretative Description: A Non-categorical Qualitative Alternative for Developing Nursing Knowledge. *Research in Nursing and Health* **20**: 169-177

Thornhill, S., Teasdale, G. M., Murray, G. D., McEwen, J., Roy, C. W. and Penny, K. I. (2000)
Disability in young people and adults one year after head injury: prospective cohort study. *British Medical Journal* 320, **7250**: 1631-1635

Tilley, S. A. (2003)
"Challenging" Research Practices: Turning a Critical Lens on the Work of transcription. *Qualitative Inquiry* 9, **5**: 750-773

Tilley, S. A. and Powick, K. D. (2002)
Distanced Data: Transcribing Other People's Research Tapes. *Canadian Journal of Education / Revue canadienne de l'éducation* 27, **2/3**: 291-310

Tod, A. (2006)
Interviewing. In: K. Gerrish and A. Lacey (Eds.)*The Research Process in Nursing.* 5th Edition Blackwell Publishing Ltd, Oxford.

Todres, L. (2007)
Embodied Enquiry: Phenomenological Touchstones for Research, Psychotherapy and Spirituality. Hampshire & New York: Palgrave Macmillan.

Turner-Stokes, L. (2003) *Rehabilitation following acquired brain injury: national clinical guidelines.* Turner-Stokes, L. (Eds.) London: British Society of Rehabilitation Medicine/Royal College of Physicians.

Turner-Stokes, L., Sykes, N., Silber, E. and Sutton, L. (2008)
Long-term neurological conditions: management of the interface between neurology, rehabilitation and palliative care. Number 10 National Guidelines. Concise Guidance to Good Practice Guideline Development Group.

Vanderploeg, R. D., Curtiss, G. and Belanger, H. G. (2005)
Long-term neuropsychological outcomes following mild traumatic brain injury.
Journal of the International Neuropsychology Society **11**: 228-236

van Manen, M. (1997)
Researching Lived Experience. Human Science for an Action Science Pedagogy. 2nd Edition, Ontario, Canada: The Althouse Press.

Veltman, A., Cameron, J. I. and Stewart, D. E. (2002)
The experience of providing care to relatives with chronic mental illness. *The Journal of Nervous and Mental Disorders.* 190, **3**: 108-114

Watanabe, Y., Shiel, A., McLellan, D. L., Kurihara, M., and Hayashi, K. (2001)
"The impact of traumatic brain injury on family members living with patients: a preliminary study in Japan and the UK." *Disability and Rehabilitation* 23, **9**: 370-378

Webb, C. (1999)
Analysing qualitative data: computerized and other approaches. *Journal of Advanced Nursing,* 29, **2**: 323-330

Weiss, R. S. (1973)
Loneliness: the Experience of Emotional and Social Isolation. London: MIT Press.

Weiss, R. S. (1982)
Issues in the study of loneliness. In: L. A. Peplau and D. Perlman (Eds.) *Loneliness: a Sourcebook of Current Theory, Research and Therapy.* New York: John Wiley and Sons. (pp. 71-80)

Wellard, S. and McKenna, L. (2001)
Turning tapes into text: Issues surrounding the transcription of interviews, *Contemporary Nurse* 11, **2/3**: 180-186

Welman, J. C. and Kruger, S. J. (1999)
Research methodology for the business and administrative sciences. Johannesburg, South Africa: International Thompson.

Wood, R. L. (1990)
Neurobehavioural sequelae of traumatic brain injury. New York: Taylor and Francis.

Wood, R. L. and Yurdakul, L. K. (1997)
Change in relationship status following traumatic brain injury. *Brain Injury* 11, **7**: 491-502

Wood, R. L., Liossi, C. and Wood, L. (2005)
The impact of head injury neurobehavioural sequelae on personal relationships: Preliminary findings. *Brain Injury* 19, **10**: 845-851

Wongvatunyu, S. and Porter, E. J. (2005)
Mothers experience of helping young adults with traumatic brain injury. *Journal of Nursing Scholarship* 37, **1**: 48-56

World Health Organisation (2001)
Year 1992-1994 International Statistical Classification of Diseases and Related Health Problems, 10th Version, ICD-10 Vol. 1-3 Geneva: World Health Organisation.

