

**The experience of families and healthcare professionals
supporting people with prolonged disorders of consciousness.**

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A thesis submitted for the degree of Doctor of Philosophy

Declaration of Authorship

I, Sonja Soeterik, hereby declare that this thesis and the work presented in it is entirely my own. Where I have consulted the work of others, this is always clearly stated.

Signed

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Abstract

For some people after a severe brain injury, states of changed awareness and consciousness can occur. Although relatively rare, when these states persist they are known as prolonged disorders of consciousness (PDoC). Research is limited on understanding the factors that make PDoC so psychologically distressing for the wider family and how best to support families. Little is known about the experiences of healthcare professionals who work with this unique clinical population. The current thesis sought to understand the experience of supporting people with PDoC in order to design an intervention to improve the psychological wellbeing of families and professional caregivers.

Chapters Two and Five, used qualitative methodologies to understand the experience from the perspective of families and healthcare professionals. Chapter Two employed an Interpretative Phenomenological Analysis methodology ($n = 9$) and led to an understanding of the possible factors that contribute to distress in families and proposed a model for the perpetuation of the complex loss they experience. Chapter Five used thematic analysis of three focus groups ($n = 21$) of healthcare professionals skilled in working with people with PDoC. Professionals were noted to experience difficulties balancing competing demands and conceptualizing family distress. A reciprocal interaction was observed between family distress impacting on professional distress and therefore professionals' distress impacting further on family distress.

In Chapters Three and Six employed quantitative methods and online cross-sectional research designs. Chapter Three described difficulties found in recruiting families of people with PDoC ($n = 8$) using an on-line methodology and proposed a theoretical model for understanding family distress. Chapter Six showed that working with people

with PDoC and their families, was associated with elevated levels of burnout and a lack of compassion satisfaction for healthcare professionals ($n = 91$).

Chapters Four and Seven, tested the proof of concept as part of the development of interventions designed based on the formative research findings from the earlier studies in this thesis. The family intervention was found to be acceptable to a panel of professionals and a lived experience expert in the area ($n = 8$) and the pilot families ($n = 2$) themselves. Healthcare professionals ($n = 60$) in Chapter Seven, reported gaining more confidence in working with distressed families following a psycho-educational training session.

Finally, Chapters Eight and Nine present the contribution of this research to the understandings of families and healthcare professionals supporting people with PDoC and reflections on future research design with this population.

Dedication:

For Tania Proudfoot whose life touched and taught many

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Chapter One

Introduction

1.1 The Impact of Severe Brain Injuries on Families

Severe brain injuries can strike previously completely healthy people without warning. The common causes of brain injuries include; traumatic brain injuries (such as from road traffic accidents, assaults and falls), acquired brain injuries (such as a stroke or a lack of oxygen to the brain, for example following a cardiac arrest) or infections (such as meningitis) (Kraus & McArthur, 2006). The first 48 hours after an injury are critical for mortality, with 98% of deaths occurring in this period (Park, Bell & Baker, 2008). As gains in medical care have increased, so too have survival rates from severe brain injuries (Leonardi, Giovannetti, Pagani, Raggi & Sattin, 2012). In survivors of severe brain injury, outcomes vary widely (from having to re-learn to walk, talk, and skills to enable a return home and/or to work, through to being totally dependent on 24 hour care, unable to eat, drink, communicate, or move independently, and at extremes lacking awareness about one's self and environment).

Rehabilitative efforts have in the past been centered on the needs of the injured person (Bowen, Yeates & Palmer, 2010). Whilst the brain injury happens to an individual, the effects are felt throughout their wider networks (Illman & Crawford,

2017). More recently there has been an increased focus in the literature that rehabilitation should take a broader view to encompass the family and recognition of the long term nature of supporting people with brain injuries (Brunsden, Kiemle & Mullin, 2015). Research has shown families are important to the injured person's rehabilitation outcomes (Kreutzer, Marwitz, Godwin, & Arango-Lasprilla, 2010) with reciprocal relationships between family functioning and the brain injured person's mood (Schonberger, Ponsford, Olver, and Ponsford, 2010). In addition, many families will provide care for their fully dependent or semi-dependent relative. Hanks, Rapport and Vangel (2007) reported that families described substantial dissatisfaction with many aspects of caregiving, especially a sense of burden and lack of mastery. Importantly, Marsh, Kersel, Havill and Sleigh (1998) found providing care for a family member who had suffered severe traumatic brain injury impacted on the caregiver's own wellbeing, with symptoms of depression and anxiety reported in more than one-third of carers. These symptoms have not been demonstrated to just improve with time (Schonberger et al., 2010).

Families are noted to be subject to complex stressors (Brunsden et al., 2015), that create great psychological distress (Kreutzer et al., 2010). These stressors last over the long term (Morris, 2001) and contribute to carer stress and burden (Nabors, Seacat & Rosenthal, 2002). Much of the brain injury literature has focused on the challenges for families to cope and adjust to the changes within the injured family member. This might include new behaviours and changes in cognition and communication (Crawford & Beaumont, 2005). Distress in families is more commonly reported as occurring in response to the cognitive and behavioural changes in the person with the brain injury (Sander, Maestas, Clark & Havins, 2013), rather than physical disabilities and alterations to the person's ability to complete activities of

daily living (Marsh, Kersel, Havill & Sleigh, 1998; Allen, Linn & Gutierrez, 1994). In dementia, caregiver burden and reduced quality of life are predicted by passivity and low mood and behavioural changes in the person (Branger, Enright, O'Connell & Morgan, 2017). In comparison, it is the aggressive behaviours of people with brain injuries that contribute to significantly more burden, poorer quality of life and mental health for their families (Jackson, Turner-Stokes, Murray, Leese & McPherson, 2009).

The long term challenges associated with brain injury can place severe strain on coping skills of families (Serio et al., 1997) and can lead to the dissolution of families (Kreutzer, Marwitz, Hsu, Williams & Riddick, 2007). In addition to the range of traditional carer support groups that operate (such as charities like Headway), systemically addressing relatives' needs during rehabilitation is recognised as crucial in governmental policy within the National Service Framework for Long Term Conditions (Department of Health, 2005). Despite conceptual and political will to recognise the valuable role families contribute to rehabilitation and the need to focus on their wellbeing, families are often reported as feeling misunderstood, isolated and unsupported (Brunsden et al., 2015).

Whilst investigations into the needs of families in severe brain injury (Schonberger et al., 2012; Marsh et al., 2002; Lezak, 1998) has occurred, little has been published on attempts to intervene and improve families' psychological wellbeing. A review of intervention literature reported only four studies attempting to intervene on caregiver distress in brain injury, and commented on randomised controlled trial studies failing to show strong evidence supporting any specific intervention for families despite an abundance of anecdotal and descriptive support (Boschen, Gargaro, Gan, Gerber & Brandys, 2007). Oddy and Herbert (2003) noted that few

studies have evaluated the effectiveness of family interventions after brain injury, despite many reporting the need for family based interventions.

1.2 Disorders of Consciousness after Severe Brain Injury

A small number of people after a severe brain injury will develop a condition known as, a disorder of consciousness. Consciousness encompasses two key characteristics; wakefulness (eyes open and a degree of motor arousal) and awareness (the ability to have and the having of experience of any kind) (Royal College of Physicians, 2013). Disorders of consciousness include three distinct conditions; coma, vegetative state and minimally conscious state (Royal College of Physicians, 2013). In a coma, a person is not awake and not aware. In contrast in the Vegetative State (VS), the person has states of wakefulness (periods of time where their eyes are open and periods of time where they appear to be sleeping) but without having awareness and behaviours without purpose that are purely reflexive and spontaneous. In the Minimally Conscious State (MCS), the person is assessed as having both wakefulness and minimal, inconsistent but definite behavioural evidence of reproducible signs of awareness of themselves or the environment (such as using objects functionally or following simple commands). The clinical features of disorders of consciousness are displayed in Appendix A.

In contrast to disorders of consciousness, a person who does have full awareness, full consciousness and fully intact cognition, but lacks ability to communicate or physically move (often the only movement under their control is being able to raise their eyes upwards), is therefore “locked” within their body. This is known as Locked in Syndrome (Royal College of Physicians, 2013). Locked in Syndrome has been popularized in the book and subsequent film, *The Diving Bell and the Butterfly* (Bauby,

1997). The key clinical features and differences between Locked in Syndrome, disorders of consciousness and brain death are displayed in Appendix B.

1.3 Prolonged Disorders of Consciousness (PDoC)

Once a disorder of consciousness has lasted more than four weeks, it is called a *Prolonged Disorder of Consciousness* (Royal College of Physicians, 2013) and this is the term that is used throughout this thesis. It is difficult to know how many people have prolonged disorders of consciousness (PDoC) due to historical difficulties with definitions and diagnosis (other terms include: Apallic Syndrome (von Wild et al., 2007), Unresponsiveness Wakefulness Syndrome (von Wild et al., 2012), Persistent Vegetative State (Jennet & Plum, 1972 cited in von Wild et al., 2012), Permanent Vegetative State, Vegetative State, Minimally Conscious State (Giacino et al., 2002), Minimally Responsive State (Giacino & Zasler, 1995). The epidemiology of people with prolonged disorders of consciousness in the UK is not known. Internationally, some studies have suggested estimates of 2 to 4 people per 100,000 (Andrews, 1996), others have suggested it is lower 0.5-2 per 100,000 (von Wild, et al, 2012) and most recently it has been estimated at 5-25 per million people (Elvira de la Morena & Cruzado, 2013). The frequency of survival with this severe brain injury has been reported to be increasing in Europe in relation to gains in medical interventions (Cruzado & Elvira de la Morena, 2013).

Prolonged Disorder of Consciousness (PDoC) can last a person's lifetime. Typically most people do not survive more than 10 years (Giovannetti, Leonardi, Pagani, Sattin & Raggi, 2013) but some people do survive 20 years or longer. There are case reports of people emerging from PDoC after years or even decades (Fins, Schiff & Foley, 2007). However this is rare in VS (after more than 12 months from a traumatic brain

injury or more than six months after acquired brain injury) and after more than five years in MCS (Royal College of Physicians, 2013). Wijdicks and Wijdicks (2006) reviewed 30 movies from 1970 to 2004 and showed that 60% of the film depictions of PDoC were typified by a “sleeping beauty” actor, lying peacefully with their eyes closed and later suddenly awakening with cognition unaffected. This is not the case. In general, the longer the person has lived in a PDoC, the more significant the person’s physical and cognitive disabilities (Katz, Polyak, Coughlan, Nichols, & Roche, 2009) when fully ‘awake’. For example, it is possible to regain awareness and still have limited functional recovery (such as requiring 24 hour nursing care, having global cognitive impairment, be unable to walk, swallow and communicate).

There is no simple, single clinical sign or test of awareness and it must be deduced (Royal College of Physicians, 2013). For assessment and rehabilitative purposes, and future long term management planning, it is important that clinicians’ distinguish a person’s diagnosis correctly. Assessment of PDoC is not straight forward, with estimates of misdiagnosis around 40% (Sattin et al., 2014) especially when blind or visually impaired (Andrews, Murphy, Munday & Littlewood, 1996) which makes assessment complex and requires a multidisciplinary team with suitable experience and expertise (Wade, 2014).

Despite a deep and prolonged alteration of consciousness that renders the person inaccessible to those around them and unable to make voluntary and meaningful responses to stimuli and the environment (Crawford & Beaumont, 2005), the person may not be sitting or lying still. They can show behaviours such as: moving their arms or legs, smiling, crying, grimacing and grinding their teeth (Royal College of Physicians, 2013). These behaviours are normally associated with emotional responses in people

without brain injuries. In PDoC these behaviours are not usually purposeful or indicative of subjective distress, and can merely reflect subcortical functioning (Crawford & Beaumont, 2005).

1.4 The Impact of Prolonged Disorders of Consciousness on Families

The Royal College of Physicians (2013) clinical guidelines acknowledged the very severe distress of families and their need for support. Having a family member who does not respond to you but wakes and sleeps, moves and makes noises and may appear to be in pain or distress, presents great emotional and social challenges for families. Unsurprisingly in the context of the injured person moving and making noises, researchers have found 90% of family members believed their relative is aware of some external stimuli, such as verbal conversation or a family member's presence (Tresch et al, 1991). Some families incorrectly interpret movements or reflexes as proof of positive prognosis (Chiambretto, Rossi Ferrario & Zotti, 2001). Many families reasonably perceive these behaviours as indicators that person is trying to 'wake up' (Jacobs et al., 1986) and that they therefore must have cognition. In the absence of communication it can be hard to understand the underlying severity of cognitive damage. In one study a third of family members (of 45) considered that the person with a PDoC could communicate, irrespective of their diagnosis (Moretta, Trojano, Cardinale, Loreto & Estraneo, 2017). Despite the formal diagnosis and opinion of the professionals, a German study found 24 % (of 44) of families did not agree with the healthcare professionals views and all families were found to maintain high hope that the person would be able to communicate in the future (Jox et al., 2015) and had unrealistic expectations of recovery (Crawford & Beaumont, 2005).

The Royal College of Physicians (2013) clinical guidelines recognise the key roles families play in assessment, clinical decision making processes and the direct care

families may provide. Studies show caregivers spend a lot of time with their family member even if they also work (Covelli, Cerniauskaite et al., 2014). However, perhaps related to the low frequency of people in PDoC, families have received limited attention in the research. Understanding of families' psychological experiences of PDoC is an emerging field. Literature remains very sparse on the unique psychological needs of families of people with PDoC (Cruzado & Elvira de la Morena, 2013; Li & Xu, 2012) despite recognition of their special needs (Royal College of Physicians, 2013), which are often forgotten (Crawford & Beaumont, 2005) and unmet (Coleman, Bekinschtein, Monti, Owen & Pickard, 2009).

A key study on the experiences of families of a person with a PDoC, is the nationwide study of the experiences of the main caregiver conducted in Italy (Leonardi et al., 2012). The strength of this study was a large sample ($n = 487$), multi-centres (69/78) and multiple regions (16/20) in Italy. The vast majority of the people with PDoC were in long-term care facilities run by religious orders ($n = 297$), some were cared for at home ($n = 58$) or in post-acute rehabilitation settings ($n = 132$). Participants were primarily female (69.2% of 487) with fewer males (28.5% of 487) and a few participants who did not specify (2.3% of 487). More than half the sample was over 50 years of age (56.1% of 487). Data was collected over a 10 month period and participants' completed a 90 minute self report battery of questionnaires assessing burden which was defined as a composition of financial, physical and psychosocial dimensions (Leonardi et al., 2012). As such a number of measures were administered assessing; health, mood, burden, coping and grief. Severe emotional burden was reported with lower physical and mental health found compared to the general population. More than 70% (of 487) reported depressive symptoms with 59.5% (of 487) showing clinically significant levels of depression. All participants' showed high

levels of anxiety relative to the normative Italian population. Close to a third of participants (27.6% of 487) were identified to experience Prolonged Grief Disorder (a clinical diagnosis of a persistent, complicated form of loss). Almost all participants stressed a high need for information and communication with the treating professionals, and the need to be involved in decision making. Religion and acceptance were frequently reported as adaptive coping strategies. This study is important as it has provided a cross sectional picture of the family experience and provides large sample enabling confidence in the findings. It identifies substantial physical and mental health challenges for relatives of people with PDoC. However, characteristics of the injured person such as diagnosis and time post injury are not recorded. It is not clear if the participants' provided a self report of the injured person's diagnosis, as research has highlighted both the challenges of misdiagnosis and the need for regular reviews of the diagnosis particularly in long term care settings (Andrews et al, 1996; Royal College of Physicians, 2013). Therefore, determining if the diagnosis of VS or MCS makes a difference and the impact of the passage of time post injury on longer term coping is not possible. The nature of the cross sectional design does not allow for inferences of causality. Nor was it reported if the participants' had any pre-injury difficulties, certainly the age of the participants (most were over 50 years of age) and the effects of normal ageing could relate to the physical health reported difficulties in this sample relative to the general population. Lastly, the nature of the role of religion was highlighted in that the long-term care facilities typically are run by religious orders and that religious based coping was prevalent. This may not be consistent with the wider international experience where it could be argued that the role of religion in society and care is less visible.

A recent Italian study assessed the impact of distress on cognitive functioning of 27 caregivers on neuropsychological tests of memory, executive functions and attention relative to 15 matched controls (Moretta, Masotta, Crispino, Castronovo, Ruvolo, Montalbano, Loreto, Trojano & Estraneo, 2017). Caregivers obtained lower scores on tests of selective attention, verbal fluency and long term spatial memory than the matched controls. The authors noted half the participants met the criteria for Prolonged Grief Disorder and showed high level of clinically relevant anxiety and depression, burden and reduced quality of life (Moretta et al., 2017). It is not clear why this would be the case. The sample is small and may not be representative of the wider population as many families return to work post-injury (Leonardi et al., 2012) and therefore would be likely to have adequate cognitive abilities to do this, but indicates that supporting families in distress needs sensitivity to their ability to cognitively and emotionally process the complex information about the injury (Rodrigue, Riopelle, Bernat & Racine, 2013).

A systematic review of the literature of the nature, frequency and severity of psychological experiences of people who have a close relationship with a person with a PDoC was conducted as part of this thesis (see Soeterik, Connolly, Playford, Duport & Riazi, 2017) using a range of databases: Cochrane Library, Web of Science, PsycINFO, PubMed, Embase®, MEDLINE®, Allied & Complementary Medicine™ from their inception until 01 December 2016. As described above (in 1.3) the term Disorders of Consciousness is used within the United Kingdom encompassing both the Vegetative and Minimally Conscious States and the search also included terms that have been used both historically and internationally (such as; Apallic Syndrome, Unresponsive Wakefulness Syndrome, Persistent Vegetative State, Minimally Conscious State, Minimally Responsive State and the Low Awareness State. The

search was restricted to peer reviewed journal articles, published in English, on humans. A manual search of the reference list of included articles to find articles that may have been missed in the electronic search strategy was conducted.

Most of the empirical studies on families' experience found were from 2010 onwards, despite having searched databases from inception. Studies pre-dominantly reported the experiences of families in southern Europe with no studies identified from the United Kingdom. Studies typically had small sample sizes (ranging from 16 to 56 participants), with the exception of the one landmark nationwide study ($n = 487$) limited variables and reliance on observational methods, which affected quality and limited generalization of findings.

The systematic review identified 18 studies that met the following inclusion criteria:

- (1) The participant had a close pre-injury relationship with a person with a PDoC
- (2) the non-injured caregiver was (the participant) the focus of the research
- (3) the psychological variables and experiences of the participant were directly studied and reported on in the article
- (4) the article was not focused on the experiences of proxy clinical decision making for the injured person or end of life care as it was not possible to determine if the psychological findings were primary or secondary to these specific decisions in this study
- (5) the methodology employed psychological self-report measures to identify the range of psychological experiences of the non-injured family member
- (6) the focus was on understanding and directly assessing the participants' psychological experience
- (7) the article was published in a journal that uses peer review
- (8) the article was published in English.

The majority of the studies identified focused on the primary caregiver (15/18). A total of 23 standardized psychological measures were identified in order to investigate 13 psychological variables experienced by the families. These variables were then grouped and abstracted to the higher order psychological construct that they assess: (i) loss and grief (ii) psychological wellbeing changes (encompassing depression, anxiety, anger, trauma, hopelessness and perceived quality of life) (iii) experience of burden and (iv) employment of coping strategies (including social support, coping styles, perceived caregiver needs, attachment style, health status). These four family experiences are reported below.

1.4.1 Wellbeing changes

Having a family member with a PDoC is an emotionally complex personal and family experience and difficult to face (Elvira de la Morena & Cruzado, 2013). Clinically significant levels of low mood typically ranging between 23-33% of the sample (Cruzado & Elvira de la Morena, 2013) have been found relative to the normative population in families of people with PDoC (Corallo, Bonanno, De Salvo, Giorgio, Rifici, Buono, Bramanti & Marino, 2015; Chiambretto, Moroni, Guarnerio, Bertolotti & Prigerson, 2010; Bastianelli, Gius & Cipolletta, 2016; Pagani, Giovannetti, Covelli, Sattin & Leonardi, 2014; Pagani, Giovannetti, Covelli, Sattin, Raggi & Leonardi, 2014; Cipolletta, Gius & Bastianelli, 2014; Cruzado & Elvira de la Morena, 2013; Giovannetti et al., 2012; Chiambretto et al., 2001; Guarnerio, Prunas, Della Fontana & Chiambretto, 2012; Leonardi et al., 2012; Giovannetti, Leonardi, Pagani, Sattin & Raggi, 2013; Covelli, Sattin, Giovannetti, Scaratti, Willems & Leonardi, 2016; Giovannetti, Covelli, Sattin & Leonardi, 2015).

Cruzado and Elvira de la Morena (2013) studied 53 Spanish caregivers of 43 patients in PDoC in an inpatient long term care service using self report questionnaires and found high levels of psychological distress relative to the normative population for each measure. Difficulties adjusting to the situation were found in 84% (of 53) of the caregivers (on a six item Spanish maladjustment questionnaire) and 30% (of 53) met the criteria for clinically significant low mood (on the Beck Depression Inventory). Cruzado and Elvira de la Morena's (2013) sample were two to four years post injury, from only one centre, primarily were female and had mixed relationships to the injured person, which all limited generalizability. However, their results concur with Giovanetti and colleagues (2013) who reported that the main caregivers are frequently in distress and showed half of the participants on self report questionnaires had a clinically significant decrease in mood. 70% reported higher levels of anxiety and depressive symptoms, lower physical and mental health.

The impact of the passage of time on family members' distress is unclear in the research. Some studies suggest low mood has been associated with less time post injury (Chiambretto et al., 2010). Whereas others have found it remains stable over time. Chiambretto and Vanoli (2006) surveyed 30 family members of people with PDoC and found significant emotional and psychophysical distress, with high levels of anxiety and depression, that did not appear to change in the 16 family members who were followed over a five year period. However, Chiambretto, Rossi Ferrario and Zotti (2001) found in a sample of 16 family members that emotional distress increased with time post injury, with men showing greater emotional distress and anxiety than women.

It is difficult to ascertain from the research how the length of time post injury

interacts with the care location. Research has suggested the location that an injured person receives care in, does influence families' wellbeing. Poorer mental health and higher anxiety were described in the post-acute facilities, possibly reflecting the earlier stage of injury compared to those with family members in long term care (Giovannetti et al., 2013). Care at home was superior to long term care facilities for others (Chiambretto & Vanoli, 2006), possibly reflecting higher control over care for the chronic condition.

Few studies have discriminated between the diagnosis (MCS versus VS) in PDoC. In those that did, the nature of the diagnosis did not seem to make a difference to the family experience of distress. Moretta, Estraneo, De Lucia, Cardinale, Loreto and Trojano (2014) studied 24 Italian family caregivers on admission to an inpatient post-acute rehabilitation unit and found irrespective of the patient's diagnosis (VS or MCS) 20/24 family members with depressive symptoms and 16/24 family members with high levels of anxiety. However, a difference was found between the needs of MCS caregivers who reported the need for more emotional and social support facilities (Giovannetti et al., 2013). This would be expected with the behavioural patterns and emerging awareness and therefore the possibility of emerging hope in caregivers.

1.4.2 Burden

Diagnosis does not appear to effect perceived burden or distress (Covelli, Cerniauskaite, et al., 2014). Emotional burden in providing care was shown to increase in 18 family members in Italy over an eight month time period (Moretta et al., 2014). This is broadly consistent with the large nationwide cross sectional study (Giovannetti, Leonardi, Pagani, Sattin & Raggi, 2013) whose findings suggested that the more care and time spent with the person with a PDoC, the greater the reported

perceived burden. This was not influenced by location of the care environment, time post injury or diagnosis but seemed mainly associated with the family members' own personal characteristics. Using the same data, Pagani and colleagues (2014) reported high levels of perceived burden accentuated distress symptoms in the participants and played a pivotal part in shaping the family members' reported needs (as assessed on the Caregivers Needs Assessment). Participation in the study was reported to have been voluntary and there was not an equal distribution of diagnosis or facility, which may have resulted in some sampling bias. The authors do not specify how the patient's diagnosis was confirmed and it may have changed over time and misdiagnosis is not uncommon in this clinical population (Andrews et al., 1996; Royal College of Physicians, 2013). In addition, only the main caregivers were participants, which does not allow sampling of the range of distress within the same family. For example, Crawford and Beaumont (2005) postulated members of the same family may experience completely different psychological reactions, like a partner accepting the situation earlier than the person's parents, thus a reduction in visiting by the partner could be viewed by the parents as a betrayal and detrimental to the person's chances of recovery. The dynamics and differences in coping between members of the same family therefore has the potential to decrease the social support and possibly impact on perceived burden.

1.4.3 Coping difficulties

Cruzado and Elvira de la Morena (2013) investigated common coping strategies (as assessed on the Coping Orientations to Problem Experiences measure) and found acceptance was highly protective but denial, self blame and emotion focused strategies were associated with higher distress. Using the same measure, Cipolletta, Gius and Bastianelli (2014) found carers' employing social support, positive attitude

and problem oriented coping strategies had better wellbeing, lower burden and grief than those using avoidance strategies.

The impact of time post injury on family members coping ability is unclear. Some researchers have found it remains stable over time. Giovannetti, Leonardi, Pagani, Sattin and Raggi (2013) found in 487 family members the use of coping strategies, was irrespective of the time post injury or the patient's diagnosis.

1.4.4 Grief

Grief was directly investigated in 9/18 studies (Corallo, Bonanno, et al., 2015; Chiambretto et al., 2010; Bastianelli et al., 2016; Elvira de la Morena & Cruzado, 2013; Guarnerio et al., 2012; Moretta et al., 2014; Cipolletta et al., 2014; Leonardi et al., 2012; Giovannetti et al., 2015) and all nine studies operationalized this using the measure Prolonged Grief-12, previously known as the Inventory of Complicated Grief (Giovannetti et al., 2012). This measure enables a diagnosis of Prolonged Grief Disorder.

1.5 Prolonged Grief Disorder

Prolonged Grief Disorder (PGD) is a complex syndrome associated with intense longing and yearning for the lost person and bitterness and desperation for life to return to how it used to be (Chiambretto et al., 2010). Grievers have debilitating reactions and are preoccupied by regret and sorrow, experience intrusive thoughts about the absence of the person and feel isolated (Prigerson, 2014). People with Prolonged Grief Disorder feel a part of them died with the person and feel unable to move beyond a state of mourning (Prigerson, 2014). PGD is a proposed clinical syndrome defined as persistent, debilitating grief reactions post-loss (Prigerson et al.,

2009) and this disorder is to be included in the 2018 International Classification of Diseases (ICD-11) (Maercker et al., 2013). Approximately 10% of bereaved people will develop PGD (Davis, Deane & Lyons, 2016) however, the systematic review showed a higher prevalence of PGD in families of people with PDoC ranging from 15% (Leonardi et al., 2012) to 60% (Giovannetti et al., 2013). PGD in PDoC was found to be distinct from depressive symptoms (Chiambretto et al., 2010). The presence of symptoms sufficient to reach a clinical diagnosis of PGD, did not appear to change over time (Pagani et al., 2014) or be related to the diagnosis of the injured person (Leonardi et al., 2012; Guarnerio et al., 2012). Characteristics of family members with PGD were linked to typically being younger themselves and supporting a person who was injured at a younger age (Chiambretto et al., 2010). The use of active and problem focused coping styles was associated with fewer grief symptoms, whilst denial and self blame were associated with more (Giovannetti, Covelli, et al., 2015). In one study, women were twice as likely as men to meet the criteria for PGD (Cruzado & Elvira de la Morena, 2013) whilst another study found no difference in gender (Pagani et al., 2014).

In the large Italian national study, close to a third of families met the criteria for PGD compared to the normative sample (Leonardi et al., 2012). Unfortunately, time post injury was not described, so no inferences about how the main caregivers' grief may change over time are possible. Nor was it reported how being the "main" caregiver was defined or the response rate in this study, therefore it is not possible to understand how who participated has affected the results. It is possible that people who were coping well or who were very distressed opted not to participate, for example.

Guarnerio, Prunas, Della Fontana and Chiambretto (2012) recruited 40 main caregivers of people with PDoC within two long term care units to complete a range of questionnaires assessing the prevalence of grief, depression and post traumatic stress. Caregivers were primarily female (77.5%) and less than half were employed. 40% of were spouses. 45% of the sample was diagnosed with PGD or Depression on the basis of their responses to questionnaires, or Post Traumatic Stress Disorder (through structured clinical diagnostic interview), with 25.71% receiving at least two diagnoses. There was no significant difference between main caregivers of people with diagnosis of VS or MCS. Post traumatic stress disorder symptoms on the Davidson Trauma Scale were predictive of developing PGD. The data collection was quite protracted (over an 11 year period) and it is difficult to assume other variables were able to be held constant as the nature of care and knowledge about PDoC in the two long term care units is likely to have changed over that time period in response to recent developments within in the field on assessment and diagnosis. It is therefore likely that a degree of bias was introduced. Nonetheless, the study adds to the literature on the role of loss, grief and distress amongst primary caregivers.

Elvira de la Morena and Cruzado (2013) also found grief and loss in a study in Spain using the Prolonged Grief Disorder questionnaire. A cross sectional study of 53 primary caregivers of 43 patients in PDoC (diagnosed for less than 3 years) who were resident in a long term care hospital showed a high prevalence of grief. Whilst this represents a small sample size, it also demonstrates the experience of loss and grief in primary caregivers within the family, and supports the Italian findings. However, a significant limitation of all the studies is that the operationalizing of grief utilised the PG-12 questionnaire, which was conceived to study the effects of a finite and death related bereavement.

1.6 Loss in Prolonged Disorders of Consciousness

Research in families of people with PDoC has shown a complex form of loss (Chiambretto, 2001; Hamama-Raz, Zabari & Buchbinder, 2013). PDoC do not produce a death and there is no clear and finite situation to adjust to. Families' losses are enduring and they remain emotionally and materially in the injured person's life (Leonardi et al., 2012). Lezak (1988) recognised families of people with a severe brain injury as being unable to mourn their loss, because it is socially unacceptable to mourn whilst the person's body remains alive. An early descriptive paper described the VS as causing an "emotional paradox" for families (Stern, Sazboon, Becker & Costeff, 1988). The family has to face the paradox of not being able to rely on traditional ideas and tasks of mourning to cope with their losses, as the person is not dead (Stern et al., 1988). This complex loss was also described more recently by Chiambretto (2001), who also found spouses suffered from an emotional paradox as their partners were neither dead nor alive (in a familiar way) which created a situation that made it difficult to mourn.

Qualitative research has suggested different ways to understand families' loss in PDoC. The systematic literature search conducted as part of this research, also identified six qualitative studies. An Italian study using grounded theory constant comparative method with 20 family caregivers of people with PDoC found four themes; another person with a past in common; losing and finding myself; old and new ways of being in the relationship; dealing with concerns (Giovannetti et al, 2015). Participants were interviewed for an average of 37 minutes which seems quite brief to establish the depth of understanding of such an emotionally distressing topic. Participants had a wide range of ages (32 to 74 years), were mainly female (n=15/20),

with a variation in time post injury (1 to 17 years), diagnosis (VS $n = 11$, MCS $n = 9$) and location of care (home $n = 8$, long term care facility $n = 12$). All were parents or partners. This reliance on the primary caregiver, makes it unclear if wider familial networks would report similar information. They concluded, in keeping with the earlier authors description of the situation as creating an “emotional paradox” (Stern et al., 1988; Chiambretto, 2001), that the core and salient feature of all these themes is the experience of “ambiguous loss”.

Similarly, Hamama-Raz et al (2013) found two of their participants described a sense of loss that their husbands “*were present but missing: they were not in the world of living but were also not in the world of the dead*” (Hamama-Raz et al., 2013, p.236) - a sense of mourning which the authors considered was not a traditional mourning concept. This Israeli study examined the meaning of being Jewish and the wife of someone in a VS following medical complications (Hamama-Raz et al., 2013). The 12 participants were found to have an “emotional duality” in that they were in process of finding significance in the situation based on accepting the husband’s condition and focusing on positive emotions and values such as love, commitment and loyalty. However, they were also coping with an increase in negative emotions such as sadness, pain, loneliness, loss and grief with ambivalent thoughts about their husband’s future death. There are limitations to this study. The methodology of their qualitative study is unclear, the sample characteristics are varied with a range in the time post injury (14 months to 10 years) by age (38 to 85 years), length of relationship with the injured spouse and experience of having had therapy for the situation ($n = 4$ of 12). All mechanisms of the development of the PDoC stemmed from an underlying medical condition and did not include traumatic brain injuries. The authors reported

recruitment challenges, four potential participants declined due to fears of becoming emotionally overwhelmed by sharing their feelings.

In Iran, longer term PDoC care is delivered by the family and funded by the family. Goudarzi, Abedi, Zarea and Ahmadi (2015) employed a content analysis method and reported data saturation at 16 participants. They used a very diverse sampling technique comprised of their own observations, both male and female participants and home based carers who were either family members or professionals. Family and professional caregivers reported caring to be difficult physically, financially and emotionally, with a wider impact on the family system more than just the primary caregiver effected (Goudarzi et al., 2015). Another Iranian study using a grounded theory method achieved data saturation at 12 participants (Noohi, Peyrovi, Imani Goghary & Kazemi, 2016). There was heterogeneity in participants with both professional ($n = 2$) and familial caregivers ($n = 10$), and inclusion of three males and nine females. There were differences in relationship to the injured person and duration of time caregiving (6 months to 60 months). This study identified four categories relating to the roles of family, the roles of healthcare staff, specifically nursing, in assisting family knowledge and skills, the roles of the wider social network and the lack of support experienced. Participants' described a sense of rejection from the medical team by feeling forced to take injured family members home irrespective of their concerns. They also described a lack of governmental support and the gradual loss of support of their own support networks.

The exact nature of the methodology of Covello, Cerniauskaite, Leonardi, Sattin, Raggi & Giovannetti, (2014) study on 15 female caregivers is unclear. They reported using both a thematic analysis and a grounded theory approach to analysis. However, their

description in the method section suggests a thematic analysis was used. The authors did not find any differences in the experience of mothers or wives nor by the injured person's diagnosis, however time post injury and location of care did have an effect. Six themes were identified (changes in life perception, pragmatic changes in everyday life, changes in individual perceptions, changes in interpersonal relationships, expressed needs and perception about future). Importantly, Covello and colleagues (2014) describe the women *"living in the present but longing for the past, with an unthinkable future"* (pg 6) and the mixed use of past and present tenses when the women spoke about the injured person. They defined this a "time gap experience". All the participants were 5 years post injury. Given the emotional content of these interviews, it was surprising that many were conducted in 40 minutes or in as short a time as 32 minutes. This is a potential limitation in trying to establish depth and breadth of experience whilst managing rapport and engagement.

1.6.1 Ambiguous Loss

Pauline Boss (1999) first described Ambiguous Loss as created by situations where the losses are complicated and undefined. When a person survives an initial injury, a PDoC creates an ambiguous loss because the injured person is physically present (lying in bed or seated in a wheelchair) but is psychologically absent (unable to communicate, respond meaningfully or look at their visitors) (Illman et al., 2017; Giovannetti et al, 2015; Hamama-Raz et al., 2013). Boss (1999) argues Ambiguous Loss blocks grieving, as it is not readily clear what is to be grieved as gone when the person (their physical self) is still present. In other forms of ambiguous loss, the person may be psychologically present but physically absent, such as: children after divorce, military personnel who are missing in action, or the families of the missing in the 9/11 World Trade Centre collapse or missing on board the Malaysian Airline.

Ambiguous loss has been reported previously in dementia (Garwick, Detzner, & Boss, 1994; Caron, Boss & Mortimer, 1999). However ambiguous loss in PDoC whilst similar in form (psychological absence but continued physical presence) differs in a number of important ways. In dementia, the person is typically older, there are early warning signs, investigations and then a formal diagnosis that provides a sense of a turning point (Garwick et al., 1994) and the possibly an opportunity to plan together as a family how to manage the advancing condition. Dementia is a familiar concept in the lay public and follows a fairly typical trajectory with the eventual psychological loss and increasing absence happening increasingly and slowly over time. In PDoC by contrast, there is a limited understanding of complex concepts of awareness and consciousness in the lay public and unhelpful representations of PDoC in the media (Rodrigue et al., 2013). PDoC creates an immediate, sudden and unexpected relationship change (Cipolletta, Pasi & Avenasni, 2016) with a lack of certainty about the prognosis (Elvira de la Morena & Cruzado, 2013) and the uncertainty about responsiveness (such as, if someone's eyes open when I speak, does this mean he recognises my voice?). The static nature of the condition and uncertain future (Giovanetti et al., 2013) contributes to intense emotional suffering (Noohi et al., 2016). Families have been described as wanting an end to the situation, but feeling ambivalent about that being an end to the person's life (Hamama-Raz et al., 2013; Cipolletta et al., 2016), and questioning of the value of the person's life (Illman & Crawford, 2017). Crucially in PDoC, families maintain hope for recovery, but any gains that meant only increased awareness in the injured person of their situation, were not desired (Cipoletta et al., 2016).

Boss (1999) described ambiguous loss as a “frozen grief” because it is unclear how to adjust to it. Boss (1999) posits that because of an inability to resolve ambiguous loss (such as dying or recovering in PDoC), it has to be tolerated. Coping with a persisting ambiguous loss has been demonstrated to inhibit meaning making, coping and grieving resulting in depression, anxiety and family conflict (Berge & Holm, 2007). Without overt death, it seems premature to grieve and

- Uncertainty means adjustment can not occur because it is uncertain what one is supposed to adjust to
- Rituals are not available (such as a funeral) and there are few social supports (people are confused about whether to express sympathy or maintain a stoic sense of normalcy or hope)
- The irrationality of life is on display, it is hard to feel that there is a rational world when nothing seems clear or rational
- The grief is unending, the uncertainty drags out and there is little ability for resolution.

In contrast to the European approach where diagnoses of PGD as a description for the experiences of families has predominated, Ambiguous Loss a “goodbye without leaving” (Boss, 2007; Frank, 2008) has begun to gather interest as a construct to understand the experiences of families of people after brain injury within the United Kingdom and North America. Kean (2010) studied ambiguous loss in 24 family members of nine male patients with severe brain injuries in an intensive care unit (ICU) in Scotland. The methodology was constructivist grounded theory and focus groups of members of the same families. Kean (2010) concluded that experiencing loss in the presence of the person, causes confusion and suffering. Furthermore, that uncertainty about how to move forward in future whilst in an ambiguous situation,

described by Kean as “mapping the future” was identified. As all the families involved had a relative in ICU they were at a very early point in the injury process and uncertainty about the short and medium term is to be expected.

1.6.2 Psychological theories of loss and grief

Traditional grief theory has focused on themes related to the rupture of the attachment and bonds the person had with the deceased (Bowlby, 1980). Prominent in the literature are the stages (Kubler-Ross, 2009; Parkes, 1972), tasks (Worden, 1982) and phases (Bowlby, 1980) that someone affected by loss must do to progress to a point of establishing their new normal and ability to enjoy life, despite their loss. Grief does not simply resolve with time, but the person must *do* something to actively manage/work through their pain, in keeping with the classical “grief work hypothesis” of Sigmund Freud (Stroebe & Schut, 1999). Normal grieving has been defined therefore in terms of progress with moving on with life and abnormal grieving, a failure to “accommodate” to the loss.

More recently there has been a paradigm shift. Some authors have argued that the traditional discourses of grief have focused on practices or pathologizing (Kitzinger & Kitzinger, 2014) those living with loss (Ord, 2009), others have observed that there is no actual conclusion to the grief process, but rather an integration of the grief into an individual's life (Tully, 2003). Despite the classical grief theory ideas about the need to let go of the deceased to be free to make new attachments and construct a new identity, modern research has shown there seems value to having a sense of holding on and still being connected to the deceased. The Continuing Bonds Theory (Klass, 1996) built on attachment theory, asserts that although still recognising and acknowledging the death, it is still possible to have an ongoing but transformed

emotional relationship with the deceased. In this way, the task is to hold on to a bond rather than to sever it and let go. This is illustrated by the ways families acknowledge their bonds with deceased family members, for example by mentally talking to them, toasting them at special events, visiting the graveside etc. In addition, The Dual Process theory built on Bowlby (1998) task ideas in grieving and the phases of disorganization and re-organisation (Strobe & Schut, 1999). Strobe and Schut (1999) envisioned an ongoing process of “oscillation” between loss orientation and restoration orientation. This oscillation allows the bereaved individual to both recognize the loss and experience the grief, and have time away from active grieving to focus on rebuilding one’s life. This recognizes that it is not possible to solely grieve, and that a person must continue to do daily tasks (restoration orientation) but as thoughts or triggers occur in the day the person may move to the (loss orientation) form of grieving. This enables a dose effect of grieving (Strobe & Schut, 1999). Contemporary research is interested in the theory of Meaning-Making after stressful life events such as bereavement. Neimeyer (2000) theorises that the grieving process is a way of meaning making, incorporating sense making and benefit finding. Loss of a loved one challenges the assumptions that once gave meaning to life and the process of making meaning involves imposing a structure on life so it is coherent, organized, understandable and predictable (Hadad, 2009).

1.7 Limitations of the evidence base

Firstly, the wider international experience has been reported (of Spain, Iran, Israel and Italy) but there is an absence of information about the experience of families in the United Kingdom (UK). The cultural differences, especially the role funding for long term care and of religion in these societies, expectations about the extended family network providing long-term support and potentially less tolerant views to separation

or divorce by the spouse of a brain injured patient, may have led to cultural differences and results that may not be anticipated in the British setting. The UK also clearly has differences in health and social care provision. In the UK care is largely state funded, provided in large specialist hospitals and residential facilities or supported at home. It could also be argued that the UK has a large multi-cultural and multi-faith based population, but has a secular culture in provision of care.

The experience of having a family member with a PDoC is clearly unique and distressing. The systematic search of the quantitative literature has research to date has focused on four themes; grief, burden, coping and wellbeing but there is a dearth of information on the lived experience and meaning making of families with a person with a PDoC. The systematic search yielded only six studies that employed qualitative research methods to explore this unique area. Variation in methodology was apparent in the six qualitative studies identified that attempted to understand the lived experiences of participants. These used primarily grounded theory methods and thus heterogeneous samples to build a group picture to develop theory and generalizability, but are limited by sample sizes of less than 20. Only one study (Cipolletta et al., 2016) described Interpretative Phenomenological Analysis (IPA) methodology. However, the design and data analysis of this study raise questions about their implementation of IPA, as the authors reported searching for themes across the whole sample rather than at a participant level, a large sample and concluding the study to theoretical saturation, which are not processes of interpretative phenomenological analysis (Smith, 2017). Further, this study involved heterogeneity in the characteristics of the large sample ($n = 24$) including gender, relationship to the injured person, age (32 years to 70 years), time since injury (less than a year to 27 years) that is not common in IPA, which rather seeks to establish

homogeneity in a small sample (Smith, 2017). It is also not established if the Italian context of this study has theoretical transferability to the United Kingdom context.

A lack of homogeneity was also observed in recruitment of participants in the existing qualitative literature. Variations in the participants' characteristics (such as gender, age, relationship to the injured person, level of responsibility in providing care), the setting the injured person is cared for in and the nature of the person's injury (such as diagnosis, time post injury, cause of injury) are apparent and limit broader interpretation about experiences. For example, Iranian research described both male and female family and professional participants who provided and funded care at home (Noohi et al., 2016; Gourdarzi, et al., 2015), in Italy (Cipolletta et al., 2016) where both male and female carers were sampled in long term care settings and Israel (Hamama-Raz et al., 2013) where Jewish female spouses of a person with a PDoC that arose from medical complications and are cared for in a hospital setting have been studied.

In the 18 relevant studies identified in the quantitative literature, research has been challenged with balancing relatively small numbers of people with PDoC with the need to recruit sufficient research participants in a similar setting, who are themselves often distressed and focused on the care of the injured person not on themselves. Whilst some samples have been large, recruitment challenges have led to small sample sizes (often less than 50 participants) or collection of data over a protracted period of time (over 11 years in one study). Studies have mainly employed cross sectional designs limiting making causal conclusions and little is known of the longitudinal experience of these families. Few studies have been able to stratify the sample and describe the impact of time on coping with a family member with a PDoC

and it is anticipated that the family systems would make adaptations to their functioning over time. Indeed, in other areas of severe brain injury, few studies investigate caregiver experiences past five years post injury (Vogler, Klein & Bender, 2014).

Researchers have noted the loss and grief of families and measured this using bereavement related grief questionnaires, whilst commenting on the peculiarity of the non-death loss. Kitzinger and Kitzinger (2014) were critical of the PGD research focus on pathology in families with a relative with a PDoC, rather than understanding family emotion as a normal response to a terrible situation. Ambiguous Loss as a construct is beginning to gather research interest and this allows for a new way of understanding and investigating non-death losses without seeing interpreting the pathology as sitting within the family member, but rather within the situation.

The focus of all the literature is on the individual carer within the family system. Family systems are constructivist in nature, where members construct, maintain and share their independent and interdependent lives. The quantitative cross sectional methodologies used have been on questionnaire based self reports of the identified primary, main family member who is often a female spouse. In practice, there can often be more than one family member who could qualify as the main caregiver. For example, a person with a PDoC wife may have had to balance work and spending time with their children, so instead a retired parent (such as the injured person's mother) may devote more time to the bedside. Understanding the needs of the wider family is important as the interactions between family members can help with a sense of coping and support or create additional stressors. The limitation of the focus on the primary caregivers has led to the potential of missing a range of important

experiences and understanding the possible impact of the different relationships with the injured person and gender on the experience.

Future research would benefit from a wider selection of variables, longitudinal design and comparisons of participants' responses, not only with the normative sample for the measure, but also with comparison groups that may have clinical parallels, for example profound neuro-disability but with a reliable yes/no communication method. This should help to identify the specific group and timing of those who need targeted support from professionals.

1.8 Conclusions drawn from the literature on the family experience in Prolonged

Disorders of Consciousness

Illness changes family functioning (Noohi et al., 2016). The experience of having a family member with a very severe brain injury has been increasingly described in the literature and illustrates that having a family member with a brain injury is both psychologically distressing and burdensome. Families of people with severe brain injury report physical disability is less problematic than behavioural changes. In contrast to what has been identified as challenging for families after brain injury, families with a person with a PDoC are faced with their profound physical disability and a distinct *lack* of behaviour or behaviours that can not be interpreted as always meaningful. However, the unique challenges of having a family member with a PDoC has only just begun to receive research interest. Whilst quantitative literature has addressed frequency of families of people in PDoC sense burden, loss and grief and ongoing psychological distress, this measures the impact but does not help understand what makes the PDoC distressing in the first place. The qualitative literature has described a form of unending loss. There is a need to better understand what underpins (the precipitating and perpetuating factors) the psychological loss and

distress reported as some families do find ways to manage independently but others exhibit clinically significant psychological distress that does not change over time alone and may get worse. Further research is need to establish how to best understand and support their psychological needs.

1.9 Challenges for Healthcare Professionals in Prolonged Disorders of Consciousness

As described above, PDoC, caregiving involves little, or no meaningful interactions with the person with the PDoC (Royal College of Physicians, 2013). In addition to the support of families, most people with PDoC in the United Kingdom receive their substantive rehabilitation and care from healthcare professionals. PDoC are chronic conditions. Crawford and Beaumont (2005) described traditional ideas of professional job satisfaction as being tested due to little improvement or change in a person with in PDoC presentation over time. In other areas of practice such as oncology palliative care, the discrepancy between curative training models for professionals and the clinical situation that can not be altered, can contribute to a sense of helplessness, personal failure and burnout (Whippen & Canellos, 1991).

Montagnino and Ethier (2007) interviewed eight nursing staff caring for children in PDoC and concluded that the experience was both emotionally conflicting and stressful as well as ethically challenging. Ethical questions arise for healthcare professionals in PDoC in regard to long term clinical management, particularly in relation to decisions not to treat acute infections or other life threatening conditions and indeed regarding the withdrawal of artificial hydration and nutrition from a person, which will ultimately lead to their death. In the United Kingdom, families may make applications to the Court of Protection in regard to the withdrawal of artificial hydration and nutrition (removal of the feeding tube), which will subsequently lead to

the end of life of the person with a PDoC, and the same team who have been caring for them and keeping them alive will be required to support their end of life care (Royal College of Physicians, 2013). However, little has been published on the perspectives of healthcare professionals (Rodrigue et al., 2013).

In a survey of the views of British consultant medical staff about the best care and management for people with PDoC, 90% (of 1027) considered that not treating acute infections and other life-threatening conditions was best, and 65% (of 1027) considered that the withdrawal of artificial nutrition and hydration was appropriate (Grubb, Walsh, Lambe, Murrells & Robinson, 1996). This finding is similar to research carried out fifteen years later with European PDoC healthcare professionals, where 66% (of 2475) agreed that the withdrawal of artificial nutrition and hydration for people with chronic VS (>1 year) was appropriate (Demertzi et al., 2011). However, this differed by profession, with fewer nursing staff (28% of 2475) agreeing that it was right to withdraw treatment, and by condition, with respondents considering the MCS worse than the VS for patients (54% of 2475) and their families (42% of 2475) (Demertzi et al., 2011). Demertzi and colleagues (2011) also investigated the conflict between what healthcare professionals would want for themselves in a similar situation and treating others. The authors reported that 82% (of 2475 European healthcare professionals working in this area) of the respondents to the questionnaire wished not to be kept alive if they themselves were in a VS.

This research indicates that there are PDoC specialists who provide intensive complex assessment and care for people with PDoC but may have a level of personal conflict and discrepancy about this (Rodrigue et al., 2013), believing it is best not to continue their care (Grubb et al., 1996), and not wanting to have their own life maintained if

they were in a similar situation (Demertzi et al., 2011). In addition, PDoC specialist healthcare professionals are challenged by their unique relationship with their patients, in which patients are unresponsive or mainly unresponsive and this may be lifelong, and, where they, as professionals, have little ability to alter the situation. This can challenge their professional self-perception about the nature of their role and their job satisfaction (Crawford & Beaumont, 2005).

1.9.1 Burnout

The nature of healthcare work in general is linked with a high risk of wellbeing changes, burnout, moral distress and compassion fatigue (Sanchez-Reilly et al., 2013). British healthcare professionals have been found to have poorer psychological health (26.8% of 11637 respondents, compared to 17.8% in the general population) on the General Health Questionnaire-12 (Wall et al., 1997). Quality of life of healthcare professionals can be affected in those who provide care for people with complex (a combination of profound intellectual impairment and serious motor difficulties) and severe difficulties (Rousseau et al., 2017). A systematic review of healthcare professionals' wellbeing and burnout showed an association with medical errors and patient safety (Hall, Johnson, Watt, Tspia & O'Connor, 2016).

Schaufeli and Greenglass (cited in Kristensen, Borritz, Villadsen & Christensen, 2005) define burnout as resultant from long-term work that is emotionally demanding, creating emotional, mental and physical exhaustion. Two studies were identified that investigated burnout in healthcare professionals supporting people with PDoC in the European context (Italy and Belgium) using the Maslach Burnout Inventory (Leonardi, Pagani, Giovannetti, Raggi & Sattin, 2013; Gosseries et al., 2012). In a national study in Italy, 41.7% of 1149 healthcare professionals working with people with PDoC in the

long term care and post-acute neuro-rehabilitation settings, showed high scores on at least one subscale of the Maslach Burnout Inventory (Leonardi et al., 2013). They noted their sample (73% response rate) showed similarities to the scores of dementia healthcare professionals, but were lower than oncology professionals and the normative data of Italian healthcare professionals in general (Leonardi et al., 2013). The study found nursing professionals reported statistically significantly higher levels of depersonalisation (a lack of feeling and impersonal responses toward the person you provide care and treatment to) and lower levels of Personal Accomplishment compared to other professional groups. There was a tendency for those working the longest with this clinical population to show higher rates of burnout. The authors concluded that prevention of burnout symptoms and enhancement of the well-being of healthcare professionals was important to the care and quality of life of the person with a PDoC (Leonardi et al., 2013).

Burnout was identified in one fifth of healthcare professionals (18% of 568) of people with PDoC in Belgium particularly amongst nursing professionals, in longer term care nursing home settings and who had spent longer periods of time with patients (Gosseries et al., 2012). This study obtained a 53% response rate to a nationwide recruitment across centres specializing in PDoC. This study showed nearly double the reports of emotional exhaustion (33% of 523) and depersonalization (36% of 523) compared to the findings of Leonardi and colleagues (2013). This difference appeared to mainly relate to the different scoring criteria of when the authors considered a person had reached a clinically significant score. They ignored the Personal Accomplishment arguing it was not consistent with burnout and if one of the two remaining subscales on the Maslach Burnout Inventory was elevated they defined that as moderate Burnout and if both were elevated, high burnout. In contrast, the

Leonardi and colleagues (2013) study used cut off points per scale to group low, moderate and high scores defining one high scale of the three as meeting the criteria for burnout.

1.9.3 Collaboration and support with the families of people with Prolonged Disorders of Consciousness

In addition to the challenges of assessment and diagnosis described earlier in recognising people with a PDoC, it is also not possible to ascertain the views of the injured person in the absence of advance care plans. In many areas of healthcare, adult patients are typically able to provide information about their own wishes, life choices and decide what treatments they accept. This is not possible when a person has continued unconsciousness and instead families must be closely and fully involved from admission, contributing and giving information as part of the best interests decision-making process and be involved in best interest's meetings (Wade, 2014). Families are often with the person with a PDoC a lot and therefore play a key role in assessment and diagnosis, and it has been noted that many people with PDoC respond at an earlier stage to familiar people (Royal College of Physicians, 2013). Other researchers have advised that accuracy and improvement in the diagnosis has been found when families have been present during assessments (Moretta, Trojano, et al., 2017; Sattin et al., 2014).

However, scientific information about PDoC remains incomplete (Farisco, Alleva, Chiarotti, Macri & Petrini, 2014) and misunderstandings about diagnosis is a common source of difficulty and disagreement between healthcare professionals and families (Moretta, Trojano, et al., 2017). Crawford and Beaumont (2005) hypothesized that misunderstandings may arise from a lack of clarity by professionals when explaining

the diagnosis to the relatives leading to false hope; in part from the uncertainty of the prognosis or that professionals may communicate their own lack of certainty. As mentioned above (see *The Impact of Disorders of Consciousness on Families*) families' understandings and expectations in PDoC can be very different to the healthcare professionals' views. Edgar, Kitinger and Kitinger (2015) analysed 51 interviews of people who have or have had a family member with a PDoC using a philosophical analysis (an approach to examine a research problem by challenging embedded assumptions underpinning an area of study; Lynn University, 2017), which suggested that tensions and ruptures in communication between staff and families can be explained by the healthcare professionals reliance on a medical science framework, such as the findings on standardized observation tests. In contrast, families were more likely to use an interpretative framework combining their sense of the patient's uniqueness and the family relationship to them as a social being (for example, interpreting a grasp of their hand as holding their hand). Family members have been reported as showing hostility towards staff caring for the person with a PDoC (Stern et al., 1988) and of making seemingly minor complaints about nursing tasks, or cleaning standards on the ward (Crawford & Beaumont, 2005).

Some families have been noted to request treatments that healthcare professionals do not consider will benefit the person (Latchem, Kitinger & Kitinger, 2015) which Crawford & Beaumont (2005) postulated may reflect an underlying belief that recovery is related to the amount of treatment provided. Others have found that the purpose of interventions such as physiotherapy, can be misinterpreted by family members (Latchem et al., 2015).

For healthcare professionals working with people with PDoC the assessment and diagnosis is complex and needs a team approach (Wade, 2014), families are distressed and have high needs and demands for information and communication with the professional (Leonardi et al., 2012), expectations for recovery (Jox et al., 2015) and desire for treatments that may not be seen by the professional as required (Latchem et al., 2015). PDoC settings are demanding and have the potential to be emotionally confronting to the healthcare professional placing them at risk of burnout. These challenges are embedded amongst broader ethical questions for the healthcare professional (Demetrzi et al., 2011). Research to date has examined the frequency of burnout but not what specifically contributes to this in PDoC.

1.10 Aims of the present research.

1. To investigate the psychological experience of families and healthcare professionals who support people with PDoC.
2. To investigate what needs changing to improve their psychological condition.
3. To develop and pilot a proof of concept psychological intervention to enhance coping for families and facilitate confidence in health care professionals working with families of people with PDoC.

1.11 Objectives of the research.

This thesis is presented in two parts. In Part One, formative mixed methods approaches were employed to investigate the experiences of families in order to develop a theory informed, acceptable psychological intervention.

In Part Two, formative research methods were used to investigate the experiences of healthcare professionals in order to provide an intervention to enhance healthcare professionals' understandings and interactions with families.

1.12 Clinical Significance

Due to the rarity of PDoC, clinical healthcare professionals do not currently have much of an evidence base in the scientific literature to draw from in designing and selecting interventions to use specifically with families of people with PDoC who present as complexly distressed. To date it has been assumed that interventions effective for other conditions have merit for families of people with PDoC and are routinely modified and used by clinicians. This thesis is intended to explore the appropriateness of the current practice of modifying interventions designed for other conditions and add to the evidence base for practitioners, thereby improving the scientific evidence base and thus treatment and services offered to families.

It is intended that the results of the investigations reported in this thesis will improve the psychological wellbeing of families of people in disorders of consciousness both at the research site, the Royal Hospital for Neuro-disability a national tertiary referral centre for severe and profound brain injury, and for families more widely, as findings could form the basis of a best practice model for clinicians in the field, nationally and internationally. This will also enable services to meet their policy requirements of supporting families prescribed by government policy in the National Service Framework for long-term neurological conditions.

PART ONE

The experiences of families supporting people with
prolonged disorders of consciousness

Chapter Two

“Neither a wife nor a widow”: The experiences female family members supporting people with prolonged disorders of consciousness.

2.1 Introduction

Research in PDoC has demonstrated that the injury impacts not only on the injured person, but also on all the people they have relationships with (Illman & Crawford, 2017; Noohi et al., 2016; Gourdarzi et al., 2015). Hamama-Raz and colleagues (2013) noted women are commonly expected to be caregivers and are greatly distressed by disruptions in interpersonal relationships in PDoC. Chapter One showed there is a limited research base on the experience of families with a few descriptive discussion papers, 18 quantitative studies focused on four psychological constructs, and six qualitative studies published on the experiences of families of people with PDoC. The literature describes psychological distress and a higher prevalence of prolonged grief disorder in families of people with PDoC, but also acknowledges that there are unique challenges in grief for family members of a person with a PDoC (as families have to deal with the psychological absence of the person they knew, in the presence of the body of the person they love). Little has been reported about what that unique loss is like and what the psychological effect of this is on the family. As described in Chapter One, previous qualitative research with families of people with PDoC may not have theoretical transferability to the UK setting.

Qualitative research is helpful in exploring a phenomenon that has had limited research focus, as a tool to understand individuals and to develop a more in-depth understanding of the complexity and issues (Barker, Pistrang & Elliot, 2016). Understandings of the experiences of families in PDoC remain in their infancy. Interpretative Phenomenological Analysis (IPA) is a methodology designed precisely for psychological examination of participants' lived experiences (Smith, Flowers & Larkin, 2009) and is particularly suited to examining "unexplored territory" where there are theoretical gaps (Reid, Flowers and Larkin, 2005). IPA seeks to understand the idiographic (unique to the individual) focus and the pattern of meaning making across individuals to offer theoretical transferability (Smith et al., 2009). In recognizing that there is no direct way to investigate the phenomenon of research focus, IPA was developed by Smith (1996) as an approach to get "experience close" (Smith, 2011) and examine how people make sense of their major life experiences and aims to understand what it is like to experience particular conditions and how people manage in certain circumstances. By examining the participants' psychological world (Willig, 2013), meanings and experiences, it enables the researcher to gain an "insiders" perspective (Smith, Jarman & Osborn, 1999) to the phenomenon of interest.

IPA has theoretical basis in both phenomenology and hermeneutic (interpretative) enquiry (Smith et al., 2009). IPA assumes that when the person describes their experience of the phenomenon of research interest to you, the act of describing and finding words to explain it, is already a process of interpreting and making meaning about their situation. In this way IPA methodology involves a double hermeneutic (Smith, 2011) where the participant attempting to explain and make sense of their

own situation, whilst the researcher is interpreting through their own conceptions (Willig, 2013) and making sense of the participant reports of their experience.

IPA draws from a range of philosophical phenomenological stances into a research methodology, which allows for these to complement each other rather than compete (Smith et al., 2009). From the work of Husserl, IPA employs the concept of “bracketing” and adopting the phenomenological attitude as vital to research (Biggerstaff & Thompson, 2008). This is a way of consciously and deliberately taking a step aside from the theory and ideas brought by the researcher into the room, in order to focus on what is important to the particular participant and on what their own meaning making is (Smith et al., 2009). This creates an epistemological openness, in that there is an acceptance of what the participant says as a reflection of their experience of their reality and this is tempered by their own context (culture, time situation etc.) (Smith et al., 1999). This allows IPA to be an inductive approach, seeking to build from the interview transcripts to aid theory generation, rather than searching the “data” to test a priori hypotheses and confirm prior assumptions (Reid et al., 2005).

IPA’s concern with depth of the participants as particular people in a particular context, means that it does not seek to offer generalizability to wider population but rather that it offers a “theoretical transferability” (Smith et al., 2009, pg 38). This is useful in formative research where investigating lived experience can guide identification of constructs for study in larger quantitative research. IPA is increasingly used as a specifically psychological research method (Willig, 2013), and has been regularly used in psychological distress and carers’ experience research (Smith, 2011).

Other qualitative approaches were considered but rejected. IPA was considered as more useful to this research question as a methodology than thematic analysis as rather than identifying the themes at face value, it is more focused on depth and use of hermeneutics to understand how participants are making sense of their experiences and stems from a critical realist/contextual constructivist epistemological perspective. This was judged as important in order to situate the participants' experiences within a social context and to be able to reflect upon how broader contextual factors impact upon the way the women understand their situation and experience of having a family member with PDoC.

Grounded theory was also considered but rejected as the focus of the research question was exploratory and focused on developing an understanding of the nature and essence of how participants make sense of the phenomena of having a family member with a PDoC, rather than identifying from the "bottom up" the theoretical-level social processes that account for the phenomena (Willig, 2013). It was important as preliminary research to be iterative, in-depth and understand the "person in context" (Larkin et al, 2006) and identify themes of relevance at this exploratory stage, rather than seeking to be able to generalize and build a theoretical model.

Discourse Analysis (DA) was also considered but rejected. DA examines language features to understand how people construct their social world (Willig, 2013) through how they describe their experience (Biggerstaff & Thompson, 2008) with the aim to be able to generalize across participants. However, the focus on language does not attend to the underlying subjective questions about self-identity and underlying

mental states (Willig, 2013). In contrast IPA explores how people ascribe meaning to their experiences and make sense of them (Smith, 2011). Whilst both DA and IPA focus on linguistics, Smith (2011) considered that IPA is a method to explore how people make sense of their experiences that they then share through language. As participants' individual, embodied experiences and their cognitive and emotional reactions to the situation of having a close relationship with someone with PDoC was the primary focus of study, this discounted DA, as IPA uses language and cognitive and emotional processes.

The aims of this study were therefore to add to the understanding of the experience of having a close family member with a PDoC in the UK, by using IPA and a small homogenous sample to understand: 1) what is it like to have a close family member with a disorder of consciousness and 2) how do female family members negotiate their relationship with the injured person and 3) how this affects them.

2.2 Method

2.2.1 Qualitative Design

As the aim of this study was to describe and explore in detail the experience of having a close relationship with someone with a PDoC, Interpretative Phenomenological Analysis, a qualitative methodology was selected.

2.2.2 The research questions:

To understand what the experience of having a close family member with a PDoC is like?

To understand how having a family member with a PDoC affects those women closest to them?

To understand how female family members negotiate their relationship with the injured person?

2.2.3 Ethical Considerations

A primary ethical consideration is of power, conveyed by my job title as Consultant Clinical Psychologist and my title as a Research Fellow at the Institute based at The Royal Hospital for Neuro-disability in London, the sponsor site. This could mean I would be viewed as an insider, and it was important that I sought to distinguish that with participants and focus on my role as a researcher and post-graduate student both in the Participants Information Sheet and in person, by verbally outlining this during the recruitment phase.

In addition, as potential participants had to have a family member with a PDoC there was an ethical issue about identifying potential participants without identifying the person with a PDoC. In order to protect both the confidentiality of the injured person (the person with a PDoC) and to protect the confidentiality of their family members who may not wish to be involved, potential participants were approached in the first instance by the clinical staff at the research sponsor site (the Royal Hospital for Neuro-

disability). The injured person's diagnosis was not shared with the researcher, other than confirmation that the person had a PDoC and therefore a presumed diagnosis of VS or MCS. This was achieved and approved by the ethics panel by the nature of the required recruitment process (described in 2.2.5 below).

2.2.4 Ethical Approval

Once the study had been designed, the research site sponsor Research Governance Committee reviewed and approved it. An ethical review was conducted by The National Research Ethics Service, London, Bloomsbury Committee (13/LO/0562) and subsequently the Royal Holloway University of London Psychology Department ethical approval was obtained.

2.2.5 Informed consent and confidentiality

The ward medical officer discussed the study and provided potential family members with a Participant Information Sheet (see Appendix C). This protected both the confidentiality of the injured person (the person with a PDoC) and protected the confidentiality of their family members who may not wish to be involved. Interested potential participants or those with additional questions were able to contact the researcher directly, or provide their contact details to the medical officer to supply to the researcher. It is not possible therefore to ascertain if or how many people self selected not to participate. All people who made contact or provided their details for the researcher to contact them, were recruited and did go on to participate in the study.

Once potential participants met one-to-one with the researcher, the Participants Information Sheet and Participants Consent Form were discussed again in person. This included reiterating that a decision not to become involved in the research would not in any way affect the care and rehabilitation that their injured family member received. It also included information that the study would be published and excerpts of their interview would be anonymised and used for this purpose. Recruited participants were able to ask any further questions and signed the Participants Consent Form (see Appendix D).

Saunders, Kitzinger and Kitzinger (2015) described that anonymising qualitative research data can be difficult in PDoC and that balancing richness of interview material and at the same time protecting the confidentiality and concealing the identity of participant's is a challenge, especially when they may say things during the research that they state they would never say aloud to anyone else (such as they wish their relative had died). In this study, participant's revealed very intimate, personal and sensitive information, not only about themselves but also their injured family member, their wider networks and healthcare professionals. Confidentiality was ensured in several ways. Firstly participant's names were changed to pseudonyms. Pseudonyms were considered preferable to referring to participants by either a code or number as this seemed impersonal and it was important to maintain the humanity of their situation. Secondly, consideration was given to explicitly stating the causes and nature of the family members brain injury, but this was excluded as it may enable identification of the participant. Lastly, names of others (family, friends, the injured person, healthcare professionals) were excluded and details such as occupation, place, and ethnicity were avoided.

2.2.6 Potential distress

Although other researchers have reported that some research participants describe the process of reflecting on their experiences as therapeutic (Birch & Miller, 2000), as the nature of the research was focusing on the experience of having a family member suddenly inaccessible to them, there was a distinct possibility that participants may have become distressed during participation in the research. Potential distress was managed in several ways. Firstly, The Participants Information Sheet had a section about possible distress to allow potential participants to consider this prior to consenting to the research. Secondly, when the participants met with the researcher they were reminded that they were not obliged to answer any questions and that they could withdraw from the study at any time. Thirdly, participants were interviewed in a private space at a time and location selected by them. The researcher (who is also a Consultant Clinical Psychologist), was used to working with people in distress and was trained and prepared to manage distress as it arose. Fourthly, at the conclusion of their participation, they were asked if they felt additional support was needed. Lastly, any participants who appeared in the interview or on the measures used to be requiring additional support were advised about the possibility of onward referral. Provision was made to arrange this on their behalf through the Head of Clinical Psychology within the Royal Hospital for Neuro-disability should they want additional support either immediately or on reflection in the weeks following the interview.

2.3 Participants

2.3.1 Recruitment

Purposeful sampling was necessitated by the requirement to have participants who had experienced a similar life event (Mays and Pope, 1995); a family member with a

PDoC. As purposive sampling was used to firstly identify family members of people with this rare condition. One medical officer at the Sponsor Site discussed the research and provided the Participants Information Sheet to families of people with PDoC admitted for assessment and rehabilitation to a specialist national tertiary referral centre who met the inclusion criteria. Contact details for those who expressed interest in participating were passed on the researcher. The researcher then made contact with potential participants to respond to any questions about the research and coordinate the arrangements for the interview. It could be argued that the medical officer may have considered some potential participants were not suitable to approach for reasons other than the exclusion criteria, but this was a limitation imposed by the stringent ethics criteria in order to protect the confidentiality of the injured person by the sponsor site. Eight of the nine participants were recruited through the one sponsor site medical officer. In addition, one of the participant's approached the researcher directly following hearing about the research through other families.

Participants were recruited from June 2014 through to November 2015.

2.3.2 Inclusion criteria

The study aimed to recruit a reasonably homogenous group of participants (Patton, 2002), however there were of course differences between participants in terms of their individual situations. The parameters for inclusion were the primary female caregiver of a person with a PDoC. IPA focus is on depth of data rather than large numbers of participants in order to maintain an idiographic focus (focus on the particular experience) with ten participants at the higher end of most

recommendations (Smith et al, 1999; Reid et al, 2005). This enables strength in the size of the small sample, to allow for depth of analysis and allow for the voices of all participants to be heard within the results. Nine female primary caregivers who experienced the phenomenon of having a close family member with a PDoC were recruited in order to fully understand the experience.

2.3.3 Exclusion Criteria

Whilst there was no particular reason to assume that there would be a specific gender difference as this was not highlighted in the literature review, as previous studies have reported that caregivers are primarily female (Covelli et al., 2014) and to obtain a homogenous group consistent with this use of IPA methodology (Smith, 2017), males were excluded. This is also consistent with other qualitative research in this area has also excluded males (Covello et al., 2014 and Hamama-Raz et al., 2013).

Participants had to be over 18 years of age and have sufficient English language skills to be able to participate in the interview and to complete the written measures. The medical officer had detailed knowledge of the families on the unit and initially approached potential participants based on their awareness of the person's age and language skills.

The participants' characteristics are displayed on Table 2.1 below. In relation to the confidentiality protection (described in 2.2.5 above) the mechanism of injury is not detailed on the table below, but it was shared during the research that two of PDoC resulted from self inflicted injuries, the others related to infection, accidental traumatic brain injuries, or lack of oxygen to the brain (hypoxia).

Table 2. 1 *Sample Participants' Characteristics*

Name*	Age	Ethnicity	Relationship	Length of relationship	Time since injury	Time in RHN	Family members injury	Time to travel to RHN
Anna	46-55	White	Mother	21 years	3 years^	Over 1 year	TBI	25 mins
Kate	56-65	White	Wife	35 years	20 years^	Over 1 year	Meningitis	20 mins
Jean	56-65	White	Mother	32 years	9 years^	Over 1 year	Hypoxia	90 mins
Imogen	56-65	White	Sister	59 years	27 years^	Over 1 year	Hypoxia	90 mins
Samantha	56-65	White	Mother	29 years	8 years^	Over 1 year	TBI	20 mins
Rebecca	56-65	White	Partner	30 years	9 months	3-6 months	TBI	60 mins
Bronwen	46-55	White	Sister	51 years	6 months	3-6 months	TBI	6 hours
Zoe	35-45	Asian	Daughter	44 years	11 months	< 3 months	TBI	90 mins
Jessica	26-35	White	Wife	9 years	20 months^	Over 1 year	TBI	2 hours

Note. *names are pseudonyms, ^ Long term care ward, RHN: Royal Hospital for Neuro-disability, the research sponsor site; TBI: Traumatic Brain Injury

2.4 Measures

2.4.1 Demographics, wellbeing and needs

Participants completed a number of validated psychological measures (assessing hope, psychological distress, psychological wellbeing, changes to their work and social life, needs for information and sense of who is in the family and what their roles are), a rating of their understanding of the person's injury and their expectations for future change and a demographics questionnaire relating to their age, ethnicity, relationship to the person with a PDoC (the measures used are shown in Appendix E through J) The purpose of this was to situate the sample and examine participants unmet needs and mental health concerns.

2.4.2 Herth Hope Scale

The Herth Hope Scale (HHS; Herth, 1991) was used to assess the participants' self reported level of hope. The HHS is a 30 items self-report scale with responses on a four point likert scale (0 – Never applies to me, to 3 – Often applies to me). A total scale score is obtained by summing the ratings for the subscales. Scores can range from 0 to 90, with higher scores indicative of higher levels of hope. Subscales are based on the three factors; temporality and future, positive readiness and expectancy, and interconnectedness (Herth, 1991), however only the total score was used in this study. Herth (1991) reported acceptable cronbach coefficient alpha of ($\alpha = .75$ to $.94$) and good test-retest reliability of ($\alpha = .89$ to $.91$) across 3 week intervals. Similar coefficient alphas of ($\alpha = .92$ and $.93$) have been reported by other researchers (Arnau, Martinez, Nino de Guzman, Herth & Yoshiyuki Konishi, 2010). Herth (1991) documented convergent validity of HHS scores (with a negative correlation of $-.69$) with the Beck Hopelessness Scale.

2.4.3 Work and Social Adjustment Scale (WSAS)

The impact of the injury on the life roles of the family member, was assessed by their scores on the *Work Social Adjustment Scale* (WSAS; Mundt, Marks, Shear & Griest, 2002). The WSAS is a 5 item self-report measure of general impairment that assesses the impact resulting from a given difficulty (in this case having a family member with a PDoC) on functioning on work, home management, social leisure, private leisure and interpersonal relationships on an 8 point likert scale (Mundt et al., 2002). Improving Access to Psychological Therapies in England routinely employ this as an outcome measure (IAPT, 2010) and it was found to measure a distinct social functioning factor, with high internal reliability, and sensitivity to treatment effects (Zahra, Qureshi, Henley, & Byng 2014). The test authors reported Cronbach's alpha of internal scale consistency ranged from acceptable to excellent ($\alpha = 0.70$ to $\alpha = 0.94$) with a good ($\alpha = 0.84$) test-retest correlation (Mundt et al., 2002). Scores are summed and range from 0 to 40, with higher scores indicative of greater impairment in functioning. Lower scores are indicative of better functioning, with scores between 0-10 classified as normal, 10-20 associated with significant functional impairment, and score between 20 -40 suggesting moderately severe or worse difficulties.

2.4.4 Hospital Anxiety and Depression Scale (HADS)

To determine the participants' levels of psychological distress the HADS was administered. The 14 item *Hospital Anxiety and Depression Scale* (HADS) was designed to assess clinically significant anxiety and depression symptoms (Zigmond & Snaith, 1983) over the preceding week. The HADS is a 14 item self report scale with a total score ranging from 0 to 42 (higher scores indicating more symptoms and severity of distress). The subscales have seven items with four response categories (scored 0 to 3). Subscales are summed with higher scores representative of higher levels of

depression (HADS-D) or anxiety (HADS-A). A review of the use of HADS in 2002 showed over 400 papers had employed the measure in clinical practice and research and the measure had best sensitivity and specificity when the score of 8 or above was used as the clinical cutoff (Bjelland, Dahl, Haug & Neckelmann, 2002). Other authors have commented that the measure is reliable with demographic factors having little influence on the scores (Crawford, Henry, Crombie & Taylor, 2001). The HADS measures symptoms of anxiety and depression (Zigmond & Snaith, 1983) and has been widely used in research with carers, including carers for people with brain injury (Fortune, Rogan, & Richards, 2016) and dementia (Livingston, Barber, Rapaport, Knapp, Griffin, King, Livingston, Mummery, Walker, Hoe, Sampson & Cooper, 2013). Cronbach's alpha was reported as high in a sample of carers of people with brain injuries ($\alpha = 0.91$; Fortune et al, 2016) and good ($\alpha = 0.86$) in a large non clinical United Kingdom adult sample (Crawford, Henry, Crombie & Taylor, 2001). Scores for HADS-A and HADS-D were interpreted using the largest population based normative data for this measure from the Epidemiology of Functional Disorders Study in England (Breeman, Cotton, Fielding & Jones, 2015). Crawford, Henry, Crombie and Taylor (2001) found that combining the Anxiety and Depression scores to create a total score of psychological distress (HADS-TS) and this reference group was used to interpret the HADS-TS.

2.4.5 Warwick Edinburgh Mental Wellbeing Scale (WEMWBS)

The emotional and functional components of mental wellbeing was assessed by the 14 item *Warwick Edinburgh Wellbeing Scale* (WEMWBS; Tennant, Hiller, Fishwick, Platt, Joesph, Weich, Parkinson, Secker & Stewart-Brown, 2007) which was developed and validated in the United Kingdom to measure subjective well-being and psychological functioning. Positive aspects of mental health are examined by

participant's self report rating on the 14 positively worded items, over the preceding two weeks. There are 5 response categories (none of the time, rarely, some of the time, often, all of the time). The WEMWBS has been validated internationally and has population norms for England data of 2011 (WEMWBS). The psychometric properties of the scale suggest high internal consistency ($\alpha = .90$) as well as good content validity and test-retest reliability ($\alpha = 0.83$; Tennant et al., 2007). Scoring involves summing the responses, the minimum scale score is 14 and the maximum is 70 (higher scores are reflective of better wellbeing). Scores of below 40 are indicative of lower than average wellbeing.

2.4.6 Boundary Ambiguity Scale (BAS)

To assess ambiguous loss and participants' relationships with where and how the injured person now fits into their family, the *Boundary Ambiguity Scale for Dementia* (BAS6; Boss, Greenberg & Caron, 1990) was used. The BAS6 is a 14 item scale, with five response categories (1 strongly disagree, 2 disagree, 3 agree, 4 strongly agree, 5 unsure how I feel) which has been designed for families of people with dementia. Scores range from 14 to 70, with higher scores reflective of greater ambiguity and confusion about the relationship with the person. Boss (1977) empirically established the construct validation of the original Psychological Presence Scale (now titled the Boundary Ambiguity Scale) on missing-in-action families with items based on a theory of stress created by ambiguous family boundaries. Variations of this original scale have since been created and used in a wide variety of research areas including dementia (Caron, Boss & Mortimer, 1999), children of divorce (Pearce-McCall & Boss, 1990), and paediatric illness (Carroll, Olson & Buckmiller, 2007). Whilst it is accepted that alterations to the wording of an item on the scale will affect the psychometrics of the scale, it was important to make the scale suitable for the current research

population. A wording change was necessary on one item by changing the location of the question from home to hospital, illustrated below:

Original BAS6 item: *"I feel guilty when I get out of the house to do something enjoyable while _____ remains at home"*

Modified item: *"I feel guilty when I get out of the house and do something enjoyable while _____ remains in hospital".*

Another item in the scale was not considered suitable for the research population (original BAS6 item: *"I'm not sure what I should expect _____ to do around the house"*) as the person with the injury is bed bound and incapable of consistent purposive action and as such was deleted. It was decided to replace this removed item with one similar to the ambiguous loss measure for veterans missing in action that the BAS6 scale is based on. As such the item from that scale *"I will never be satisfied until I have positive proof of my husband's death"* was modified to *"I will never be satisfied until _____ recovers"*.

Finally, alterations to the title and instructions were made to remove references to dementia and Alzheimer's Disease. The title of the scale "For caregivers of patients with dementia" was removed, just leaving the BAS6 as the title. The original instruction: *"The following statements are about your relationship with the Alzheimer's patient"* was modified to read "The following statements are about your relationship with your injured family member".

2.4.7 Family Needs Questionnaire Revised (FNQ-R)

The Family Needs Questionnaire- revised (FNQ-R; Kreutzer, Serio, & Berquist, 1994) was developed in the United States but has been used internationally (Norup, Perrin, Cuberos-Urbano, Anke, Andelic, Doyle, Quijano, Caracuel, Diaz Sosa, Espinosa Jove & Arango-Lasprilla, 2015). The FNQ-R is a 37 item self-report scale to assess if perceived needs of families after brain injury are: met, partly met or unmet. Scoring consists of summing the number of yes, partly or unmet responses by subscale. A factor analysis (Serio, Kreuter & Witol, 1997) identified six subscales: Health Information (information about the condition, progress, changes in status), Emotional Support (recognition of family member's needs, normalizing of feelings), Instrumental Support (practical assistance and support for tasks away from caring), Professional Support (prognosis, therapy for the injured person, resources for the family such as in relation to finances, respite or psychological), Community Support Network (understanding and recognition of the impact of the injury in the person's wider networks), and Involvement in Care (provide opinions and input into daily care of the injured person and get updated on care daily). The authors report the highest subscale Cronbach alpha for Health Information ($\alpha = 0.89$) and the lowest value for Involvement in Care ($\alpha = 0.78$; Serio et al, 1997). Content and construct validity, and high internal consistency and reliability have been established (Arango-Lasprilla, Quijano, Aponte, Cuervo, Nicholls, Rogers & Kreutzer, 2010).

2.4.8 Opinion on the Diagnosis and Prognosis

Finally, a scale was developed to assess *Perspectives on Diagnosis and Prognosis of the Person with a PDoC*. This was designed to determine any discrepancies in opinion about the diagnosis and prognosis between all the people involved in the life a person with PDoC. Participants' perspective of how congruent their views are with the

healthcare professionals involved and with different members of the same family, was assessed on a likert scale. Participants were asked to rate how they understood the medical team considered the person's condition to be (understanding of the formal diagnosis), what they truly believed the persons condition to be (own view of the diagnosis) and what they understood their other family members thought the condition was (their perception of the wider family's view of the diagnosis). Participants then rated how they envisaged the situation would be in 10 year's time (own prognosis). Participants rated this on an eight point likert scale (1. Brain working as normal and no support needs, 2. Despite having had a brain injury, minimal long term problems and support needs, 3. Severe brain injury with multiple long term needs, 4. Locked In, brain working normally but body unable to move, 5. Minimally Conscious State (MCS), awake and probably aware sometimes, inconsistent meaningful responding, 6. Vegetative State (VS), awake but not aware, no meaningful responding, 7. Coma, not awake, not aware, 8. Dead).

2.5 Semi-structured interview schedule

A semi-structured interview schedule was designed to allow for the participant to talk one-to-one about what has significance and existential importance to them. Smith, Flowers and Larkin (2009) suggest the semi-structured interview flexibility of approach enables rich data to be obtained. A female family member of a person with a PDoC known to the researcher agreed to participate in a pilot to establish and refine the interview schedule. Given that the PDoC is long term, the pilot showed the challenges of talking about the present (question two of the schedule wording was modified to capture present thoughts by adding "at the moment"). The pilot highlighted that families may have some awareness on how they have changed in their own understanding and coping over time and it would be important in

interviews to probe to discover when shifts in understanding occurred. Modifications were made to phrasing as a result (see Appendix K for this schedule).

2.6 Procedure

The interviews took place at a location preferred by the participant (at home $n = 1$, in a care home $n = 1$, at the sponsor site hospital $n = 7$) and at a pre-determined time chosen by the participant. The Participant Information Sheet was reviewed and an opportunity to seek clarification and ask any questions was provided. The Consent Form was then completed alongside a reminder of the limits of confidentiality in relation to publication.

The semi-structured interview was treated as a narrative, a complex whole rather than a series of questions and answers aimed at gathering information to allow for more meaningful discussion about thoughts, feelings, interpretations and personal meanings. Each interview was voice recorded. Following the interview, the participants completed the series of standardized questionnaires.

In line with managing the potential of distress resultant from participating, each participant was asked at the conclusion of the interview and administration of questionnaires how they were feeling and if any onward referral was needed at this time, and remind how to seek support over the following weeks if needed.

2.6.1 Transcription

Participants' interviews were typed verbatim by the researcher. This allowed for deeper immersion with the data.

2.6.2 Data Analysis

The analytic procedure described by Smith and colleagues (2009) was followed. For each participant, initial exploratory coding was conducted. Coding was conducted on a word by word, line by line basis. In this way looking at the description of what that participant was saying and not saying, the linguistic components of how they were saying it and the conceptual component of what it means to that participant were examined and recorded. At the completion of a participant's transcript analysis, the next was sequentially studied. This enabled transcripts to be analysed independently, in isolation and idiographically.

Next, the transcript was read and re-read to ensure deeper abstraction and analysis with the immersion within the data. Emerging themes were identified and recorded, which captured the psychological essence of what the participant was describing about the phenomenon of having a family member with a PDoC. Transcripts were considered for descriptive and conceptual comments (Smith et al., 2009) and themes were identified. These themes were abstracted and synthesized by clustering themes on a participant-by-participant basis. Microsoft Excel was utilised to manage the large number of initial coding themes identified and to assist with the clustering of superordinate themes for each participant.

Once all nine transcripts had been analysed, then a cross case analysis was performed where each participant's data was then compared and contrasted across the whole sample searching for convergent and divergent pattern in the data and leading to higher order categorization, to create a master table of superordinate themes that contain enough particularity to be grounded and enough abstraction to be conceptual (Smith et al, 2009). Themes were renamed and rearranged to ensure that the final

main themes encapsulated a defined interpretation of the participants' experiences and that this was transparent.

2.6.3 Reliability and Validity

Reliability is generally accepted in qualitative research to refer to "trustworthiness" of the findings (Golafashni, 2003). Quality was managed by adhering to Elliot and Yardley (2000)'s four main criteria and Smiths (2011) quality evaluation guide. Whilst some authors (Elliott, Fishcer & Rennie, 1999) argue that final validity checks should be completed with participants, this was deliberately not done. IPA moves beyond the descriptive level provided by the participant and involves the researcher's abstraction and interpretation process (Biggerstaff & Thompson, 2008) that leads to the themes and links, which may not necessarily concur with how the participant would view their world (Smith, 2004). The data was only coded by the researcher and not double coded. Double coding is often used in some forms of qualitative analysis such as thematic analysis (Clarke and Braun, 2017) however it is acknowledged that the researcher has a subjective role in establishing the findings as one's values and assumptions impact in the decision making about what to interpret from the detail of the data (Murray & Chamberlain, 1999). In IPA it is transparent that the researcher is not neutral and is actively interpreting from the data and as such double coding is not required. Instead, authenticity was achieved by grounding, using multiple quotes to illustrate each theme and the fidelity was checked by the research supervisor.

2.6.4 Situating one's perspective

Unlike quantitative methods where the positivist epistemological positions suggest that research obtains objective knowledge that is impartial and unbiased by the

researcher, qualitative methods acknowledge the researchers view of their role in the process and how they impact on the outcome (Willig, 2013). This acknowledges that the findings are influenced by researcher's subjective values and assumptions in the decision making about what to interpret from the detail of the data (Murray & Chamberlain, 1999). In my work with clients with particular challenges (such as mood, adjustment or brain injury) as a clinical psychologist, this requires that I "bracket" and hold what I know about a particular challenge, whilst I explore what the persons own experience and attributions about their situation are, in essence adopting a phenomenological attitude. I accept the persons lived "truth" about their life and situation. This allowed me to find familiarity and synergy with my clinical work and the IPA methodology. The need for reliability and validity in my own interpretations of client's information to be consistent with what other practitioners may discover and comes from a biopsychosocial formulation, an embodiment of mind, physical, social, cognitive and societal ideas. IPA fits with my professional and personal views about the contextualized idea of what it is to be a person as someone connected by their interpersonal relationships, culture, language etc. The aims of the study lend themselves to the use of a contextual constructionist epistemological position, which recognizes the subjective role of the researcher, that knowledge is situation dependent and that findings can differ according to the context in the way data is collected and interpreted (Madill et al, 2000).

2.7 Results

The participants' responses to the measures (see Appendix for individual participants scores) showed acceptable levels of wellbeing (WEMWBS range 41 – 66) and high levels of ongoing hope (HHS range 49 – 82). Disruptions to work and social

functioning were reported by seven of the nine participants (range 4 – 30). Clinically significant levels of anxiety symptoms were reported by six of the participants (HADS-A range 5 – 16), whilst two participants reported clinically significant levels of depressive symptoms (HADS-D range 0 – 12). Overall, six of the nine participants reported difficulties with their emotional functioning that was within the clinically significant range (HADS-TS range 6- 28). Participants experienced not having at least half of their needs adequately met across a variety of domains as displayed on table 2.2 below.

Table 2. 2 Percentage of unmet needs on FNQ-R reported by participants

Need	Percentage of items unmet need was reported by Participants (<i>n</i> = 9)
Professional Support	(65%)
Involvement with care	(62%)
Health Information	(60%)
Community Support	(57%)
Network	
Instrumental Support	(56%)
Emotional Support	(51%)
Total needs unmet	(58%)

2.7.1 Summary of Super-ordinate Themes and Sub-themes.

The first Super-ordinate Theme is “*Loss without a name*” encompassing the sudden experience of the initial injury which creates a confusing non-death related loss, that was hard to understand and in some ways worse than the actual death of the person. Constant threats of loss for the family continue through the person’s post injury life in relation to fluctuating medical instability, which contributes to continued sense of uncertainty.

The second Super-ordinate Theme is *“Relationship without a title”*. For the participants, the severity of the injury creates great uncertainty about the person’s awareness of them at all, and leads to a new and complex one-sided relationship. These symbolic relationship changes were hard to understand and did not easily map onto societal understandings and established titles of relationships.

The third Super-ordinate Theme is *“Symbiotic relating”* comprising the participants sense of joining and being part of the rehabilitation process themselves. The sense of being ‘one’ with the injured person seems to drive a deep commitment to prevent the person from being abandoned by their networks and advocating and fighting with professionals and the systems to have a voice and be part of the team who support them.

The final Super-ordinate Theme is *“Frozen futures”* which demonstrates how the women are grappling with the uncertainty about their family members prognosis and work to the model that things are likely to remain much as they currently are which prevents them from moving forwards. In the context of coping with uncertainty about the future and their complex loss, the women described ways to cope and continue to have a relationship with the changed person. This involved developing new routines and new relationships that are honouring of the person’s pre-injury self.

These themes are displayed on the table 2.3 below.

2.7.2 Summary Table of Super-ordinate Themes and Sub-themes.

Table 2. 3 *Super-ordinate themes and subthemes*

Super-ordinate Themes	Sub-Themes
<p>Loss without a name</p> <p><i>"Who I know is gone, but there's a body there"</i></p>	<ul style="list-style-type: none"> • Not a death and worse than a death • Constant threats of loss
<p>Relationship without a title</p> <p><i>"what is my relationship with him?"</i></p>	<ul style="list-style-type: none"> • Not being known • Unreciprocated one-sided relationship • Transformed relationship not easily understood
<p>Symbiotic relating</p> <p><i>"I will never rest until I've done everything I can possibly do"</i></p>	<ul style="list-style-type: none"> • Advocacy • Abandonment • Fighting with professionals
<p>Frozen futures</p> <p><i>"My sense is he's not going to get much better, so I feel stuck"</i></p>	<ul style="list-style-type: none"> • Coping with an uncertain prognosis

2.7.3 Loss without a name: "Who I know is gone, but there's a body there"

The injury for all participants was sudden and unanticipated; Zoe explained; *"so it was just sudden because if it, if it's somebody who has a cancer or something, sort of, it's a process and you start losing them, or dementia, whereas when it's accident it's just sudden ..."*. (line 212).

2.7.4 Not a death and worse than a death

The PDoC created a condition that was difficult for participants to understand. The PDoC had not led to a death, but did not allow for a life either, and this meant there was little opportunity to see their way forward. For Bronwen this was an intolerable situation; *“Um, the- this is **just an ongoing** ... I-I’ve also classed it as a **living nightmare**”* (line 85). Kate described that having hoped her husband would not die, she had never contemplated he would be alive but so different; *“...right at the beginning, when you are very involved in a church, people are praying madly that he will get better, you know, and at least that he wouldn't die, in the first few months it's all about is he going to die you know, but of course he didn't die, so you sort of think, but **none of us had any, any idea or conception that he could ever survive but not be better...**”* (line 38). Anna too was astounded to find this new way of being alive; *“No, didn't even know it existed. You knock your head, **you either get up or you die**. Simple. There's nothing in between, well ...I **didn't know there was anything in between...** You just don't hear about it...”* (line 125).

The lack of clarity in this in-betweenness between life and death, for Rebecca felt more challenging than facing a death; *“I've got quite a lot of experience dealing with death and that is one thing that least **there's a clarity and a certainty to it**, about what you're dealing with”. (line 110) ... “Um, because I think it, yeah I think if, I think if he had died [on the day of the accident] it would have been really hard, but I think, I kind of would of, I would be beginning to **get on with life and accept it** and deal with it. Um, but I feel like **I can't**, because like I'm still **caught between two lives** really”* (lines 120-122). For Jessica and Imogen, it also raised questions about surviving at all; *“I always hate saying this out loud, but there are elements of me, that you know think, it would have been **far easier for everybody including [her husband], if he hadn't***

survived the accident" (Jessica, line 322). *"Would it not have been better? Isn't it the natural thing in life actually, if they hadn't intervened? That um, she would have been better off?" So, what that- He questions the value in her life. When, where- Is her life of value? Is her existence as it, as it is now, of value? And that's quite challenging"* (Imogen, line 198).

The sense of knowing that the injured person would not have wanted the life they now had, but that any window of opportunity for death had now passed, was challenging; *"He wouldn't want to be like this. Um he's only, just, sort of these apocalyptic scenarios and stuff like that, and was saying you know, "If anything happens to me, you've got to just get rid of me and you know", so he wouldn't have wanted to survive like this"* (Jessica, line 326), *"He was a very active man, intellectually, and physically. Um, I absolutely know him probably more than any of us, he would have said back in January, for God's sake pull the plug, this is ridiculous"* (Rebecca, line 205).