World Health Organisation (2008)
Violence, Injuries and Disability Violence, Biennial Report 2006-2007 Department of Injuries and Violence Prevention. Geneva Switzerland: WHO Press.

Ziebland, S. and McPherson, A. (2006)
Making sense of qualitative data analysis: an introduction with illustrations from DIPEx (personal experiences of health and illness) *Medical Education* **40**: 405-414

Zinner, E. S., Ball. J. D., Stutts, M .L. and Philpot, C. (1997)
Grief Reactions of Mothers of Adolescents and Young Adults with Traumatic Brain Injury. *Archives of Clinical Neuropsychology* 12, **5**: 435-447

Bibliography

Abelson-Mitchell, A. (2006)
Rehabilitation after traumatic brain injury: A survey of clients' needs and service provision in one English region. British Journal of Neuroscience Nursing 2, 6: 285-304

Abelson-Mitchell, A. (2008)
Epidemiology and prevention of head injuries: literature review. Journal of Clinical Nursing 17, 1: 46-57

Arango-Lasprilla, C. J., Ketchum, J. M., Dezfulian, T., Kreutzer, J. S. O'Neil-Pirozzi, T. M., Hammond, F. and Jha, A. (2008)
Predictors of marital stability 2 years following traumatic brain injury. Brain Injury 22, 7-8: 565-574

Ayres, L. (2000)
Narratives of Family Caregiving: The Process of Making Meaning. Research in Nursing & Health 23: 424-434

Beech, I. (1999)
Bracketing in phenomenological research. Nurse Researcher 6, 3: 35-51

Boyle, G. J. and Haines, S. (2002)
Severe traumatic brain injury: some effects on family caregivers. Psychological Reports 90: 415-425

Black, K. and Lobo, M. (2008)
A Conceptual Review of Family Resilience Factors. Journal of Family Nursing 14, 1: 33-55

Clarke, A. (2006)
Qualitative interviewing encountering ethical issues and challenges. Nurse Researcher 13, 4: 19-30

Colbourne, L. and Sque, M. (2005)
The culture of cancer and the therapeutic impact of qualitative interviews. Journal of Nursing Research 10, 5: 551-567

Conneeley, A. L. (2002)
Methodological Issues in Qualitative Research for the Researcher/ Practitioner. The British Journal of Occupational Therapy 65, 4: 185-190

Curtiss, G., Klemz, S. and Vanderploeg, R. D. (2000)
Acute Impact of Severe Traumatic Brain Injury of Family Structure and Coping Responses. Journal of Head Trauma Rehabilitation 15, 5:113-1122

Currid, T. J. (2008)
The lived experience and meaning of stress in acute mental health nurses British Journal of Nursing, 17, 14: 880-884

Danielson, C.B., Hamel-Bissell, B. and Winstead-Fry, P. (1993)
Families, Health and Illness: Perspectives on Coping and Intervention. St Louis, Missouri: Mosby.

Dikmen, S. S., Machamer, J. E., Powell, J. M. and Temkin, N. R. (2003)
Outcome 3 to 5 years after moderate to severe traumatic brain injury. *Archives of Physical Medicine and Rehabilitation* 84, **10**: 1449-1457

Emden, C. and Sandelowski, M. (1998)
The good, the bad, and the relative, part one: conceptions of goodness in qualitative research. *International Journal of Nursing Practice.* **4**: 206-212

Emden, C. and Sandelowski, M. (1999)
The good, the bad, and the relative, part two: goodness and the criterion problem in qualitative research. *International Journal of Nursing Practice* **5**: 2-7

Frank, A. W. (2002)
Why study people's stories? The dialogical ethics of narrative analysis. *International Journal of Qualitative Methods* 1 (1), Article 6. Retrieved 17th October 2006 from http://www.ualberta.ca/~ijqm/