Participants' struggled to make sense of this situation as finding the loss of the psychological person they had known but still be in the presence of their body; Rebecca explained *"Umph... I mean well, really tricky, really tricky. I guess it's, I guess it's, it's a, what it means is... is [my partner] who I knew is gone... Um, but physically there's still a body there. So it's really perplexing that's the thing I find really hard is that, um, yeah I, ah yeah... My way of dealing with it is to say, [my partner] I knew isn't there anymore. That [my partner] went on the [the date of the accident], that, that's you know, the person I see I don't feel is him. I don't really see much of [my partner] in him really, um, because he can't speak, he can't move, he can't do anything"* (lines 94 – 100). Jean also articulated this loss, but she made sense of it as a

change and as another facet of the same person; *“Uh, because at the end of the day, the way I think, I lost my daughter 10 years ago. This is the other side of my daughter you see.”* (618-620).

2.7.5 Constant threats of loss

For Anna, Kate, Imogen, Samantha, Jean and Jessica following the initial injury on going fluctuations meant constant threats of new losses and new risks of possible death to cope with that contributed to increased uncertainty; *“I mean in the early days, he was so up and down. I mean, he did go through various points where you know, sort of they couldn't say whether he was going to make it through the night, whether he was going to survive”* (Jessica, line 338). These threats of new possible losses happen multiple times; *“And the, the three times they felt she wasn't going to make it but her, you know, she is a fighter and she comes back”* (Jean, line 318).

The fluctuating medical instability continued for a long time, with each new medical issue a concern *“He spent most of the first year and a half, in hospital, with every infection you can possibly imagine. He also had, um, he had the shunt put in. He had the plate put in. He had, um, uh, I. He had pneumonia, I would think, probably 4 or 5 times. He had, um, urine infections, um, he got everything; everything you can imagine”* (Samantha, line 58).

Imogen described that the injury led to additional losses for the wider system that were difficult to cope with; *“And his visits became less and less. They were, they were ... 'Til eventually, I think it was probably three or four years, I don't know exactly, but [my sister's husband] divorced (her). But the consequence was that my children lost their uncle, my children lost their auntie. Um, we lost a member of our family, um,*

and **my father** couldn't come to terms. He found it quite difficult to come to terms with [my sister] being the way she is". (line 142)

2.7.6 Relationship without a title: "What's my relationship with him?"

PDoC require the non-injured person to design, initiate and carry all activities and conversation with the injured person in the absence of any feedback from them. No eye contact, no smiles, no sounds in any meaningful or consistent response to what the non-injured person creates, leads to a sense of operating in a vacuum and a strange, new, unreciprocated, one-sided relationship.

*Would she really know any difference if I was here or if I'm not here? And I think mostly I have to say... probably... would... definitely... it, itmakes little difference to her. The person it makes the biggest difference to is me (Imogen, line 494). Bronwen too considered it hard to know if visiting mattered "From what we've seen over the last six months, he's mostly asleep. Um, if he does have his eyes **open he kind of stares right through you** and moves them from left to right but not, there's **no fixation** where you, you... where you think, you know his pupils might dilate or whatever. There's, there's just nothing, it's just ... we've said just like, **the lights are on but no one's at home**" (line 15)*

For Rebecca "Um, I guess I do understand, it, it, severe brain injury, um, and, um, which means he can barely move. He can't communicate. Um, he can't eat. Um, I guess the thing that, um... Yeah, I guess the thing that's stills just, that questions do still keep asking about **how much does he understand?**" (Line 54) "And so my main concern, I guess at the moment is about frustration on his part if there are times when he understands. Um, **my gut feeling around it is he doesn't, because he doesn't seem**

***distressed.** So, my gut feelings are there are moments when seems to understand, when he does respond to requests, but that's fairly few and far between” (line 58).*

With uncertainty about the nature of any understanding and any awareness of interaction attempts, new uncertainties about the nature of their interpersonal relationship grow. Societal ideas about what relationships now are and how one should act within relationships, created uncertainty about where the women stood.

2.7.7 Not being known

For Anna, Samantha and Jean there was uncertainty about their injured child’s level of awareness and even if they knew that they were their mother; “ *Uh, well, **we don't know** exactly. Uh, the only, we think, is that... we don't know. If she uh, **recognizes us like we used to be for her** - mum, brother, friend, uh, sister-in-law, you know, because she doesn't talk” (Jean, lines 92-94). “Now, **whether he knows I'm mum, that I don't know**” (Samantha, line 237). “uh uh, no nothing. Occasionally when you come in he opens his eyes, but it **could be anyone really, I don't know.** We think he’s starting to react a little bit more, but it’s very hard to know” (Anna, line 224).*

Jessica too was uncertain if her husband had any concept of her relationship to him now; “Well **I don't know.** I don't know whether it's because I've been with him every day pretty much since the accident and so it's **just a recognition of sort of familiar person, that's been there steadily ...**” (line 86). For Jean, the new familiarity took precedence over the loss of the historical relationship; “But uh, in my mind, uh, **it doesn't really worry me** that much. Because if she **doesn't know me as her mum, she knows me now,** as who I am now. Uh, by the voice, by the touch. You know, so the way you, you handle her or, so **she knows me now. I don't know if she knows from before**” (lines 96-104).

Whilst Jean managed her uncertainty that her child may not know her as Mum, but instead now knows her as someone new, Kate in contrast has managed her uncertainty by assuming initially her husband did know who she was. Over time she has a new level of acceptance that he doesn't know her, but has taken a deliberate approach to managing the ambiguity and uncertainty of her situation "*...the Doctor said very specifically your husband will never recognize you, will never know you, and um, and I went back to him [her husband] on the ward, and he kind of held my hand and squeezed my hand and looked at me and it was my birthday and I thought this is rubbish, of course he recognizes me. So I remember that, because it was my birthday, obviously you do, you remember these key moments, so, um, I think from then on, I thought well, ok so that's the prognosis, but, I will continue to believe that and go on living and live our lives as if he knows who we are and is still part of our family and wants to be part of our family, you know, I will give him the benefit of the doubt are the words I might have used at the time to friends people who asked, because people always say well how do you know, does he recognize you, and do you know 20 years on and to this day I still say, well, probably not, but I can't prove it, really I have no proof of whether he knows me or not and therefore I go on believing that maybe he does, but at exactly the same time as I say that, I think, I kind of hope that he doesn't, because if he does, I'm not being very good, because I'm not like with him all the time and we have moved on so much in lifestyle and I know I'm not here for him all the time, I'm not as with him as I was certainly for the first few years, and like a lot of relatives here are, very hands on, very completely 100% focused on him and I'm absolutely not like that now, well, you can't be over the long term"* (line 20).

Bronwen too shared that irrespective of her perception of the loss of the relationship from her brother's perspective it did not alter her commitment to him; "*I think we*

may be able to see [him] sitting in a chair without the trache down the line at some point. But he can breathe on his own but I just ... **whether or not he'll know who we are, I doubt very much. I think it's just a case of making him as comfortable as possible and just, just caring for his needs**" (line 28).

2.7.8 An unreciprocated one-sided relationship

The nature of the PDoC is that the injured person is unable to make consistently meaningful responses. The participants' identified the one-sidedness of their relationships. For Imogen, it was through the observation of her son during a visit they made to her injured sister about the lack of reciprocation that got her thinking about how it also felt strange to her; *"To be honest, I ... [my son] said to me that he doesn't understand how I can sit with [her injured sister] and interact when **there's nothing coming back**, and he just feels uncomfortable and, and I think there is a degree of that"* (line 500). Rebecca too described the strangeness of interacting in a one-sided way; *"I don't know what he takes in or doesn't, but I just hope a familiar voice, of familiar presence helps, um, but **I can find it quite hard, yeah, going on my own. Especially saying goodbye to him, I guess it's really weird saying goodbye to somebody who can't say goodbye to you.**"* (line 148). For Zoe, the lack of reciprocation in communication with her mother was the most difficult loss *"my **not being able to talk to her**"* (line 158). Jessica explained that for her the lack of emotional reciprocation signified the relationship was changed; *"Well, he can **no longer a be a proper husband to me. He can't, he can't return the feelings**"* (line 132-133)

2.7.9 A transformed relationship not easily understood

Jessica's awareness that the relationship was one-sided and unreciprocated led her to consider that it had transformed. but it was not easy to explain into what it had transformed into: *"Um but I'll always, always love him, um but that sort of husband/wife relationship, doesn't really exist anymore. It's **evolved into something different** really. Um but that in itself takes time to adjust yourself to. So again, I just try to not sort of think too hard about it". Jessica (line 133-136).* For Kate the relationship was changed but she also found it hard to describe what it had become; *"I don't have a husband because **all you have really is a body** and you have none of the feedback whatsoever and none of the relationship, the **relationship doesn't exist either physical or emotional or intellectual in any way**. Um what was the question again? What does it mean to me? The real negative I guess is that I am **stuck in a limbo** between having a marriage relationship and being free if you like, to be a single woman and to have the opportunities you have whatever as a single woman..." (line 56).*

For Rebecca understanding her situation within typical relationship paradigm was also difficult; *"Yep. I feel stuck. Yep, I feel stuck. I can't let go of, you know I can't, and I don't want to let go, we don't want to get, yeah, it's um, yeah. You know it's a diff... I'm quite worried **about society** in a sense, it's like, you know, am I, **am I single? Do I still have a partner**, yes I have a partner, but he's... I haven't spoken to in 9 months, **that whole where do you fit?**" (line 126).* Rebecca had no societal examples to model how to conceptualise her new relationship; *"Um, well I think it is a difficult thing about **what is my relationship with him**. I found that I have struggled with that. What is my relationship with him? Um, that I found hard, um, ugh, I think, as I've been talking about it with other people, people who, people who don't know, it's quite a*

*difficult thing to say to.... Because I think most people haven't.... You know I **didn't know anybody that, had experienced you know....***" (line 110)

Bronwen shared she felt lonely and missed her brother even though his body was still present and he is alive. She talked of him in the past tense, a sense he had emotionally gone and the body remaining was not the brother she had before; ***"I just feel totally alone** an it- you know, I could phone [her brother] up until midnight and we were always on the telephone. We'd phone each other 3 or 4 times a week or we'd see each other at Dad's. We'd go around for meals to his house, he would take me and [his niece] out. Um, it's the, it's the missing all that. **He's terribly, terribly missed"*** (line, 79).

2.7.10 Symbiotic relating: "I will never rest until I've done everything I can possibly do"

The dependency of the injured person, the need for bedside closeness and the turbulence of the fluctuations of the condition seemed to promote a deeper sense of interconnectedness between the family member and the injured person. In speaking about their experiences, the women used the inclusive term of "we", a shared sense of entwining in the awfulness of the experience and an active part of rehabilitation.

Samantha's language included herself in the experience of having a medical issue; *"Because **you're** either in an acute hospital, **fighting an infection of some form**, where doctors tend to talk very negatively, and very, um. They're not. They're in many cases, certainly at [local hospital], they have no idea how to deal with somebody with the severity of brain injury"* (Samantha, line 102).

For Anna, it was a sense she too had been let down, not just her son by limited access to rehabilitation; *“We’ve never been assessed.... He’s never been on the SMART programme, we’ve never, he’s never had any eye gaze testing; he’s never had anything. ...”* (line 45). *“You know, and we never had the rehab because he wasn’t well enough. As I say I’m really cross about that, yeah I feel really cheated, but... cause I just feel that nobody has ever bothered to, I mean they’ve tried, but nothing is going to come of it, yeah...it’s frustrating”* (Anna, line 357).

Rebecca described transitions between rehabilitation and care providers as a transfer she was also coupled with; *“Albeit way back when he was at [first acute hospital], um, or at [tertiary referral neurorehabilitation specialist hospital]. Um, and back particularly before we left Putney, I was very keen to talk to the doctor there to get, because was my last chance to really talk to him, he’s a real expert in sense to the doctors who know about brain injury. Once we got to the nursing centre, it was a different world of nursing and looking after him, but not experts in brain injury necessarily”* (line 89).

Jessica talked about how uncertainty of her husband’s medical stability was entwined and also impacted on her own sense of stability; *“And we’ve had period of stability but then we just got over another infection which is kind of thrown it all out again”* (line 62) and *“But we still have experiences, though, you know he’ll have a nasty infection and because he has these issues with heart rate and temperature, his blood pressure then drops so significantly and he can’t absorb antibiotics and, so we’ve have had, I mean I’ve had times when I’ve had to come in, in the middle of the night. Not knowing, what I’m going to turn up to really”*. (Jessica, line 340). For Kate her husband’s medical stability is also linked with her sense of stability and is her focus;

*“now I don't look for changes, I look for stability for him to be comfortable, it's horrible when he suddenly has a problem, I still hate it when he, he was in hospital about a year ago, he was pneumonia, it was horrible that **we had a crisis situation** and we thought we would lose him, errr, that's a whole another story”* (line 38).

For Imogen who is her sister's Court of Protection appointed Health and Welfare Deputy, she is inextricably linked with her sister through law, and she has become embodied as the voice of her sister in her care *“Um, sometimes I'm, there was, um, she needed, she needed an injection **and they should really be asking me.** There's something- It's just that all we have to get, and um, **they'd forgotten to get permission**”* (line 370). Bronwen also had legal roles for her brother as his Friend in Litigation and his Property and Financial Affairs Deputy, yet saw this more as something she could do for him and was doing in order to honour him.

Jean expressed the conscious feeling of giving over herself to help her daughter; *“Uh, I don't know really.... I suppose as a mum. You have because you love her and everything, you know, you have that, not obligation, but in a way that you want **to give her the best the more you can of yourself** to her”* (line 258).

This symbiotic experience was not expressed by Zoe (whose mother was injured). Instead she viewed this change in relationship as a reversal of care and something that may have come into her life anyway, *“I think, I'm uh thinking, **each person's life it will go through a cycle anyway..** where there are **times you look after somebody and other times when they look after you** so I think it's her time to be looked after now”* (line 208).

2.7.11 Advocacy

Knowing that you were ensuring all the things that could be done, even novel ideas, were being done mattered to the women. Samantha explained; *“I mean, I've always said, listen if moon dust would help [my son], I'll be on the next space ship to the moon, (laughter) you know. Whatever; **there is nothing that we wouldn't attempt to try for him.** Oh, within reason. I don't want to, I wouldn't hurt [my son], to get him better”* (line 390). Getting the right care was emotionally helpful to the women, Bronwen said; *“I'm so at peace because he's there and he's getting the proper care and they are so wonderful”* (line 134).

The women were all clear that they were committed to obtaining the best care and as much rehabilitation for their family member as they could. Bronwen talked of her deep commitment to her brother; *“we'll all **be there for him.** It's family, it's and it's **love”*** (line 91). Samantha was consciously aware of having reaffirmed her commitment to her son; *“We sort of **made a pledge** to each other, in a silent sort of way; not a sort of, this is what we're going to do. It was more of a sort of a, he needs us. We're here. **We're not going anywhere”.*** (lines 72-74).

Rebecca who felt her partner fundamentally no longer existed, was determined to honour his pre-injury self and her commitment was renewed towards his body; *“So I guess for me, I feel the [man] I knew isn't, yeah is gone, um, but there's still a body there that **I will absolutely look after'.*** (line 101).

For Samantha, she saw her role as both voice for her son but also as the holder of information for him; *“So it's partially advocacy, because he can't speak and say the*

things, so that you're having to **advocate on his behalf**. And it's partially, **you know his medical history so well now**" (line 123).

Imogen described her deep sense of knowing about her injured sister triggered a sense something was not right during a visit and her investigations led to finding an error in her care; *"I mean I came in today, and um, I realized there was **something that was different, and it was sensory actually. I wasn't hearing the clicking of her, her feed, and I thought "Oh." I looked at her feed, it was completely empty, and I went and saw the nurse and said "Have they changed her feeding regime? Because she's always feeding at this time, it's very, very unusual."** He went away and found out they forgot to put it on at 11:00."* (line 364).

However, finding one's way through the health and social care systems was an unfamiliar experience that Zoe described finding difficulties obtaining information about; *"When **we** came here, I spoke to some of the families and it was quite good to understand **the system**, because, you know, **it's complicated** about not only **the care then what do you do next**. You know it's a whole mind game, in a whole place where I **have to find funding** and all managers ... All of that is **complex** and just helped talking to other families"* (line 134).

In advocating for her husband Jessica described additional pain of having to fight the system; *"Um I would say one of the **biggest like stressors** and strains that we've had coming back to it again is, having to deal with **our CCG** um and **given the trauma** of what we've been through and the physical and mental strain that we've been under, to be then, to have that **added to us**, is just **appalling**"* (line 486).

The need for acute medical care necessitates admissions to other hospitals where the rarity of the condition means the ignorance of some professionals to the condition and a lack of trust and faith in the healthcare team to support the injured person; *"...So you experience things, which you had never thought possible. And you. That's why you never leave them. Because they can't talk"* (Samantha, line 110-114).

2.7.12 Abandonment

The sense of symbiotic relating and the women's strong sense that they had to become the persons voice and advocate for them perhaps contributed to the feelings of all being troubled by reductions in contact from the persons social networks and professionals creating a growing sense of abandonment.

Jessica talked about her sadness at the sense of abandonment of her husband's friends over time as he did not recover; *"all of his friends wanted to be very, they wanted to come up and see him all the time to start with and I'm sorry to say that I had to actually put a rota in and put like times that people were coming um, because otherwise you get so many people turning up that actually they can't come in at the same time and it was just a nightmare. So, the initial stages, his friends were very involved. Um and then as time has gone on, it's dropped and dropped and dropped and then now really, sort of not, they don't really come up at all which is quite sad"* (line 260).

Anna described a sense of abandonment from the professionals in her sons life; *"yeah, basically it was like you're in an elephants graveyard, sorry that is what I felt like that ward was like, it felt like a graveyard, that is where you totally lost hope, cause everybody else has, they've written him off, there is nothing we are going to do"*

*for him, tough, we are going to get him up in the morning, sit him in his chair, stick him in front of the telly and put him back to bed at night, **that's his life now**. That is not what anybody wants for their child."* (line 331).

2.7.13 Professionals versus family battles

Kate described that comments from professionals chipping away at hope had been especially hurtful; "*Another statement that absolutely **burns in my brain** and I'm sure fires me up sometimes was a social worker who came in, it was the [previous hospital] and she was a **real busy body** woman about 55 and she obviously knew stuff, obviously **knew the prognosis was not good**, and she came over, probably trying to be really kind, I don't know, I can't remember that bit, anyway she must have said something like have you got any problems, and I said No, no problem at all, were fine and she said oh well you just wait there will be one day or something like that, **sort of ha ha you don't know what's coming to you**. I've never forgotten that, I really hated what she said. I can't now remember, I mean she can't have said it like that, can she? She can't have said that? **I think I annoyed her** because I was **being really positive and extra robust**, I was **being determined**, I was not going to let this get me down. I don't know, perhaps she couldn't cope that maybe I came over a bit arrogant. I'm not blaming her particularly, but I thought I'm not going to let her win. But of course, there were problems since'.* (line 113)

The abandonment over time of family, friends, professionals and the system was a key component to women fighting with professionals. For Anna the professionals abandoning her son was painful and frustrating; "*I also feel completely **let down**, nobody gives a toss, **nobody wants to help**, they've just labelled him and **left him** and that is so hard. Because we know there is more in there, you don't get anything....*

Sorry (sobbing) ... **it's just horrendous**" (line 29). "we feel something else happened, we don't know, but something else happened that **we weren't told about**, well that's what we feel, I don't know, but I'm pretty sure that something else happened that we weren't told about" (line 97).

Jean experienced the professionals holding all the information and feeling excluded about what had happened to her daughter; "So uh, what **I don't find** is doctors, **they communicate with the patient's family**" (line 232)... "It's **very stressful for, for a family member**" (line 238). Imogen and Bronwen described a similar sense of exclusion about their siblings despite being the next of kin and that they as family were irrelevant and unimportant invalidating their relationships with their siblings; "I also think that these surgeons should speak, should find out, you know, **who the family members are and sit down and talk to them and talk to them all.** (sniff) Fathers, mothers, brother's sisters, wives. Those **key people in that person's life.** They're important too. I've, I've experienced none of that." (Bronwen, line 101) and "Three times I've now been asked, "Oh, so **you're the next of kin are you?**" Really it should be, it, **it should be there**" (Imogen, line 368).

Samantha, Zoe and Jessica explained that feeling involved mattered to them; "I think, um, I don't think it's a ... you never know how it could easier, because it's a hard process anyway. Uh, but, I think, uh, if **having more input in the care and being able to voice it** would make it **easier**. You know, and also I think it's quite good here, because the **doctors here give us some time.** The doctors back in [previous hospital] did but having that, um, being part of the process helps, without you being ... the Doctor's very nice too, he's always listening to any, he respects you ... But um, but my

*the reason I came here was because there's suddenly we got a letter saying something about being discharged and **we didn't know about it**" (line 234, Zoe).*

Imogen also described a sense of having to fight professionals who were trying to abandon her sister and wanting to stop rehabilitation before the family felt everything had been tried; *"Where they wanted to put her, we felt it was that they were just going to say, "This is the way it is," **no input**, and my father wasn't going to have that. He was insistent that everything should be done to see what, what there was. Um, and, um, so **he wouldn't allow her to be moved** to, I don't know what it was then, but just one of the wards. **He fought for her** to be put into this ward where she would be assessed, and, and she would have hydrotherapy, and all of those things, and they would look into what her mental, um, uh, capacity, how much brain damage that happened. That **we weren't sentencing her**, does that make sense?" (line 298).*

Jean too was concerned by lack of professional input for her daughter; *"I mean when I come, I stretch her arms and everything as much as I can and uh, you know. So at the beginning, it used be **upsetting a lot, why they don't do it for her?**" (line 192).*

2.7.14 Frozen futures: "My sense is he's not going to get much better, so I feel stuck"

The women describe a sense of great uncertainty about the future but typically with the exception of Samantha and Zoe, did not expect any further positive progress in their family members condition.

For Anna the sense of being unable to tolerate uncertainty about the future was a torture; *"mmm.....it's just the permanence of it all I think, if he'd died, that would be it – it would be over, but we haven't got that, we've got this for 5 years? 10 years? 15*

years? 20 Years? **We don't know.** We don't know if we'll ever get any more, ...we just don't know, ...and **that's the worst thing of all**" (line 113).

Rebecca also talked about the challenge to trying to look ahead; "...um, yeah **I don't quite know what I'm dealing with, and I guess it's the not knowing where its heading as well, I guess that's very hard too I think that um, you know is this going to go on for a year, two years, three years, twenty years?**" (line 110-111).

Jessica shared that she tried to operate in the present to cope with the difficulties of dealing with the challenging thoughts about her husband's prognosis; "Um well I'm well I mean as I said sort of before, I try to not look too far into **the future, because it's overwhelming**". (line 298)

For Jean, she expressed a sense of resignation at her daughter's situation but uncertainty about how long her life would be; "So but, uh, there's **not gonna be any changes as I'd say. This is what it is...** And over the time it might get worse and deteriorate... I believe so... So, because uh, she can last **an hour, a day, maybe 10 years more** because her organs, they are okay." (line 202-212).

Imogen too had become resigned to the idea that change was unlikely; "And actually believing that, um, that she would recover and make a full recovery. I genuinely believed ... **I hoped for a full recovery, um, and did things like, um, joined a healing circle. And became quite spiritual about it, about wanting that, that it would change. That she would come back, and she-** There might be some differences, but actually she, she, she would be my sister. And um, **it took me quite a long time to come to terms with the fact that actually, she wasn't**" (lines 282-290).

The frozen future and the passing of time highlighted to Kate how her husband is suspended in a time vacuum; “Yes, I do talk to him, in fact that is the main thing I do, talk about... because it’s so incredible... because I know that when he fell ill **we didn't have the internet, he'd never sent an email, he'd never used a mobile phone, well mobile phones were like bricks, he'd never sent a text** and I go on at him and say to him oh [their daughter] has just texted me and said blah blah and I think you don't really know what texting is and **its really weird** but I still obviously, that is how one talks, so you talk like that, so it is a bit odd!”(line 72).

Jessica and Rebecca described the problems with the mixed messages they felt they had received from healthcare professionals; “I think we **were given false hope** to a degree. I think we were kind of given an impression which actually **was detrimental for us**, because actually if you build up your hopes, then actually they come crushing down. Um so I think we were **given the wrong impression**. So, I think actually for other hospitals, they should be more informed on what really disorders of consciousness is” (Jessica, line 418).

In the absence of communication from the person with a prolonged disorder of consciousness, life is more uncertain. Zoe talked about hoping for communication to develop, as this will be key to help the family become more certain about her mother’s awareness levels; “You know, you know ... It's really important to us that she can communicate and **if that can happen we'll know**, because we don't know **what's going on in her head**. She used to love talking and spend time, spending time in the family and she is not able to express it. I know it would be good if she could just get it out to (trails off in her speech)”(line 80).

For Anna, the only certainty in the future was the death of her son; *“mmm, I don't think things are ever going to change, they **certainly aren't ever going to go back to what they were...** but I don't know I imagine in the not too distant future... the average span is about 5 years, we've done 3...**horrible way of looking at it, but... yeah**”* (line 250)

Kate twenty years post injury, related that she had also accepted the status quo of her husband's condition; *“I think that is what people often find difficult in this minimally conscious thing we think that when people get better, they're better and you go back home and they're normal and you carry on as normal, umm, so, so, there are still people that I know who feel that it is right to continue to pray for him to be healed or whatever, and **I have long moved on** from, from sort of, voicing that, but I still sort of hold, yeah it would be lovely if something happened and he made some progress or that would be great but at the same **time I totally accept the situation as it is** and I will just do, continue to be as good a wife as I can be in the circumstances whilst as good a mother as I can be for the kids because I know that's **what he would have wanted**”* (line 38).

2.7.15 Coping and wellbeing

Kate's desire to live a life her husband would have approved of, helped her to cope and continue living. Anna described the deep aching pain of walking alongside her son post injury; *“You spend your life in tears”* (line 377). Despite visiting her daughter daily for many years, Jean explained it was *“Yeah. Very painful”* (Jean line 298). Samantha too described a sense of heartache at her son's condition but that she had deliberately decided to create only a positive atmosphere around him to encourage

and facilitate any gains he could make “I mean, absolutely **streaming tears**, but **when we were in that room, there was no tears**” (line 441).

For Zoe and Kate, their faith was critical to helping them cope; “*Even going through the process, because you know, **God always has the best plan for you whatever happens. And whatever you do you end up with him anyway so it doesn't matter the process***” (Zoe, line 218).

Gaining support from others living with someone with a PDoC in their family helped Samantha; “*And we didn't have to make excuses. We **didn't have to explain***” (line 382).

Support from existing networks was more complex; “... *And, and, um, yeah I've had **people try to be terribly positive**, um, which I find hard, because, I'm like having to say, "it's not going to be like that" (line 281)... “[he] might come back, and I just found that really hard, because ah, yeah, because I think it's hard, when **I have to hear myself going, "no, it's not going to be like that", because you think then you're sort of, voice of doom, and then...**” (line 295) “*Its, it's been um, urghh, yeah, I get I yeah, I get all, I, the yes, there's been people who have been very positive been hard to deal with, I mean like I said, you know, like, the, the "we are all hoping for a miracle" people. I guess **that's left me slightly, annoyed**. It's like, but it's like, in a way its bit like, phew, you know, **they're the ones that aren't quite dealing with it.***” (line 340).*

For Anna who was deeply committed to her son and felt she was constantly fighting to get him rehabilitation and a high standard of care, the words of a close friend who voiced their opinion that her son had no quality of life which was perpetuated by her

was incredibly painful; “Yeah, I had a big argument with one of my best friends, who very kindly suggested on New Year’s Eve that I should think about pulling his feed tube out cause **I was being cruel to him and inhumane** and that it would only take him 2 days to die. Stupid cow, so **I’ve not spoken to her for over three years.** I mean **your friends change totally**, the ones that you think are going to be there for you, are just completely hopeless and the ones that you had no idea about, are the ones that turn out to be the good ones” (line 117).

The women shared that looking forwards is too frightening and implicitly that looking to the past was too painful. Samantha explained the living in the moment was the only way to cope with the enormity of the changes to their lives; “Because I think, **too much thought is not a good thing.**” (line 317). For Jessica, a day to day focus also helped; “But you, obviously you can put things in place, but um, I always say like, there's no point in trying to rush myself into what am I doing next, what's going to happen, because **actually it's too big to take on**, so actually if you just **take a little bit at a time** and think, “Well I'll do this **today, I'll do that** and will get that sorted.” (line 122). Bronwen too deliberately did not look forwards; “I'm not 100% there yet, I'm probably 80% in acceptance of it. But there's a little switch when it's, **when I start to think of the future**, probably without him as he was, **I can't go down that road yet.** I'm- I'm just keeping myself busy reading about his condition, looking after his property and affairs and doing the practical things” (line 32).

Jessica shares that being with her husband was emotionally easier for her than being apart; “No, not at all. It's a funny thing actually. It's always, I've always felt **more relaxed being with [her husband], than being away from [him]**, because it's actually when I'm away from him, **I worry more, because I don't know how he is, or can't see**

physically that he's okay. Because I've, was away for a period of time because I've spent so much time with him, I've become his expert and I know the small little signs of when something's wrong or starting to go wrong and I can pick them up very quickly um, probably even more quick as perhaps some of the Doctors because lesser signs, that I know well when that's happened previously this has been the result in the end.” (line 214)

For Samantha and Anna building new routines helped. Anna has taken a role in providing rehabilitation exercises; *“we’ll watch telly sit in his room, try and do some exercises, stretch him out a bit”* (line 169) and in her son’s personal care; *“well they do the basics, but I do his shaving, clean his ears, check his nose to get bogeys out, do all his washing and ironing (sighs) fighting”* (line 195). Imogen described that her shared love of music with her sister has meant she has had to evolve what they listen to on her sister’s behalf; *“And um, so I've introduced some, some new music as well”* (line 252). Jessica now reads to her husband things he would like but has discovered a new shared interest with binds them; *“But actually, what I've actually found interesting about it, is I'm reading bits that he would've have enjoyed and what he would be interested in, not necessarily, what I would be interested in, but that I found myself really enjoying them which is interesting”* (line, 210).

For Zoe, she made sense of her mother’s needs now as a transition to a new part of their family lifecycle; *“Um, it's a new role that she's playing, because that, to be fair when I was a baby she would have played a different role. This process ended. I can't ... People have seasons, this, her season is to be looked after and same as if you have children. Even in your marriage, your relationship it was at different stages you are supporting each other in different ways”* (lines 258-260).

2.8. Discussion

This study aimed to explore the experiences of women having a close family member with a disorder of consciousness, how this affects them and how they seek to negotiate their relationship with the injured person.

2.8.1 Summary and discussion of the main findings

This research shows that for the nine women, the experience of grappling with the sudden and unique condition of a disorder of consciousness has been complex and created much uncertainty in their lives. As shown in Table 2.5 from their lived experience through the application of Interpretative Phenomenological Analysis methods, four main superordinate themes have been identified; (1) Loss without a name (2) Relationship without a title (3) Symbiotic relating and (4) Frozen futures. These difficulties were associated for the majority of the women on psychological measures with disruptions to their work and social functioning and their overall emotional functioning on the measures, despite maintaining a sense of ongoing hope.

2.8.2 Loss without a name; “Who I know is gone, but there’s a body there”

Participants’ descriptions are of a sudden and dramatic change to life, not a slow and progressive decline as in illnesses (such as cancer or dementia) where there has been a growing awareness that something was “wrong” and a sense of a turning point with a diagnosis (Garwick, Detner & Boss, 1994). PDoC created a deeply distressing and painful loss that was hard to describe, not easily named or addressed by the women’s pre-existing understandings of loss and grief. They shared a sense of unending grief at being with someone who has been so profoundly injured to be now psychologically unavailable to them, but who still physically remains present. This finding concurs

with the early descriptive papers of family experience (Stern et al., 1988; Chiambretto, 2001), emerging qualitative research (Giovanetti et al., 2015; Cipolletta et al., 2016; Hamama-Raz et al., 2013) and resonates with Boss (1999)'s concept of Ambiguous Loss. Further, this corresponds with Doka's (1999) "disenfranchised grief" proposition, that losses that are unacknowledged and not publicly mourned lead to a complex form of loss.

The enduring experience of loss in families of people with PDoC has been mapped against Prolonged Grief Disorder in the quantitative literature (see Corallo, Bonanno, De Salvo, Giorgio, Rifici, Buono, Bramanti & Marino, 2015; Chiambretto, Moroni, Guarnerio, Bertolotti & Prigerson, 2010; Bastianelli, Guis & Cipolletta, 2016; Elvira de la Morena & Cruzado, 2013; Guarnerio, Prunas, Della Fontana & Chiambretto, 2012; Moretta, Estraneo, De Lucia, Cardinale, Loreto & Trojano, 2014) recognizing families in PDoC grief does not resolve. This reflects the enduring and long-term nature of PDoC which does not fit easily with linear, traditional stage and phase models of grief (Illman & Crawford, 2017) where the aim of the grief work is letting go and moving on. Further the description of Prolonged Grief Disorder does not inform what underpins the enduring sense of loss. As described in Chapter One, this suggests conceptualizing family experience in Prolonged Grief Disorder terms may not be the most useful way of understanding their experience. However, post-modern loss and grief models do resonate with their descriptions, in particular the Continuing Bonds theory of grief that advocates holding onto bonds but in a revised way (Neimeyer, Baldwin & Gillies, 2006). The losses from the PDoC were further compounded and complicated by a post-injury life full of multiple new medical challenges and instability persisting for prolonged periods. This constant threat of loss increases the experience of ambiguous loss and makes coping with loss confusing, as it is so unclear for the

families what they should be adjusting to (Boss, 2002), as no sooner have they got a sense of status quo, a new medical problem seems to emerge and a new threat of loss occurs. This study suggests PDoC are also distressing for some participants' as creating an intolerable position to cope with, that the PDoC meant the injured person did not have a true life and that this was worse than an actual physical death. This is consistent with findings of Cipoletta and colleagues (2016).

2.8.3 Relationship without a title: what's my relationship with him?"

Relational ruptures were apparent in this study. Families are faced with finding new ways to relate to the injured person and foster new relationships. It has been argued that healthcare professionals have a core role in developing and supporting these reformed relationships (Noohi, 2016). PDoC mean the person is unaware of themselves and their surroundings despite being awake for periods of time with their eyes open and moving around. The absence of any consistent or meaningful interaction creates for the women a strange unreciprocated and one-sided relationship where all the responsibility and effort for the interaction and contact rests on them. Similar to the Cipoletta and colleagues (2016) findings, the participants' shared their uncertainty about whether or not the injured person fundamentally even knew who they were and that they were even present. This combines to lead to the women questioning what their relationships are at all with the injured person and difficult to describe what they had become. This is highlighted by the statement made by one person *"I'm neither a wife nor a widow"*. This uncertainty about the nature of their relationships is hard to understand for themselves and hard to articulate to others as typical relationship labels and paradigms failed to address their new and transformed relationships.

The lack of responsiveness conversely was helpful for some participants to recognize that the relationship was significantly changed. They felt lonely and deeply missed the person, even though they were still physically present. A key difference to loss by death, is that as the person is still physically alive, hope is implicit for families that the injured person who has been psychologically lost, may return. Crucially, families reported that their idea of how a recovery for the person would occur was through the input of the right skilled professional. That is, what the professional would do to the injured person, would enable recovery. The process of trying to make sense of experiences and what they mean, is known as meaning making (Neimeyer, 2006). Some of the women attempted to rebalance their uncertainty by deliberately choosing to give the person the benefit of the doubt that they had some awareness or had awareness of a new sense of familiarity with them, which took precedence over the loss of the historical relationship. For others, lack of awareness of their relationship was considered irrelevant and they focused on their commitment to the person.

2.8.4 Symbiotic relating: “I will never rest until I’ve done everything I can possibly do”

Two participants took on legal roles post injury that meant they acted on behalf of their family member, and legally act as if they *are* the family member. For others, the dependency of the injured person seemed to lead to the development of a shared embodied experience. Their language use in describing their experiences involved the term “*we*”, a shared sense of involvement in the awfulness of the experience and a sense of participating in the process of rehabilitation. One participant caught herself in her description and temporarily reverted back to “*I*”, but lapsed again in descriptions to the shared “*we*”. This symbiotic relating meant that when fluctuations

in medical stability occurred significant emotional instability for the women also occurred.

The identification with and suffering alongside the person with the PDoC has previously been noted (Hamama-Raz et al., 2013). Perhaps by feeling so embodied in the experience, the women were deeply hurt by the reductions in contact and visits for the injured person as is common by friends and family over time (Noohi et al., 2016). Whilst intellectually voicing an understanding of the need for people to continue their lives and the sense that visiting maybe irrelevant anyway, on an emotional level it appeared they perceived this to be abandoning of the injured person and themselves. The women were most frustrated by the sense that professionals were giving up and abandoning, as changes to long term chronic disability management occurred (Noohi et al., 2016), both themselves and the injured person and failing to provide the type and nature of care and rehabilitation that their family member needed (Cipolletta et al., 2016). This symbolic joining coupled with the deep commitment to the new and transformed relationship, perhaps contributes to the strong sense of advocacy the women felt towards the injured person.

This fighting to prevent abandonment, culminated in battles with healthcare professionals. The participants' described a sense that they should be involved and that this mattered to them, but experienced a lack of access to information and a sense of being excluded from decision making. 58% of this small sample reported unmet informational needs. However, other PDoC research has suggested it is difficult to satisfy family needs for information (Crawford & Beaumont, 2005; Leonardi et al., 2012). Research has demonstrated that families may request continuations of treatment even if clinically not indicated and have different understandings about the

purpose of a treatment (Crawford & Beaumont, 2005; Latchem, Kitzinger & Kitzinger, 2015). Given, families apparent beliefs that the mechanism of change and recovery seemed to relate to the input that professionals would provide, any reductions in professionals input and transfer to long term residential care, signalled to them that no further change could be achieved. This is experienced as a sense of rejection from medical professionals in the context of fading of support from social networks (Noohi et al., 2016) and disagreements and conflicts with healthcare professionals in PDoC has been noted (Rodrigue, Riopelle, Bernat & Racine, 2013). Given the amount of time spent with the person, families were well versed in the running of the organisation, aware of its' limitations and experienced losses of trust in medical professionals (Cipolletta et al., 2016).

Klass, Silverman and Nickman (1996) propose a Continuing Bonds Theory, where after a bereavement people are challenged to find a new way of remaining bonded (for example, this may typically take the form of visiting the graveside, or the place of death, lighting candles, celebrating anniversaries, talking to them etc). In the absence of death but faced with the lack of reciprocation in their relationship, challenges the women to find ways of remaining bonded. These included continued physical presence with the person (Cipolletta et al., 2016), contributing to significant skill acquisition (Gourdarzi et al., 2015) and becoming expert in recognition of changes their family members health (Cipolletta et al., 2016) as well as knowing in depth their condition and medical history. Participants' shared ways of coping with their pain and distress by developing new routines, new ways of interacting (Cipoletta et al., 2014) becoming a part of delivering the care (Cipoletta et al., 2016; Noohi et al., 2016), managing the quality of the care (Hamama-Raz et al., 2013) and rehabilitation team around the person. Cipolletta and colleagues (2016) hypothesised that relationship

transformations in PDoC are solely managed by the provision of physical care of the body and acting as if the essence of the person remains. This gives families a valued purpose and tangible tasks. However, navigating the health and social care systems and being given a space to share this knowledge with professionals was frustrating and confusing, leading to creating additional pain and distress for the women.

Participants shared other ways of coping with the pain and distress of their loss by developing new routines and becoming a part of the care and rehabilitation team around the person. For others support from friends helped. However, old friends were also described as being falsely optimistic or pessimistic which made interacting difficult and creating a greater sense of isolation. Support from others experiencing the same condition was described as helpful for some participants, but also showed the differences in how families approached the situations.

2.8.5 Frozen futures: *"My sense is he's not going to get much better, so I feel stuck"*

The participants were full of uncertainty about the prognosis and the future, in part due to the mixed messages they felt they received from healthcare professionals. Their struggle with so much uncertainty meant it was very frightening to look forwards and too painful to look backwards, leaving them living solely in the moment. The Dual Process Model of coping with loss (Stroebe & Schut, 1999) observes that people adopt a present moment focus to facilitate carrying on with the tasks they have to do and oscillate to managing their emotional struggle with their losses in a dose effect that they can cope with, which mirrors the description of how these women coped with uncertainty. Being with the injured person focused in the moment was easier for many than being apart, where avoidance of the losses in their

wider life of the person was more evident. In this way, they have a dose effect, coping with uncertainty and their grief in manageable chunks.

Whilst two of the participants hoped for future changes, the other seven shared that they manage this by a sense of resignation that there will be no real change in their family members awareness. Given that people with PDoC could have a normal life span, it was challenging for the participants to look forwards and imagine the future, instead they were suspended in the moment. For some this was a deliberate way to cope with the tragedy they faced, of the person being frozen in the time of their injury. Cipoletta and colleagues (2014) also noted the challenge of the future being “unthinkable” and called this the “time gap experience”. They noted the confused use of tenses of family caregivers and the sense that the person is fundamentally different but that they have a past in common. This description is also similar to the description of how ambiguous loss and confusion in caregivers of people with dementia creates “immobilization” (Caron, Boss, Mortimer, 1999).

2.9 Summary and conclusions

This research shows the women are grappling with an unconventional loss not easily named or understood by them, with ongoing threats of further loss, as they strive to continue to hold on to an unreciprocated, one-sided, transformed relationship with their family member. Although the injured person can no longer communicate, the women fight to ensure that they are not forgotten and the best care and rehabilitation is achieved for them whilst facing an uncertain future for the injured person and themselves. Kitzinger and Kitzinger (2014) encourage healthcare professionals to respect the variety of ways families may cope with the injury and see these as normal responses to an abnormal and deeply distressing situation. It is

important to recognise the breadth of families' responses and the unique impact on each family member relative to their role and relationship to the injured person (Gourdazi, 2015) particularly as this can become more confusing and difficult as time progresses (Hamama-Raz, 2013). PDoC are chronic conditions and families require long term support (Noohi, 2016) and need to talk about and share their situation (Cipolletta, 2016) as they struggle to live alongside it.

The present study has established in an in-depth way, an understanding of these participants' experiences in an under-researched area. Rather than descriptive or assumption driven research (testing hypotheses) that has predominated about what families of people with PDoC experience, this study has sought to ask what the experience is like for them. The aim of IPA qualitative research is not to produce generalizable findings, but rather to ascertain theoretical transferability (Smith et al., 2009).

Given the research to date has focused on the ongoing loss and distress families report from the perspective of Prolonged Grief Disorder (for example, Giovannetti et al., 2015; Elvira de la Morena & Cruzado, 2013), the findings of this study propose a novel way of conceptualizing and understanding the family experience in PDoC. This is conceptualised as the Preliminary Model of Chronic Uncertainty, displayed on Figure 2.1 below. It is proposed that families' psychological distress and difficulties are precipitated by the initial injury factors of: suddenness, the person's unstable medical status, coupled with limited initial understanding about PDoC in the family and therefore hopes for recovery. The uniqueness of the PDoC leads to multiple coping challenges that are difficult for families to manage. As time progresses without recovery, families are locked, immobilized and frozen in a present moment focus.

There is no ability to obtain “closure” or complete grief work because there is no certainty about which direction the family should move in and there is no end on the horizon of the condition. These factors are possibly what perpetuates and underpin the sense of prolonged grief described in the literature to date.

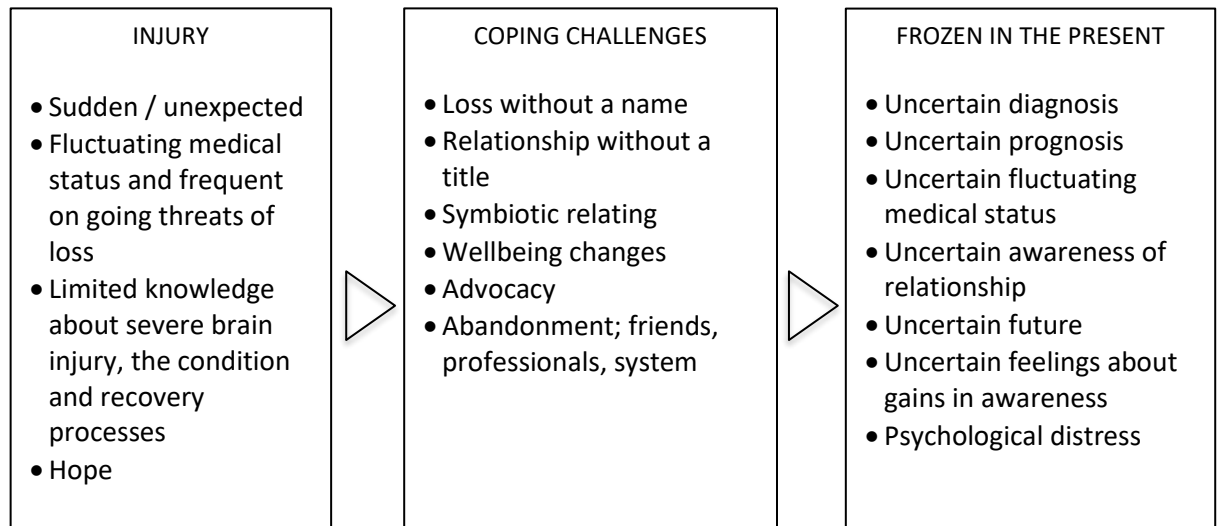


Figure 2. 1 The Preliminary Model of Chronic Uncertainty.

This Preliminary Model of Chronic Uncertainty proposed, also suggests several points for possible psychological intervention. It seems important that a wider perspective of rehabilitation includes’ helping families to develop new understandings of their situation and roles and supporting thinking about how to cope with their situation and emotions. Further research is needed to establish if this could also be true for the wider family network coping with a member with a PDoC.

2.9.1 Limitations and Future Research

An obvious limitation of this study is that the sample had less homogeneity than desired. As PDoC are a unique and rare condition, gaining participants with experience of it meant that despite purposive recruitment of only females who were

the primary caregiver, the relationships with the injured person varied (wives, mothers, partners, siblings). Kate described in her interview that her impression was the relationship with the injured person mattered *“I’ll tell you the other thing I’ve noticed over the years, I’m convinced I’m right. I think it is a completely different situation depending on if you are a spouse or a parent. So the parents, who have a child, albeit an adult child who becomes minimally conscious, find it impossible to let go and...because their child has become dependent, assuming they were 18 or whatever, they’ve got back a dependent child and they take back that parental role. My husband’s parents were like that and they wanted to be here every minute of every day, his mum stopped basically eating because she had to be here, unless I was here, she’d be here it drove me a bit mad, because it was like ahhh. Then she had a stroke and died and 9 months later her husband had a stroke and died because of the stress, in a way, I mean it’s medical, but she just could not cope, absolutely could not cope emotionally and in any way with it, I mean she was completely devoted and she never came to terms with the reality of what she was facing”* (line 86). This study recruited the main caregiver, which is consistent with the wider literature in the family experience of PDoC that is mainly centred on the primary caregiver. However, further research is required to determine if relationship is a factor in differentiating family experience. In addition to differing relationships, the time post injury varied (from 6 months to 27 years), the nature of the cause of the person’s injury varied (including one participant who reported the injury related to a suicide attempt) and participants were also interviewed where they chose (home versus hospital) which may influence the contextual nature of the interviews. However, none of these characteristics appeared to show substantial divergences in the data of this study, nor in a previous study (Covelli et al, 2014).

The research site medical staff initially approached potential participants. The study was designed like this to maximize confidentiality and decrease any pressure on families who are complexly distressed and at a time of huge personal turmoil. As such the participants were a self-selecting group, who have all remained involved with their family member over time. It is possible that participants had already emotionally reached a point where they have done some sense making of their situation and they were now able to articulate that. However, all participants varied in the length of time post-injury and this did not show any divergences in the data.

Finally, a key limitation is that the methodology of IPA is also its strength. IPA seeks to achieve a depth of understanding of the lived experience of people familiar with a particular phenomenon of interest. To achieve depth, this means creating homogeneity in the sample to enable theoretical transferability of the findings. Further research is required to establish if this proposed model is applicable to males and the family members with different relationships to the injured person.

2.9.2 Implications for clinical practice

Crucially this study suggests that rehabilitation needs to take a systemic approach and that the work of clinical teams must involve not only the identified patient with a brain injury, but their wider networks who are complexly distressed and grappling to find new roles and ways of still being together in the changed family system. The proposed model is consistent with Ambiguous loss literature, which suggests intervening with the family as a whole is important and that healthcare professionals can play a central role in supporting families to retain connectedness, in part by helping label the uncertain nature of the condition and how it disrupts family life (Garwick et al., 1994). The proposed model suggests psychological support to

demonstrate a sensitivity to this loss, a validation of their loss, a framework for naming the loss, provision of education about the condition and ways to enhance coping with a chronic situation seem useful starting points.

A consistent finding was that families felt their distress was made worse by healthcare professionals lack of recognition of them as important and thus an invalidation of their relationship with the injured person and the lack of information to meet their needs about the injured person. Families need for information (Leonardi et al., 2012; Giovannetti et al., 2013) in PDoC has previously been reported as difficult to satisfy. Families have been identified as needing time for them to appreciate what has happened and understand complicated concepts around consciousness and awareness (Rodrigue, Riopelle, Bernat & Racine, 2013). This suggests current systems of sharing information with families would benefit from review in terms of their nature and frequency (for example, are multi-disciplinary meetings that families attend the most useful means of providing information to a family? Would principles from expert patient training benefit families of people with PDoC?).

2.9.3 Reflexivity

Reflexivity is at the core of both hermeneutics and phenomenology, a task of reflection to examine the role of the researcher's presuppositions (Shaw, 2010) and as essential for the validity of the research (Mortari, 2015). During the interviews, I became aware of my own expectation that participants' would not articulate the in-betweenness (Kitzinger & Kitzinger, 2014) of their situations, as my clinical experience is that families tend to strongly believe their relative is locked in their body but aware or totally unaware. In fact, I was surprised by the ability of the women to describe this.

I was also surprised by the women's lack of expectations of substantial future change. The families in my clinical work and the common belief amongst treating teams, is that families unrealistically seem to hope for and expect change. I noted the expectation of all the families that the mechanism of change was the input that the professionals providing rehabilitation would give, and thus more input was best. However, as a clinician my experience is that clinicians think that stabilizing the person's medical condition and physical condition using a disability management approach enables the person to be in the best position to spontaneously make gains. This was a striking and total paradigm conflict and I reflected that perhaps explains some of the conflict with relatives seen on the wards of people with PDoC.

I was frustrated and saddened by the lack of information and contact with professionals and indeed the conflict with professionals that the participants described which had made their experiences of coping with this condition even more painful and difficult. It seemed to me that the participants often experienced the rehabilitation as something they as a family participated in (the use of inclusive language "we were transferred here...") however the way services are set up and the legal requirements around the limits of confidentiality for adults, creates a barrier to open information sharing. This seems an unhelpful paradigm for thinking about the design of services for this clinical population where the identified patient can not consent to share their information and if they could have expressed it, they may well have wished to do so. Indeed, their family are also service users who hold the information and use it to make other decisions on behalf of the person such as long term placement or views on further procedures.

I reflected on the issue of being a researcher who is also a trained clinician and the need to remain in my researcher position and refrain from engaging in supporting and problem solving with families. I used debriefing from the field supervisor to recognize the tensions between maintaining care for the participant in the absence of a therapeutic relationship and to maintain a researcher stance.

Finally, I became aware the focus in psychological therapy with families in PDoC, tends to centre on grief, distress and coping through self care, setting up sustainable visiting and balancing the needs of the injured person and themselves. I had not anticipated their frequent description of the ongoing threats of multiple near death loss (on top of the change in the person due to their initial injury) as the person's health status fluctuated, which led them to being both fearful of further illnesses and hopeful that it may mean an end to the interminable situation that both they entwined with the PDoC lived out. This led to my desire to honour the openness they had shared with me and a tension as a researcher of wanting to have all these women's voices 'heard' but the battle to include enough of their own voices to allow for rigor - but not too much, was a challenge! These interviews contributed to a new way of understanding what is really needed for families in therapy, a need to make sense of their situation by validating and labelling it.

Chapter Three

Is there a link between loss, distress, and meaning making?

3.1 Introduction

Although no studies were identified that systematically investigated the psychological experience of families within the United Kingdom, Chapter One discussed the international literature that living with a person with a PDoC in your family can be distressing, create a complex form of grief, be burdensome and difficult to cope with, but in spite of this some families do manage independently to cope. Chapter Two added to the understanding of family experience and showed that families were faced with a time of much uncertainty, complex losses, challenges with making sense of their relationship and a sense of being entwined with the injured person. This resulted in them, becoming immobilised and having difficulties with future focused thinking. This is captured in proposed theoretical model, The Preliminary Model of Chronic Uncertainty (displayed on Figure 2.1 on page 113).

The injury that leads to the development of a PDoC precipitates a sudden, unexpected sense of loss for families. Chapter One described that loss in families in PDoC to date has been based on the concept of a finite loss (such as in death), modelled on Prolonged Grief Disorder and has been operationalized and investigated using one measure (the PG-12). This suggests the person has failed to “get over” their grief, and it has become prolonged as they yearn for the person to return. However, in PDoC

there is no death, the person can not return and thus the situation does not resolve and the family is stuck in the same unending position. Chapter One questioned Prolonged Grief Disorder as pathologizing and unhelpful as a model to understand families' experience. Chapter Two showed families felt frozen in the present and that their experience is unending, very distressing and difficult to make sense of.

Meaning making is considered critical in adjustment following bereavement and stressful life events (Holland, Currier & Neimeyer, 2014) and encompasses an ability to make sense of a particular life event (comprehensibility) and hold onto a larger sense of meaning (footing in the world), such as in relation to belonging, values, goals sense of purpose and direction (Holland, 2015). Park and Folkman (1997) developed a framework to understand the critical concepts of "meaning making" in adjusting to unwanted and stressful life events that was grounded in the transactional model of stress and coping. Park (2010) later further expanded this in an integrated meaning-making model, displayed in figure 3.1 below.

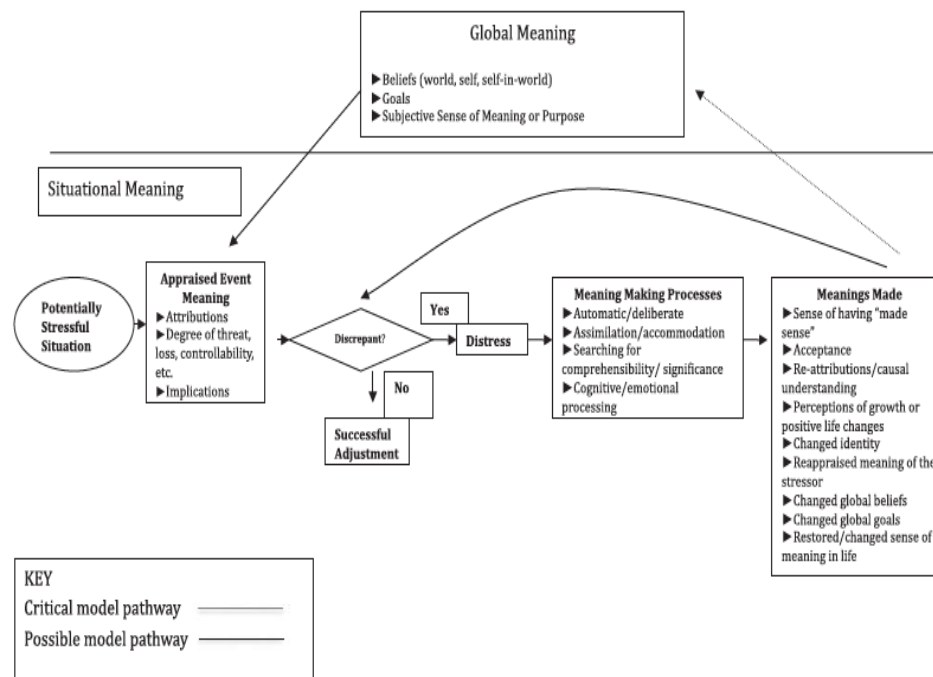


Figure 3. 1 *The meaning-making model.*

Reprinted from “Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events”. By C. Park, 2010, *Psychological Bulletin*, 136(2), p. 258. Copyright 2010 by the American Psychological Association.

Park and Folkman (1997) defined *global meaning* (what a person believes and desires) as relating to the person’s overall ideas about what is right and how the world operates in terms of predictability, justice, control and the person’s desired events and goals (like love, health, work, achievement). This is developed through life and adapted through experiences. Global meaning encompasses the internal guiding sense of purpose and individualised sense of what gives life meaning (Park, 2010). Global meaning (what people believe and desire) is challenged by a diagnosis of PDoC in the family, goals for life and plans for the future are violated and important global beliefs such as fairness, predictability of the world, sense of personal control and sense of invulnerability shaken.

In contrast to these globally held meanings, *situational meaning* is defined by Park (2010) as a set of processes including appraising and assigning meaning in response to a stressful event (such as why it happened, implications for the future, ability to control it). In illness research, the meaning ascribed of the illness is based on information the person receives (including from healthcare professionals) and how this is appraised is predictive of coping and adjustment (Park, 2013). In Chapter Two, families reported initially expecting the person would recover and holding out hope, and in spite of multiple medical complications the person continued to survive. Efforts to therefore assimilate the illness into their pre-existing global meanings or change their global meaning to accommodate the situation are required (Parks, 2013).

When there are differences between the deeply held global meaning and the person's appraisal of the meaning of the event, this determines the level of distress the person experiences (Park, 2010). Park's Meaning-Making model argues that reducing this perceived discrepancy is required through various meaning making processes, which are not processes of coping assessed by traditional psychometrics (such as the COPE-28) that has been used with families of people with PDoC to date.

This Meaning-Making Model was adapted in line with the findings of Chapter Two, where the potentially stressful situation is the occurrence of brain injury. As early appraisals of meaning of this event occur, the degree of threat is high as the injury is typically unexpected and sudden, the fluctuating medical status of the person often leads to ongoing threats of further loss and the family retained high hope for rehabilitation and recovery, in part because of limited knowledge about brain injury, PDoC and recovery processes. The implications of the injury create coping challenges and uncertainty. This in turn is discrepant with possible global views such as; "he is strong and can pull through this", "when you get the right professional help you get better", "bad things shouldn't happen to good people", "this is not deserved", "even if some small residual level of disability remains life will be worth living" etc. Park's Meaning-Making model (2010) would then suggest this discrepancy in PDoC leads to distress. This is a form of cognitive dissonance (Festinger, 1957), where discomfort arises when the family member holds two opposing views at once (for example conflicting thoughts that they will recover yet they are not recovering). This adaptation to the meaning making model with the is shown with the integration of the Preliminary Model of Chronic Uncertainty shown on Figure 3.2 below.

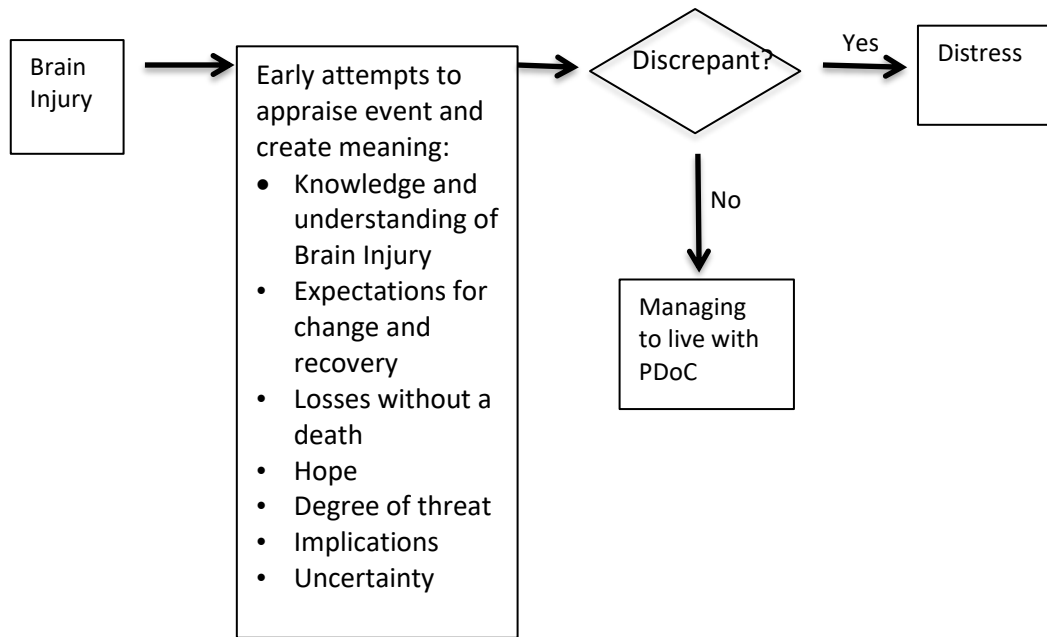


Figure 3. 2 How distress arises when early meaning making attempts are discrepant with reality and global beliefs.

Adapted from The meaning-making model and integrated with proposed Preliminary Model of Chronic Uncertainty. Reprinted from “Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events”. By C. Park, 2010, *Psychological Bulletin*, 136(2), p. 258. Copyright 2010 by the American Psychological Association.

Previous research and Chapter Two has shown that family members experience distress. This could suggest early attempts to appraise the event and create meaning are discrepant with more globally held meanings about how the world works. This thesis has shown other ways of conceptualizing complex loss, such as Ambiguous Loss (Boss, 1999). This is supported in the qualitative literature of families of people with a PDoC, as well as in Chapter Two of this thesis where families described trying to make sense of their feelings of loss when the person was still alive but so different to before their injury. The feeling of being unable to make sense of the situation, is suggestive of difficulties with early appraisals of meaning. Boss (1999) argued that ambiguous loss blocks meaning making. Chapter Two showed the families try to make sense of the situation and establish new ways to continue their relationships with someone physically present but psychologically absent. Strong levels of continuing bonds have

been viewed as helpful in the initial phases of finite (such as in death) loss (Field, Gal-Oz & Bonanno, 2003) and can help meaning reconstruction to make sense of the loss, find benefit in their experience and reconstruct a positive sense of identity (Neimeyer, Baldwin & Gillies, 2006). These alternative theories have not been investigated for their relevance to the experience of families of people with PDoC.

This study aims to investigate within the first UK sample, the nature of symptoms reported by families of a person with a PDoC. Secondly, this study aims to investigate which is the most appropriate loss measure to identify family members in PDoC who may be in need of additional support. Thirdly, to identify how successful meaning making attempts are for families after a PDoC. Finally, to establish if there is a link between the injury, ambiguous loss, meaning making difficulties and distress. This is formative research towards understanding their experience and therefore being able to design an intervention to support families coping with PDoC.

3.2 Method

3.2.1 Design

As there is currently no national register of people with PDoC in the UK, on discharge from inpatient NHS services they may return home or to long term residential care units. This means families are dispersed, hard to reach and have multiple demands on them post injury. To investigate the psychological experiences of families of people with PDoC in the UK, an online survey was considered best to be able to reach a wide group of potential participants, as an online method could enable them to participate at a time and place that best suits them (Lefever, Dal, & Matthíasdóttir, 2007). This method is argued to have advantages in providing a sense of anonymity when

researching sensitive and personal areas (Flanagan, Greenfield, Coad & Neilson, 2015). There are conflicting opinions as to whether online data collection affects representativeness of the sample (Barker, Pistrang & Elliot, 2016) and response rate (Lefever et al., 2007), particularly as not all potential participants have access to digital technologies (Flanagan et al., 2015). Traditional postal surveys response rates are commonly considered acceptable at 30%, whereas online surveys report response rates varying between 15 and 60% (Lefever et al., 2007). However, as recruitment can be targeted via websites online data collection is especially helpful in rare conditions (Barker, Pistrang & Elliot, 2016) and as participants can highlight the research to other members of their own family and other families in their network affected by PDoC, (Latchem, Kitzinger & Kitzinger, 2016), known as snowballing (Flanagan, Greenfield, Coad & Neilson, 2015). It was intended that the online method would enable the opportunity for both male and females, and family members with differing relationships to the injured person to participate. Online data collection was seen as enabling a cross sectional design and had potential to enable participation in the study of families at different points post injury than would have been found in a specialist inpatient rehabilitation setting where families are at an earlier point in living with the PDoC. Cross sectional surveys are helpful to investigate the prevalence and extent of characteristics of a population (Visser, Krosnick & Lavrakas, 2000).

3.2.2 Procedure:

A brief explanation of the study was provided on the home page of the Brain Injury is BIG website (www.braininjuryisbig), an online support forum and information source for families of people with PDoC. The support group was established in 2013 and has 539 registered community members, including clinical professionals and researchers. The home page of the website detailed a brief introduction about the research which

was possible to view on the website home page when visiting it, even if not a member of the Brain Injury is BIG group. This introduction contained a link to the on-line survey, hosted on a widely used platform (SurveyMonkey), that potential participants could click and go directly to the research. Once on the SurveyMonkey portal, potential participants were able to read the Participant Information Sheet (see Appendix N) and decide if they wanted to participate. No information was collected unless the person completed a Consent Form (see Appendix N), thus it is not possible to know how many people may have read the Participant Information Sheet and decided not to participate. Participants completed the measures and basic demographic information. Completion of all the measures took approximately 20 minutes. On the last page was a debriefing form. Potential distress associated with focusing on their situation and participating in the research was managed by signposting people to the BIG forum moderator and to self refer to their GP (primary health care provider) if required.

Data was collected from August 2015 until December 2016. This period of data collection was extended to increase recruitment. To further bolster recruitment, the website moderator also posted an alert on the Notice Board in the Members Only section of the forum to alert the community to the study and the opportunity to participate.

3.2.3 Measures

To assess participants' psychological experiences wellbeing, anxiety, depression, general psychological distress, work and social functioning were assessed.

Several measures described in Chapter Two were used; The *Work Social Adjustment Scale* (see Appendix F), The *Hospital Anxiety and Depression Scale* (HADS; see Appendix G), The *Warwick Edinburgh Wellbeing Scale* (WEMWBS; see Appendix H), The *Boundary Ambiguity Scale* (BAS6; see Appendix I) and The *Perspectives on Diagnosis and Prognosis of the Person with a PDoC*.

The *Continuing Bonds Scale* (CBS; Field et al., 2003; see Appendix O) was used to measure the perceived extent of emotional connection still maintained with the injured person. In bereavement research, continuing bonds are conceived as an ongoing inner relationship with the deceased (Schut, Stroebe, Boelen, & Zijerveld, 2006). Due to the impact of the injury preventing the person with PDoC from having any psychological relationship with the family, the concept of an ongoing inner relationship is argued as equivalent here. It has 11 Likert-type statements which range from 1 (not true at all) to 5 (very true) such as “When making decisions, I imagine my loved one’s viewpoint and use this as a guide in deciding what to do”. One item was reworded to reflect that non-death loss that a PDoC creates from the original item “Even though no longer physically present, my loved one continues to be a loving presence in my life” to the revised item “My loved one continues to be a loving presence in my life”. A total score was calculated, with higher scores indicating a higher degree of connectedness. Good internal consistency has been reported ($\alpha = .87$) as well as being positively related to ratings of relationship satisfaction (Field et al., 2003).

In addition, other measures associated with loss in the grief literature were used. The *Prolonged Grief Disorder-12 Caregiver Version* (PG-12; Prigerson, Horowitz, Jacobs, Parkes, Aslan, Goodkin, et al. 2013; see Appendix P). The PG-12 assesses self reported

grief symptoms relating to sense of meaningless, interpersonal disengagement, yearning and bitterness (Chiambretto, Moroni, Guarnerio, Bertolotti & Prigerson, 2010) on a likert scale. The PG-12 is a validated measure originally designed for dementia caregivers (Kiely, Prigerson & Mitchell, 2008), and has been the only measure of grief that used in caregiver research in PDoC to date (Soeterik et al., 2017). There is no UK data on the prevalence of this in families of PDoC.

Lastly, Participants' ability to gain perspective, make sense and find meaning following their stressful life event was assessed by *Inventory of Stressful Life Events Scale* (ISLES; Holland, Currier, Coleman & Neimeyer, 2010; see Appendix Q) which was developed from the Park and Folkman Meaning-Making Model. The ISLES has 16 statements with Likert-type responses (ranging from 1-strongly disagree to 5-strongly agree). Three scores were calculated, a total score and two sub scales. The subscale of Comprehensibility, assesses the sense made from the stressful event and how it has been assimilated, integrated and adapted to. The Footing in the World subscale examines the sense of purpose and security accommodations in meaning making following an event in which the world does or does not make sense. Higher scores reflect more adaptive meaning making with a total ISLES score of 52 or lower classifying bereaved young adults with elevated complicated grief with 90% sensitivity and 74% specificity. The test author states that Comprehensibility scale scores of 16 or less, and scores on the Footing in the World subscale of 36 or below are indicative of problems (personal communication with Holland, 2017). Strong internal reliability is reported ($\alpha = .80$ to $.92$) with moderate test-retest reliability over 2-3 months ($r = .48$ to $.59$), and concurrent validity with other meaning-oriented measures in the general stress and bereaved samples (Holland et al., 2010). A factor analytic study has shown ISLES scores are distinct from general distress and post traumatic stress symptoms

(Currier et al., 2011) and is able to predict mental and physical health (Holland et al., 2014).

3.3.4 Participants

Thirty participants completed the online consent form to participate in the study. This is consistent with the sample sizes of other research published in families of PDoC (Romaniello, Farinelli, Matera, Bertolotti, Pedone & Northoff, 2015; Moretta, Estraneo, De Lucia, Loreto & Trojano, 2014; Giovannetti, Pagani, Sattin, Covelli, Strazzer, Castelli, Trabacca, Martinuzzi & Leonardi, 2012). This would suggest a response rate of 5.5% (of the 539 registered members of Brain Injury is BIG, although this figure included clinical professionals and researchers who did not meet the inclusion criteria). 14 participants were excluded due to incomplete data (12 entered no data at all, 2 did not complete the whole first measure of the survey). This left 16 participants for analysis, however 5/16 completed only the first question and 1/16 completed only the first three questions. These participants did not complete their demographic information. Their results are included in the analysis only on the measures they completed fully.

Therefore, only 10 participants' data were available for analysis on all measures. The characteristics of these 10 participants are displayed in Table 3.1 below. There were nine females and one male, ranging in age from 26 – 76 plus years. Participants' had a variety of relationships to the injured person; three were the parents of the injured person, two were sisters, three were children of the injured person and two were the spouse/partner. Only one person with PDoC was cared for at home (a partner/spouse), the other nine resided in specialized settings (hospital or care home). The range of time post injury was less than 3 months to 21 years.

Table 3. 1 *Participant Characteristics*

Participant	Gender	Age Range	Ethnicity	Relationship to the injured person	Time since injury	Injured persons location
1	Female	36 -45	White	Child	5 years	Hospital
2	Female	26 -35	Asian	Child	21 years	Hospital
3	Female	76 +	White	Mother	4 years	Hospital
4	Female	46 -55	White	Spouse / Partner	4 years	Home
5	Female	56 -65	White	Sibling (sister)	11 years	Care centre
6	Female	26 -35	Black Caribbean	Sibling (sister)	< 3 months	Hospital
7	Male	76 +	White	Father	6-12 months	Hospital
8	Female	46 -55	White	Mother	2 years 11 months	Hospital
9	Female	36 -45	White	Child	2 years	Care centre
10	Female	46 -55	White	Spouse / Partner	6-12 months	Hospital

3.4 Results

Due to the small sample size available for analysis ($n = 10$) the planned inferential statistical calculations were not performed. Instead the data obtained was analysed descriptively.

3.4.1 Grief

Participants ($n = 10$) completed four separate measures of grief (BAS6, PG-12, CBS, ISLES), Figure 3.3 below displays the number of measures reaching clinically meaningful scores (scores that the published test materials report as clinically significant) across the participants. For all ten participants, at least two measures were suggestive of clinically troubling levels of grief. Three participants met the criteria for three measures of grief and three participants met the criteria for all four measures of grief.

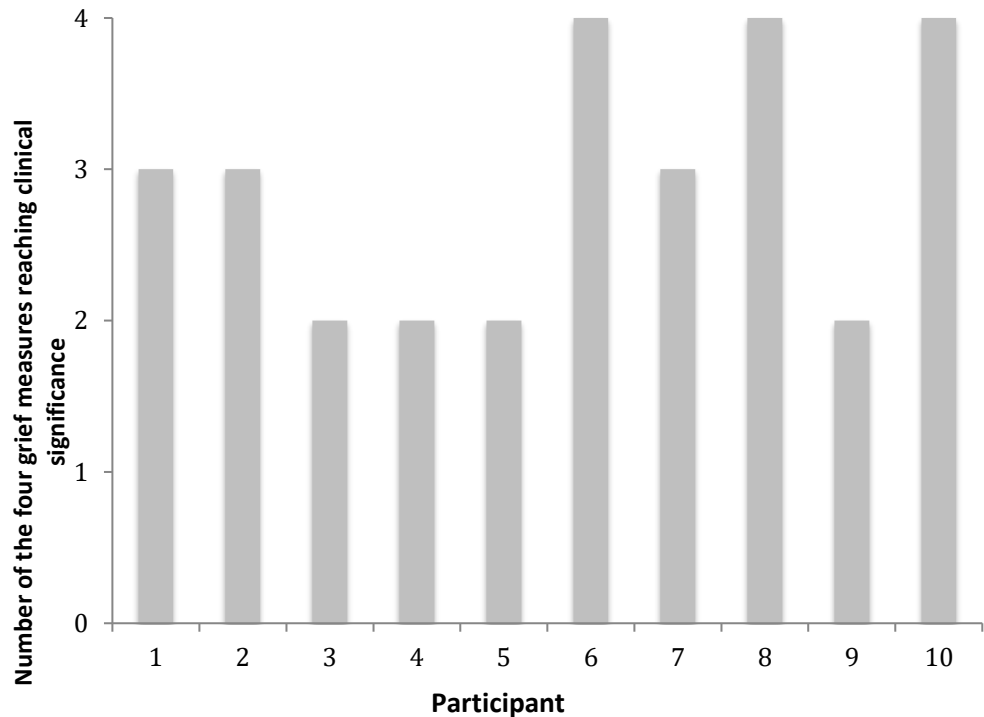


Figure 3. 3 The number of grief scales reaching clinical significance for each participant.

One measure identified all ten of participants as symptomatic, the Boundary Ambiguity Scale assessing Ambiguous Loss. The Continuing Bonds Scale identified eight of the ten of participants as having high levels of continuing bonds and the ISLES identified eight of ten of the participants as showing elevated complicated grief and difficulties making sense of the stressful situation they face. Participants' sense of comprehensibility reached clinical significance in nine (of 10) of the participants. Participants' ability to make sense and meaning of the event in a more global way was assessed by the Footing in the World subscale. Subscale scores showed eight (of 10) of participants were having clinically significant difficulty in integrating the event in their wider perspective on life such as; having a sense of purpose, clear direction, stable values and view of the world. The PG-12 which has been used widely in research with families living with PDoC classified three of the ten participants as meeting the DSM-IV criteria for Prolonged Grief Disorder, a further three the participants were sub-threshold needing only one additional item to have led to clinical significance.

As 11 Participants completed the Boundary Ambiguity Scale, they were all used in the analysis of ambiguous loss. This showed that five (of 11) continued to feel the injured person was part of their family, but six were no longer sure how the injured person now fitted within their family. Six of the participants felt that things were different and the person no longer felt like their family member seven endorsed that they felt they could never be satisfied until the person recovered. The person was often on their mind and seven found themselves thinking about how the injured person was doing when they were not there. All participants ($n = 11$) indicated confusion about the new nature of the relationship with the injured person (defined as scores more than 28).

3.4.2 Perception and level of agreement about diagnosis and prognosis

An analysis of the likert scale ratings of congruency between families and healthcare professionals' views of the person with a PDoC diagnosis, showed nine (of 10) agreed with their understanding of the diagnosis they understand to have been made by the healthcare professionals, with one (of 10) believing the diagnosis was actually worse than their understanding of the medical opinion. Relative to their wider family, six (of 10) of the respondents considered there was shared agreement about the prognosis across the family, but four (of 10) indicated that the wider family were more optimistic about the diagnosis and did not think the injured person was as severely brain damaged as they did. In terms of the future, half of the participants expected no changes over the next ten years. Others were optimistic for further improvements (4 of 10) but continued to expect their injured family member to have multiple needs and be coping with a severe brain injury. Only one participant considered the person would deteriorate in condition and die in the following 10 years. This is displayed in Table 3.2 below:

Table 3. 2 *Discrepancies within families and between families and professionals' views of diagnosis and prognosis*

Participant	Professionals view	Their view	Perception	Wider family view	Perception	Future	Perception
1	VS	VS	=	MCS	+	VS	=
2	MCS	MCS	=	SBI	+	SBI	+
3	SBI	SBI	=	SBI	=	SBI	=
4	BI	SBI	-	SBI	=	SBI	=
5	SBI	SBI	=	BI	+	SBI	=
6	VS	VS	=	Locked In	+	SBI	+
7	Coma	Coma	=	Coma	=	Coma	=
8	MCS	MCS	=	MCS	=	Dead	-
9	VS	VS	=	VS	=	SBI	+
10	VS	VS	=	VS	=	SBI	+

Note. VS: Vegetative State, MCS: Minimally Conscious State, SBI: Severe brain injury, BI: Despite having a brain injury, minimal longer term problems and support needs

3.4.3 Level of psychological difficulties experienced by participants

Nomothetic measures compare individuals to the norm-referenced test population (Barker, Pistrang & Elliot, 2016), such as the HADS, WEMWBS, CBS, and BAS. Criterion referenced measures compare individuals against a standard (Barker, Pistrang & Elliot) such as the PG-12. Participants' responses were analysed against the clinically significant cut-off for the respective measures. Of the 10 participants who scores were calculated for all of the 11 measures and subscales, all participants had three or more clinically significant scores (range 3-11 measures per participant). This is shown on the Figure 3.4 below.

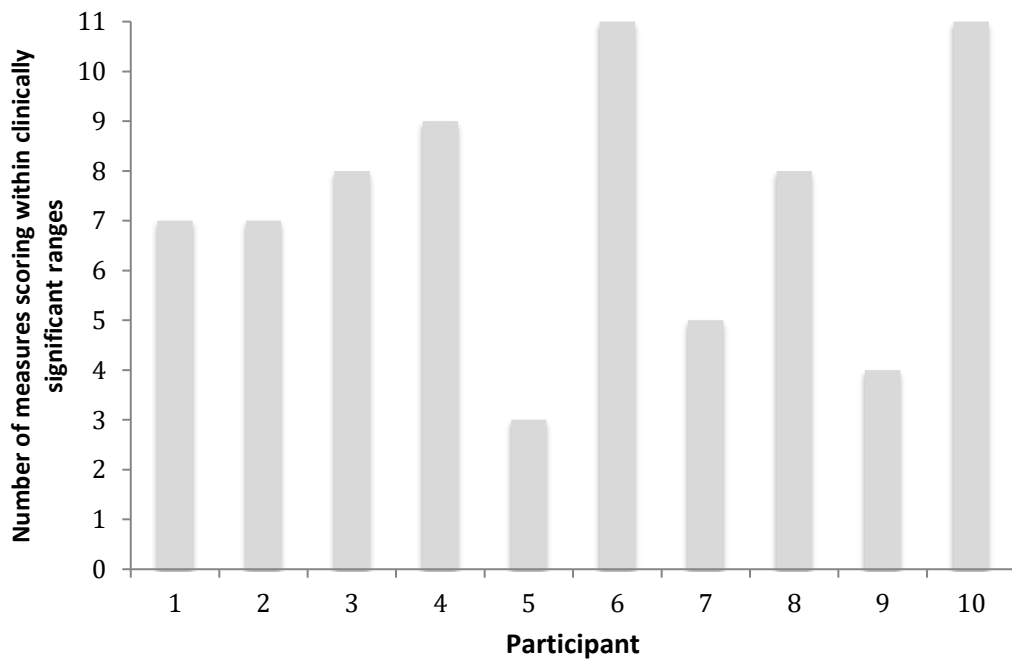


Figure 3. 4 Number of measures and subscales obtaining clinical significance by Participant.

3.4.4 Wellbeing

Sixteen participants completed all the items of the WEMWBS. Reduced wellbeing was reported in ten (of 16) participants.

3.4.5 Psychological Distress

Participants ($n = 10$) scores on the HADS-D, showed five of the participants had normal levels of mood, and five showed clinically lower mood (4 mild symptomatology and 1 moderate to severe). In contrast anxiety (HADS-A), was elevated in eight participants (six in the moderate to severe range and two in the mild range) with only two participants scores consistent with normal levels of anxiety. These results are displayed on Figure 3.5 below with the cut off line marked showing the number of participants scoring within the clinically meaningful range (scores of 8 or above). When the HADS-A and HADS-D subscales were combined to calculate a Total Distress Score, seven (of 10) of the participants had elevated distress and three (of 10) were within the normal range.

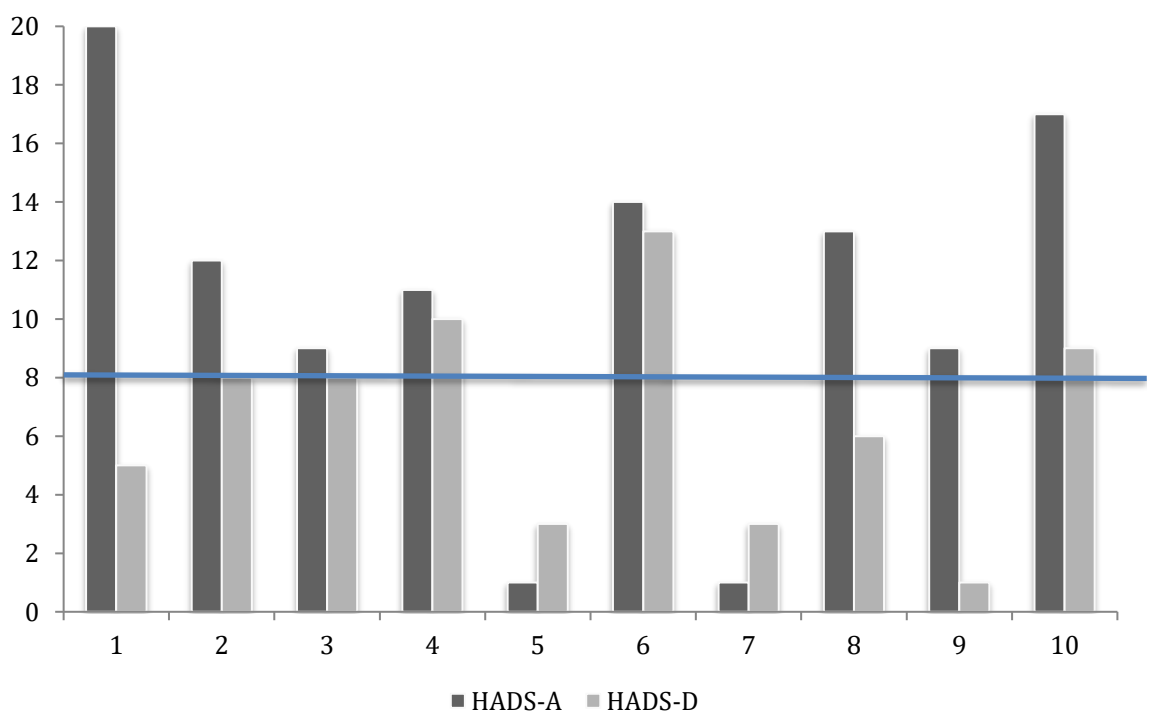


Figure 3. 5 Participants level of distress compared to the clinical cut-off.

Work and Social Functioning

The seven of the ten participants indicated great difficulties (1/7) or severe (6/7) functioning difficulties as a result of their family members condition. No difficulties were reported by three (of 10) of the participants.

3.5 Discussion

The recruitment expectations were not met in this study. Given the number of participants who completed the study, it is not possible to assert that this is representative of a larger group nor analyse the data using inferential statistical methods. The measures administered provided published thresholds to interpret individual scores for clinically meaningful relevance. Instead, the data obtained was looked at in descriptive terms on an individual basis to understand what the ten participants profiles were like. This enabled a practical and clinical analysis of the data, rather than attempting to make inferences about how this small sample differs from other groups. Therefore, this study enabled a summary of patterns and their clinical relevance in a small sample of family members of a person with a PDoC.

All family members showed medium to high levels of Ambiguous Loss, indicating high levels of confusion and ambiguity about their relationships with the injured person. Difficulties coping with loss were found on multiple measures with the vast majority (8 of 10) reporting complicated grief. A third of the sample in this study met criteria for Prolonged Grief Disorder (PGD) with a further third sub-threshold. This is broadly consistent with the findings of larger samples in Italy (Leonardi et al., 2012) and Spain (Elvira de la Morena et al., 2013). However, 30% of families of someone with a PDoC, appears higher than other clinical groups, such as in caregivers of terminally ill cancer patients where reports are of PGD in 10-20% of participants (Nanni, Biancosino &

Grassi, 2013) and 20% after death from dementia (Chan, Livingston, Jones & Sampson, 2012). This perhaps reflects the understanding of caregivers of the terminally ill and dementia where the conditions typically appear more slowly, there is often a clearer prognosis and an understandable pathway, the disease process is more commonly understood by the wider public and persons' social networks, and the situation is finite with a chance to say a slow goodbye. In contrast, in PDoC there is sudden injury in an otherwise typically healthy person, with an unclear diagnosis and prognosis, limited understanding about the condition in the networks and the ongoing hope for recovery.

This study highlighted a sense of strong enduring connections between the family and person with PDoC (8 of 10), in bereavement continuing bonds predict higher levels of prolonged grief if the bereaved person is unable to make sense of the loss (Neimeyer, Baldwin & Gillies, 2006). Nearly all participants were found to experience difficulties with meaning making and integrating this event with their sense of their lives and how the world works. Meaning making has been identified as a key component in the development of Prolonged Grief Disorder (Lobb, Kristjanson, Aoun, Monterosso, Halkett & Davies, 2010).

In this study, meaning-making of their situation was indicated in most families' beliefs congruence with the medical diagnosis and the majority considered the person's longer-term prognosis to be poor (similar to the present or worse). Even the participant hopeful of gains over time, at best believed the person would continue to have a severe brain injury with longer-term needs. As this was a self-report measure, there was no objective means of contrasting these perceptions with the patients' actual diagnosis and prognosis. However, this finding is broadly consistent with a

German study where 76% (of 44) were in agreement with medical opinion, 7% (of 44) thought the patient had a better level of awareness than the clinicians and 17% (of 44) believed they had a lower level of awareness (Jox, Kuehlmeier, Klein Herzog, Schaupp, Nowak, Koenig, Muller & Bender, 2015). However, the authors highlighted that close to a quarter of the sample disagreed with medical opinion and this created a risk for conflict and tension with staff (Jox et al., 2015). The present study builds on this work and shows that tension is not just between the family and the clinicians, but also another clear point of potential for disagreements is within families, with nearly half the participants believing there was greater optimism in the expectations in the wider family compared to their own views.

In terms of psychological experience, participants' wellbeing was lower than the general population with significant or severe disturbances to their functioning in work and social domains, consistent with previous studies (Corrallo et al., 2015; Giovanetti et al., 2012). Psychological distress was greater compared to the normative population with elevated anxiety. This finding confirms previous Italian studies that have shown greater levels of psychological distress (Giovanetti et al., 2015; Pagani et al., 2014) including higher levels of anxiety related symptoms (Moretta et al., 2014). Family members of a person with PDoC can show significant impairments in functioning and many researchers have called for specific interventions for this unique population (Bastianelli et al., 2014; Pagani et al., 2014; Moretta et al., 2014; Cipolletta et al., 2014; Giovannetti et al., 2013) yet to date only two studies appear to have attempted to do this (Corrallo, Bonanno, De Salvo, Giorgio, Rifici, Lo Buono, Bramanti & Marino, 2015; Li & Zu, 2012).

3.5.1 Limitations

Clearly the lack of response rate and subsequent sample size has limited interpretation and inferential statistical analysis. This suggests that research with this population may not be conducted best by using typical research methodologies and measures. Whilst it can not be suggested that this small number of participants is representative of the population, it is broadly consistent with previous research. The difficulties with recruitment and dropouts between consent to participate and failure to complete the measure is similar to other research with families of people with PDoC that has also reported dropouts in relation to families becoming fearful of being emotionally overwhelmed by focusing on their situation (Hamama-Raz et al., 2013). Palliative care researchers have also reported challenges with recruiting participants (Hudson, Trauer, Lobb, Zordan, Williams, Quinn, Summers & Thomas, 2012). The primary reason for this has been described as related to the sheer load and tasks families take on (Davis et al., 2017). Families living with PDoC are a small population, that are hard to reach in part because of the many new and additional roles they adopt post injury and in part by the distribution of them post-rehabilitation into residential care units and their own homes. Due to the rarity of PDoC, with estimates of 1.9 per 100,000 in the Vegetative State (Stepan, Haidinger & Binder, 2004), research on families in this area has typically had smaller samples ranging between 16 (Chiambretto et al., 2001) and 53 (Elvira de la Morena & Cruzado, 2013). There is an exception, which is a large sample of 487 participants in a large national study in Italy (Giovanetti et al., 2013). Attempts were made in this study to maximize recruitment using online data collection and then to bolster recruitment by extending the data collection period and adding an additional online pointer to the survey. It is possible that the online method of the survey may have limited recruitment, as all previous studies on families of people with PDoC using standardized questionnaires have

administered these in a face to face setting with the researcher (such as Moretta et al., 2014; Elvira de la Morena et al., 2013) during the post-acute rehabilitation phase. This current study design was intended to enable both male and female family members who have caregiving responsibilities, multiple demands on their time and potentially less access to meeting with a researcher, who may not live within access of London to participate. By using an online community specific to the condition, it was thought that this may enable better recruitment of participants for a rare condition and capture the cross sectional experiences of people who are at different time points post injury, and who have different relationships to the injured person that would not have been possible by researcher administered meetings in an inpatient post-acute rehabilitation setting.

It is not clear what the longitudinal issues are for family members from this study, only two participants had been coping for more than 10 years with PDoC. As this condition can be life long, little is known about the longitudinal nature of the family response and remains an area for future study. Some research has indicated that time makes little difference to families coping with this condition (Romaniello et al., 2015; Moretta et al., 2014) or deteriorations in functioning are observed (Bastianelli et al., 2014). It is also not possible to determine if there are specific relational issues relative to the connection the participants' have with the injured person, and this remains an area for further study as highlighted in Chapter One, much of the literature to date has focused on the primary caregiver experience. The broadening the research to include different family members seems important, particularly in light of the reports in this study of likely differences within families about the injured person's skills. The limited sample does suggest that multi-site, face to face

recruitment is likely to be needed for future research on families of people with PDoC in the United Kingdom.

It is not possible to make assumptions about why 20 people consented to participate after reading the Participant Information Sheet but then either responded to only a few questions or none at all. It is possible that the nature of the questions may have been distressing or that participant's thought the idea of the study was worthy of participating but did not then want to share personal information or focus on their experience once confronted with the reality. It is possible that given the study was online and allowed for people to come back to completing it at a later date, that they were simply called away and never got around to returning. It is possible that having looked at the questionnaires the number of these were overwhelming. In palliative care, researchers have hypothesized that the nature of completion of forms for research purposes may in of itself be off putting (Hudson, Truaer, et al., 2012). Finally, it is also a possibility that as this online community also includes healthcare professionals and researchers in this area, those interested in the study may have consented to participate with the intention to examine what was being looked at for professional curiosity and interest.

A number of key lessons were learnt from this study to inform future research with this population. The results of this study provide a useful foundation to develop further hypotheses for examination in a larger sample. A number of methodological needs were highlighted, particularly in relation to recruitment and specific measures. It seems that research with this population is more likely to recruit sufficient sample sizes through conducting research in person where some rapport can be built with the researcher in order to share the intimate and personal experience created by the

injury. This rapport can also be useful to maintain momentum in completion of a large number of questionnaires. Further, direct contact may make immediate validation and acknowledgment of their contribution to the research area apparent. The research setting is likely to have relevance, research may be best at the location of the injured person's domicile (such as hospital, care facility or home) or the participant's home in order to reduce the additional demands of participating in research at a time of multiple new life demands. The demands of the research in terms of the duration and number of measures also requires thought. It is possible that having consented to participate, people were then discouraged by the number and range of questions. Finally, this also points to the value in creating measures specific to this population that will resonate and have higher face validity for participants.

Notwithstanding the limitations, whilst the data is limited and was hard to collect, it is valuable. This study does enable observations of the experiences of a small and difficult to reach sample and provides an initial exploration of experiences of the participants. As discussed in Chapter One and Two and found in this study, families of people with PDoC clearly experience psychological distress. These findings are consistent with larger samples in Italy and Spain. This study shows that for this sample, loss was also problematic. All families met the ambiguous loss criteria, supporting the findings of ambiguous loss as a helpful model of understanding loss in PDoC. High levels of continuing bonds also show the ongoing emotional relationship with the injured person. Finally, this study adds that at least for some family members, meaning making difficulties do occur. This has not previously been reported, but as eight of these ten participants are reporting meaning making problems, this highlights a potentially important point in how families facing this

situation can be supported, by targeting meaning making. This is developed further in Chapter Four. Future research is needed to better understand the needs of families of people with PDoC and how to best structure services and support for them.