Gan, C. and Schuller, R. (2002)
Family system outcome following acquired brain injury: clinical and research perspective. *Brain Injury* 16, **4**: 311-322

Golden, C.J., Jackson, M. L. Peterson-Rohne, A. and Gontkovsky, S.T. (1996)
Neuropsychological Correlates of Violence and Aggression: A Review of Clinical Literature. *Aggression and Violent Behaviour* 1, **1**: 3-25

Gordon, P. A. and Perrone, K. M. (2004)
When Spouses Become Caregivers: Counselling Implications for Younger Couples. *Journal of Rehabilitation* 70, **2**: 27-32

Islam, N. (1986)
On the Question of Validation in Qualitative Methodology. *Social Science Review* III, **1**: 16-31

Janesick, V. J. (1999)
A Journal about Journal Writing as a Qualitative Research Technique: History, Issues and Reflections. *Qualitative Inquiry*, 5, **4**: 505-524

Johnson, B. P. (1995)
Family's Experience with Head Injury: A Phenomenological study. *Journal of Neuroscience Nursing* 27, **2**: 113-118

Lefebvre, H., Pelchat, D., Swaine, B., Gélinas, I. and Levert, M. J. (2005)
The experiences of individuals with traumatic brain injury, families, physicians and health professionals regarding care providing throughout the continuum. *Brain Injury* 19, **8**: 585-597

Man, D. W. K. (2002)
Family caregivers' reaction and coping for persons with brain injury. *Brain Injury* 16, **12**: 1025-1037

Mezirow, J. (2000)
Learning as transformation: Critical Perspectives on a Theory in Progress. (Eds.) Francisco: Jossey-Bass.

Miller, J. F. (1983)
Assessment of loneliness and spiritual well being in chronically ill and healthy adults. *Journal of Professional Nursing* **1**: 79-85

Morris, K. C. (2001)
Psychological distress in carers of head injured individuals: The provision of written information. *Brain Injury* 15, **3**: 239-254

Morse, J. M., Barrett, M., Mayan, M., Olson, K. and Spiers, J. (2002)
Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods* 1, *2:* Article 2. Retrieved from http://www.ualberta.ca/ijqm/ on 13 October 2006.

Parker, J. (2006)
Good Practice in Brain Injury Case Management. (Ed.) London: Jessica Kingsley Publishers.

Peshkin, A. (1988)
In search of subjectivity - One's own. *Educational Researcher,* 17, **7**: 17-21

Peshkin, A. (2001)
Angles of vision: perception in qualitative research. *Qualitative Inquiry,* 7, **2**: 238–253

Ritchie, J. and Lewis, J. (2003)
(Eds.) *Qualitative Research Practice: a guide for social science students and researchers.* London: Sage Publications.

Tasker, S. L. (2003)
Acquired Brain Injury: Meaning-Making Out of Lived Trauma. *Brain Injury* 11, **4**: 337-349

Tate, R. L. and Broe, G. A. (1999)
Psychosocial adjustment after traumatic brain injury: what are the important variables? *Psychological Medicine* **29**: 713-725

Thorn, S. (2000)
Neurological rehabilitation nursing: a review of the research. *Journal of Advanced Nursing* 1, **5**: 1029-1038

Todres, L. and Wheeler, S. (2001)
The complementarity of phenomenology, hermeneutics and existentialism as a philosophical perspective for nursing research. *International Journal of Nursing Studies* 38, **1**: 1-8

Wallace, S. E., Evans, K., Arnold, T. and Hux, K. (2007)
Functional brain injury rehabilitation: Survivors experiences reported by families and professionals. *Brain Injury* 12, **13-14**: 1371-1384

Webb, D. (1998)
A 'Revenge' on modern times: notes on traumatic brain injury. *Sociology* 32, **3**: 541-555

Wongvatunyu, S. and Porter, E. J. (2008)
Helping Young Children with Traumatic Brain Injury: The Life-World of Mother *Qualitative Health Research* **18**: 1062-1074