Chapter Four

Development and pilot of the acceptability of an intervention to support families of people with Prolonged Disorders of Consciousness

4.1 Introduction

This thesis has highlighted complex forms of loss, psychological distress, multitudes of uncertainties and a sense of immobilization that can arise from having a family member with a PDoC. These are challenges beyond the coping responses of most people and providing support without medicalising understandable distress seems important. Yet evidence-based psychological interventions for families of people with PDoC are limited and have only recently begun to be systematically investigated. Only two previous studies were found (in China and Italy) that attempted to improve the psychological wellbeing of families in PDoC (Li & Xu, 2012; Corallo et al., 2015). No studies were identified from the United Kingdom. A lack of evidence based interventions, makes it challenging for clinicians who work with these families to be certain they understand what is of importance to the family members and their needs in order to design appropriate interventions.

Li and Xu (2012) argued that seeing a family member with an altered level of consciousness created a highly stressful event, and based on the psychological first aid ideas of Mitchell (1974), a Critical Incident Stress Debriefing approach was implemented. This single session intervention was delivered for families 48 – 72 hours after the diagnosis of VS. It is not clear from their publication how long the

patient had a PDoC prior to the intervention, only when an official diagnosis was given. The intervention for 107 participants (in groups of three to ten), lasted three to four hours. It had four components; the facts stage where participants gave a description of events, a thoughts phase where participants' first thoughts about the event were discussed, an assessment phase where emotional reactions and physical and psychological symptoms were discussed and finally, an assisting stage to help develop coping abilities and re-examine feelings of hopelessness. At follow up one month later, both the intervention and control groups had improved. The level of distress on most subscales of the Symptom Checklist 90-Revised was better in the intervention group, although participants continued to have elevated somatization, anxiety, depression and obsessive compulsive symptoms (Li et al., 2012). Clearly, part of the challenge for families is coping with hearing the difficult diagnosis of PDoC, but as described in Chapter One the ongoing challenges of living with someone with PDoC in your family is not addressed in this study. Whilst it is promising that the intervention was helpful to participants, it is limited to helping families cope with diagnosis and the short term (one month). Of interest is that the control group also improved, which confirms the literature reported in Chapter One, that some families do manage to cope independently. However, the continuation of psychological distress as reported by the ongoing elevations on the Symptom Checklist 90-revised illustrates this intervention is not enough to manage the longer term needs. Further research is required to understand how to assist families cope with the chronicity of PDoC.

Families of VS and MCS patients ($n = 48$) in Italy participated in 24 sessions of closed group therapy over a six month period with the aim of reducing anxiety and depression, and integrating the PDoC into the family's life narrative (Corallo et al.,

2015). No differences were noted by patient diagnosis. It was not clear how long post injury these sessions occurred as the authors do not report on this. In comparison to the control group, families showed better psychological wellbeing (less anxiety, depression and grief), better health and ability to meet their carer needs (Corallo et al., 2015). Participants were the primary carer of the injured person. The research appears to have been conducted at one site and it is not clear if the participants knew people in the other arm of the intervention as this introduces a possible source of contamination in their findings. The nature of the exact intervention or the psychological framework underpinning it is also unclear in the publication, but it appears to have involved a psycho-educational component about PDoC and how to interpret patient behaviours, enhancing family members' awareness of their own emotional responses and supported problem solving to improve resources and communication in the wider family. They concluded that psychological support was important in assisting caregivers to process the experience of the PDoC.

Formative research is used to guide intervention development (Rohm Young, Johnson, 2006). As part of the formative research phase, this thesis has presented a review of the existing literature (presented in Chapter One) and mixed methods studies (Chapters Two and Three) to consider new ways of understanding family distress in PDoC and therefore indicate where support maybe needed. Feasibility studies are indicated when there is unique population to consider, with little previous research and when earlier studies were not guided by in depth research (Bowen et al., 2009). This is an important phase in developing interventions for caregivers prior to wider distribution and evaluation (Davis et al., 2017). Feasibility studies provide the first stage of determining whether an intervention is suitable for further efficacy testing and enables identification of any modifications to research methods and protocols

that may be required (Bowen et al., 2009). This study sought to develop an intervention and assess its' acceptability.

4.2 Research aims:

To investigate the acceptability of an intervention to enhance family members' perceptions of being able to cope with having a family member with a PDoC.

Specifically, this study aimed to:

1. Develop psycho-educational intervention session and delivery protocol
2. Review the proposed intervention with a multi-disciplinary PDoC expert panel
3. Pilot the intervention with three family members of people with PDoC
4. Evaluate the intervention acceptability and applicability
5. Evaluate the most appropriate and sensitive outcome measure to assess the intervention effectiveness

4.3 Design

This study had three stages; development of an intervention, review of the intervention by a multi-disciplinary expert panel and a proof of concept trial of the intervention's acceptability and feasibility using naturalistic systematic single case studies to pilot the intervention. This methodology has previously been employed in intervention development in caregiver research (Hudson et al., 2012). Barker, Pistrang and Elliot (2016) suggest that whilst single case experimental designs are commonly used in behavioural orientated research, the focus on cognitions and emotions which are not observable and typically not reversible following an intervention make naturalistic case study designs more appropriate. As single case studies are idiographic and enable close examination of a person in depth, they are

limited in establishing generality. However, by replicating the same study with several participants, the external validity of the findings can be enhanced (Barker, Pistrang & Elliot, 2016). Elliot (2002) argued that small-N designs should aim to demonstrate change (through use of standardised measures, individualized measures, several assessment points, clinical replication and a qualitative approach). Elliot (2002) also argues that evidence that the change relates to the intervention (such as participant self report of effectiveness, reliable change etc.), alternative explanations for change (such as statistical or relational artefacts) and discussion on which processes in therapy may have led to the change (such as therapeutic relationship measures) as important when developing interventions.

4.3.1 Part One: Intervention development

The first part of this study involved the development of an intervention. The findings of the formative exploratory research IPA study (Chapter Two) showed that in the absence of the death of the injured person the participants' sense of loss and relational transformations were very difficult to describe and articulate. The women talked of avoiding looking back into the past because this was too painful but also avoiding looking forwards as this was too frightening, so they were suspended in time unable to plan for their futures and faced with constant threats of more loss from the persons' medical instability. As the injured person may not emerge from a PDoC, the family is required to find a way to understand and make sense of their experience and manage their responses to the disorder.

4.3.2 Theoretical framework of the intervention

The basis of this intervention development stems from the concept of helping families to firstly develop a psychological formulation of their experience of the condition to

help contextualize, normalize and make sense of their feelings, and secondly, having identified what has precipitated and perpetuates their distress to learn some strategies to help manage their emotional responses to the situation that is outside of their control and has to be lived with.

4.3.3 Developing a psychological formulation to help with sense making

Smith (2009) stated that the meaning bestowed by the participant on their experience can be said to represent the experience itself. The British Psychological Society (2011) acknowledges that all people are “meaning –makers who create narratives about their lives and difficulties” (pg 7) and described psychological formulation as creating a framework that makes sense of a person’s problem or needs, how these developed and are maintained. Creating a psychological formulation is informed by psychological theory and research, and typically is a collaborative process between the psychologist and the client that enables a shared understanding which indicates the most helpful way forward (BPS, 2011). Shared formulations are thought to have a number of therapeutic benefits (Gladwin & Evangeli, 2012). Formulations are suggested to offer a person centred and less pathologizing approach and within some therapy models are considered an active part of the intervention (Gladwin & Evangeli, 2012).

In Chapter Two, The Preliminary Model of Chronic Uncertainty was proposed that formulates the experiences of families of people with PDoC, this is displayed in Figure 2.1 on page 113 (for ease of reference this is repeated below). This model is consistent with the descriptions of Ambiguous Loss (Boss, 1999) and Disenfranchised Grief (Doka, 2002). Boss (1999) states that when a loss can not be resolved (such as when the person has neither died or emerged from a PDoC) the ambiguous loss blocks

meaning making and therefore making sense out of ambiguity is critical. Doka (2002) reported that lack of recognition from others of one's loss increases distress. The literature suggests interventions for families coping with ambiguous loss in dementia are important (Keily, 2010) and within PDoC (Bastianelli et al., 2014; Pagani et al, 2014; Moretta et al., 2014; Cipolletta et al., 2014; Giovannetti et al., 2013).

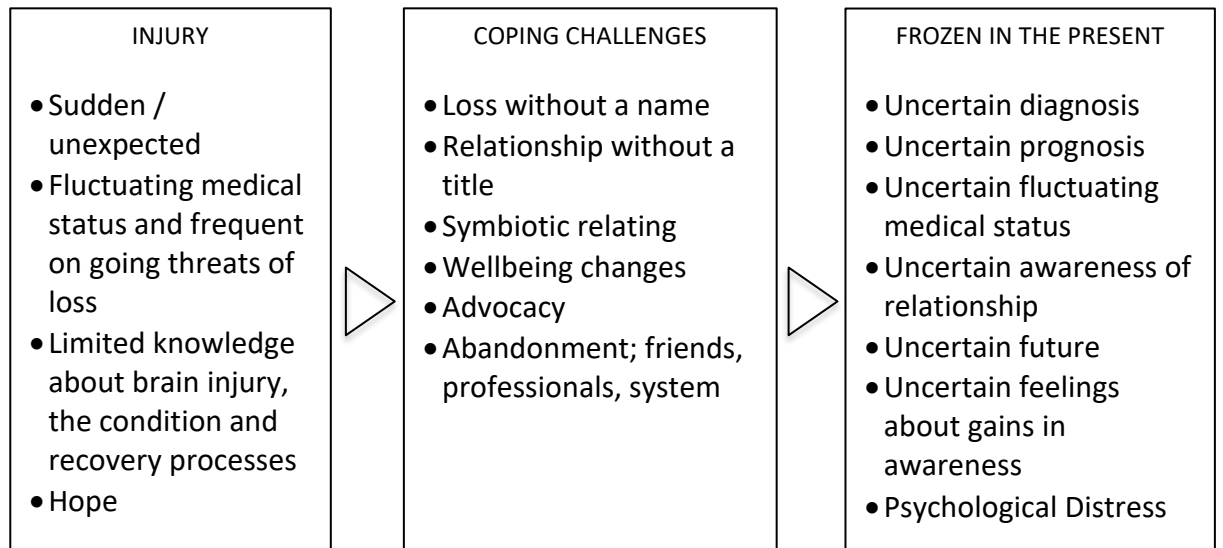


Figure 2.1 The Preliminary Model of Chronic Uncertainty - reprinted from page 113.

In Chapter Three, distress was suggested to arise from unsuccessful early attempts to appraise the injury (for example, the belief that the person is strong, will surprise the medical professionals and when receiving the right rehabilitation will change) and the creation of meanings that are discrepant with a persons' global meaning about themselves and the world (for example, people get ill and recover or existential issues about what makes a life worth living). This is consistent with the adaptations to the model of meaning making (Park, 2010) proposed in Chapter Three, shown in the Figure 3.2 on page 123 repeated for ease of reference below:

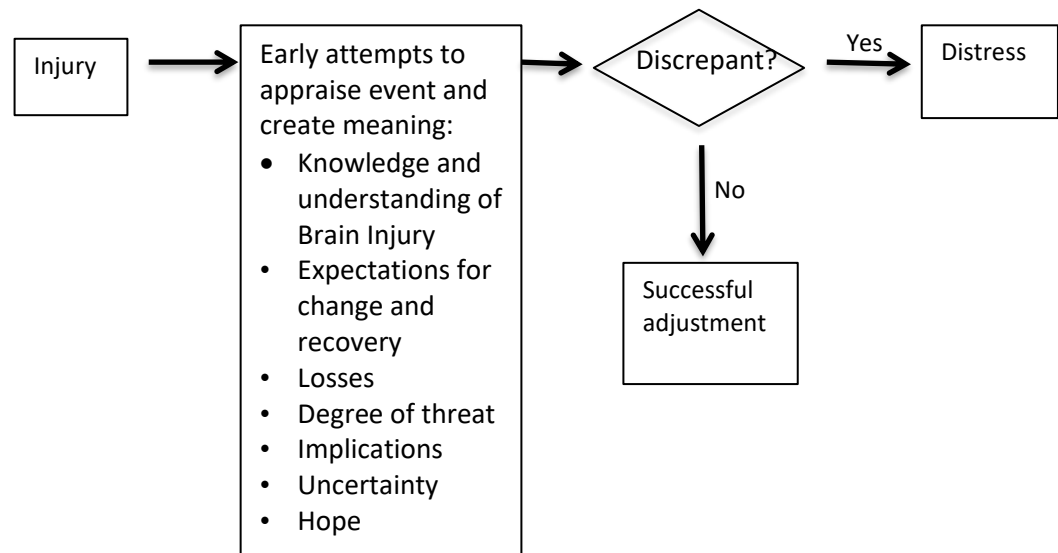


Figure 3. 2 How distress arises when early meaning making attempts are discrepant with reality and global beliefs. – reprinted from page 123.

Adapted from The meaning-making model and integrated with proposed Preliminary Model of Chronic Uncertainty. Reprinted from “Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events”. By C. Park, 2010, *Psychological Bulletin*, 136(2), p. 258. Copyright 2010 by the American Psychological Association.

The Meaning Making Model (Park & Folkman, 1997) suggests that meaning making processes to reduce the discrepancy between their global beliefs and the situation they are in, are needed to occur to reduce distress (shown in the box on the right in Figure 4.1 below). This occurs through integrating the understanding the person has of the illness with their global meaning (Park, 2013). This is consistent with the views of Boss (1999) who argues that people can succeed in meaning making in ambiguous loss in that although their situation does not change (the person remains in PDoC) but rather what they hope for does (for example advocating for managing the condition as best as possible or raising awareness about the condition). Gilles and Neimeyer

(2006) observed that increasing sense making predicted reductions in complicated grief, other research showed breast cancer survivors participating in a meaning making intervention had significantly higher self-esteem, optimism and self-efficacy than a control group (Lee, Cohen, Edgar, Laizner & Gagnon, 2006). Park (2010) commented many psychotherapies involve meaning making either implicitly or explicitly. However, interventions directly focused on meaning making are limited (Park, 2010).

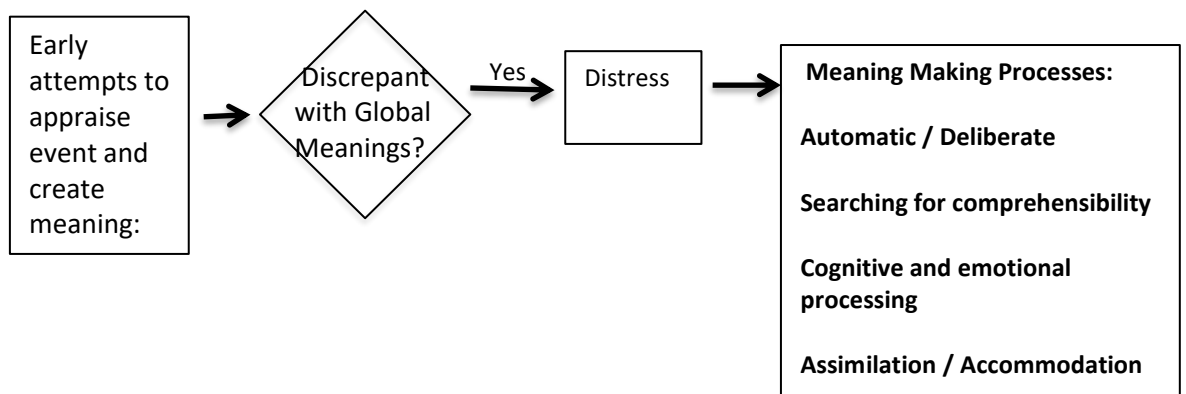


Figure 4. 1 Meaning Making Processes need to reduce the discrepancy between a persons’ situation and their global meanings.

Adapted from The meaning-making model. Reprinted from “Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events”. By C. Park, 2010, Psychological Bulletin, 136(2), p. 258. Copyright 2010 by the American Psychological Association.

Therefore, the first component of the intervention aimed to create a psychological formulation with the family that provided a framework for acknowledging their loss (Disenfranchised grief) and understanding and making sense of their situation (Ambiguous loss). This targets the “Deliberate” and “Searching for comprehensibility” components of the meaning making processes requirement shown in the Figure 4.3 above.

4.3.4 Strategies to manage the emotional response to PDoC

Understandably, families of people with PDoC can experience painful thoughts and feelings about the situation that are overwhelming. Increasingly how people relate to their thoughts and feelings, has been associated with their psychological wellbeing, rather than the nature of the thought (such as how negative it is) or feeling itself (Bond et al., 2011). Acceptance Commitment Therapy (ACT; Hayes, Stroschal, & Wilson, 1999) is a form of psychotherapy that fundamentally encourages people to accept what is out of their control and that psychological pain is inevitably part of that, and carry on living a life that is rich and meaningful. For this reason, the second part of the intervention seeks to support families faced with an unchanging situation found in PDoC, with strategies grounded in ACT to manage their relationship to their psychological distress.

ACT argues that suffering stems from two psychological processes “cognitive fusion” and “experiential avoidance” (Hayes et al., 1999). Experiential avoidance describes an unwillingness to remain in contact with unwanted private events (such as feelings, thoughts, memories and sensations) and becomes problematic when this gets in the way of being able to do what is important and meaningful for someone in their life (Hayes, 2012). Cognitive fusion describes how people become inseparable from their thoughts, without awareness that they are just thoughts and these dominate behaviour (Harris, 2009). ACT aims to enable a person to continue with what is important to them in the presence of the discomforting thoughts, feelings, memories, sensations and images that may arise (Ruiz, 2010) without trying to change, avoid or control them. The opposite of these avoidance strategies is acceptance (Hayes, Stroschal & Wilson, 2003). Acceptance can be described as metaphorically opening

space in the mind for these unwanted private events, expanding around the thoughts and feelings and giving them permission to exist (Harris, 2009). By developing a different relationship with these unwanted private events, they are no longer perceived as negative experiences to be avoided and controlled. Acceptance does not equate with resigning to or liking the private events, rather that the person can open up and accept these as passing psychological events integral to being human (Kashdan, 2010) and in conjunction, take action in line with what the person values (Harris, 2009). ACT focuses on increasing psychological flexibility and engagement with a valued life, this is accomplished through six processes; acceptance, present moment, values clarification, cognitive defusion, self as context and committed action (Harris, 2009). Therapy utilizes metaphor and experiential exercises to target the core processes in ACT and enable learning and developing confidence to try new approaches to managing unwanted private experiences (Harris, 2009). ACT does not target symptom reduction per se, but rather focuses on commencing living again in a manner consistent with one's values and changing the relationships with the symptoms that impede this. This means that symptom reduction can often be an effect of the intervention (Harris, 2009).

ACT is described as a "third wave" of behaviour therapy building on cognitive and behavioural therapies traditions (Gaudiano, 2011). Some critics have raised assertions that ACT does not represent a new treatment approach and the mechanism of change in ACT is unclear as it can borrow and use techniques from other therapies, such as CBT. ACT is argued to consider techniques a means to an end and thus may use techniques similar to CBT but the selection and use of the techniques remains guided by an explicit underlying behavioural theory and philosophy (Hayes et al., 1999). Gaudiano (2011) in a review of ACT described criticism that the outcome

research base is weak, limited by methodological quality and a lack of measurement of adherence to the ACT model. However, a developing research literature does suggest efficacy of ACT. In a 2006 meta analysis, 24 studies with varied clinical populations showed an effect size of cohens d of .66 at both post treatment ($n = 704$) and at follow up ($n = 519$) (Hayes, 2006) with similar results are reported in a other reviews (Gaudiano, 2011).

4.3.5 ACT for grief

Davis, Deane and Lyons (2014) commented that applying ACT in grief research has been limited, but highlighted the suitability of ACT for contexts where the circumstances are unchangeable and participating in enriching activities despite these circumstances as integral to ACT principles. Romanoff (2012) argued the values clarification guiding committed action in ACT is appropriate for grief and consistent with the Restoration-Orientation of Stroebe and Schut Dual Process Model of Grief. In bereaved populations, experiential avoidance is associated with prolonged grief symptoms and psychological distress, whilst acceptance is critical to adjustment (Davis et al 2016B). Davis and colleagues (2014) argued the theoretical rationale for ACT suitability to enhance the wellbeing of caregivers coping with the stresses of end of life care without them necessarily having to have a diagnosis, as ACT has been found to be useful to people both with and without psychopathology.

Harris (2011) described an ACT based self help guide for people suffering loss that has four components. These are: (a) “hold yourself kindly” centred on self compassion and care, (b) “drop the anchor” grounding skills to cope with painful emotions and be able to take effective action (c) “take a stand” what dignifies the suffering experienced

and helps a person continue and (d) “find the treasure” acknowledge pain and also appreciate what life has to offer.

No observational or intervention research has been conducted that examines the efficacy of ACT with families of people with PDoC. ACT interventions are transdiagnostic and often implemented for difficult problems (Ruiz, 2010) and the evidence base for ACT as an effective therapy for a range of psychological difficulties has been increasing (Davis et al., 2017; Ruiz, 2010) including with spouses of people with brain injuries (Williams, Vaughan, Huws & Hastings, 2014).

Therefore, to target the second component of this intervention (the family member’s relationship to their pain arising from the unchanging PDoC), ACT based experiential exercises were used to facilitate supporting cognitive and emotional processing meaning making by increasing psychological flexibility in learning strategies to cope with unwanted private events and to begin to consider how to accommodate to living alongside the PDoC in their life (as shown on the Figure 4.3 above). The specific meaning making process, the intervention aims and the intervention activity to facilitate that aim are displayed in Table 4.1.

Table 4. 1 *Park (2010) Meaning Making Processes and the related intervention protocol*

Meaning making (Parks 2010) processes targeted	Intervention aim	Intervention protocol task
Deliberate	Structured Intervention Session	90 minute Individual formulation intervention Session
Search for comprehensibility	Psycho-education about ambiguous loss, recognition of the loss naming, labelling the	Psycho-education about ambiguous loss and the feelings arising from this in PDoC

	loss	
Cognitive and emotional processing	Defusion / Acceptance	ACT in a nutshell exercise (Harris, 2011)
	Present moment	
	Acceptance	ACT Anchoring exercise (Harris, 2011)
		ACT Compassionate hand exercise (Harris, 2011)
		Tree metaphor
Accommodation/assimilation	Value engagement	Values clarification exercise

The logic model therefore of this intervention is that families present as distressed and have difficulties naming their loss and making sense of their situation. By co-creating a formulation to make sense of their situation, learning techniques to manage fusion and avoidance by acceptance, and focussing on their values this will enable participants to feel their situation makes more sense to them and that they will be able to cope with the range of feelings that have.

4.3.6 Format of the intervention

In this study, various formats for the delivery of a meaning making and an ACT informed intervention were considered. Multiple families in peer group sessions were considered, as group based interventions have benefits in terms of being cost effective to deliver and useful in enabling sharing between participants (Hudson, Trauer, Lobb, Zordan, Williamns, Quinn, Summers, Thomas, 2012). In families of hospitalized palliative care patients invited to a single session family psycho-educational group intervention, there were frequent difficulties in getting all the intended participants to the group due to a combination of personal and patient related unforeseen issues, and the intervention had to be delivered to only one person at times (Hudson, Trauer, Lobb, Zordan, Williamns, Quinn, Summers, Thomas,

2012). Obtaining a suitable time for multiple families to attend a group could be problematic and was envisaged as a possible challenge for this study. The research site is a national tertiary referral centre and many families travel some distance to visit, and some families will have already returned to work given the time of admission post injury. For practical and pragmatic reasons, it was therefore decided that an individual session was best and this would enable the opportunity to fit the session in with a participant's other commitments. Whilst individualized sessions miss the opportunities of peer support that a group session can offer, it was reasoned that this is available within the organisation's existing family support group sessions and is possible via specialist charities such as Brain Injury is BIG. Comments received from the expert panel (reported below) confirmed this and were also instrumental in the design of an individual session intervention.

4.3.7 Duration of the intervention

Ruiz (2010) in a review of the efficacy of ACT studies noted that a number have utilized "extremely short" interventions effectively. Recent studies report protocols of 75 minutes for a single session ACT intervention to disrupt negative thinking (Ruiz, Hernandez, Suarez Falcon & Luciano, 2016). Single session therapy offers opportunities for therapists to make their services more accessible. There is growing research that single session therapy can be effective, clients find it helpful and are not upset by the notion of one meeting (O'Neill, 2017). A single session intervention for post traumatic stress disorder found high levels of acceptability and feasibility enabling some reductions in symptom severity and setting up openness for potential future trauma treatment (Mills, Ewer, Dore, Teesoon, Baker, Kay-Lambkin, Sannibale, 2014). Critics of single session interventions point to the lack of an underpinning theoretical approach and the assumption that the client is ready for change by the

time of the session (Hymmen, Stalker & Cait, 2013). In contrast, traditional multisession therapy was reported as off putting to families of people with cancer in part due to their reluctance to be viewed as “patients” needing help (Goodenough et al., 2008). Goodenough and colleagues (2008) also suggested that single session efficacious ‘self-help’ oriented interventions are required which have acceptable face validity as ‘supporting the normal’ rather than ‘curing the crazy’. This is consistent with the views of Kitzinger and Kitzinger (2014) who encouraged clinicians to respect the variety of ways PDoC families respond and see them all as normal responses to a deeply distressing and abnormal situation.

In summary, this thesis posits intervention development informed by the psychological experience of complex ambiguous loss and the impediment this creates for meaning making after PDoC is important. Therefore, the proposed intervention directly targets meaning making processes and strategies to cope with the psychological challenges of PDoC through a novel psychological multi-component intervention. This is a theoretically informed intervention from grief literature, meaning making literature, ACT literature and the previous studies in this thesis. The proposed protocol was initially reviewed to confirm its’ psychological theoretical basis and feasibility for clinical delivery, by the Consultant Clinical Neuropsychologist and PDoC specialist involved in supervision of this research. On agreement, the proposed protocol was both theoretically and clinically feasible, the second phase of development was progressed.

4.4 Part two: Intervention Development - Multi-disciplinary Expert Panel Review

The second part of this study involved review of the proposed intervention with an expert panel ($n = 8$) who had specialist skills in clinical contact with people with PDoC

and their families, had clinical research expertise, had pastoral contact with families of people with PDoC and who had lived experience of the condition. Expert panel members were approached and invited through personal contact with the researcher and opportunity sampling. A family member of a person with a PDoC, who is expert by experience was met with individually to enable candour as their family member had received care within the organisation, and a private meeting was considered best to ensure any comments they may want to make about their experiences and the research were possible. The rest of the expert panel was purposively recruited for their expertise in the care of people with PDoC and comprised; senior medical consultant, consultant clinical psychologist, senior specialist social worker for their direct clinical experience in contributing to patient care and family support. A consultant in rehabilitation medicine, a family specialist registered nurse and the research advisor to the sponsor site hospital who are experts in designing and carrying out clinical research were recruited. Finally, the hospital chaplain joined the panel for the pastoral role and support offered to families of people with PDoC.

Consistent with appropriate areas of focus for feasibility studies as recommended by Bowen et al., (2009), the panel were asked to appraise the protocol in terms of:

- a. practicality (resources, time, commitment),
- b. demand (level of perceived interest for a single psychological session),
- c. acceptability (perception of the theoretical rationale and tasks),
- d. implementation issues (could the intervention be delivered as proposed),
- e. limited-efficacy testing (applying techniques useful with other clinical populations with the PDoC families by assessing it in a limited way)

- A. Practicality (resources, time, commitment):

Individual sessions not a group of multiple families were agreed as more feasible and suitable for this clinical population. This view was supported by the healthcare professionals who confirmed that a group based approach to family support has consistently failed to work on this unit in the past. They associated this with families feeling their situations were unique and their coping responses quite individual. The panel commented that most families were travelling long distances to the specialist hospital and were back at work at this point in the injured person's rehabilitation, so for practical reasons it has been difficult to conduct group based support, even when run in the evenings or weekends. Further, that the organisation already has a weekend based family support group, which is poorly attended and is the process of being disbanded. There was broad support for the intervention to be delivered on an individual basis and in the context of wider societal invalidation of the loss as there is no death, individual sessions could provide a forum for this validation to occur. The family expert by experience panel member concurred with this and advised that they would not have wanted to have been part of a large meeting with multiple families and stated *"I knew that there were people on the ward who planned to take their relative home, I already felt very guilty about knowing I just simply could not have done that, I wouldn't have wanted to have to justify how my family worked to others"*.

The expert panel explained that families were often "running at full capacity" and would find it difficult to have too many additional demands put on them such as for additional recording and completion of measures. The family expert stated they had felt it was important to develop research and understandings of people in their situation but only where that was also likely to have been of direct benefit to them too. The family expert commented to the researcher that they would have *"valued knowing there were regular meetings through the admission, that would have felt*

containing” with the researcher and importantly that only when the diagnosis was made did their experience of loss become more cogent.

For this reason (that knowing there were multiple meetings with the researcher would be a potential confound as rapport has begun to develop and perceived as potentially beneficial in its’ own right) and the difficulties found in getting all the consenting participants to complete all the online measures highlighted in Study Two, the frequency of recording was agreed best to be supported by the researcher at the three contact points (baseline 1, intervention and follow-up meetings).

B. Demand (level of perceived interest for psychological session),

The panel was in agreement of the value of the intervention being a single session. The psychologist, chaplain and social worker all reported that rarely did families want to meet with them focused on their own psychological wellbeing, instead their focus was on the care of the injured person and wanting any time available from professionals to be targeted for the person.

The family expert had sought their own single session psychological support during their partner’s admission to talk through the difficulties they noted in coping. The family expert stated they would have been interested in participating in a single session had that been available at the time, but commented that they had already returned to work and it would have been difficult to obtain time off to attend multiple sessions within working hours.

Given the protocol was for the intervention to be delivered in a single session, concerns about how families could be supported after the research project if required

were addressed. The consultant clinical neuropsychologist, chaplain and senior social worker were all in agreement to provide additional support to participants, if this was identified as needed at the follow-up appointment.

C. Acceptability (perception of the theoretical rationale and tasks),

In relation to the proposed content of the intervention, the family expert expressed interest in the ideas and asked to try some out themselves as they thought that they would still be of help to them even now. The family expert commented on liking the fact that a formulation framework for understanding their situation was proposed, and stated it was an accurate fit for their own personal circumstances.

The family expert recommended having something written down for the participants to take away was important. Others in the expert panel agreed that materials used in the intervention session would be important to provide in a written format for participants to take away from the session and that the proposed intervention and rationale seemed intuitively to 'make sense'.

In terms of additional content, the family expert stated they felt they would have benefited from information about PDoC, for example; how it is assessed, what the roles of the different professionals are etc. However, the professional experts reported the organisation was in the process of developing its own resource packs for families and they preferred the organisation to be the source of information given to families about the conditions (VS and MCS), the diagnosis process and techniques and care pathways.

D. Implementation issues (could the intervention be delivered as proposed),

In terms of timing for the intervention, the initial idea proposed of working with families in the first weeks of the admission was not agreed with. The family expert commented that they had felt very positive and hopeful on admission, that there had been a real sense that the specialists at this organisation would really have the critical input that would change things. Until the diagnosis meeting where they had learned their family member had a diagnosis of VS, they had maintained hopes and expectations that ongoing changes would occur to the person's presentation. This was supported by the others on the expert panel, there was agreement that the intervention would be best following the diagnosis meeting (around Week 6 of the admission) when the realities of what the families were having to cope with and adjust to was clearer to them. For this reason, the protocol was modified and the initial baseline was not on admission as previously planned, but following the diagnosis meeting.

Further modifications to the protocol arose following comments from the professionals in the panel. The panel debated and considered that eligibility of participants should include a family member with either a presumed diagnosis of VS or MCS, but that the gender and role criteria was important to keep similar which would enable homogeneity in the pilot study. In addition, they advised that there were differences in the way the services were delivered dependent on the medical consultant responsible for a person's admission. It was recommended to reduce variability in family experience, participants would be best to all be families of people in the care of the same medical consultant.

E. limited-efficacy testing (applying techniques useful with other clinical populations with the PDoC families by assessing it in a limited way)

The expert panel supported the concept of limited efficacy testing in the form of a small pilot study with three participants. Given the high levels of distress experienced by many families at this point of the person's rehabilitation pathway, it was viewed as critical to establish that the intervention was acceptable to them prior to trialling the intervention with a larger group of participants.

4.5 Revised Final Single Session Intervention Protocol

Duration: 90 minute single session for an individual family member of a person with PDoC.

Delivered by: A Consultant Clinical Psychologist trained in ACT, with experience in PDoC, family distress and working systemically.

Location of the session: Royal Hospital for Neuro-disability, in a meeting room off the ward area.

Inclusion criteria:

- Have a family member admitted to the Royal Hospital for Neuro-disability for assessment and management of a presumed disorder of consciousness (presumed diagnosis of prolonged disorder of consciousness of less than 6 months)
- “Family” self-defined, someone having a close relationship with the patient
- Family member of a person with PDoC under a specific medical consultant
- The person’s diagnosis has already been discussed with the family by the medical consultant
- Female
- Sufficient English language skills to be able to participate in a talking therapy intervention and complete written questionnaires
- Over 18 years old
- Able to give informed consent to participate

4.5.1 Measures

General characteristics about the participant were collected: Relationship to the identified patient, Age, Marital status, Religion, Education level, Employment status, previous and current experiences of psychological therapy. General characteristics about the injured person were collected; Gender, Age, Assumed diagnosis(VS/MCS), Time since injury, Type of injury, Narrative of injury (see Appendix R through U).

The primary variables of interest were the acceptability and effectiveness of the intervention on having a helpful psychological formulation and strategies to live with their distress. There are no specific measures for families of people with PDoC. *Acceptability of the Intervention* was determined by participants' responses to seven likert scale purposely designed items ranging from "strongly agree" to "strongly disagree" following the intervention and recording of qualitative comments made during the intervention.

Effectiveness of the intervention was assessed by responses on an eight point likert scale questions ranging from "strongly agree" to "strongly disagree" investigating normalization of experience, certainty, understanding of situation, coping, meaning making formulation, valued action, coping with distress, self care and sense making.

The secondary variables of interest relating to distress, wellbeing, acceptance, continuing bonds, meaning and sense making, the following measures were employed:

Wellbeing was explored using the *Short Form of the Warwick Edinburgh Mental Wellbeing Scale* (SWEMWBS; Stewart-Brown, Tennant, Tennant, Platt, Parkinson &

Welch, 2009). This scale is described as having superior internal consistency as it was constructed following Rasch analysis from the longer WEMWBS described in Chapter Two. Scores range from 7 to 35 and higher scores indicate higher positive mental well-being and good internal consistency (α .89) has been reported (Vaingankar, Abidin, Chong, Sambasivam, Seow, Jeyagurunathan, Picco, Stewart-Brown & Subramaniam, 2017).

To assess general psychological distress, the *Hospital Anxiety and Depression Scale* (HADS) was administered and has previously been described in Chapter Two.

To assess acceptance, psychological flexibility and experiential avoidance of unwanted private experiences, the *Acceptance and Action Questionnaire-II* was administered (AAQ-II; Bond, Hayes, Baer, Carpenter, Guenole, Orcutt, Waltz, & Zettle, 2011). The AAQ-II has seven statements on a seven point likert scale from 1 (never true) to 7 (always true) with good reliability and validity is reported (α .84). In line with previous literature, scores were reversed so that higher scores are reflective of greater acceptance (Davis, Deane & Lyons, 2016; Ruiz, 2010).

To measure the meaning made of the stressful event of having a family member with a PDoC, the *Integration of Stressful Life Events Scale – Short Form* (ISLES-SF; Holland, Currier, Neimeyer, 2014) was administered. The ISLES-SF is a six item version that was compiled of the top three items from the longer ISLES (described in Chapter 3) following a confirmatory factor analysis and contains the subscales of Comprehensibility and Footing in the World (Holland et al., 2014). A total score of less than 20 is indicative of meaning making difficulties (Holland, 2015).

Meaning making was assessed as described by Neimeyer, Baldwin and Gillies (2006). Four items investigating sense making (“how much sense would you say you have made of the loss?”), benefit finding (“despite the loss have you been able to find any benefit from your experience of the loss?”), identity change (“do you feel that you are different or that your sense of identity has changed as a result of this loss?”) and its’ direction (“for the better; mixed; worse”) which have previously been used in loss studies and are reported to be helpful in differentiating complicated grief (Neimeyer, Baldwin & Gillies, 2006) were used. Sense making was assessed on a four point likert scale, benefit finding and identity change were assessed on a five point likert scale. Higher scores reflect stronger sense making.

To assess loss and the extent to which the injured person continued to remain part of the participants’ life was assessed using the *Continuing Bonds Scale* (CBS; Field, Gal-Oz & Bonanno, 2003) previously described in Chapter Three. The maximum score is 55.

4.5.2 Protocol:

The protocol involved three meetings. The first meeting (T1) was 30 minutes in duration and used to establish informed consent to participate in the research pilot study, to gather participant characteristics and administer the baseline measures (baseline 1). The second meeting (T2) was held two weeks later, this was 90 minutes in total. The first part of this meeting comprised obtaining further baseline (called Baseline 2) psychometric scores. Then the individual intervention was delivered within this single session. Lastly, the participant completed the post-intervention measures. A third and final meeting (T3) of 30 minutes was held to complete the follow up measures and discuss the application of any strategies.

4.5.3 Outline of T2 (collection of baseline 2 measures, the intervention session, the post-intervention measures) protocol

1. Administer Baseline 2 psychometrics (15 minutes)

2. Opening (5 minutes)

Use of relational motivational interviewing techniques where the client is recognised as the expert of their own processing and meaning making (Miller & Rose, 2009). Use of exchanging information technique (Rollnick, Butler, Kinnersley, Gregory & Mash, 2010):

- Elicit: “what is your own understanding of the impact of this injury to you all in the family?”
- Create Gap in knowledge: “I have some information that has been helpful to other people in your situation to make sense of what is going on for them”
- Permission and Provision: “Would it be ok to share some information on this unique type of experience with you?”

3. Search for comprehensibility (12 minutes)

- Development of a psychological formulation to explain the confusing feelings – through psychoeducation about Ambiguous Loss
- Rationale: to highlight sensitivity to the loss, validate the loss, name the losses – non death loss, relationship loss, high uncertainty
- Identifying and linking to support that creates certainty at a time of huge uncertainty
- Provision of the Ambiguous Loss description and review of the Ambiguous Loss Handout (see Appendix V).

4. Cognitive and emotional processing (12 minutes)

- “My mind works overtime” – struggling with private events: unwanted thoughts, feelings, urges and sensations
- Rationale to highlight the battle between Cognitive Fusion and Avoidance and an alternative strategy of Acceptance
- ACT in a nutshell exercise

5. Cognitive and emotional processing (12 minutes)

- “Coping with my emotions” - finding a way to cope with unwanted, painful feelings.
- Rationale: to highlight present moment, acceptance, self compassion/mindfulness.
- ACT anchor exercise.
- Anchoring handout.

6. Cognitive and emotional processing (12 minutes)

- “Finding a way to care for yourself”
- Rationale: increasing tolerance for ambiguity and acceptance.
- Tree metaphor and Compassionate hand exercise.
- Compassionate Hand exercise handout and the tree metaphor picture handout.

7. Accommodation/assimilation (12 minutes)

- “Life changing events means life changes”
- Rationale: highlight moving forwards despite uncertainty.
- What matters to you in the big picture? What can guide you through this period?
What is the purpose that comes out of this pain for you?

If you can not change things by wanting it to be different and just live by your values about what matters in life to you – what will you be doing?

What now is really important (values, preparing for the future)

8. Administer post session acceptability and feasibility measures 10 minutes

4.6 Part three: Pilot testing Systematic Case Studies

4.6.1 Participants

Consistent with the revised protocol following the expert panel review, a single medical consultant in a specialist tertiary referral unit for people with presumed PDoC at the Royal Hospital for Neuro-disability identified three potential female participants, all were partners of people with PDoC whose diagnosis had recently been shared with the family. This enabled a purposeful convenience sample.

Potential participants were contacted by telephone by the researcher and provided with a brief description of the study. All expressed interest in meeting to hear more and review the Participant Information Sheet and attended the T1 meeting. From the initial three participants recruited (intention to treat) only two participants completed all three meetings (baseline, intervention and follow-up). One participant attended T1 (the first baseline data collection stage) but did not attend the intervention (T2). Her baseline 1 scores are presented for comparison below.

The Participant characteristics are displayed on Table 4.2 below.

Table 4. 2 *Participants' Characteristics*

Participant	Age range	Ethnicity	Relationship to person with PDoC	Length of relationship	Person with PDoC diagnosis	Time since admission	Average Journey time to the hospital	Average time each visit	Previous Psychological therapy	Faith
1	26 - 35	Black British	Fiancé	12 years	MCS (TBI)	12 weeks	2 hours	4 hours	No	Christian
2	36 - 45	Asian	Wife	Life long (also first cousins)	VS (HBI)	4 weeks	2 hours	3 to 4 hours	No	Muslim
3	36 - 45	Black African	Wife	10 years	VS (HBI)	4 weeks	1.5 hours	4 hours	No	Christian

Note. TBI: Traumatic Brain Injury sustained in a road traffic accident; HBI: Hypoxic Brain Injury sustained following a cardiac arrest

4.6.2 Synopsis of Participants.

4.6.3 Participant One:

Participant one's fiancé sustained a traumatic brain injury following a motorcycle road traffic accident some 7 months earlier. She reported that his injuries had been severe and she had not been able to facially recognize him at the acute hospital. She had checked for a birthmark on his body to confirm it really was him. He had not been expected to survive the initial injury but following surgery and a coma for several weeks had lived. She reported that he was admitted to the Royal Hospital for Neuro-disability some three months earlier and had been diagnosed as in a MCS. She reported that she thought this diagnosis was correct and for the most part he "didn't know what is going on" but had moments when she felt "he really understood". Her hope was that he would continue to improve and life would return to fairly similar to life before the injury. She described actively maintaining hope by reminding herself "of how far he has come" and that "he's young" and "it's early" in the recovery process. Her plan was to provide care for him at home in the longer term and to help in his rehabilitation.

The couple has been in a relationship for 12 years and have four young children together (ranging from less than one year old to 12 years old). Her fiancé had been a stay at home father whilst she is in full time education training in healthcare. She had suspended her studies since the accident. She reported that she continued to listen to voice messages on her telephone that he had left in the months prior to his injury "just to hear his voice" and wearing his clothes at home "to feel him". His family were supportive of her but also were reported to have their "own ideas" and be "controlling" and left her hoping he could temporarily communicate to show them she did really know what he would want. She described feeling tearful every

day and sad about the injury. Most of the time she reported asking “why has this happened, he’s so young, we were so happy, he had plans”. She reported her Christian faith had always been important in her life and she had close friends, both of which were a source of strength to her at this time. She had no previous experience of psychological therapy and was not involved in any at present. Her average time to travel to the hospital was two hours each way and she came most days visiting for 4 hours, if she was unable to visit another family member would come.

4.6.4 Participant Two:

Participant Two was surprised when her husband had suffered a cardiac arrest four months earlier, as he had previously been fit and well. She knew his brain injury was “*very severe*” but did not know that any formal diagnosis for his condition had been made or that it was VS. He had been at the hospital for four weeks. She had known her husband since they were children (they are first cousins) and spent their childhood in Asia. Their families had arranged the couples’ marriage. She had trained as a teacher but had not worked since her marriage. She has lived in the UK for 18 years and had English as an additional language. Her English skills were adequate for the intervention. The couple have five children together (aged between 1.5 years and 18 years of age). She reported that most of the children still share her bed and this is customary within her culture and so the fact her husband is not there at night is not so difficult for her.

She reported being a devout Muslim and framed the injury as a test and a challenge from Allah, which was part of a bigger plan for her life. She felt very well supported by her mother who still lives in Asia with whom she communicated daily and who

was a source of strength and positivity that she would be able to manage this situation. She has help from a neighbour and an uncle that she is grateful for, particularly in managing systems and practicalities in the UK "*she comes with me to the council and will sit all day and wait to help me*". She reported their marriage had been based around traditional roles and since his injury, she had taken on a great deal more responsibilities and decision making authority. She was aware that she had become more "*independent*" and felt this was a real benefit that had arisen from the tragedy of his injury. She was aware her own identity had developed and considered herself to be "*very different*" which was "*for the better*" because she was "*strong*". She described her husband's family as having different ideas to her and wanting her to do what they thought was right. However, she was determined to hold on to decision making power "*I have to decide*". She stated the family differences, were "*difficult, not easy*". In addition, she reported that there were cultural expectations, such as his mother being the primary mourner and griever for his injury and as a result the focus in the wider family was the patient's mother's distress, not his wife's. She had no previous experience of psychological therapy and was not involved in any at present.

She reported that she had decided never to let her children see her crying about this and focused on creating an atmosphere of everybody trying hard at school and being hopeful, however she had little expectations that he would progress more than he currently was. She felt that it was better for her to have him at home to provide care to as she did not drive and travelling to see him was difficult with her other childcare responsibilities. Her journey time to the hospital on public transport with her children was often in excess of two hours each way, visiting for 3 to 4 hours each time.

4.6.5 Participant 3

Participant Three is originally from Africa and has lived in the UK for twenty years. Her husband of ten years had a cardiac arrest 5 months earlier and was “hypoxic”, she did not know of any other diagnosis of his injury and reported feeling “concerned that not enough gains are being made” in the 4 weeks of his admission. She reported clear expectations that significant rehabilitation gains should be achieved and she would advocate and push anyone required to make sure he received the rehabilitation she thought he deserved. She was unimpressed at the lack of activities for patients on the ward. She reported having a masters degree and had returned to full time employment. She had no previous history of psychological therapy and was not participating in any currently. She is a Christian and her faith has a large role in her life. She did not want to share any details about her home life or support structure.

4.7 Measures

As detailed in the revised protocol presented above.

4.8 Procedure

As detailed in the revised protocol presented above.

4.9 Results

4.9.1 Acceptability and applicability of the intervention.

Overall, the two participants who completed all meetings were very positive about the content of the intervention and were compliant with it. The results of the intervention evaluation questionnaire are shown in Table 4.3 below and show the participants’ considered the intervention was helpful, relevant and appropriate to

their situation and was something that they would recommend for other people in a similar life situation.

The participants' responses support the expert panel opinion that an individual based session was more acceptable to them than group based session. Participant One commented that she would not have wanted to have been in a session with other families but thought more members of her own family could be useful as all her family were finding the situation difficult and that the information shared would have been applicable and helpful to them too. She also added that the flexibility for the meetings to have been out of hours (evenings and weekends) had been beneficial to her attendance.

Table 4. 3 *Participants' reports of the acceptability of the intervention*

Statement	Participant One responses	Participant Two responses
Do you think that the meeting with the researcher was helpful for you	Strongly agree	Strongly agree
Do you think this meeting has helped you to think about ways to cope with the situation you are in	Strongly agree	Strongly agree
Do you think you would recommend this kind of meeting to others in a similar situation	Strongly agree	Strongly agree
Do you think you would benefit from more of these type of meetings	Agree	Strongly agree
Would you have preferred this meeting to have been with other families coping with a similar situation	Strongly disagree	Strongly disagree
How important is it to you to take care of yourself as well as your injured family member	Neutral	Important

T2 Intervention: Participants' qualitative reports of acceptability of the exercises within the intervention:

Psychological Formulation:

During the description of Ambiguous Loss, Participant One remarked that it was a good explanation for her situation; *"Exactly! That's exactly what it's like!"* and that the description was useful in sense making: *"can I take this away? I want to show this to [other members in the wider family], I think it would really help them understand it too"*. Participant Two also shared that the description of Ambiguous Loss resonated for her, she described *"Yes. He is here, but no talking or thinking, more like a baby, it makes me sad, he was a good man and he is gone"*. She thought it was a helpful way of thinking and looking forwards was something she had to do now even though the future was uncertain.

4.9.2 Strategies to manage distress arising from a situation that is out of their control:

ACT in a nutshell exercise, Participant One commented *"you've taught me something new... I do that [avoidance and fusion]"*. Participant Two appeared familiar with the idea of openness and acceptance of unwanted private events and nodded during this exercise and commented *"you don't worry, you leave it in Allah's hands"*.

Compassionate Hand exercise, Participant One became very tearful. Following the exercise, she was invited to share what the experience had been like. She reported *"I always went to him for a hug to feel better, now I realize I've got to do this on my own"*. She confirmed that she had found it helpful and considered that she could

use this in her day to day life when coping with her own distress. Participant Two reflected on how warm her hand had felt to her and her sense of feeling calm.

Tree metaphor: Both participants seemed to connect to the tree metaphor in different ways. Participant One talked about the “spikey bike” and the need to open to accommodate it as reflecting the pain not going away. Participant Two appeared to resonate with the tree metaphor and personalized and extended the idea to include that Allah had given her roots and a foundation to be able to grow around and accept this difficult situation so although she was being “*tested*” she had the skills to manage.

Values connection and action. Both participants were planning to take their partners to live at home, however needed extensive property modification and equipment to achieve this. Both reported focusing on the needs of the injured person, then their children and lastly themselves. Both acknowledged their own self care had deteriorated since the injury. Participant One talked about weight gain, lack of personal grooming activities previously enjoyed (such as having her hair and nails done regularly), Participant Two described weight loss and eating less, just focusing on preparing things for her children.

In relation to how effective the intervention was as assessed by the purpose designed questionnaire, the participants’ responses are shown on Table 4.4 below:

Table 4. 4 *Participants' responses to the effectiveness of the intervention*

Statement	Participant One responses	Participant Two responses
Normalisation: I think that the way I feel about life right now is completely normal for anyone going through what I am going through	Agree	Strongly agree
Certainty: I have a greater sense of certainty about my situation	Agree	Strongly agree
Meaning making formulation: I feel I have a framework to make sense of what I am experiencing since the injury	Agree	Strongly agree
Valued action: I have a better understanding of what I think is important to do	Strongly agree	Strongly agree
Coping with distress: I have a way to manage things when I feel overwhelmed	Agree	Strongly agree
Valued action: This event has made me less purposeful	Disagree	Disagree
Self care: I feel my needs are less important than helping my injured family member with their needs	Disagree	Agree
Sense making: My feelings do not make sense to me as [my injured family member] has not died	Neither agree nor disagree	Strongly disagree

4.9.3 T3 Follow-Up: Participants' qualitative feedback of being involved in the pilot research

In terms of the experience of being involved in the research, Participant One reported that she had looked forward to the meetings and found that having the ability to have meetings out of hours had helped her attend and juggle her other responsibilities. In relation to the intervention she described "*it made me feel, not a relief, but made a greater sense of understanding for me*". She reported that she had tried the Compassionate Hand technique and found it calming when feeling distressed one evening. She also had used the Anchoring technique when in a family meeting with her partner's wider family and experiencing a sense she was getting increasingly distressed and lost in her negative thoughts about why she was in this situation. This had helped her re-engage in the meeting and manage her emotions. She reported that she thought the strategies could be helpful, but it was hard to spontaneously recall to use these after only one meeting. She expressed interest in having further meetings had these been available. She was therefore referred to post-intervention clinician (the lead clinical neuropsychologist in the organisation).

Participant Two's husband's discharge planning had also begun. She had agreed to an interim care placement whilst her own property was adapted to meet his needs, but she still planned in the longer term to be able to have him return home. She reported this acceptance of the need for interim care had led to a difference of opinion within his family. His family think she had been wrong in agreeing to this. She felt his family still expected significant rehabilitative gains, but she did not.

Her experience of being involved in the research was positive "*it's good*". In relation to the intervention, she reported that the Ambiguous Loss "*was right*" and

she reported that she felt *"life is hard but still going on"*. She talked about a clear sense of deliberate reconnecting with her husband through thinking about positive memories and current imaginal conversations with him. In relation to the acceptance part of the intervention she confirmed this was how she felt she was deliberately approaching things *"It is for Allah not for me to worry"*. She commented that the tree metaphor had been helpful and that she hoped she was *"strong enough"* for the challenges she would face ahead.

4.9.4 Researcher perspective of delivering the protocol.

There were no difficulties in delivering the protocol and it was possible to complete all tasks within the allocated time. However, practical issues about delivery were apparent, it was difficult to locate a room of the ward area that did not get interrupted even when this was out of standard working hours. Given the childcare responsibilities of the participants, it was also difficult to find times when their dependents could receive care from someone else to enable their parent to attend the research meetings alone. It was also difficult to locate items like do not disturb signs, tissues and glasses of water which had to be brought separately by the researcher to meetings. Participants appeared engaged and interested in the intervention session. Participants appeared to find the exercises acceptable and helpful.

4.9.5 Secondary Variables

In relation to the secondary variables of interest; acceptance, distress, wellbeing, continuing bonds, sense making the participants' scores are presented in Table 4.5 below. Participants' responses to the Meaning Reconstruction Questions (Neimeyer, Baldwin and Gillies, 2006) are presented in Table 4.6 below.

Table 4. 5 *Participants' scores across time*

Participant	Time point	AAQ-II+	HADS-A	HADS-D	HADS-TS	SWEMWB+	CBS+	ISLES-SF+	ISLES-SF- C	ISLES-SF-F Footing in the world
One	T1 Baseline 1	43 / 49	5 normal	8 mild	13 moderate	30 excellent	51 / 55	27 / 30	12	15
	T2 Baseline 2	41 / 49	4 normal	10 mild	14 moderate	27 good	52 / 55	27 / 30	13	14
	Follow-up	35 / 49	11 mild	10 mild	21 severe	25 average	51 / 55	23 / 30	10	13
Two	T1 Baseline 1	29 / 49	8 mild	11 mod-severe	19 severe	25 average	43 / 55	22 / 30	11	11
	T2 Baseline 2	30 / 49	8 mild	9 mild	17 severe	26 average	43 / 55	26 / 30	15	11
	Follow-up	35 / 49	4 normal	11 mod-severe	15 severe	24 average	53 / 55	24 / 30	11	10
Three	T1 Baseline 1	33 / 49	19 severe	16 severe	35 severe	15 poor	36 / 55	9 / 30 clinically significant	3	6

Note. + Higher scores are reflective of greater acceptance, wellbeing, continuing bonds, sense making, ISLES-SF-C Comprehensibility, ISLES-SF-F Footing in the world,

Table 4. 6 *Participants’ responses to the meaning reconstruction questions*

Participant	Time point	Meaning Reconstruction Questions			For the: • better • mixed • for the worse
		“How much sense would you say you have made of the loss?”	“Despite the loss have you been able to find any benefit from your experience?”	“Do you feel that you are different or that your sense of identity has changed as a result of this loss?”	
		1 no sense-----4 good deal of sense	1 no benefit -----5 great benefit	1 no different---- 5 very different	
One	T1: Baseline 1	3	1 <i>no benefit</i>	3	Mixed
	T2 Baseline 2	3	1 <i>no benefit</i>	1 <i>no different</i>	Mixed
	Follow-up	1 <i>no sense</i>	1 <i>no benefit</i>	4	Worse
Two	T1 Baseline 1	4 <i>good deal of sense</i>	4	4	Better
	T2 Baseline 2	4 <i>good deal of sense</i>	4	4	Better
	Follow-up	4 <i>good deal of sense</i>	5 <i>great benefit</i>	4	Mixed
Three	T1 Baseline 1	1 <i>no sense</i>	1 <i>no benefit</i>	1 <i>no different</i>	Worse

Note: Higher scores suggest stronger meaning making and benefit finding

The three participants initial baseline 1 (at T1) show variation in their psychological responses. As a group, all showed clinically lower mood than the normative population. Participant Three was the most distressed across all measures, showing severe mood disturbance, poor wellbeing, significant difficulties with sense making and the lowest connection to the injured person. Despite having returned to full time employment, she is experiencing significant psychological difficulties coping with the impact of the PDoC. Participant Three did not attend any further meetings after the Baseline 1 meeting.

For the other participants, their profiles across the research period were different. Participant One's wellbeing scores (SWEMWBS) although still within the average range had deteriorated over the assessment period. Her scores show increasing psychological distress (HADS-TS) in response to increasing anxiety (HADS-A). Increasing distress was associated with a decrease in her willingness to accept and tolerate these unwanted private events (on the AAQ-II). Her commitment and sense of connection (CBS) remained consistent to her partner but deterioration in scores of sense (ISLES-SF) and meaning reconstruction were observed. Critically at T3 follow-up session, she reported her fiancé was due to be discharged. She had begun to realize that her initial plan of him moving from the ward to their family home was not going to happen and that she would have to identify an interim nursing home placement for him to go to, which was overwhelming to her. The reality that he was not coming home after all this time in hospitals was very distressing for her. She was quite tearful and reported feeling more worried about the transfer to long term care and that this reality had made her feel "*a little less optimistic*" about his potential for further recovery. She reported that she had attended an acrimonious meeting since the intervention meeting with her fiancé's

siblings and there were a number of arguments about who was next of kin and who had decision making authority for him.

Participant Two in contrast showed average range levels of wellbeing (SWEMWBS) and her anxiety levels reduced (HADS-A) but she experienced consistently high levels of distress (HADS-TS), largely in relation to ongoing low mood (HADS-D). She showed increasing willingness across the measurement period at accepting and tolerating negative private events (AAQ-II) and increasing sense of connection with her partner (CBS) despite his PDoC remaining unchanged. Her sense making fluctuated but did not go below the clinical cut-off and her meaning reconstruction scores showed strong attempts at sense making, benefit finding and positive identity change.

4.10 Discussion

This study addresses a key gap in the literature of how psychological support to family members of people with PDoC could be provided. PDoC are rare states, this study is the first attempt to use formative research with this population to devise a psychologically informed multi-component intervention.

The specific theoretically informed intervention content was developed, evaluated by an expert panel and piloted to evaluate its accessibility and acceptability. The satisfaction and acceptability of the intervention was not independently assessed, however there was convergent evidence in terms of qualitative reports of the participants, their self-report on acceptability measures and the opinion of the expert panel. Although the study was a small, exploratory proof of concept, pilot study, both the expert panel and the pilot participants gave positive feedback about the

intervention, it seemed generally acceptable to them in principle, and something that participants would recommend others in a similar situation to try. Anecdotally a different family member has since requested the intervention on the recommendation of one of the participants. Participants reported independently using the principles of the intervention delivered within only a single session. The intervention was straightforward to deliver and the researcher was able to deliver the content within in the time limit of the session. The design was a single-arm proof of concept reflecting the formative stage of this research and evolving understanding of both the needs of PDoC families and possible areas for intervention.

None of the participants had previous experiences of psychological therapy. Following the intervention both participants thought that they could benefit from more meetings with the researcher, with one requesting onward referral. It is a possibility that in line with the aims of this single session; it created a framework to make sense of their situation, instilled hope that they could find a new way to live with the painful experience of their partners PDoC and normalized their experience without pathologizing them personally. This may in turn enable family members an entry point to a more traditional model of psychotherapy and support (multi-session) and a potential means of differentiating who needs additional support and who can manage independently. It could be argued that this design was not a single session design as there were three meetings with the researcher (baseline assessment and induction into the research, the intervention session and the follow-up assessment) However, this format is common in other single session intervention delivery models (Paul & van Ommeren, 2013). This research has shown the intervention component is able to be delivered within one meeting – hence a single session. To determine the relative effects of the baseline and follow-up assessments in future research, these

could be conducted by a research assistant.

This intervention had multiple components, as is common in psychological interventions (Drotar et al., 2014) and therefore it was not possible to evaluate the efficacy of any specific component of the intervention (for example, could the psychological formulation framework component alone have been sufficient?). Consistent with the expert panel, both participants agreed that they preferred the individual nature of the session and would not have wanted to do it with other families. The possible value of individual sessions is further highlighted by the findings that both reported the intervention had strong acceptability and appeared to have both gained something from the intervention, but their difference in psychometrics secondary variables scores suggests they may have both benefited in different ways. One participant showed increasing acceptance, connection with her husband and meaning making which is the one of the proposed mechanisms of therapeutic change and useful as a primary outcome measure for future trials, and decreasing distress which is a secondary outcome useful to monitor. Elvira de la Morena and Cruzado (2013) noted a lowered presence of prolonged grief disorder in family members with higher acceptance scores on the COPE-28 and increased acceptance has also been noted in families in palliative care to be associated with less prolonged grief disorder (Davis, Deane, Lyons & Barclay, 2017). Increased meaning making in breast and colorectal cancers has been associated with greater optimism, self esteem and self efficacy (Lee, Cohen, Edgar, Laizner & Gagnon, 2006), this could be useful as secondary variables in further studies in PDoC. The other participant in the present study, showed increasing distress and reflects the literature (presented in Chapter One) whereby some families will manage the challenges of PDoC without professional support and others will be likely to require formal intervention. This is consistent with

other meaning making literature where reported levels of psychological distress in advanced ovarian cancer were not impacted by gains in meaning making (Henry et al., 2010).

The timing of the intervention also needs further thought. The expert panel identified the timing of the intervention to be important and suggested it was most relevant when the chronicity of the PDoC was becoming apparent. Families are often advocates for the person with a PDoC, driving the admission to specialist rehabilitation, arguing with NHS England to obtain funding for such a specialist admission and are full of hope and expectations that once finally in the right setting, further gains will be achieved. At the point of this study, the rehabilitation pathway had transitioned from acute care to rehabilitation. However, by follow up, a new transition was underway from rehabilitation to long term chronic care. This clearly means that the many original hopes and expectations of the admission had not been met and the reality that discharge from hospital will not mean coming home is understood. This appears to be a critical point for support. Partly, because this prompts another meaning making point about the injury not following their assumed understanding of recovery paths and partly because life has been suspended and frozen whilst the family waits for this recovery to occur. The main reported focus of the participants was on caring for their partners, rather than their own needs. In line with previous studies of caregivers of people with brain injuries (Williams et al., 2014), the participants reported limited focus on their own self care, which perhaps points to the less than eight months post injury time period of participants in this study and the need to move from the shorter term coping techniques (life suspended and frozen to focus on the person with a PDoC) to longer term sustainable strategies. At the transition from rehabilitation to long-

term care, a further period of change and uncertainty is created. Further demands are placed on the family caregiver, who is already at a vulnerable psychological position to; navigate and facilitate this transition successfully, to adjust to the realization of longer term illness than initially anticipating, to begin to consider longer term realignment of all the other roles and tasks the injury has required them to take on, to advocate for the injured person's needs in the new setting, to cope with their anxiety about the change and build trust with a new group of professionals who may have limited experience of a complex condition.

Despite general reports of acceptability, one participant did not complete the research trial. The reasons for her dropout were not known. When initially approached by telephone to explain the study, she wanted to know what specifically she would personally get out of the meetings. It is possible that as the Baseline 1 stage did not offer any intervention and she showed clear psychological distress on the measures, she may have dismissed this process as not meeting her needs and requiring too much time, when she is managing multiple life demands. Other contextual factors may have been relevant; she was working full time, had a long journey time to the hospital and the medical condition of her partner was quite unstable. The burden of participation in clinical research has been associated with recruitment challenges, attrition and subsequent effects on validity (Drotar, Cortina, Rohan, Somers, Hilliard & Maddux, 2014) previously. There is a clear challenge of doing research with PDoC families who express concerns that by considering their own needs this could be shifting or diluting professional input to the injured person, who, is clearly their focus for any useful support and can be reluctant to be seen as themselves as an identified patient. In the context of having to take on so many additional roles to keep continuity in other areas of life, families have limited time and

personal resources left, and this can be problematic in asking them to take repeated measurements at a time of intense personal stress and emotional distress. Family members limited time leads to a tendency to prioritise any time they do have, to focus on the identified patient and not themselves.

This is important to consider in relation to the development of further research in continued evaluation of the efficacy of this as a feasible intervention for families, particularly balancing the need to increase experimental rigor and the option of employing repeated idiographic measurement (such as in a single case experimental design) as there are no specific measures for this population. It is likely that idiographic measures could have higher face validity for participants and be taken frequently through the assessment, intervention and follow-up phases to isolate effects for individuals but this must also be balanced with increasing demands on a population already feeling overburdened. Such as idiographic measures focused on the triggers of distress (for example Participant One when alone during the day talked about cognitive fusion with thoughts of “*why him?... he’s so young....we had plans*”) and the experiential avoidance strategies (of trying to convince herself that he could still recover further) could be useful to pursue. Avoidance strategies in PDoC carers have been associated with higher grief and lower wellbeing in previous studies (Cipolleta et al., 2014). However, this approach needs to be cautiously balanced with reports that developing awareness of experiential avoidance of painful and difficult private events can increase distress in caregiver populations (Williams et al., 2014). In a meaning making intervention for women with advanced ovarian cancer, dropouts from the study seemed related to the distress associated with “loss of defensive denial” (p. 1346; Henry et al., 2010). This suggests caution is needed in thinking about how to develop focus on cognitive

fusion and experiential avoidance, as both a research measure technique and using ACT acceptance ideas with this population. It is important to balance what maybe a positive experience during a natural process of life evaluation with respecting how people respond as the PDoC trajectory progresses.

A clear area for further development is how the outcome of the intervention can be measured reliably and validly. This study, in line with the Morley (1996) assessment measure funnel, employed well researched psychometrics for global level measurement. Standardised measures have a role in global measurement as they have known psychometric properties (Gladwin & Evangeli, 2014) and normative data, but are not often suitable for frequent repeated use and measure what people have in common rather than specific change within a person (Morley, 2015). Global measures were useful to help contextualize understandings of the participants' psychological experiences. However, the limited change recorded using these global measures indicates that modifications are needed to the how the intervention is evaluated to achieve the intended effects on outcomes and clinical meaningful change. Given the life challenges for participants, a dramatic effect from a brief single session intervention was not expected on global measures of distress and wellbeing, particularly as psychological distress symptoms were not specifically targeted by the intervention. This intervention sought to only to normalize the participants' distress, provide a framework to interpret their distress and strategies to cope with their distress, in what is a prolonged distressing situation. Other research highlights that reductions in caregiver distress are difficult to achieve in the face of an ongoing situation and interventions may need to be of a longer duration to achieve this (Hudson, Trauer, Lobb, Zordan, Williams, Quinn, Summers & Thomas, 2012; Corallo et al., 2015).

Obviously with an exploratory pilot study, no comments can reasonably be made about the representativeness of the participants or the generalizability or causality. A number of variables of potential interest were not measured in this pilot. The participants were all recruited from the same centre, their family members care was from the same consultant and they participated in an intervention with the same researcher. Future research of this intervention could include manualising and integrating the intervention to be delivered within existing models of care without additional burden to the ward psychologist, enabling more researchers and sites. This would help to identify if there are specific therapist, team or site variables. All of the participants reported their faith to be important to them. Spirituality as a coping strategy of relatives of people with PDoC has been previously reported to have benefits (Puggina & Paes da Silva, 2016; Leonardi et al., 2012). This may link with the ACT concept of acceptance and also global meaning making (such as this event is part of God's plan). Adapting the ACT principles into existing faith frameworks has previously been described (Williams et al., 2014).

This study has suggested a way to understand what contributes to the distress seen in families and how to better help families of people with PDoC live with a situation full of losses, that is very uncertain and beyond their control. This intervention appears to have been both acceptable and helpful in increasing understanding for families about why they feel the way they do and enabled hope for being manage their feelings and thoughts in a new way. Further systematic exploration of this intervention is now needed.

PART TWO

The experiences of healthcare professionals supporting people with prolonged disorders of consciousness

Chapter Five

“It’s quite shocking the level of disability”: A mixed methods study of the experiences of healthcare professionals supporting people with a prolonged disorder of consciousness.

5.1 Introduction

This thesis focuses on experiences of caregiving in prolonged disorders of consciousness (PDoC). The impact of the condition on patients’ wider social networks was discussed in Part One. Chapter Two showed that families in this study described that the PDoC created immobilisation and relational changes in the family that are difficult to make sense of and stemmed from an ambiguous loss. Families themselves embodied the experience, taking on roles of providing and supervising care and experienced changes in clinical management as a personally felt abandonment. Chapter Three showed that when early attempts at meaning making were discrepant with the realities of the condition, families were distressed and unable to move out of the limbo of ambiguous loss. Chapter Four suggested that providing education about this form of loss with information about managing both the loss and the emotions surrounding it was perceived as helpful to cope with ambiguous loss and meaning making.

Part Two of this thesis addresses the caregiving experiences of healthcare professionals working with people with PDoC and their families. Chapter One highlighted that healthcare professionals report experiencing caregiving challenges

too (Crawford and Beaumont, 2005; Puggina, Paes da Silva et al., 2012). Healthcare professionals have a central role in care of people with PDoC (Rodrigue et al., 2013). They deal with the complexity of diagnosis, medical management of someone who can not consent nor communicate, have to make views on prognosis that can impact on withdrawal of life sustaining treatments, have a role in the rationing of healthcare, whilst holding a range of views about what they would want for themselves in a similar situation. In addition, healthcare professionals support families who are distressed, may be in conflict with the team and are often learning about the condition for the first time.

The combination of these challenges is demanding and has the potential to be emotionally confronting to healthcare professionals creating risk of wellbeing changes, quality of life changes and burnout. Yet, there is little research on the experiences of healthcare professionals in this clinical area (Rodrigue et al., 2013). The aim of the present study was to investigate what healthcare professionals working with people with PDoC experience and what healthcare professionals think about their work with patients' families. This was seen as formative research with the intention that findings could inform the future programme development to support staff in their work with families.

5.2 Method

5.2.1 Design

To investigate the experiences of healthcare professionals, a mixed methods design was used. The qualitative research design component, employed thematic analysis of three focus groups. Focus groups enable collection of rich data as participants

discuss, interact and react to each other's comments (Willig, 2013). At the conclusion of the focus group, participants completed a standardised questionnaire, the Copenhagen Burnout Inventory (CBI) and basic demographic details.

5.2.2 Procedure

The Royal Hospital for Neuro-disability provides a level one service funded by NHS England, which is a tertiary and specialized rehabilitation service for people with highly complex impairments after severe brain injuries and neurological conditions. There are two wards that specialize in the assessment and rehabilitation of people with suspected or diagnosed PDoC who admit on average 30 people a year (approximately equivalent numbers of people in VS and MCS) with highly complex needs for therapy and equipment (The Rehabilitation Complexity Scale –Extended version 13 scores range from 15 to 19 with an average on admission of 16.53; The Northwick Park Nursing Dependency scores on admission range from 38 to 71 with an average of 53.06). The clinical teams are led by Consultants in Rehabilitation Medicine who have many years of direct experience working with clients in PDoC. The lead allied healthcare professionals range from Band 8a-8c and also have several years of direct experience with this clinical population. The wider teams are comprised of healthcare professionals graded from a minimum of Band 6 up to Band 8a. Healthcare professionals on the unit are given training and clinical supervision specific to working with these clients and they are expected to contribute to the regular training events that the organisation runs to give external clinicians skills for working with this complex clinical population.

Using a purposive and opportunistic sampling method, multi-disciplinary healthcare professionals working on these two wards were invited through the regular monthly research seminars that are attended by nurses, physiotherapists, occupational therapists, speech and language therapists, music therapists, medics and clinical psychologists within the organisation, to participate in this research. This recruitment strategy meant the healthcare professionals self-selected whether they wanted to participate in the research.

Data collection through three focus groups was conducted over a six month period (September and October 2014 and February 2015). All focus groups were held at the hospital, in meeting rooms, with seating arranged in a circle. Each focus group took approximately an hour and was conducted during the participants' working day. On arrival at the focus group, potential participants were given an explanation on the nature and method of the study and issues of confidentiality. They were asked to sign the consent form.

Participants were encouraged to share their experiences and situations they had encountered. A semi-structured topic guide (see Appendix W) was used to elicit views. The topic guide centred on themes of understanding and descriptions of (i) the experience of working with people with a PDoC (ii) the experience of interactions with families of people with PDoC and (iii) understandings and descriptions of factors that help or hinder their work role. The same topic guide was used for all three focus groups. These Focus Groups were audio recorded and transcribed verbatim by the researcher. Following the focus group, participants were then asked to complete a written questionnaire comprising a standardized measure and demographic details.

5.2.3 Participants

5.2.4. Inclusion criteria

Focus groups were composed of healthcare professionals with a common background in assessing and rehabilitating people with suspected or diagnosed PDoC.

Participants included were:

- (1) healthcare professionals employed on a permanent full time or part time basis within the post-acute neuro-rehabilitation service in the organisation and
- (2) working with people with a PDoC as their primary role and
- (3) able to converse in English satisfactorily to participate in a talking based focus group and read and write to complete the questionnaire.

Purposive self-selection of the 21 participants was necessary in order to identify healthcare professionals who have experience in this clinical area, as PDoC require specialist expertise and few professionals who specialize in neurology would even come in to contact with this clinical population in their routine practice. Participants generally knew each other and were part of pre-existing groups (such as a clinical team or member of the same professional department). This is advantageous when investigating personal feelings and thoughts, as the pre-existing rapport between the participants enables open sharing (Raibee, 2014) and similar interactions to outside of the research setting (Willig, 2013). Familiarity also can enable the ability to connect with other participants' views and therefore participant's potential to challenge these may be greater (Kitzinger, 1994).

As the selection was opportunistic, the sizes of each focus group varied (with $n = 4$, 6 and 11 participants). There is no consensus on the optimal size of focus groups. Willig (2013) suggests between six and eight participants are best for obtaining contributions from all participants and accuracy in transcription. The majority of participants were occupational therapists ($n = 7$), physiotherapists ($n = 4$) and speech and language therapists ($n = 4$), the range and number of professions is shown on Table 5.1.

Table 5. 1 *Participants' Professions*

Healthcare Profession	Number participating
Neurological Occupational Therapy (OT)	7
Neuro-Physiotherapy (PT)	4
Speech and Language Therapy (SLT)	4
Music Therapy (MT)	3
Clinical Neuropsychology (CP)	2
Medical (M)	1

Similar to NHS reports of gender in the workforce (NHS, 2016), the participants' characteristics showed the vast majority of participants were female (20/21). Only 1 participant (of 21) was male. 74% (16 of 21) of the participants worked in a full time capacity within the specialist service and 26% (5 of 21) worked on a part time capacity. The range of service time on the specialist unit ranged from 1 month to 11 years, with the average being 3 years, 3 months. Of the participants, 29% (6 of 21) had been working in this area for more than five years and 71% (15 of 21) had worked less than five years. Twenty one healthcare professionals participated in the focus groups and 19 healthcare professionals completed the standardized questionnaire (19/21, a 90% return rate).

5.2.5 Measures

The Copenhagen Burnout Inventory (CBI) was developed and normed as a measure of burnout for health and social care workers (Kristensen et al., 2005; see Appendix AA) and has been widely used in health worker research (see Jordan, Fenwick, Slavin, Sidebotham & Gamble, 2013; Atkinson, Rodman, Thuras, Shiroma, & Lim, 2017; Lyndon, Henning, Alyami, Krishna, Zeng, Yu & Hill, 2017; Creedy, Sidebotham, Gamble, Pallant & Fenwick, 2017). The CBI does not attempt to distinguish between physical and psychological fatigue or exhaustion and instead seeks to understand the psychological processes of meaning making that people do in interpreting and attributing their symptoms (Kristensen et al., 2005). The CBI measures burnout in three domains;

Personal Burnout - the degree of physical and psychological fatigue and exhaustion experienced by the person. (six items)

Work Related Burnout - The degree of physical and psychological fatigue and exhaustion that is perceived by the person as related to his/her work (seven items)

Client Related Burnout - The degree of physical and psychological fatigue and exhaustion that is perceived by the person as related to his/her work with clients (six items)

The nineteen item measure uses a five-point Likert-type scale. Possible score ranges for all scales is 0-100, with scores of 50 or greater considered positive for burnout. Reliability of the tool was assessed by the original authors, reporting Cronbach's alpha between items of 0.87 in the personal and work related subscales, and 0.85 for the client related burnout scale (Borritz, Rugulies, Bjorner,

Villadsen, Mikkelsen & Kristensen, 2006) indicating that items within the sub-scales were well correlated.

Kristensen and colleagues (2005) argued that in line with other researchers' definitions of burnout (Schaufeli and Greenglass, 2001, Pines and Aronson from 1988, Shirom, 1989 all cited in Kristensen, Borritz, Villadsen & Christensen, 2005) that the core of burnout is fatigue and physical and emotional exhaustion that arises when professionals are involved in long-term emotionally demanding work situations. Commonly the Maslach Burnout Inventory (MBI) is used to measure burnout however it is not argued to define burnout in the same way, rather it asserts the burnout construct as comprising; emotional exhaustion, a lower sense of personal achievement and an increased sense of depersonalization, which are described as distinct and different dimensions. However, Kristensen and colleagues (2005) considered recent research that indicated reduced personal accomplishment develops independently from the other two dimensions and could instead be argued as a consequence of long term stress. As a result, coping strategies for long term stress (such as depersonalization) evolve and therefore are not a central dimension of burnout (Kristensen et al., 2005). Finally, they asserted that the content of the questions of the MBI had been identified by some of their healthcare professional participants as offensive and caused negative reactions and anger such as "I don't really care what happens to recipients (of my care)" and have questioned its value as measure for human services burnout.

The CBI was therefore selected for its specificity to health and social care workers, its availability within the public domain, the provision of reference group scores, the underpinning model of the questionnaire's definition of burnout, and lastly that

the measure is described as seeking to understand the psychological processes of meaning making that people do in interpreting and attributing their burnout symptoms: to their work, their client work or their home life. This CBI measure was chosen over the Maslach Burnout Inventory (MBI), for these reasons in spite of the knowledge that the MBI had been employed in two previous studies by European researchers with Italian and Belgian healthcare professionals working in this clinical area, and as such would have enabled direct comparison between the present study and their results.

In addition basic demographic questions were asked and details relating to perceptions of the responsibilities for family support (see Appendix X).

5.2.6 Methodological theory

Discursive analysis was considered and rejected as a method for the analysis of focus group data, in favour of thematic analysis. The basis of this decision was that the research question and the epistemological orientation of the study was realist not social constructivist in nature (Willig, 2013). This position asserts that there are processes that can be identified and described by the researcher using their knowledge and experience to uncover what is occurring as opposed to the social constructivist approach of how the participants as a group create and position their experiences (Willig, 2013). Braun and Clarke (2006) describe thematic analysis as a method for identifying, analysing and reporting themes which is compatible with a spectrum of epistemological positions from purely reporting experiences, meaning and reality of the participants (essentialist and realist), to critical realism (acknowledging meaning making within the social context), and constructionist (the effects of discourses on events, realities and meanings). Thematic analysis can be

inductive (data driven) (Clarke & Braun, 2016) and is a method for exploring an entire data set to identify patterns or themes of meaning, whilst recognising the researchers' active role and series of judgments on what is within the data set (Braun & Clarke, 2006).

5.2.7 Reflexivity

As the researcher and focus group facilitator, I have nearly 23 years of experience of working in clinical settings and within multi-disciplinary clinical teams. Of this, 17 years were spent working within services that have assessed and provided rehabilitation for patients with PDoC and their families as a consultant grade clinical psychologist. This meant I was also known to some of the participants in my professional capacity and seen as an "insider". Being seen as an "insider" has been argued to create validity issues in research as the results may be distorted and lose objectivity (Rooney, 2007). Rooney (2007) raised five points about insider research that could impact on validity such as the researchers tacit knowledge may lead to false assumptions or miss potentially important data and that participants could be hindered from speaking freely by the researcher being a member of the community being researched. In contrast it can be argued to be helpful to be seen as a researcher who both understood the challenges of the clinical work but also the nature of the range of roles people have within the team. Being an "insider" is consistent with the recommendation of Kreuger and Casey (2000) who argue that the facilitator should have sufficient background in the area to be discussed to be sure of providing perspective and follow up critical comments. My epistemological position is a realist orientation, which assumes the existence of meaning making and processes that can be identified using your own skills, experience and knowledge (Willig, 2013). Although the data obtained in the focus groups was to be

examined using an inductive data driven approach, I acknowledge my familiarity with the topic and that I am not coding in isolation and as such play an active part in searching and identifying patterns and themes in the data.

5.2.8 Data analysis of focus group transcripts.

The three Focus Groups audio recordings were transcribed. Then the six phase recursive process outlined by Braun and Clarke (2006 and 2013) was followed. This involved firstly, familiarisation with the data set by listening to the audio recordings of the focus groups and reading and then re-reading the transcripts. At this point any initial analytic observations were noted.

Secondly, codes for key features of the data relevant to the research question were created. The data set transcripts were read for semantic and conceptual content with systematic initial coding of each data item made giving full and equal attention to each data item. The codes were collated and the relevant data extracted. Thirdly, themes were constructed from the coded data to identify coherence and meaningful patterns relevant to the research question. Fourthly, themes were reviewed to consider what each theme meant, what assumptions underpinned it and what its implications were. This enabled a check of the link between the coded extract and the wider data set by the production of the thematic map of the analysis. Fifthly, the themes were refined, defined and named. Lastly, the process of writing the analysis and the selection of extracts enabled a further process to confirm the analysis and the contextualize this within the existing literature.

5.3 Results

Most participants completed the standardized questionnaire (19/21 participants, a 90% return rate) at the conclusion of the focus group. Their responses on the CBI were calculated by each subscale and evaluated for burnout (those obtaining an average score of ≥ 50). Exhaustion and fatigue were attributed by seven of the participants to personal reasons, by four of the participants to work related reasons and only three of the participants to client related reasons. Two participants reported all three subscales as elevated, four participants had two subscales elevated and four participants had scores on one subscale that was reflective of burnout.

Comparison of this sample of healthcare professionals with the large reference group of professionals working in health and social care settings (as described by the measure authors, Kristensen et al., 2005) was conducted in order to determine if there are unique issues in working with people with PDoC. The three burnout scale means were compared to the reference group of using one sample t-tests. Due to the size of the sample and much larger reference group, Hedges g was used as a measure of effect size and interpreted using Cohen d convention, consistent with research of Hofmann, Sawyer, Witt and Oh (2010). A statistically significant difference between the healthcare professionals and the reference group on Work Related Burnout ($t(18) = 2.35, p = .03, g = .53$) with a medium effect size found. The PDoC healthcare professionals had a higher mean score ($M = 42.42, SD = 17.45$) compared to reference group ($M = 33, SD = 17.7$). There was no significant difference between the healthcare professionals and the reference group for Personal Related Burnout ($t(18) = 1.88, p = .077, g = .46$) or Client Related Burnout ($t(18) = -.27, p = .791, g = .07$). This suggests that participants reported similar levels

of client and personal related burnout to the reference group, but experienced far more burnout that they attributed to work than the reference group. The descriptive statistics for the participants and the reference group are displayed on Table 5.2.

Table 5. 2 *Burnout in participants compared to the reference group*

Burnout Domain		This study	Reference group
Personal Burnout (six items)	Mean	43.53	35.9
	Std Dev.	17.70	16.5
	Sample size	19	1898
	Range	13-83	
	P value	0.07	
Work Related Burnout (seven items)	Mean	42.42	33
	Std Dev.	17.45	17.7
	Sample size	19	1910
	Range	14-75	
	P value	0.03*	
Client Related Burnout (six items)	Mean	29.68	30.9
	Std Dev.	19.68	17.6
	Sample size	19	1752
	Range	0-88	
	P value	0.79	

Note. * statistically significant difference between the reference group on this scale at $p < 0.05$

A repeated measures ANOVA was performed to compare between the participants' attributions of the origin of their burnout. Mauchly's test of sphericity was significant and indicated the assumption of sphericity had been violated ($\chi^2(2) = 13.34, p = .001$) therefore the more conservative Greenhouse-Geisser values were interpreted. A significant difference between the three burnout scales was obtained ($F(1.30,23.32) = 10.27, p = .002$). Pairwise comparisons were used to determine the nature of this difference and showed ratings of Client Related Burnout ($M = 29.68, SD = 19.68$) to be significantly lower ($p < .001$) than Work Related Burnout ($M = 42.42, SD = 17.45$) and significantly lower ($p = .006$) than

Personal Related Burnout ($M = 43.53$, $SD = 17.70$). Healthcare professionals were less inclined to link feelings of burnout to their work with clients, than their general work life and their personal life. There was no significant difference noted between Work Related Burnout and Personal Related Burnout ($p = .652$) attributions.

As Client Related Burnout attributions were significantly lower than Work Related attributions, the item that asks about the emotional exhaustion experienced in their work was examined separately. Participants (17 of 19) reported work to have “somewhat” of an emotional toll for them or to “a very high degree”. When participants who found work emotionally exhausting to a “high degree” or “a very high degree” were analysed (8 of 19) endorsed this. Only one participant reported work was emotionally exhausting “to a low degree” (1 of 19) or “to a very low degree” (1 of 19).

5.3.1 Interactions with families in distress

All but one of the healthcare professionals reported having done something in the previous week to support families (18 of 19) despite only around a quarter having received specific training in addition to their profession to support families (5 of 19). Whilst most (13 of 19) viewed this contact as being within their role, clearly around a third of the interactions were not seen by staff as related to their professional role and the contact had not been initiated by them or planned (17 of 19) and tended to relate to providing emotional support for the family (13 of 19), educating (11 of 19) or dealing with concerns being raised (11 of 19). Of concern is that three participants (3 of 19) assessed the interaction as having been personally upsetting to them (this is displayed on Table 5.3 below).

Table 5. 3 *Percentage of participants interacting with patients' families*

Item	Percentage	n / 19
Things to support families within last week	95%	18
Things done were within their professional role	68%	13
Received specific training to support families	27%	5
Interaction was upsetting to the healthcare professional	18%	3
Pre-planned contact with families over past week	53%	10
Ad hoc contact with families over past week	89%	17
Contact focused on emotional support to family	68%	13
Contact focused on educational support to family	58%	11
Contact focused on managing concerns raised by family	58%	11

5.3.2 Focus Group Themes

Following initial coding, 23 collated codes were identified. These were organized (see Appendix Y) and refined into five main themes with an overarching theme of "Imbalance".

The experience of working with people with PDoC produced a range of experiences for the healthcare professionals that reflected a constant sense of imbalance and their attempts to redress this;

- (1) balancing use of clinical time spent with the patient versus their wider familial networks
- (2) balancing families hope versus their grief
- (3) balancing the professionals' self care versus care for the family in distress
- (4) balancing what is contracted versus their sense of what is right or required
- (5) coping with the loss of the old person in the presence of the new person

5.3.3 Theme 1: Imbalance – therapy time with the patient versus dealing with the patient’s wider networks.

Healthcare professionals expressed feeling torn about how their limited time was used each day. They described dilemmas of following their daily scheduled timetable and completing the tasks they had scheduled for patients, as opposed to responding to pressing need or queries from patients’ families. Families tended to have ad hoc contact with healthcare professionals rather than have scheduled sessions. This was described as creating predicaments for the healthcare professionals about who to prioritise their time for.

“Yeah, like you could have another patient timetabled, but a family member will catch you, talk to you for 20 minutes ... they're eating into another patient’s therapy time... And it’s really difficult to try to get out of conversations, even when you say you have another patient and you've got to move on, they just ... I think it’s quite difficult because families can only catch you at certain times, once they catch you, they kind of don’t want to let go of you. See, that does affect other patients. “ [OT]

“I think you have it in different ways its draining from the kind of energy, it takes a chunk of day and knock on effect on other things, if you go to do something with a patient and then you end up that a family catches you very distressed on another matter, you give them the time and you have to manage that situation and it might be that takes 15 minutes or half an hour when you would have been seeing another patient, and everything else is out of sync with your day, your plan for day has gone haywire, I mean sometimes it is for good reasons, but the time that takes to support and communicate with families and work with families that wasn't scheduled definitely isn't always recognized I don't think” [SLT]

Challenges were also reported by healthcare professionals around managing the involvement of families within patient sessions and that less could then be done with the patient.

“they have to understand that if they're going to talk within the patient session, that patient isn't necessarily being treated.” [OT]

This need for information was understood as needed as the patient can not speak or interact with the family and share that information themselves.

“well the patient can't tell the family anything that's got going on from their experience, often the relatives come in and they stay for a couple of hours but the patient can't say anything. They can't have an interaction with the patient, so. They often then look externally and look at more detail of what's happening in the nursing care and with the physio sessions for example and then they might go and have to speak to the staff more than usual.” [SLT]

Healthcare professionals described real challenges with communicating with families and often believed they had effectively explained something only to find they later would have to address the same point again with families and that the duplication of conversations were time ineffective.

“I feel like I've made some in roads when I talk to them but when I come back again next time, I'm back to square one.” [PT]

“I think however much we try to communicate that they never seem to understand or take that on board and we just continue in communicating the same thing over and over again and that can get quite exhausting” [PT]

The healthcare professionals expressed several ideas about the origins of the necessity to repeat information both relating to the families' experience of the power dynamic with staff and the families own psychological adjustment.

“I think also a lot of families can be quite respectful to us as health professionals and not necessarily say when they haven't fully understood something. So often times they'll agree with what I'm saying and later on they'll say something that makes me realize they haven't actually really understood what I've said or taken on. Sometimes I think they're a bit too polite to ...say that.” [OT]

“They'll often take it in but they won't actually take it in, fully integrate it into their beliefs because they, they're holding out too much hope maybe or denial maybe. And so, yeah, they're probably taking it in and it's hitting a barrier from, from it fully being accepted a lot of the time” [OT]

“my feeling is that we all will talk intensively and a lot to patients but are we actually communicating? and/ or are we at risk of over communicating?, because we always talk about communication and the absence of it or little of it, and I think we might be over communicating because you and I could describe the same rainbow and say something entirely different, so similarly we see the same thing as professionals and with our uni-disciplinary hats on what we take out from an MDT meeting and then we are forced to have conversations or assessments and those contact therapy times, we have to have them, and we genuinely give them the right information but what we say is, is not what they hear.”[M]

5.3.4 Theme 2: Imbalance – managing families hope versus responding to their grief

The healthcare professionals described a sense that they as a team viewed that they had an obligation to help the families have hope in this very difficult, apparently hopeless situation. However, they had to balance supporting hope with their sense of professional responsibility to be honest with families about the diagnosis and prognosis of patients and how to interpret the behaviours that patients may make which could be misinterpreted by the family as purposeful and meaningful. This awareness that it could be difficult for families to hear negative information and which may be dispiriting to them created a tension and dilemma

for the healthcare professionals who did not want to collude and create false optimism, and felt a need to give accurate and honest information was challenging.

“I ... I ... too many times I hear the ... the ... the therapist resorting to the clinical picture of, um, uh, no, it just was reflex, no, it doesn't mean anything. Why do we have to completely kill the hope dead? I feel that we have to.” [SLT]

“Realistically speaking, far be it for me to take that away from anyone [hope], but I have a duty to be professional about this and realistic about this without being unkind” [M]

Having conversations with families about prognosis and the future wasn't easy for healthcare professionals.

“ because we are nice people, and so of course you don't want to say you know that they are very unlikely to ever eat normally or whatever but there is a way to do it, it can be brave to communicate that” [MT]

Some healthcare professionals shared that whilst they were highly skilled in their professional discipline managing the clinical needs of the patient, managing the psychological wellbeing of the family was not within their expertise and they agonized about whether their interactions were appropriate.

“Sometimes when you come away and reflect on how a conversation went you wish I was a bit more, I wish I had couched it, rationalized about it, wish I had... or the other way where you reflect you did that too much and you were too kind of blunt, or too kind of, you know what I mean, it's such a fine, fine, delicate balance between being realistic and giving people accurate information, not colluding with them, not you know... but doing it in a supportive way but allowing them to retain a measure of hope because that is so important to them going forward, it's such a fine line to tread, we haven't had that kind of specialist training” [SLT]

“we are doing it without any training really, and it is a heavy burden and load emotionally and you start to question yourself, you must have been in the situation where you wonder if you had said that in a different way, done things differently if that situation would be better” [PT]

“But it's really ... like physio isn't a qualified counsellor but you have to kind of develop these skills, don't you? we are having to be that support to guide them through the grieving process on top of dealing with the patient as well”. [OT]

At times, the professionals need to be genuine and honest may involve sharing that the diagnosis is not always clear or easy to establish, but that too can lead families to being confused and less confident in the healthcare professional.

“We don't always really know and I think, so, give them a bit of hope ... but then also they get a bit unsure about your expertise.” [CP]

“...or they feel that if they repeat it [questions] over and over with every single member of the team, one of them will say what they want to hear. And that's kind of ... I think that's the biggest, biggest thing. And it's not always our fault, like we're all ... we're short-staffed, we're busy. We maybe don't have the time to meet together, um, we're caught off-guard, and ...and then one person says something slightly different from another person, and you've lost the trust of the family member” [PT]

The challenge of hoping for change and coping with grief was interpreted as being displayed by families becoming very focused and controlling about details of a person's care and therapy.

“they always try and micromanage that thing, and it's almost like sometimes I feel that they lose trust that I can manage when splints go on and off and they want them on and off at the exact time and they are always coming into our office to ask when are you coming up to take the splints off, when 5 minutes either side.” [PT]

“Do you think that they are looking, do they think they're looking to be able to have some control, or wanting a role and maybe they think their role is to Mmm because they can't do other things they used to” [MT]

Families grief was questioned as a reason why communication challenges with healthcare professionals occurred.

“I start to question my communication skills sometimes because I think that I communicate well, but I don't have any specific skills in communicating with people who are in a really complex grieving process really so relatives will come to me complaining or asking about splints or stretches or something and I continually generate the same information and I wonder if there is any training available or anything for me to put the onus back on them and try and to work out what their perception of what they're expecting, what I've said.” [SLT]

“gradually you start to realize what you can and can't achieve with families... anyway... but sometimes I think they repeat it over and over because it's all about grief, and they can't take it in.” [PT]

5.3.5 Theme 3: Coping with the loss of the old person in the presence of the new person

The professionals described observing a unique form of loss that the families had to live with, that their loved one was physically still alive but was no longer psychologically accessible to them.

“The way with their grief, and the mourning process that horrible process is not there, their relative hasn't passed away but they are not the person that they used to be and they had a relationship with and you can't really move on because they haven't died it sort of perpetuates ... “ [SLT]

The balance of knowing about the old person (pre-injury) but having to clinically treat the new person (post injury) troubled the therapy team who were aware of

how they psychologically detached from the patient's life story to make provision of their clinical input easier for them.

"That's one of the hardest parts, like this was what they were like before. You kind of end up just dissociating a little bit, don't you, to make it easier to work with, but I do find that really sad, for me it's to see the photos up around the bed." [OT]

This exposure to loss without death, led to healthcare professionals reflecting on what that experience meant for them in terms of existential issues surrounding life and death.

"Well, it's ... personally, personally, when you talk about disorders of the consciousness, it's huge questions of what that really means and there's ... there's the idea of losing your loved one and yet not losing them... And that's really ... that's ... I don't know it must be so, so hard, and then, yeah, it is quite big, life and death questions you're faced with." [SLT]

"I feel that when I was younger, whether it was here or in other work, I wasn't like always emotionally developed enough to even grasp how awful it was and then now, I'm older, and I have more life experience, I'm like, ahh, the depth of grief these people must be feeling. I have more appreciation of it now than maybe I did before." [PT]

5.3.6 Theme 4: Imbalance – managing own self care as a healthcare professional versus responding to family distress

As much as the professionals were aware of the distress of families, they also experienced distress in dealing with the severity of the injury and the prognosis for their patients.

"When you come and work here, it's quite shocking, the level of disability." [OT]

"I think you have to have quite a lot of emotional resilience to work with this case load and not to let it get to you or take it home" [OT]

Managing interactions with distressed family members was described as frequent and these interactions were experienced as cumulative and difficult to cope with for the professionals.

"you can have 4 or 5 of those incidents happen you are just expected to take that on board and it's not, you can't, we have to have some way of channelling it so we don't keep taking it on to our shoulders, because I had an example of a relative, I'm not involved in the patient at all, I was just on the ward and they asked me about him and I was just doing a specific task and then it opened up a whole can of worms and I was there for an hour dealing with this relative very well out of my work day. Where they want very specific information "please be direct, please be open, please be honest" but just going around in a circle saying "I can't give you that information, I'm not one of the people treating him" getting very emotional and then having to say ok, now I have to calm you down now and you get literally caught in that whirlpool... and I left knowing that he was distraught, I can't give him anything, I don't feel I was able to give him anything, I couldn't pass that message on to anyone, I had to wait a whole weekend before I could pass it on to anybody to go and speak to that person and then he didn't come in again until a week later. That's the type of emotional turmoil that we just take and don't have an outlet..." [OT]

Participants were aware that some patients' lives paralleled their own and resonated with them and their knowledge that there was always the chance of being the patient themselves is highlighted.

"when you're with a family you see their distress, it hits you more and, like, always whenever any referral comes in I have a moment, I look at their age, I look at the accident or how it happened and if they're anywhere near my age or my family's age or somewhere I know really well, then I'm like, "Oh, God." And then I try and detach. Then when you meet the family it kind of keeps coming back in. (General agreement)" [CP]

“Now I have a child, like everyone that comes in with a son, I just think, I ... oh, my God, I think, that could be mine.” [PT]

Despite having to cope with their own sense of distress in dealing with this clinical patient group, when faced with the range of ways families showed distress, this was seen as more emotionally impacting than the emotion of the patient at times.

“Outcome measure [part of the required statistical record keeping] which has emotional load, but more often than not the emotional load is coming from the family not the patient, more often than not, I mean all it should be is the patient score...” [OT]

Families appeared difficult to ever satisfy; making complaints, criticisms and challenges to the healthcare professionals and they shared they felt attacked at times and their response to this limited their ability to help family distress.

“I think from the family perspective there is also an element of anger, anger at their loved one, or anger at the situation that it happened and I think sometimes that is easier to take it out on the team who are working as they can't take it out on the person” [MT]

“... that sort of chips away at the team (group agreeing) or the, especially I think the nursing staff (group agreeing) who are around with them all the time (group agreeing) and it, it can, you know, difficult not to become slightly hostile if people are like picking at you the whole time. And that really breaks down that ability to empathise and you know, give the support that you need, or you want to give, if you know, the family is sort of attacking you back all the time.” [SLT]

Part of the challenges of dealing with family distress was the sense that families failure to cope meant that at times they may become angry and be perceived as attacking the healthcare professionals.

"I've never had a family member shout at me until I worked here" [OT]

"they can sometimes get quite personal sometimes I mean if they are criticizing you it can start to feel sometimes that they are not criticizing from a professional point of view but from a more personal point of view sometimes as well so that more emotional aspect of it which is quite challenging to deal with really" [SLT]

"I remember once, basically one specific one where I just, get, got out of the, went to the toilet and just cried. I'm like, "What am I doing here if these people are so unappreciative" and see what's going on and then I'm like "How would I feel if... if I was in their shoes? But it's when you, you feel you're tried a lot. You've really tried. And there's nothing. You're not making any impact at all. [the patient remains in VS] They don't realize... you may not be making impact with the patient, but it's the relatives side that I find very difficult." [PT]

In response to coping these feelings there was a risk that families missed out on the support the team really thought they needed.

"one of the things I notice when the team of really, um, find the family difficult, is everybody puts their professionalism on. Their professional face comes out, the professional manner comes out and you have a load of stony faced people. If they're worried that we're not caring enough and doing enough, that professional face can look like we're not listening or look like we don't care, when that that's not what it is, it's anxiety." [CP]

There was frustration that simplistic, reductionist understandings from the organisation's management that family complaints to the organisation were simply the result of the healthcare professionals lack of communication.

"It's trying to get that warmth and humanity whilst not confusing the message, and you know, my big problem with this would be a frustration when I think the sort of management executive team, whoever, think that the issue here is about us not being very good at it [communication with families], because this really complex stuff, to get the language right, to get the interaction right, to be able to adapt that to each individual person, you

know, not just a family, but a patient might have five family members, and you need to address it all differently.” [CP]

Whilst highly skilled in their own discipline, participants reported feeling at a loss about how to respond to family distress and not having had training for that.

“I never know what do, which happens quite often, when I'm talking to the relative and they break down. (General agreement). I never know what to do. What do I do now? It would really help.” [PT]

“I would really like to have some training in, umm, not not specific counselling as such, but helping families through the grief process ... Because I (general agreement) haven't had any formal training in that (general agreement) and help recognize their reactions sometimes (general agreement) and judge what kind of strategy might be best to try and help them with that particular stage they're at, at the time.” [OT]

5.3.7 Theme 5: Imbalance – having professional knowledge and awareness of the evidence base and contractual duties versus expectations of what is right or needed.

An additional layer of stress in their roles related to the healthcare professional's description of mismatches in expectations between themselves and families about the purposes of admissions and the diagnosis.

“their perception of what they want to achieve from being here is just so widely different so for a lot of our patients we are looking at more of a disability management programme whereas they are thinking of rehabilitation and it's just.... Miles apart...”[PT]

Whilst families were confused about diagnosis or believed they were able to communicate with the patient, coping with the responsibility for accurate diagnosis and uncertainty of diagnosis for professionals was also challenging.

“Which then contributes to my feeling of uncertainty because what if this family is saying they can see something, we're saying no. Definitely VS. What if it isn't. Probably it is VS, but what if it wasn't. That would be awful.” [CP]

These mismatches were also present between the professionals' expectations of themselves in their role and their contractual requirements.

“the question now is, you know, outcomes, patient lengths of stay, get people in and out, nice and quickly, prove what you've done, um, less staff, more patients. So you are squeezing what you are doing for the patient down to the bare minimum of what they need” [OT]

“It's difficult when we get people now that are more acutely unwell than we once did, because that then so muddies the water, about trying to do those assessments or the input that we're trying to do.” [PT]

There was a level of dissatisfaction that shorter time with patients in response to healthcare funding pressures may be disadvantaging them and led to staff discomfort, but also confusion about how to best use the time they did have funded with the patient.

“we've seen those changes of people starting off on a [DOC ward] and going to a [transitional living ward]. And knowing those changes can happen, uh, I ... it doesn't make me comfortable ...”[CP]

“you don't know what the outcome is going to be and like second guessing yourself, are you doing enough, are you doing the right thing, should you be doing more, should you be ... why am I seeing them, I've just seen them for the sake of this, do I actually reduce how much I'm seeing them.” [PT]

5.4 Discussion

The findings reported here show that healthcare professionals do experience an emotional impact from their work in PDoC and that their role is very entwined not just with the identified patient, but also their wider family. A bi-directionality was

noted between family suffering influencing healthcare professionals own distress and when healthcare professionals were distressed they were less able to support family suffering. This means they are constantly attempting to balance their own needs, with the patient needs, with the family needs, and the healthcare system needs.

Almost all participants had worked with families over the week preceding the focus group and largely considered that this was part of their role irrespective of their discipline. Contact was primarily ad hoc and related to concerns and emotional distress. The need for emotional and social support has been noted particularly in families of patients with the minimally conscious state (Giovannetti, et al., 2013). However, whilst highly skilled in their own discipline, few healthcare professionals reported specific training in working with complex distress experienced by families. Some participants did not conceive the support provided to have been within their role, therefore it is important that they have confidence in recognizing symptoms that would indicate the need for referral for specialist psychological support as they are ideally placed in their contact with families to monitor their wellbeing (Davis, Deane, Barclay, Bourne & Connolly, 2017). Participants demonstrated awareness that PDoC created a unique form of loss that is not easy to cope with (such as “they can’t move on because they haven’t died”), however implicit in their discussions were concepts stemming from stage and phase models of grief (such as “denial”, “anger”, “what stage they are at”, “guide them through the grieving process”, “it’s all about their grief, they can’t take it in”) and an idea that they should be helping families to accept this all during the brief admission. As discussed in Chapter Two, psychological stage and phase models of grief do not readily help make sense of the distress these families experience. Furthermore, there is no empirical evidence for

this model and sharing it with families can be harmful (Stroebe, Schut & Boerner, 2017). How a person's grief is conceptualized by another, influences their openness to being with the person grieving and the level of support provided (Davis et al., 2017). Having an unhelpful conceptual framework suggests healthcare professionals can not best target their support for families. Given that healthcare professionals consider support to be an important part of their role and well positioned to identify families in need for specialist psychological referral, this highlights the need for training and developing understandings of family grief.

Participants described the personal impact of the work on themselves. Participants shared that PDoC confronted them with existential issues of their own mortality, questions about life and death and working with patients that they may identify with personally. Ablett and Jones (2007) noted that British and American staff confronted with similar issues in palliative care (oncology) also found this distressing but did not have higher levels of psychological distress or burnout than other specialties, and concluded these healthcare professionals were protected by a strong sense of purpose and commitment to their work. However, there are some key differences between oncology as a comparison group. Presumably, tasks in oncology palliative care are time limited and involve helping people make the most of their remaining life, manage pain, honouring and facilitating choice, and dying with dignity. In contrast, people with PDoC have a chronic condition and can have a long life span with limited prognosis (Gosseries et al., 2012) for change. They have been described as in a "grey zone" suspended between life and death, which creates questions about what it means to be alive or dead (Owen, 2017). There is typically little space in a busy clinical role to reflect on these thoughts, in

two of the focus groups participants commented informally on finding the chance to think about these things useful.

Participants experienced high empathy and personal distress at the situation of the person and their wider family. For many the interactions with complexly distressed families were also distressing to them personally and reported as being more difficult than the direct clinical role with the identified patient. They reported familial distress could manifest as conflict with professionals. Stern, Sazbon, Becker and Coseff (1988) described family members showed hostility towards staff caring for the person with a PDoC and others have also observed this in this clinical area previously (Crawford & Beaumont, 2005; Rodrigue et al., 2013; Gosseries et al., 2012).

The trajectory and timeframes for recovery for PDoC are not clear (Fins, 2013). Implicit in the healthcare professionals' discussions in this study, was their view of the mechanism of any change for patients related to; passage of time and spontaneous recovery. Their role to support this was accurate diagnosis, good disability management to minimise further complications (such as contractures, chest infections, pressure sores) and to control for fatigue and effects of medications. This is in stark contrast with the reports of the families in Part One, who consider the mechanism of change to be the rehabilitative acts and direct input that the professional provided alongside a general sense that professionals don't know if someone will recover. This mismatch in understandings and expectations provides a clear potential factor for tension and conflict between healthcare professionals and families. This highlights the value in clear admission goals and education for families about PDoC in order to attempt to align

expectations pre-admission, as well as ongoing structures during the admission to facilitate understanding.

Fins (2013) noted that families are dependent on the information being given to them, as PDoC is not an area of medicine that many in the general public will have any familiarity with (Rodrigue et al., 2013). In a recent study, a third of families considered the injured person had greater awareness than the staff opinions (Moretta et al., 2017). Participants in the present study described their concerns about balancing giving realistic information without colluding with incorrect family ideas. This has been described as important to families, as is giving it in an understandable manner that leaves space for hope (Puggia et al., 2012). Participants shared their exhaustion and the problems they observed with families making repetitive requests for information. This is consistent with other studies in PDoC (Leonardi et al., 2013) that have indicated that families' information needs can be challenging to meet in PDoC (Leonardi et al., 2012) families need time to understand what has happened (Rodrigue et al., 2013), families distress contributes to cognitive difficulties (Moretta et al., 2017) and continuous requests for information is linked to burnout (Leonardi et al., 2013). This relational nature between the healthcare professional, the patient and their family, has been referred to in the literature as Compassion Fatigue, which occurs when healthcare professionals give high levels of energy and compassion over a long period often without experiencing the positive outcomes of seeing improvement (McHolm, 2006). Research has shown an overlap between Compassion Fatigue and Burnout (Potter, Deshields, Divanbeigi, Berger, Cipriano, Norris & Olsen, 2010). In this setting, with no change in the patient and limited change in the family reaction, may contribute to a sense of compassion fatigue and burnout.

Participants' described challenges in being able to give patient care that they planned (due to family needs taking precedence and lack of time) or thought was important (due to systems limitations and funding constraints). Lack of time and resources has been noted in other studies on care of people with PDoC (Rodrigue et al., 2013). Glasberg, Eriksson and Norberg (2007) called this "stress of conscience" and reflected the cognitive dissonance between healthcare professionals' actual behaviours and their thoughts of what was right. This gap between what professionals want to deliver and what they do through not having the time to provide the care that was considered needed, not being able to meet others expectations and work impacting on life at home was associated with emotional exhaustion in a Swedish study of 423 healthcare personnel (Glasberg et al., 2007). Others have described this as a low sense of Compassion Satisfaction where healthcare professionals are not able to derive pleasure from feeling able to do their job well and overlaps with burnout (Potter et al., 2010). Previous studies on healthcare workers in PDoC have shown professionals can describe little sense of personal accomplishment (Leonardi et al., 2013; Gosseries et al., 2012). Leonardi and colleagues (2012) noted that 53% of 1149 PDoC professionals had worked in the area for less than five years and commented that staff turnover in PDoC may prevent burnout.

This study also revealed greater work related burnout than the reference group, suggesting working with the PDoC clinical population needs further investigation. A fifth of the healthcare professionals were experiencing a degree of burnout of at least one scale. Although there were only a small number of participants, this is similar to the findings of Belgium study of 523 professionals in PDoC (Gosseries et al., 2012) but lower than a national study in Italy ($n = 1149$) where just under half

the participants' had one scale elevated (Leonardi et al., 2013). This may reflect the different measure, training and support structures for staff and settings in these studies including long term care nursing homes too. Participants rated Client Related Burnout lowest in this study. People with PDoC's lack of awareness and responsiveness, means that they are not clients who are demanding on healthcare professional (such as ringing call bells and making requests of staff), which may have contributed to the low ratings of participants. However, participants attributed significantly more of their burnout to work and their personal life. It is not clear exactly what participants experienced and then attributed as work stress. When the item investigating emotional exhaustion was examined in isolation, this yielded nearly half of the sample expressing work was emotionally difficult which is consistent with their reflections in the Focus Groups. A limitation of this study is in the ability to fully interpret the possible reasons for the CBI findings. It could be that they simply differentiated clinical input with the identified patient as "client related" and difficulties articulated in the focus groups with families (such as the demands of balancing family need and their personal resonance with patients and coping with their own responses of anxiety in assessment of patients) as "work related" factors and not 'client' factors. It is also not possible to determine if elevations in work related attributions could have been connected with organizational changes that were underway at the time of the study, although this was not directly commented on by any of the participants. This finding however, is consistent with a study on Australian midwives who also rated their client burnout as low, but higher levels of personal and work related burnout (Jordan et al., 2013). This perhaps speaks to the nature of people who engage in caring professions and are client centred but then have less ability to tackle wider systems issues that

impact on their work such as job resources (like autonomy, social support, supervision), workload and job demands (Gosseries et al., 2012).

Other limitations of this study related to the absence of voices of nursing professionals. Despite attempts to recruit nurses to this study, many stated they could not be released from their clinical work to participate. It is not known therefore how discussions may have evolved had their unique perspective been present. Other research has indicated nursing staff to have higher levels of burnout in terms of emotional exhaustion and depersonalization (Leonardi et al., 2013; Gosseries et al., 2012). These authors hypothesized this related to nurses spending the most time with the patient and the high degree of emotional involvement nursing professionals share with patients and families (Gosseries et al., 2012). An alternative hypothesis is that PDoC impedes nursing staff ability to follow a Person Centred Care model which encompasses the power for care residing in the person not the professional and includes the bio-medical tasks done for a person as well as meeting their social, spiritual and psychological needs (Morgan & Yoder, 2012). As the person with PDoC is neither participative nor communicative, care could be argued to retreat to a greater task orientated focus, similar to findings in dementia care (Talbot & Brewer, 2016) and people in coma in intensive care settings (Puggina et al., 2012). In addition, Leonardi and colleagues (2013) reported after nursing, rehabilitation therapists and medical staff had the next highest burnout, with social workers the lowest. Perhaps, this relates to the differences in roles and training methods of healthcare professionals, as social workers roles commonly involve supporting the patient and family rather than trying to “fix”, “cure”, or necessarily “change” the situation (a process focused discipline) compared to the task focused and curative approaches of other disciplines (such as physiotherapy).

This is the first attempt to examine healthcare professionals' experiences of working with this clinical population through qualitative analysis and examine burnout dimensions using the CBI. The findings indicate that healthcare professionals are constantly struggling to balance the needs of the patient, family, system and themselves. Although a small sample, healthcare professionals do experience elevated work related burnout relative to the reference group of health and social care providers. Future research would benefit from establishing a more similar reference group to distinguish if there is something specific about PDoC and if their descriptions suggestive of burnout, compassion fatigue and reduced compassion satisfaction are apparent in a larger sample. This will be investigated further in the next study.

Importantly, although the contracted service is to work with the "identified patient" (the injured person with PDoC), healthcare professionals' time is also frequently spent educating, informing and supporting complexly distressed families. This raises questions about the way healthcare services are structured to meet the needs of the wider family system best. In addition, healthcare professionals require training to think about the complex distress experienced by these families and how they can best support them. Especially as research has shown the interactions with staff can have a significant effect on parental grief at the end of a child's life (Snaman, Kaye, Torres, Gibson & Baker, 2016). Healthcare professionals in PDoC report an emotional impact from their work and establishing the best support these staff is indicated. Finally, given the bi-directionality noted that families and staff impact reciprocally on each other, it is clearly important PDoC, professional caregivers need to be able to deliver high quality services for people with PDoC and their families without damaging their own well-being.

Chapter Six

The personal impact of a professional caregiving role: Wellbeing, professional quality of life and burnout in PDoC healthcare professionals.

6.1 Introduction

The experiences of healthcare professionals in PDoC are largely unknown (Racine et al., 2010). Chapter One reported elevated levels of burnout have been noted in healthcare professionals working in PDoC. Understanding what underpins this elevated burnout is important. Chapter Five showed healthcare professionals experienced a personal impact from this work and indicated that burnout and compassion fatigue were important to examine in greater depth. The aim of this study was to investigate if the nature of the clinical role of healthcare professionals supporting people with PDoC influences experiences of burnout, compassion fatigue and wellbeing. In order to better differentiate if there are unique issues with supporting this clinical population, rather than comparisons with other healthcare professional groups as previously used in the literature (Gosseries et al., 2012 and Leonardi et al., 2013) instead, a comparison group of healthcare professionals providing support for people with complex neurological injury within the same organisation was used.

6.1.2 Burnout

Burnout arises when professionals are involved in long-term emotionally demanding work situations (Kristensen et al., 2005) and is relatively common in healthcare settings in response to physical and psychological stress at work (Shanafelt et al., 2012; Ogresta, Rusac & Zorec, 2008; Gosseries et al., 2012). The impact on healthcare professionals includes: symptoms of anxiety, irritability, mood swings, a sense of failure and insomnia (Gosseries et al., 2012). Burnout is associated with absenteeism, illness and early retirement (Kristensen et al., 2005). Healthcare settings involve emotionally-charged situations, and conflicts with families and colleagues can arise and contribute to a decreased quality of care (Gosseries et al., 2012). Estimates of sickness absence in the NHS are 27% higher than UK public sector averages and 46% higher than the average for all sectors (NHS England, 2016).

There are no systematic studies of burnout in healthcare professionals working in PDoC in the UK. Chapter One described studies investigating burnout in PDoC healthcare professionals in Belgium (Gosseries et al., 2012) and Italy (Leonardi et al., 2013) which found 18% (of 523) and 41% (of 1149) respectively of healthcare professionals to be experiencing burnout on at least one scale of the Maslach Burnout Inventory (MBI). Chapter Five showed 21% (of 19) had one subscale elevated on the CBI. This suggests there may be one fifth or more of healthcare professionals supporting people with PDoC experiencing burnout. It is not clear how PDoC work differs to other clinical settings. Comparing PDoC staff to other clinical groups is challenging due to methodological differences across studies (Gosseries et al., 2012), however Leonardi and colleagues (2013) reported burnout in PDoC staff as more similar to dementia than oncology caregivers. These

comparisons do not control for organisational factors (as they work in different organisations) as differing health settings cultures have been noted to contribute to burnout and wellbeing (Watts, Robertson, Winter & Leeson, 2013). No studies have used a comparator group working with complex neurological disability from within the same organisation to help identify if there is something specific about the PDoC clinical population compared to supporting people with severe brain injury in general.

6.1.3 Compassion Fatigue and Compassion Satisfaction

Compassion Fatigue and Compassion Satisfaction are part of Professional Quality of Life (Stamm, 2010) and have an impact on retention and recruitment (Yadollahi et al., 2016). Stamm (2010) reported Compassion Fatigue comprises negative emotions associated with burnout (such as hopelessness, frustration, exhaustion, depression and anger), and the experience of secondary traumatic stress (that can arise through working with people who have had extremely severe injuries and stressful life events) (Coville et al., 2017). Compassion Fatigue relates to the build-up of physical and emotional exhaustion that can affect helping professionals over time (Mathieu, 2012). Mathieu (2012) described the impact of Compassion Fatigue as “poor bedside manner”, a gradual reduction in empathy and desensitisation to clients. Associated with this are higher rates of stress leave, clinical errors, wellbeing changes and personal life difficulties. Organisational programmes targeting improving wellbeing are thought to reduce the risks of compassion fatigue (Stamm, 2010). Reductions in compassion fatigue and increasing compassion satisfaction have been reported to have a direct impact on improving mental health for healthcare professionals (Yadollahi et al., 2016).

6.1.4 Emotion work

Healthcare settings increase susceptibility to burnout through sustained, intensive emotional involvement with patients (Leonardi et al., 2013) and their families. Healthcare professionals are expected to respond calmly and empathetically to life altering and devastating injuries, the complete distress of the family, as well as to cope and manage their own responses to this. Chapter Five showed that PDoC prompts an existential threat to healthcare professionals and can be personally upsetting. Further, interactions with distressed families can also be distressing to staff and the nature of the work can raise feelings of not knowing what to do and how to treat the condition or the family for the best. In PDoC, research has shown healthcare professionals and families have conflicts and it can be difficult to meet the family's needs for information.

In spite of such feelings, healthcare professionals are expected to be professional, compassionate, empathetic, signal trustworthiness, expert status and be caring (Sarkar & Suresh, 2013). The emotional demands and the psychological strategies needed to regulate this are defined as emotion work / emotion labour (Fischbach, Meyer-Gomes, Zapf & Rank, 2006). Emotional Labour encompasses the efforts involved in complying with the perceived requirements of the emotions that should be displayed in a work role (such as patience, empathy, etc) whilst keeping hidden others that would be viewed as unacceptable or unprofessional (such as frustration, distress, disgust, annoyance). The range of expected displayed emotions can be quite large, and is expected to be authentic and genuinely felt (Bondarenko, du Preez & Shepherd, 2017). Display rules relate to how healthcare professionals are expected to behave and originate from professional norms (Tschan, Rochat & Zapf, 2000). Rules are blended with the organisation culture and requirements such as

the policies around client contact, which healthcare professionals typically conform to and see these display rules as best practice (Bondarenko et al., 2017). In Chapter Five descriptions of feeling saddened by a person's injury, or frustrated, angry, irritated and exasperated by families were unlikely to have been displayed as the underlying professional norms do not allow this.

Emotional dissonance describes this conflict between the genuine emotions felt and those required to be displayed, and is thought to deplete emotional resources and contribute to burnout and lowered wellbeing (Fischbach et al., 2006; Zapf, 2002). Healthcare professionals have been reported to experience higher emotional demands than other professionals (Ablett & Jones, 2007). The emotional demands of healthcare work have been shown to contribute to compassion fatigue and burnout with early career nurses more at risk of burnout than more experienced nurses (Kinman & Leggetter, 2016).

Managing emotions at work to meet display rules set by the organisation places psychological demands on employees. Jonker (2012) argued that the preferred term for this emotion labour should be "emotion work", which is used throughout this chapter. The degree and strain of emotion work strongly negatively influences health and wellbeing (Sarkar & Suresh, 2013). Mann & Cowburn (2005) found in a sample of mental health nurses that emotion work was positively correlated with interaction stress and daily stress. The more intense the interaction, the more emotions were experienced, and the greater the degree of emotion work reported.

In New Zealand, a qualitative study employing thematic analysis, found community mental health workers commonly regulated the intensity of their felt emotion and

their displayed emotion when supporting families of the person with the diagnosis (Bondarenko et al., 2017). This is known as “deep acting”. Participants’ reported “deep acting” by strategies such as contextualizing client behaviour to look at things from the client perspective, in order to increase their positive emotions towards clients and their ability to be non-judgmental and empathic. Participants described their negative emotions (like fear and frustration) but believed they needed to control their felt emotion, conceal it and project appearing neutral and calm for their own safety and so as not to interfere with therapeutic alliances. Participants’ stated families’ accounts were often painful and sad. They empathised with their situation and felt they had to show this in order to portray a level of authenticity. However, they needed to determine whom displaying this felt emotion served. This contributed to feelings of mental and emotional exhaustion related to the efforts of maintaining being genuine and non-judgmental. In this way, they were ‘surface acting’ and showing emotions, they did not feel to clients.

Therefore, emotion work has three components: intensive contact with the public, the need to produce an emotional state in other people and a set of rules (implicit or explicit) about the type of emotional display that is acceptable and unacceptable in that work setting/profession. Healthcare professionals’ roles require them to manage these three aspects.

6.1.5 Aims of the study

The aims of this study were to examine the compassion satisfaction, compassion fatigue, emotion work, burnout and general wellbeing among healthcare professionals. It was hypothesized that compared to the published normative data of healthcare professionals for the relative measures, there would be no significant

difference with the healthcare professionals in this study, which would suggest that they are representative of the larger population. Secondly, this study sought to differentiate if there are any unique factors for healthcare professionals who support people with PDoC and their families, compared to colleagues working in the same organisation and providing care to people with complex neuro-disability. Comparing two groups of professionals who both work with people with profound neuro-disability and within the same organisation should allow for a more accurate understanding of the uniqueness of working with people with PDoC.

6.2 Method

6.2.1 Design

This study used a cross sectional, an online survey method in order to enable a wide variety of healthcare professionals to participate at a time that best suited them (Lefever et al., 2007) and to avoid issues with manual data entry (such as the time it takes to enter and possible human error).

6.2.2 Participants

200 healthcare professionals working in a specialist post-acute rehabilitation hospital for people after complex neurological injury at the Royal Hospital for Neuro-disability in Putney, London were invited to participate. 91 consented to participate (a 45% return rate). Participants who did not provide responses to all the measures were excluded. This provided a sample of 78 for analysis. 17 were males and 60 females, one participant did not provide this information. The healthcare participants' disciplines are displayed on Table 6.1 below.

Table 6. 1 *Clinical disciplines of the participants*

Discipline	Number
Clinical psychology	5
Dietician	4
Health care assistant	11
Medical	3
Music therapy	4
Nursing	21
Occupational therapy	13
Physiotherapy	13
Social work	1
Speech and language therapy	4

6.2.2 Measures

Wellbeing was assessed using the *Warwick Edinburgh Wellbeing Scale* (WEMWBS); described in Chapter Two.

Burnout and the attributions participants made of this relating to personal, work or client reasons was measured on the *Copenhagen Burnout Inventory* (CBI) described in Chapter Five. To attend to the interpretation limitation described in the discussion of Chapter Five, participants were instructed to: “Please think of your “client” as including BOTH the patient and their family”. It was intended to ensure participants related their work with both the injured person and their family as “client related” and did not attribute family contacts as “work related”.

Compassion Fatigue and *Compassion Satisfaction* were assessed on Professional Quality of Life (ProQOL version 5; Stamm, 2010). This measure was designed for healthcare professionals to assess the positive and negative aspects of working with people who have experienced extremely stressful life events and was developed

from the original Compassion Fatigue Self Test of Figley (Stamm, 2010). The ProQOL has been widely used (see De La Rosa, Webb-Murphy, Fesperman, Johnston, 2017; Mizuno, Kinefuchi, Kimura & Tsuda, 2013; Smart, English, James, Wilson, Daratha, Childers, & Magera, 2014). There are two scales: Compassion Satisfaction and Compassion Fatigue (which comprises subscales of Burnout and Secondary Traumatic Stress). Secondary Traumatic Stress is work related exposure to people who have experienced extremely stressful events and is related to vicarious traumatisation (Stamm, 2010). There are 30 items scored on a 5 point likert scale (from 1 - never to 5 - very often) relating to the frequency of experience in the past 30 days. There are several items that are reversed scored, with high scores indicative of high burnout, compassion fatigue and compassion satisfaction. Internal consistency is reported as high for compassion satisfaction ($\alpha = .90$) and compassion fatigue ($\alpha = 0.81$) (Mizuno, et al., 2013).

Emotion work was assessed on *Frankfurt Emotion Work Scale* (FEWS; Zapf, Seifert, Mertini, & Isic, 1999). The FEWS was recommended in a review of emotion work measures, as best for care-giving environments (Jonker, 2012) and has been widely used in healthcare research internationally (see Mizuno et al., 2013; Sarkar et al., 2013; Kovacs, Kovacs & Hegedus, 2010; Jonker, 2012; Mann & Cowburn, 2005). The 61 item measure comprises a five point likert scale ranging from 1, very rarely/never to 5, always. This measures Emotion Dissonance (“How often in your job do you have to suppress emotions in order to appear ‘neutral’ on the outside”). The measure has subscales of emotional regulation requirements: the requirement to display and handle emotions (positive, negative and neutral emotions), to be sensitive to clients’ emotions, and to show emotional sympathy. Subscales assess the possibilities for emotional regulation control (such as emotion control “How

often can you decide yourself on as to which emotions to display towards clients?” and interaction control “How often can you yourself decide upon the amount of time you devote to a client, independent of the clients’ needs?”. The internal reliability and consistency of the scales are acceptable (range from $\alpha = 0.72$ to 0.91 ; Sakar & Suresh, 2013; Zapt & Holz, 2006). Some studies have used the emotional dissonance scale only as they have determined this to have the most acceptable internal consistency at $\alpha = 0.91$ (Kinman & Leggetter, 2016).

Basic demographic details were collected relating to gender, discipline, work setting, if they had an upsetting interaction at work in the past fortnight, level and nature of contact with family members.

6.2.3 Procedure

Potential participants were contacted by the Research Department in the hospital by email to their work address with a brief description of the study and provided with a link to an online survey. The website (survey monkey) provided the Participants’ Information Sheet and details of how any questions or concerns about the research could be asked. Those willing to participate signed the online Consent Form. Data was collected from July 2015 to June 2016.

6.3 Results

The findings of this study are reported in two sections. In the first section, the pooled sample of all participants was compared to the published population normative data or reference group data. Secondly, participants were grouped

according to clinical area of practice (either prolonged disorders of consciousness (PDoC) or complex neurological care (CNC)) and compared with each other.

Parametric analyses have greater power to reject a false null hypothesis than non-parametric tests, based on the assumption of normal distribution. Whilst it was anticipated with the sample size, use of likert measures and similar means and standard deviations that the data would be normally distributed, to confirm this participants' results on the measures were examined using the Kolmogorov-Smirnov Test. This showed that both the WEMWBS and the Client Related Burnout scales were not normally distributed. A test of skewness showed WEMWBS was negatively skewed (-.208) but was less than 1 and not twice its standard error (.287) and was therefore not considered to differ significantly from a symmetrical distribution. The Client Related Burnout showed a positive skewness (.998) and was more than two times its' standard error (.032). To adjust the positively skewed data and enable all data points to remain in the data set, a log10 transformation was conducted which achieved acceptable normality (-.734, standard error = .287).

Where there was missing data, only participants who had answered all questions on the measure were used in analyses. For this reason, the number of participants in analyses varies. A 5% significance level was used throughout to compare groups. As this required multiple statistical comparisons, the Bonferroni correction to adjust probability and reduce the risk of a type I error was used (Armstrong, 2014).

6.3.1 Pooled sample compared to published normative data

The means and standard deviations of the sample on the all measures were investigated. The results of this are displayed on the Table 6.2 below.

Table 6. 2 *Healthcare professionals' mean and standard deviations on scales of Burnout, Compassion Fatigue and Satisfaction, Wellbeing and Emotion Work*

Variables	Wellbeing	Personal Burnout	Work Related Burnout	Client Related Burnout	Compassion Satisfaction	Compassion Fatigue (total)	Emotion Dissonance
<i>M</i>	52.18	48.67	46.53	32.98	39.23	44.67	2.73
<i>SD</i>	7.6	17.16	18.89	22.15	39.23	10.87	.79
<i>n</i>	78	72	71	70	66	66	55

Note. *n* ranges from 55 to 78 due to occasional missing data. All items had to be answered on a measure for inclusion

The participants' scores on all the measures were compared with the published normative and reference information using One Sample t-Tests to determine whether there were significant differences between the participants and the published groups using a Bonferroni adjustment to the alpha level of .007 per test (.05/7).

Two areas of elevated burnout were found on the CBI. Participants reported significantly more Work Related Burnout ($M = 46.53$, $SD = 18.89$) compared to the reference group of health and social care human sector workers ($M = 33$, $SD = 17.7$); $t(70) = 6.04$, $p < .001$). Participants' also reported greater Personal Related Burnout ($M = 48.67$, $SD = 17.16$) than the reference group ($M = 36$, $SD = 16.5$) which was significant, $t(71) = 6.27$, $p < .001$. In contrast, Client Related Burnout (log transformed), participants' experienced significantly less ($t(69) = -910.46$, $p < .001$) Client Related Burnout (back transformed $M = 25.42$ [95% CI 21.02, 30.75]) than the reference group ($M = 39.1$, $SD = 17.6$). This represents that healthcare professionals in the present study are more burnout than the reference sample in relation to their attributions of personal and work related burnout. But, these results show, far less fatigue and exhaustion that they associate with their work with clients than the reference sample.

Of the 18% (13 of 72) participants with elevated client related burnout, the only time Client Related Burnout was elevated was when the other two scales were also. Ten (of 72) participants had elevated burnout on at least one scale, 26 (of 72) on two scales and 13 (of 72) on all three scales.

Participants were found to have significantly lower levels of Compassion Fatigue. $t(65) = -3.99, p < .001$ and Compassion Satisfaction $t(65) = -14.73, p < .001$, than the reference group. The means and standard deviations are shown on Table 6.3 below. This finding suggests that whilst not feeling a loss of compassion in their caring role, they also do not feel satisfied by their work.

Table 6. 3 Means and Standard deviations of the participants compared to the ProQOL reference group

	This study $n = 66$	PROQOL Norms $n = 1187$
	Mean (SD)	Mean (SD)
Compassion Fatigue	44.67 (10.87)	50 (10)
Compassion Satisfaction	39.23 (5.94)	50 (10)

A stepwise linear regression analysis was used to test what predicted Compassion Fatigue. The results of the regression found that Work Related Burnout and ($\beta = .58, p < .001$) and Compassion Satisfaction ($\beta = -.29, p = .003$) were significant predictors of Compassion Fatigue, explaining 55.9% of the variance ($R^2 = .559, F(2,60) = 38.10, p < .001$).

The results of a one sample t-tests of participants' Emotion Dissonance was lower ($M = 2.72, SD = .79$) comparative to the recent Kinman and Leggetter (2016) reference group of newly qualified British nurses ($M = 3.36, SD = .46$) which was significant, $t(54) = 5.95, p < .001$ and also significantly lower $t(54) = -8.68, p < .001$ than the original test normative data ($M = 3.65, SD = .54$). Healthcare professionals in the current study report have the ability act more congruently with their true feelings, than the reference and normative comparison samples.

No significant difference between the whole sample and the 2011 population norms for the England were found on the WEMWBS, $t(77) = .661, p = .511$ [95% CI - 1.15, 2.29]).

6.3.2 Prolonged Disorders of Consciousness and Complex Neuro-disability healthcare workers

Secondly, to understand the effects of the working with PDoC specifically, the participants were divided into two groups; those who work with people with PDoC ($n = 49$) and those who work in CNC ($n = 29$). This aimed to enable organizational effects to be controlled for and clearer investigation of the unique issues of supporting people with PDoC. These two groups were compared using independent t-tests to each other.

The wellbeing of PDoC and CNC healthcare professionals was compared to each other using an independent t-test. Levene's test indicated unequal variances ($F = 3.99, p = .003$) so degrees of freedom were adjusted from 76 to 48. Scores on the WEMWBS were higher for PDoC healthcare professionals ($M = 54.29, SD = 6.41$) than CNC staff ($M = 48.62, SD = 8.26$), $t(48) = -3.17, p = .003, d = .77$. This was significant with the Bonferroni adjusted alpha of .006 (.05/8). This indicates higher wellbeing is found in healthcare professionals working in PDoC compared to their colleagues in CNC.

No significant differences were found on the CBI between CNC and PDoC staff.

There was no statistically difference between PDoC and CNC settings on independent t-tests for compassion satisfaction or compassion fatigue (for compassion satisfaction $p = .207$ and compassion fatigue $p = .095$ respectively).

Table 6. 4 *Professional quality of life by clinical area compared to the normative population*

	PDoC main role $n = 42$	Complex Neuro Care $n = 24$	PRoQOL Normative $n = 1187$
	Mean (SD)	Mean (SD)	Mean (SD)
Compassion Fatigue	42.98 (9.84)**	247.63 (12.13)**	50 (10)
Compassion Satisfaction	39.93 (5.59)**	38.00 (6.45)**	50 (10)

Note. ** Bonferroni adjusted alpha $p < .007$

Compared to each other on an independent t-test, PDoC professionals ($M = 2.49$, $SD = .78$) experienced significantly less, ($t(53) = 2.99$, $p = .004$, $d = .84$) Emotion Dissonance relative to colleagues in CNC ($M = 3.10$, $SD = .66$).

6.4 Discussion

The aims of this study were to firstly, investigate the experiences of a group of healthcare professionals relative to the normative population and secondly, to explore if there were specific features associated with supporting people with PDoC compared to similar levels of care for people with CNC within the same organisation. These findings suggest that this sample of healthcare professionals in neurological care do differ significantly to the normative population of healthcare professionals in relation to experience of burnout, compassion satisfaction, compassion fatigue and emotion dissonance, but not in wellbeing. There are

distinct differences in supporting people with PDoC than those with CNC in relation to wellbeing and the experience of emotional dissonance.

Wellbeing has not previously been reported in PDoC healthcare professionals. There are clear challenges of working with people with neurological impairments who require emotion work, physical demands in care, have behaviours that can be challenging (such as cognitive, sensory, motor, communicative, social, behavioural changes), and distressed families. Across the whole organisation, the healthcare professionals' psychological wellbeing was similar to the normative sample and positively correlated with compassion satisfaction. Speculatively, this may reflect a selection bias in the sample, perhaps those professionals most interested and feeling on top of their work participated. Potentially this could reflect a leadership effect in that the team feel supported, have a strong sense of purpose and clear understanding of each other's roles.

The healthcare professionals reported high levels of work related burnout, personal fatigue and exhaustion relative to the reference data. This highlights the difficulties with making burnout comparisons with other clinical populations (Gosseries et al., 2012). Whilst Leonardi and colleagues (2013) found lower levels of burnout relative to the national healthcare reference group in Italy, this study found the opposite - that neurological care in general was associated with reports of elevated burnout. Burnout was found on at least one scale in 14 % (10 of 72) of healthcare professionals in this organisation (on the CBI), although using a different measure to assess burnout (the Maslach Burnout Inventory) this was broadly consistent to the Belgian national study (18 % in Gosseries et al., 2012) but lower than the Italian (41% in Leonardi et al., 2013). Approximately a third of the healthcare

professionals in this study had elevated burnout on two scales (26 of 72). Elevated levels of work related exhaustion and fatigue may relate to job demands, job resources (such as autonomy, support and supervision) and the perception of the working environment (Watts et al., 2013). The contextual aspects in PDoC care (time available, resource allocation and support needed by families) have previously been highlighted as significant sources of difficulties for healthcare professionals in this thesis (Chapter Five) and the literature (Rodrigue et al., 2013). However, in this study no differences were found between the PDoC and CNC professionals in work related burnout. This suggests either the sample size has not enabled any differences to reach significance, or that neurological care in general is an area that contributes to high levels of work related fatigue and exhaustion. As the design of the study was cross sectional and within one institution it does not enable generalizability to wider settings. Replication with another organisation is needed to establish if this work related burnout is a factor with this clinical population or if this finding is just a feature of unfavourable working conditions within this organisation.

In contrast, less client related burnout than the normative population was found. This confirms the burnout pattern observed in the smaller sample in Chapter Five (that is, higher work and personal related burnout with low client related burnout) and has previously been reported in a study with midwives (Jordan et al., 2013). The focus group findings in Chapter Five, indicate that work with clients and families can be demanding and draining, however this is not obviously apparent in the participants' attributions of lower client related burnout. This study is limited by a correlational design and an inability to infer causality. The strength of the CBI is that allows participants to attribute themselves where their stress and fatigue

stems from. However, this is problematic in interpretation and trying to understand how participants have appraised things. It is possible this reflects reluctance in helping professionals to negatively appraise clients who are facing life altering situations and the effects of social desirability on the scale. It may be that the descriptions of conflicts and challenges with families shared in the focus groups in Chapter Five, are expected (a sense that this is “all part of the job”). The healthcare professionals may therefore attribute the reported constant need for information and conflict as understandable and stemming from family distress. Therefore, perceived challenges in coping with this expected component of a professional’s role, the flow on effect of using their time to attend to this could create the feeling of being time pressured and not having sufficient resources to complete all tasks. This may then be experienced by the healthcare professionals as a lack of organisational support and supervision and hence associated as a work related stress (such as insufficient staffing and resources to complete necessary tasks). Nonetheless, this samples’ below the normative data ratings of Client Related Burnout is an important finding. Client Related Burnout and was only found in the context of *also* having elevated Work and Personal Related Burnout. Whilst the sample is too small to generalise from, it could suggest that client related burnout could be the final point in evolution of burnout or that as burnout occurs in personal and work related life it eventually can not be controlled with clients. Noting both Personal and Work Related Burnout elevations could provide a warning indicator for professional wellbeing and subsequent risk to the quality of client care. PDoC staff reported similar levels in this study of Client Related Burnout and therefore it seems that the nature of largely non-responsive patients does not protect against this.

Other burnout studies in PDoC professionals have not established what contributes to burnout. They have noted higher burnout in nursing staff (Gosseries et al., 2012), then rehabilitation therapists and then social workers (Leonardi et al., 2013). This was interpreted by the authors as a factor of nurses having spent the most time with the patient. It is possible that burnout may not solely be a factor of time spent with patients and their families, particularly as the duration of contacts in PDoC maybe shorter than other neurological care areas as the patient cannot respond, and does not need the same time spent to communicate with them. Other considerations about the nature of professionals roles may be relevant, for example nurses typically are task focussed where as social workers are typically more processed focussed in their training and work practices. Future research investigating the nature of the professional's role seems important, not just the amount of time spent with patients in understanding healthcare professional burnout in PDoC.

Relative to the normative population this sample showed low levels of compassion satisfaction and low levels of compassion fatigue. Although PDoC healthcare professionals did not describe being troubled by compassion fatigue, the inability to derive compassion satisfaction from their clinical role perhaps suggests why other studies have noted an elevated turnover in PDoC care (Leonardi et al., 2013). A limitation of this study was the failure to ask about length of service, especially as other literature has suggested that the number of years providing healthcare is related to compassion fatigue (Potter, Deshields & Divanbeigi, 2010) and burnout (Jordan, Fenwick, Slavin, Sidebotham & Gamble, 2013; Leonardi et al., 2013). Chapter Five showed that 70% (15 of 21) of the focus group participants had worked with PDoC for less than five years and it is possible a similar pattern may

have been in this sample. Within UK healthcare settings many staff work a rotation training system, this means staff regularly rotate from one clinical setting to another. This sample of healthcare professionals are based in a post-acute neuro-rehabilitation setting, supporting people in the relatively early phase of their rehabilitation and disability management pathway. Future research that addresses the impact of providing longer term care for people with PDoC and their families would be valuable to add understanding to their experience. The factors that enable some staff to remain working with PDoC clients for many years would be of value to investigate in future studies as this may inform alternative ways to derive compassion satisfaction and ways to balance the work related demands.

Nonetheless, an important finding is that healthcare professionals within this organisation are experiencing elevated work related burnout and low compassion satisfaction in their work with clients, set against a backdrop of personal feelings of fatigue and exhaustion. How staff facing these clinical demands are supported is important for organisations to address.

Whilst healthcare settings are known to require emotion work, in contrast to other studies (Kinman et al., 2016) the healthcare professionals in this study seemed more able to express their genuine felt emotions. PDoC staff reported less emotional dissonance than CNC colleagues. Obviously, the person with the PDoC does not require staff to manage emotional dissonance as they are not aware of the staff. However, families of people with PDoC do require staff to show authentic emotions and remain professional. Clearly, in PDoC staff are able to express in the main their genuinely felt emotion, perhaps as reported in Chapter Five that they do recognise the sadness and tragedy the family is facing. Kinman & Leggetter (2016)

found that British nurses whose roles required higher emotion work were more burnt out, but this could be mitigated by emotional support, reflective practice and a team culture to help manage role demands. In a recent study, over half of 379,632 British healthcare professionals indicated that they thought debriefings and reflective practice opportunities would be helpful to reduce work stress and burnout (Colville, Smith, Brierley, Citron, Nguru, Shaunak, Tam & Perkins-Porras, 2017). Further investigation in developing support systems and skills to cope with the demands in clinical practice is needed.

Chapter Five described a range of challenges professionals faced in balancing the competing demands presented to them in PDoC care, however these were not captured in a straight forward way by the measures in this study. This study is further limited by the fact that it was cross sectional, online, recruited participants passively, had a limited response rate and from only one site, which limits generalizability of the findings. This was considered acceptable in the design as by providing participation opportunities on-line it was intended that nursing who were under-represented in Chapter Five, may be able to participate at a time that suited them and enable night staff to participate. This design was also considered acceptable as it enabled healthcare professionals to participate from a specialist organisation that solely serves people with neurological conditions, and as PDoC are relatively rare, this enabled gaining participants who work in roles serving this clinical population. The sample was relatively small, particularly when further grouped into secondary analysis groups and this requires caution in interpreting and extrapolating the findings. However, the target population of healthcare professionals providing PDoC care is also small and thus the sample may still be representative (McLeod, 2014). It is the first attempt to investigate this within the

United Kingdom and future research investigating a number of different sites that provide support PDoC services thus enhancing the sample size would be useful as has been done in the nationwide studies of Belgium (Gosseries et al., 2012) and Italy (Leonardi et al., 2013).

Chapter Seven

The impact on confidence after a psycho-educational training intervention for healthcare professionals supporting people with a disorder of consciousness

7.1 Introduction

Healthcare professionals working in PDoC care report support to families as integral in their own roles, but may lack the confidence, knowledge and skills to deliver integrated psychological support. In Chapter Five healthcare professionals described challenges managing family distress and interactions with families. The healthcare professionals did refer to models of loss existing within the psychological literature, but Part One has identified that these models are not the most accurate fit with the unique experience of families in PDoC. Lack of awareness of other frameworks to conceptualise the loss, means the professionals are unable to offer the best help to families. Research in palliative care has shown that whilst healthcare professionals may have concerns about pathologizing grief, they are ideally placed to identify families requiring referrals for specialist psychological services (Davies et al., 2017). However, staff had varying confidence in identifying symptoms of depression, distinguishing these from grief and discussing this with families (Davies et al., 2017).

Chapter Six discussed the challenges for healthcare professionals in gaining compassion satisfaction, experiencing upsetting interactions with families during

their working day and being troubled with elevated levels of work related burnout. Kinman and Leggetter (2016) highlighted that support for role demands in healthcare was important. Research in learning disabilities has shown that even when work demands do not change, improvements in psychological wellbeing were possible by facilitating psychological resilience in staff through emotion focused training (such as accepting thoughts and emotions without seeking to change or avoid them; Noone & Hastings, 2009).

Clinician training is a well established method to improve interactions with patients and families (Axboe, Christensen, Kofoed & Ammentorp, 2016) and is important to good practice (van Oorsouw, Embregts, Bosman & Joahoda, 2009). Research in oncology indicated experience alone does not improve these skills and patient complaints about staff have typically focused on a perceived failure to convey a sense of care and communicate, rather than clinical competence (Department of Health, 2000). Staff training in older adult care facilitated the creation of relationships and professional boundaries with families (Jones & Moyle, 2016) and better relationships between healthcare providers and families contributed to improved outcomes for residents in care homes (Bauer, Fetherstonhaugh & Lewis, 2012).

The impact of training has often been measured by gains in self-efficacy (Norgaard, Ammentorp, Ohm Kyvik & Kofoed, 2012; Ghaffarifar, Ghofranipour, Ahmadi, Khoshbaten & Sallis, 2015). Self efficacy refers to the judgments a person makes about their capability to do a particular task (Bandura, 1977) and influences the ways people think, feel and act (Schwarzer & Fuchs, 1996). General self efficacy relates to the self-belief to cope with demands in general across different situations

(Chen, Gully & Eden, 2001). High *general* self efficacy is important in employment where there are stressful job demands and enables motivation, protecting employees from possibly demotivating failures (Chen et al., 2001). This is suggested to be a motivational mastery trait, informed by previous experiences and emerging over a person's life in response to success and failure in different areas (Chen et al., 2001). In contrast, *specific* self efficacy refers to beliefs in a person's ability to perform a specific task to achieve a desired outcome (such as belief you can deal with an angry family member making a complaint). Smith, Gardner and Michie (2010) characterize people with high levels of self efficacy as more likely to view challenging tasks as something to be mastered and to recover more rapidly from setbacks. On the other hand, people with low levels of self efficacy are characterised as more likely to consider difficult tasks are beyond their abilities, avoid challenges, and quickly lose confidence in their personal abilities (Smith et al., 2010).

It is important to consider cost effective ways of training healthcare professionals to deliver routine psychological care to families, in the context of UK health services being challenged to deliver more and maintain quality with limited resources (The Kings Fund, 2014). Such training is often relatively brief. In learning disabilities, staff distress reduced significantly following one and a half days of training (Noone & Hastings, 2009). In stroke rehabilitation awareness, knowledge, skills and confidence to integrate psychological care with routine physical care with patients and families was improved following a two session (of two and a half hours per session) training course (Pragnell, Kennedy-Williams & Daisley, 2016). In general health and social care patient-focused support training, gains in confidence and self

perceived competence are found after a three hour session (Connolly, Perryman, McKenna, Orford, Thomson, Shuttleworth & Cocksedge, 2010).

One method of training that involves sharing knowledge and information to help build a theoretical and practical understanding of psychological difficulties is known as psychoeducation (Suzuki & Tanoue, 2013). This originally was used to help people learn to understand and manage their mental health conditions and has since been expanded to help their families and caregivers understand how to best support them (Banerjee, Duggan, Husband & Watson, 2006). Poppes and colleagues (2016) reported staff psychoeducation to be effective at creating changes in attributions about conditions with other clinical populations including dementia and learning disabilities. They hypothesized this related to the staff reformulating their understanding of the client. Broadly, psychoeducation encompasses systematic, structured, didactic information on the condition to improve caregivers' awareness and contribution to the management of the condition (Srivastava & Panday, 2016). Psychoeducation has been shown as improving feelings of preparedness, competence and having sufficient information (Hudson, et al., 2012). This chapter investigates a brief psychoeducation training session as a way to help staff understand issues for families and therefore to potentially be able to better support them and thus gain better compassion satisfaction and experience less work related burnout in their professional role.

Research Aims:

To investigate a psycho-educational and skills training intervention to improve confidence in healthcare professionals in supporting families of people with PDoC.

Hypothesis (1) Healthcare professionals will rate themselves as more confident in understanding the needs of families of people in PDoc after the psycho-educational session.

Hypothesis (2) Healthcare professionals will rate themselves as more confident they could manage support for a distressed family member following the psycho-educational training in either an ad hoc or planned session.

7.2 Method

7.2.1 Design

A single session 60 minutes training session was designed and provided to a multi-disciplinary group of healthcare professionals who specialize in PDoc with the aim of better understanding the distress experienced by families, their needs for information and the conflicts that can arise with healthcare professionals. The participants' confidence levels were measured using self-report survey instruments at a baseline (before psycho-educational training) and at post-test (immediately after training). The changes in the scores (post-test minus pre-test) were measured to determine the extent to which participating in the training resulted in gains in confidence.

7.2.2 Training Session

The basis for the content of the psychoeducation training session was derived from information and findings obtained in earlier studies reported in this thesis, specifically:

1. Chapter One – the systematic review of the evidence base of family experiences in PDoC of wellbeing changes, grief, burden and coping difficulties
2. Chapter Two – the family experience of PDoC, the experience of loss consistent with elements of many post-modern grief models created by the PDoC, the expectations of families that the mechanism of change and recovery related to the input from healthcare professionals
3. Chapter Three – the difficulties in meaning making families experience
4. Chapter Five – the reports of healthcare professionals of families' loss in PDoC and attempts to relate this to stage and phase models of loss, the challenge of satisfying family needs for information and managing the seemingly minor complaints of families, the personal impact of the work and the sense of responsibility shared for caring for families irrespective of role and lack of having been trained for this complex support
5. Chapter Six – the elevated work related burnout and limited compassion satisfaction in PDoC healthcare professionals, the possible increased challenge of task focus roles in working with family distress

These findings were collated into the following training learning objectives:

- a) Understand the nature of challenges facing families of people with PDoC
- b) Understand why conflicts with Healthcare Professionals and Families of people with PDoC arise
- c) Understand what can be done to improve working relationships with families in a rehabilitation setting
- d) Reflect and revise the principles of supporting families and the tools needed to form collaborative working relationships

7.2.3 Participants

Participants were 60 healthcare professionals who work in specialist tertiary referral centres with people with PDoC, who were attending a training day on working with PDoC. Four participants were excluded from the statistical analysis as they had not answered all items. This left the total number of participants as $n = 56$. The most frequent occupations were occupational therapist ($n = 16, 28.6\%$) and physiotherapist ($n = 15, 26.8\%$). The participants' occupations are summarized in Table 7.1. To investigate any differences in the findings by occupation whilst balancing the requirement to have sample sizes large enough to provide adequate statistical power to address the research questions using inferential statistics (Maxwell, 2004; Zodpey, 2004), participants were divided into two occupational groups: (a) primary healthcare providers ($n = 15, 26.7\%$) including nurses, physicians, dentists, and clinical psychologists; and (b) allied healthcare personnel ($n = 41, 73.3\%$) including therapists, students, assistants, and social workers. The majority of the 56 participants ($n = 47, 83.9\%$) were female.

Table 7. 1 *Characteristics of Participants*

Group	Occupation	<i>n</i>	%
Primary Healthcare Providers	Registered Nurse	8	12.5
	Physician	3	5.4
	Clinical Psychologist	2	3.6
	Dentist	2	3.6
Allied Healthcare Personnel	Occupational Therapist	16	28.6
	Physiotherapist	15	26.8
	Speech and Language Therapist	6	10.7
	Student/Assistant	2	3.6
	Social Worker	1	1.8
	Music Therapist	1	1.8

7.2.4 Measures

7.2.4.1 Attitudes to families

To measure attitudes and beliefs towards family and staff relationships, the first 10 items of *Family and Staff Relationship Attitude Tool* (FASRAT; Bauer, Fetherstonhaugh & Lewis, 2006; see Appendix AD)) was administered. This is originally a 26 item measure designed for older adult residential care staff and has good internal consistency $\alpha = .88$ (Bauer, Fetherstonhaugh & Lewis, 2012). The FASRAT is uni-dimensional scale assessing eight domains related to constructive relationships with the wider family in older care: recognition of the uniqueness of the resident; information sharing; familiarity, trust, respect and empathy; family characteristics and dynamics; collaboration in care; staff/family communication; organisational barriers to positive relationships; and promoting positive relationships (Haesler Bauer & Nay, 2010). Participants' rate their attitudinal beliefs on a six-point Likert-scale (ranging between '1= strongly disagree' and '6= strongly agree'). Higher scores indicate more positive attitudes and beliefs. There are no standards or normative scores for interpreting the FASRAT total score within the residential aged care sector (Bauer, Fetherstonhaugh & Lewis, 2012). Due to practical time limitations, the social desirability factors and the expectations that most staff would respond positively to beliefs about the importance of family relationships, only the first 10 questions ($\alpha = .928$, for the 10 items) of this measure were administered. The purpose was to be able to take a brief overview of attitudes using items from a validated tool, rather than developing the questions for this study.

7.2.4.2 Success at working with complexly distressed families

Participants' self perceptions of how many families they worked well with was assessed by their response to the question: "What percentage of families of patients that you currently work with do you feel you have a constructive working relationship with?".

7.2.4.3 Awareness and Knowledge

To assess awareness of family experiences in PDoC participants were asked to compare their knowledge to their perception of colleagues' knowledge on a 5 point likert rating scale from (0 – not aware at all, most of my colleagues know more than me, 2 – fairly aware, similar levels of knowledge to colleagues and 4 – very aware, I know far more than my colleagues).

7.2.4.4 General Self Efficacy

The New General Self Efficacy Scale (NGSE; Chen, Gully & Eden, 2001) was used to assess participants' general sense of self efficacy on eight statements using a 5-point likert scale from (Strongly Agree to Strongly Disagree). These scores are summed to produce a global score (which ranges from 8 to 40), with higher scores indicating higher self efficacy (see Appendix AE). The scales are both highly reliable and unidimensional (internal consistency reliability $\alpha = .86$ and $.90$; Chen et al., 2001).

7.2.4.5 Specific self efficacy (confidence)

To investigate specific self efficacy in terms of confidence in managing ad hoc and planned contacts with distressed (crying, upset, angry or agitated) families, a 5 point likert scale was created with higher scores reflective of greater confidence (0

– no confidence for almost every situation I could encounter, 1 – slight confidence, do okay some of the time, 2 – moderate confidence, do okay most of the time, 3 – high confidence, do okay nearly all the time, 5 – very confident for almost every situation I could encounter). Confidence gains have previously been reported as useful ways to evaluate training (McDonnell, Sturmey, Oliver, Cunningham, Hayes, Galvin, Walshe & Cunningham, 2008).

7.2.4.6 Demographics

Finally, a single item recorded participants' clinical discipline (see purpose designed questionnaire items at Appendix AF).

7.2.5 Procedure

a. Recruitment and consent procedure

The recruitment strategy was opportunistic. Multi-disciplinary healthcare professionals attending a study day related to the care of people with PDoC were invited to participate in the research. At the registration desk on arrival for the study day, potential participants were met by the researcher and provided with the Participants Information Sheet. There was opportunity for any questions to be clarified. Those agreeing to participate were asked to sign the Consent Form. A 67% response rate was obtained and those who opted not to participate in the research, still received the training (n =40). An alternative systematic recruitment strategy of sending all registered attenders to the training day the questionnaires in advance was considered. However, concerns about potential return rates and the inability to ensure all the consent forms were returned, outweighed this. Therefore, as the attendees were expected to arrive prior to the commencement of the training day (for the coffee and registration), it was anticipated that a number

of people would be willing to participate as part of having something to do whilst waiting for the commencement of the training day.

b. Pre-test

When a participant had completed the Consent Form, they were provided with the questionnaire and instructed to complete the first section relating to the pre-measures whilst waiting for the study day to commence.

c. Presentation

Title: Working with families of people with PDoC (see slides of this training package in Appendix AC). This session was followed by the lunch break on the study day.

d. Completion of the post-measures and provision of debriefing form

At the conclusion of the training session, participants were requested to complete the second section of the questionnaire and return it to a box in the lunch room. This enabled participants to complete the form immediately or during the study day lunch break. When participants returned the questionnaire, they were provided with a Debriefing Form about the study.

Additional qualitative information was obtained from the Study Day General Feedback Form collated by the course organisers, which was provided to each of the contributing speakers.

7.3 Results

7.3.1 Attitudes to family and healthcare professional relationships

To contextualize the sample, the FASRAT scores were examined. As expected, the total scores for family and relationship attitudes measured using the FASRAT deviated strongly from a normal distribution with 92.8% of participants endorsing attitudes that family and staff relationships are important and families should be involved in care and decisions. The FASRAT scores ranged from 11 to 60, were heavily negatively skewed (skewness = -2.66) with the mean ($M = 50.89$) smaller than the median ($Mdn = 53.00$). The majority of the participants ($n = 40$, 71.4%) scored at the higher end of the scale, between 50 and 60 is indicative of strong agreement and importance of with collaborative relationships with families. This displayed in Figure 7.1 below.

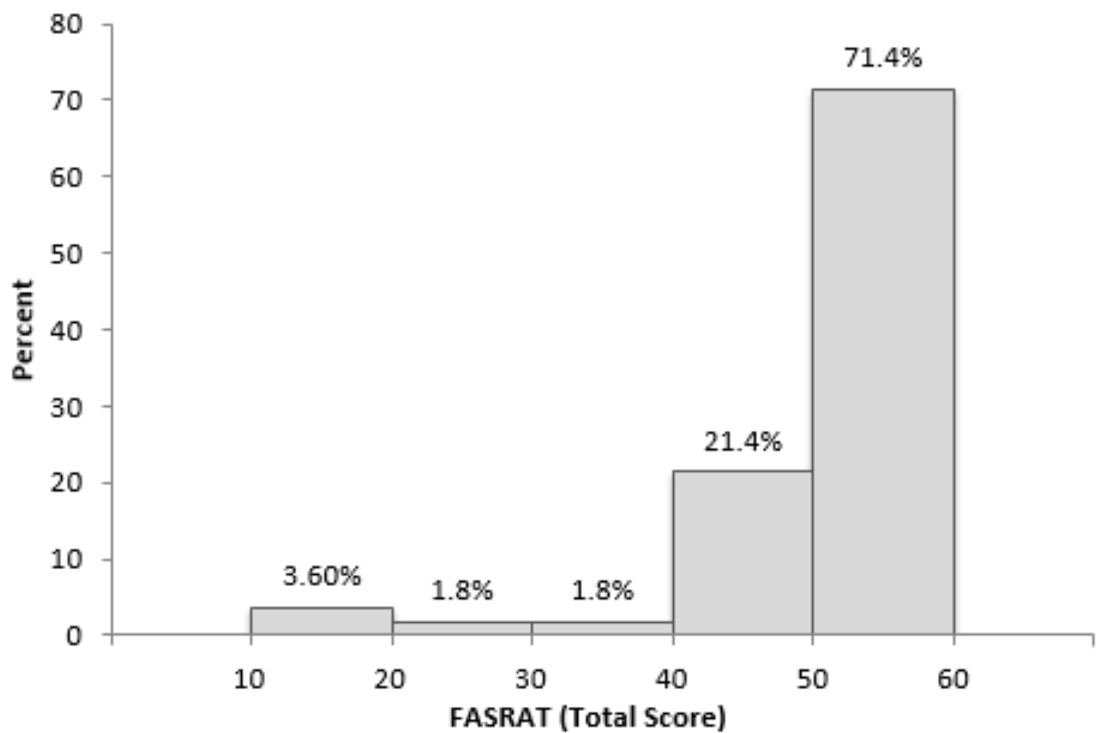


Figure 7. 1 FASRAT scores.

7.3.2 Constructive Working Relationships

Next to determine how this attitude translated in practice, participants' ratings of the percentage of families they believed they had a constructive working relationship with were examined. Table 7.2 below presents the frequencies of the responses. Two participants did not reply to the question but as this did not effect statistical analysis, they were excluded from this question but not excluded from the whole data set, leaving $n = 54$ responses. Over half of participants ($n = 30$, 55.6%) considered that they had constructive relationships with 80% to 100% of the families of patients that they currently worked with. Only a few respondents ($n = 7$, 13.0%) reported that they had constructive working relationships with only half or less of the families of patients.

Table 7. 2 *Healthcare professionals reporting constructive working relationships with the families of people with PDoC*

Percentage constructive relationships	<i>n</i>	%
90-100%	15	27.8
80-89%	15	27.8
70-79%	13	24.1
60-69%	4	7.4
50-59%	4	7.4
40-49%	1	1.9
< 40%	2	3.7
No response	2	

7.3.3 Awareness of Range of Experiences and Ways of Coping

Participants self perceived knowledge about families, relative to their attributions of colleagues knowledge showed the majority of the participants ($n = 32$, 57.1%) reported that they considered their knowledge to be at a level similar to most of their colleagues ("fairly aware"). Table 7.3 below presents the frequencies of the

responses of 56 participants. The next most frequent replies suggested some were slightly less awareness than colleagues (“some awareness” $n = 13$, 23.2%) or slightly more than their colleagues (“highly aware “, $n = 8$, 14.3%). Only two respondents (3.6%) thought most of their colleagues knew a lot more than them (“not aware at all”). Only one (1.8%), a speech and language therapist, estimated that they knew far more than their colleagues (“highly aware”). Despite working in specialist services for PDoC, a third of participants (26.8% of 56) considered they had less knowledge than colleagues.

Table 7. 3 *Awareness of Range of Families Experiences and Ways of Coping*

Awareness Rating	<i>n</i>	%
Not aware at all	2	3.6
Some awareness	13	23.2
Fairly aware	32	57.1
Highly aware	8	14.3
Very aware	1	1.8

7.3.4 Gain in Confidence Rating in Ad Hoc Setting

To determine if gains were achieved following the training session in confidence ratings for managing families distress in an ad hoc setting, the participants’ pre-test result was subtracted from their post test result. This showed that 41.8% (of 55) showed a gain in confidence in coping with distressed families that they came across unexpectedly in their working day. For 45.5% there was no difference in confidence. For seven participants (12.7%) a decrease in confidence was reported. This is displayed in Figure 7.2 below.

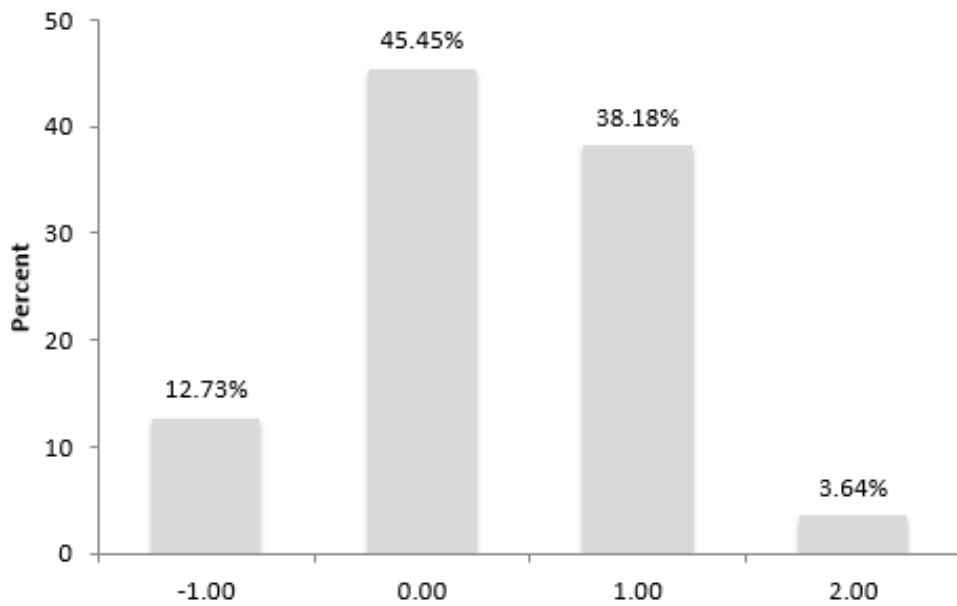


Figure 7. 2 Gain in Confidence Rating for ad hoc settings between pre-test and post-test.

A paired-samples t-test found a gain in confidence rating from pre-training ($M = 2.07$, $SD = .72$) to post-training ($M = 2.40$, $SD = .81$) which was significant ($t(54) = 3.25$, $p = .002$, $d = .43$). The results of the t-test supported the hypothesis that, after training, there was a gain in the participants' confidence rating for managing families' distress when in an ad hoc setting which was significant.

7.3.5 Gain in Confidence Rating in Planned Sessions

Next participants' confidence ratings for managing families' distress when in a planned meeting were examined. The frequency distribution of the gains in confidence rating (post-test minus pre-test) are illustrated by a histogram in Figure 7.3 below. Around 30.9% (17 participants) showed gains in confidence at managing a situation with a distressed family member in a planned session. 60% of participants did not show any gain in confidence, and 5 participants (9.1%) rated reductions in confidence.

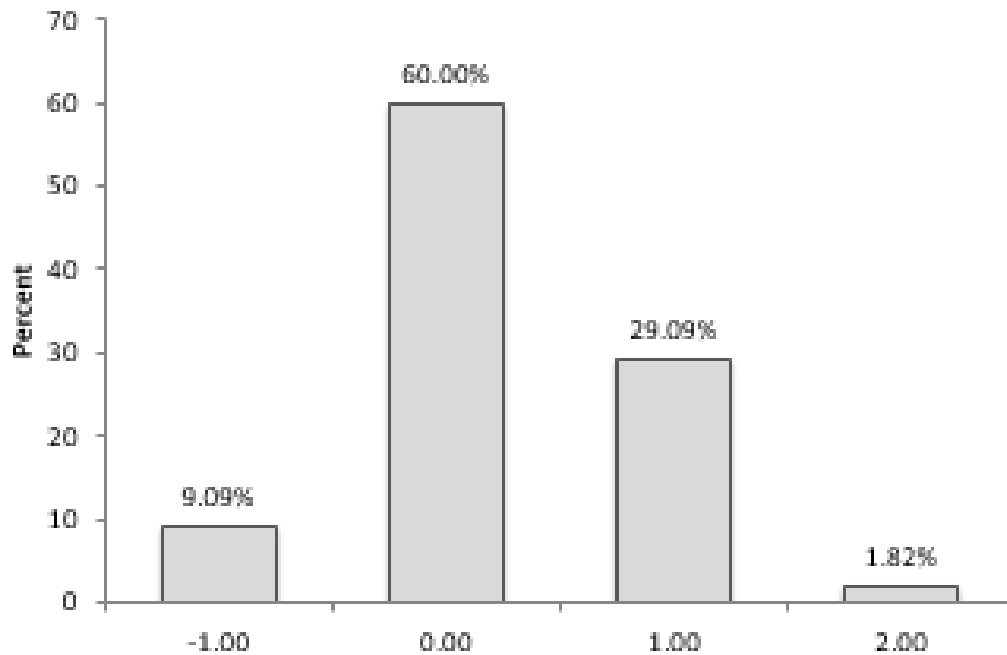


Figure 7. 3 Gain in Confidence Rating for planned meetings between pre-test and post-test.

Of those participants who indicated a gain in confidence, a one-sample t-test showed that this gain in confidence rating ($M = .24$, $SD = 0.64$) was significantly greater than zero perceived gain $t(56) = 2.75$, $p = .008$. The results of the t-test supported the hypothesis that, after training, there was a gain in the participants' confidence rating for managing families' distress when in planned meetings.

A paired-samples t-test was used to evaluate the difference between pre-training ($M = 2.35$, $SD = .84$) and post-training session ($M = 2.58$, $SD = .81$) ratings which was significant $t(54) = 2.75$, $p = .008$, $d = .28$ and illustrated a confidence gain in managing distress during planned meetings with families.

7.3.6 Self Efficacy

Self-efficacy was reliably measured ($\alpha = .819$, 8 items) on the NGSES. The frequency distribution of the total scores for the NGSES is illustrated by histograms in Figure

7.4 below. The total scores for self-efficacy measured using the NGSES ranged from 25 to 39. The mean ($M = 32.1$) was close to the median ($Mdn = 32.0$) and the frequency distribution was approximately normal (skewness = .198). Nearly half of the participants ($n = 26, 46.4\%$) scored between 32 and 36. The majority of the participants endorsed a strong general self efficacy scoring above 32 ($n = 33, 58.9\%$).

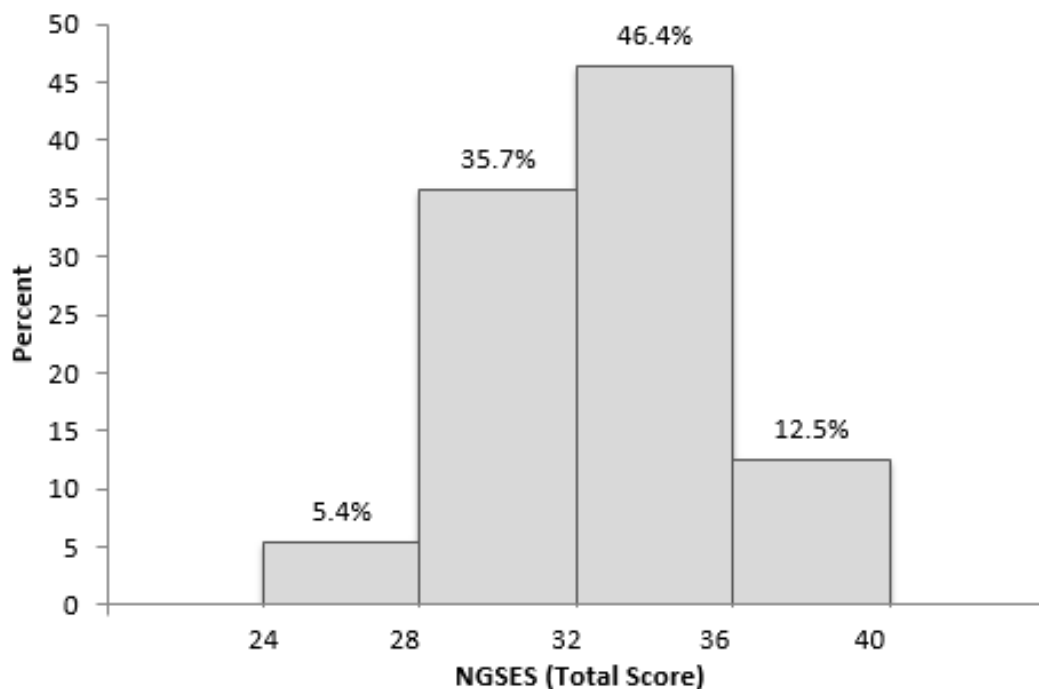


Figure 7. 4 Participants' NGSES scores.

7.3.7 Correlations between Confidence, Self-efficacy and Relationship Attitudes

To examine to what extent were the participants' gains in confidence after training related to (a) their general self-efficacy and (b) pre-existing family and staff relationship attitudes a bivariate Pearson's correlation was calculated. Table 7.4 presents a matrix of bivariate Pearson's correlation coefficients, to determine the

strengths of the associations between the scores for the gains in confidence after training, self-efficacy; and family and staff relationship attitudes.

Table 7. 4 *Correlations between gains in confidence after training, self-efficacy, and family and staff relationship attitudes*

	Confidence Gain in Ad Hoc Setting	Confidence Gain in Planned Meetings	FASRAT (Total Score)	NGSES (Total Score)
Confidence Gain in Ad Hoc Setting	1			
Confidence Gain in Planned Meetings	.783**	1		
FASRAT (Total Score)	.015	.036	1	
NGSES (Total Score)	.271*	.364**	-.031	1

Note. * $p < .05$; ** $p < .01$

The scores for the confidence gains in ad hoc settings and planned meetings were strongly positively correlated with each other $r(55) = .783, p < .001$, indicating a medium relationship and confidence gains occurred for both forms of contact. The NGSES total scores were moderately positively correlated with the scores for the confidence gains in ad hoc settings ($r(54) = .271, p = .04$) and planned meetings ($r(54) = .364, p = .006$). There were, however, no significant correlations at the .05 level between the FASRAT total scores and the NGSES total scores, or between the FASRAT total scores and the confidence gains in ad hoc settings or planned meetings. The results indicate that the participants' gains in confidence after training were related to their self-efficacy but not to their pre-existing family and staff relationship attitudes.

7.3.8 Gain in Confidence and Occupation

To evaluate to what extent were the participants' gains in confidence after training related to the participants' occupations an independent samples *t*-tests was performed. The sample sizes, were too small to differentiate gains in confidence between individual disciplines (Maxwell, 2004; Zodpey, 2004). Therefore, individual disciplines were grouped into (a) primary healthcare providers and (b) the allied healthcare providers. The descriptive statistics and results of the independent samples *t*-tests assuming equal variances are presented in Table 7.5. The scores for the confidence gains in ad hoc settings were not significantly different at the .05 level between the primary health care providers (including nurses, physicians, dentists, and clinical psychologists) and the allied healthcare personnel (including therapists, students, assistants, and social workers), $t(54) = 1.13, p = .247$. Furthermore, the scores for the confidence gains in planned meetings were not significantly different between the two groups of participants ($t(54) = 1.74, p = .088$). As the groups were not of equivalent sizes ($n = 15$ primary and $n = 41$ allied health), the Hedges's *g* was calculated to examine effect size weighted according to the relative size of each sample. A small effect size was noted for coping with distressed family members in ad hoc contact ($g = .36$) and a medium effect size seen in planned contacts with families ($g = .54$) between the discipline groups.

Table 7. 5 Comparison of gains in confidence and occupation

Variable	Occupation	<i>M</i>	<i>SD</i>	<i>t</i> (54)	<i>p</i>	Hedges <i>g</i>
Confidence Gain in Ad Hoc Settings	Primary Healthcare Providers	2.62	0.96	1.14	.257	.36
	Allied Healthcare Personnel	2.33	0.75			
Confidence Gain in	Primary Healthcare Providers	2.92	0.95	1.74	.088	.54

Planned Meetings	Allied Healthcare Personnel	2.49	0.74
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The results showed both groups gained equally in confidence after the psycho-educational training for healthcare professionals supporting people with a disorder of consciousness and that the participants' gains in confidence were not related significantly related to their occupations.

The vast majority of the 56 participants (n = 49, 86%) responded that they had thought about families and staff relationships in a similar way previously as presented in the training. However, 14% (n= 8) replied that they had not previously conceived of staff-family relationships in this way before.

7.3.9 User acceptability of the training

This information was not specifically sought, but additional qualitative information provided by participants on the generic training day form related to the training session was collated.

The aims of the training to build confidence were reported as having been achieved for some participants:

“Good tips, Re-iterated things I do and gave me more confidence.”

“I feel better equipped to deal with difficult situations”

“Very enjoyable, feel further training would be really beneficial.”

“During your session, whilst thinking through what happens on my ward I realised I actually am better at this than I thought but some of my colleagues aren’t. Because of this, family members seek me out making me feel increasingly exhausted/empty.”

The psychoeducation on loss and grief models had been important for some participants to understand the families experience in a new way.

“Really helpful to discuss theories/models”

“Very useful – enjoyed intro to grief theories”

Strategies discussed in the training appeared to help professionals consider how they approach families.

“Really good ideas of different ways of communication and different emotions relatives may be going through”

“Good tips and strategies for better communication with distressed families”

“Great examples and key points to manage conflict”

For others, the importance of family and staff contact when distress can not be “fixed” resonated as being an important part of healthcare professionals role.

“I found the talk very powerful and moving. It highlighted the importance of spending time with family, even if you cannot provide solutions. It’s one of the frustrations of working in hyper-acute + acute service - that don’t always get to meet family members, or have limited time with patients, and so feel guilty when I do see family because I haven’t spent enough time with their relatives.”

“Thank you. So helpful indeed - many tips that we can work on + ways to improve our understanding + care for the relatives”

“Made me reflect on my interactions with the family on the ward and management strategies”

Some participants stated their current practice had not been informed by an evidence base, but rather by their sense of what was needed in supporting families:

“As a staff member, I tend to ‘manage’ these situations intuitively, rather than having undergone any specialist learning to deal with this complex case.”

“I tend to manage these situations quite well naturally but I have definitely learnt a lot today and will be more thoughtful with my interactions with families/carers in the future.”

“Very good talk to increase awareness and re-evaluate own practice/behaviour/attitude”

Others highlighted the need to approach family support from a service perspective, especially in recognition of the personal impact of the work,

“It’s important to discuss sessions in the team and its’ emotional impact on relatives and patients.”

“An important factor for me is whether I will be supported, in difficult situations by my manager. I sometimes feel I need a space to offload/shove things that have been difficult. “

"I always feel all families /PDOC relative/main/NoK should have professional counselling as part of funding. Therapists should give allocated time for family."

"We need more psychological support for families in long-term care wards."

7.4 Discussion

The healthcare professionals showed significant gains in confidence in managing the distress of families following a single brief psycho-educational training session. Gains in confidence were correlated with a general sense of self efficacy in the healthcare professional, but were unrelated to attitudes about the importance of working with families or professional background. Healthcare professionals' attitudes in this study, showed they consider family and staff relationships to be important, and most are able to develop constructive working relationships with clients' families.

The results of this pilot, suggest that the psychoeducation training session represents a way of supporting staff to develop skills and confidence in supporting families who are complexly distressed. This type of training could easily be integrated into a staff induction programme within organisation's supporting people with PDoC and their families. Meta-analysis of effectiveness of training direct-care staff of people with learning disabilities has highlighted the importance of supplementing education with coaching-on-the-job (van Oorsouw et al., 2009) and measuring the effect of training through direct observation (McDonnell et al., 2008). A limitation of the design was determining how this training actually impacted on practice. Future research should investigate follow-up and support required to monitor the implementation of this training. For example, combining this training session with a reflective practice supervision group to enable

healthcare professionals to have key learning opportunities through their implementation and practice would be useful.

The majority of these participants reported previously having thought about staff and family relationships in the way presented and thus perhaps a familiarity with some of the concepts. This may also reflect effects of social desirability bias and participants' desire to respond in a way that shows them in a favourable manner. However, this finding is similar to other researchers in training in challenging behaviour for autistic spectrum disorders where gains in confidence but not beliefs were noted following training (McDonnell et al., 2008). It is not possible to discern from the response entirely what was familiar to them as the qualitative feedback implied the loss models were new frameworks to understanding family distress, for at least some participants. It is a further limitation that the core elements of what made the training acceptable are not clear. However, no professionals reported that they were working constructively with all the families they interact with. This finding points to a practice gap between the intellectual awareness of frameworks reported by these participants and the experience of families on the ground. Whilst generic training would be adequate for healthcare professionals to meet most of their needs, it may be that individualization for specific families is required. This would suggest smaller highly customized and focused support in clinical teams is needed for some family support. This should be constructed as part of the clinical programme for that family and could be assessed, formulated and co-ordinated by the clinical psychologists within the clinical team.

The training also appears to have led to some professionals recognizing the family experience is complex and re-appraised if their knowledge and confidence was as

strong as they initially thought. A small number of participants in this sample considered on reflection that they were not as skilled as they had first estimated. This finding in context with some of the qualitative comments received, suggests that for some staff intuitive practice has been how they have approached their work with families and is consistent with Chapter Five comments in the focus groups of being skilled professionals in their own right, but not having specific skills training for family support.

The FASRAT showed the healthcare professionals consider families matter and are very important. Healthcare professionals of adults typically work with the identified patient and communicate where relevant with families. Healthcare services are currently configured to this approach. In contrast, Family Centred Care is considered the standard in paediatric healthcare, where families are seen as actively involved as partners and members of the patient's team (Kuo, Houtrow, Arango, Kuhltau, Simmon & Neff, 2012). In systemic approaches to healthcare, the family system would be seen as the central unit of care, not just the identified/ill person (Rolland & Walsh, 2005). Long term chronic conditions have an impact on the whole family, their pain posed by the condition is seen as part of the treatment process. This would lead to approaches such as supporting families' knowledge, meaning making and resilience. Such systemic thinking is not integral in many clinical disciplines and requires a paradigm shift for the professional. It could also be argued that healthcare services are not currently established to meet the needs of the wider family, instead are established to focus on the needs of the injured person.

This was a pilot study limited by the absence of a control group for comparison, was delivered by one psychologist and used opportunistic purposive recruitment. Purposive recruitment is required to locate healthcare professionals working in this clinical area, and given the cost and duration of clinical training days not all in a staff team can attend, and this affected the number of potential participants. In addition, the design of research was constrained by practicalities in terms of the amount of time participants could be available to enable pre and post testing, as it was part of a larger study day. Brevity has meant that not all questions that would have been helpful in interpretation were asked, such as number of years since qualification and length of time working with PDoC. Given the cost of training days, often more senior staff could be argued to achieve the funding to attend them, and this may have been important in the analysis, particularly in terms of familiarity with the concepts. Brevity also meant simplified, single item questions were used and this has limited interpretation. It is also a possible limitation that participants may have been biased towards an optimistic view of the training, as they were there for training and thus motivated to learn. Future research that rolls out this training in other settings could evaluate this more directly.

In conclusion, a brief single session psychoeducation programme has been described, which appears suitable for informing healthcare professionals of people with PDoC about the impact of the condition on families. The results from the pilot study are encouraging and support the future development of providing psychoeducation to facilitate healthcare professionals understanding of family distress and how they can best support this.

Chapter Eight

Conclusions and Implications for Clinical Practice

This thesis has investigated the experiences of families and healthcare professionals who support people with PDoC. This chapter firstly summarises why PDoC create a unique situation for families and healthcare professionals that required specific research, secondly the findings across all studies in this thesis, and thirdly the clinical implications of the findings, the limitations of this research and how this research could be further developed for the future.

PDoC is a unique condition that can occur after a severe brain injury. PDoC whilst relatively rare, present a dramatic life changes that occur unexpectedly without early warning signs that something sinister may be developing (for example, like the symptoms that may prompt a medical assessment such as in cancer or dementia). This means families do not have any opportunity to slowly acclimatize to the idea of a PDoC and no opportunity to share in thinking about the long term impact of the condition on family life with the injured person. Families are faced with the initial threat of death, but later find the person has survived but is completely different. Whereas the lay public will generally have some knowledge

of other medical conditions (for example what how a dementia process may present and how it typically progresses), in contrast PDoC is a condition that people have typically never heard of before or had contact with. This lack of knowledge about PDoC leads to families relying on their instincts (Crawford & Beaumont, 2005). These instincts can be unhelpful in PDoC, as people with PDoC often show behaviours that are associated with purpose and emotion in normal life (such as grimacing or smiling), yet these same behaviours in PDOC are thought to be reflexive and not always purposeful. PDoC is also unique in the uncertainty and time needed to establish the diagnosis, as well as a lack of clarity about the longer-term prognosis. Despite PDoC often leading to a chronic condition, some people do recover and families show persisting hope and expectations of further recovery.

Chapter One reported a detailed systematic review of the literature that revealed both the family and health professionals' experience of PDoC is an under researched area, with no studies reported from the United Kingdom. The existing quantitative literature has found that PDoC are associated with great psychological distress in families and has alluded to a level of conflict between families and healthcare professionals. Healthcare professionals working with this clinical population were reported to experience burnout and ethical conflicts. To date the literature has measured the frequency and severity of difficulties of both families and healthcare professionals, without a comprehensive understanding of what gives rise to these problems. By investigating both the experience of the naturalistic familial support as well as the experiences of professionals supporting families and people with PDoC, this thesis aimed to improve understandings of the difficulties families and professionals face in order to determine strategies to enhance professionals' ability to provide support.

This thesis has employed a range of research methods to investigate these aims. Qualitative methodologies were used in Chapters Two and Five to gain a deeper understanding of what families and healthcare professionals actually report as being difficult for them in their experiences of helping people with PDoC. These qualitative findings informed the design of studies reported in Chapters Three and Six which used quantitative, cross sectional and online methods to establish the experience of the wider population of families and professionals supporting of people with PDoC. These formative mixed methodologies research techniques, enabled the development of theoretical understandings about family and healthcare professionals' needs and led to the design and development of interventions in Chapters Four and Seven, specifically targeting the identified needs of these groups.

8.1 Summary of findings

This thesis is the first systematic research on the experiences of families or professionals in PDoC within the United Kingdom and has established a number of original findings. Part One, investigated the experiences of families. An in depth understanding of families' experience of PDoC was established. This contextualized what contributes to the psychological distress that has previously been reported. From this theoretical development, a meaning making approach to assess grief was employed. This information informed development of an intervention that targeted making sense of the conflicting emotional experience (for example, a sense of relief the person has not died, but a sense of distress about their severe injury) and the experience of having a relationship with a person with a PDoC. The pilot intervention was found to be acceptable and helpful for in understanding their

unique form of grief and the difficulties they have with being able to make sense out of the situation they found themselves in.

Chapter Two described the use of an interpretative phenomenological analysis methodology to understand family distress from the perspective of people who experience it ($n = 9$). The findings highlight the impact of the PDoC on challenges to coping and subsequent immobilization in the face of overwhelming uncertainty. Families described difficulty with the process of trying to make sense of the experience and what it means to them (such as; loss without a name, relationship without a title, embodying and feeling part of the rehabilitation process such that reductions in treatment were perceived as abandoning to them personally and contributed to strong advocacy and disagreements with professionals). The loss reported was similar in nature to the construct and psychological model of ambiguous loss (Boss, 1999) where the injured person is physically present but psychologically absent, in line with previous qualitative PDoC research (Giovannetti, Cerniauskaite, et al., 2015). This study further developed this understanding to discuss overlaps with other existing post-modern models of loss such as; feelings their losses were not recognized (disenfranchised grief; Doka 2002), a strong sense of an on going relationship with the injured person (continuing bonds; Klass, 1996), striving to make sense of what their new relationship was (meaning making approaches; Neimeyer 2000) and focusing on the present to avoid overwhelming feelings of loss (the oscillation models of grief; Stroebe & Schut, 1999) and feeling immobilised with how to proceed in life whilst it was still unclear what to adjust to (Boss, 1999). Chapter Two proposed a new preliminary theoretical model, The Preliminary Model of Chronic Uncertainty, informed by several aspects of these

models to explain the families' experience and why their sense of distress is prolonged.

Chapter Three, investigated the relationship between meaning making, loss and psychological distress in families of people with PDoC. The lack of sufficient power of this study allowed only a theoretical association to be drawn between these variables. However, it suggested that families were experiencing loss, psychological distress and finding it hard to make sense of their situation. This complements the emerging qualitative literature in this area (Giovannetti et al., 2015; Hamama-Raz et al., 2013). It also illustrated support for ambiguous loss and the deep and committed continuing bonds families report. The meaning making model (Park, 2010) proposes that distress arises from initial attempts at meaning making being unsuccessful and that deliberate attempts at meaning making are needed. Therefore, failures to achieve meaning making, could perpetuate psychological distress. Chapter Three, appears to support this model in that families in PDoC showed difficulties integrating the stressful life event, possibly because it remains so uncertain as to what they should be adjusting to (for example, will the person recover, die, stay the same?). Importantly, the number of potential participants who did not complete the study highlighted recruitment difficulties in this research population particularly when employing online data collection methods and questionnaires that may lack face validity for the population.

In Chapter Four, an intervention was developed from the formative work of the Preliminary Model of Chronic Uncertainty created in Chapter Two and developed in Chapter Three, and tested for acceptability. This study examined whether a psychological formulation could assist meaning making, and whether ACT based

principles could assist families to cope with the situation that was beyond their control. This intervention was found to be both feasible and acceptable to an expert panel ($n = 8$) and to the pilot research participants ($n = 3$). This suggests the Preliminary Model of Chronic Uncertainty proposed in Chapter Two and developed in Chapter Three has utility in conceptualizing the family experience to design interventions from. Further efficacy testing of this proposed intervention is now required.

In Part Two, greater awareness of the challenges healthcare professionals find supporting families was developed. Importantly, a bi-directionality has been identified which means getting things right for families, also requires getting things right for professionals. Professionals were found to recognize the uniqueness of families' grief, but held existing and unhelpful models of understanding this grief that related to stage and phase models. This made it difficult to make sense of the distress that they witness in families and they are therefore less able to offer targeted support for families. Further, professionals have their own self-care needs, are also distressed and impacted by the nature of the work and the family distress. Psychoeducation for healthcare professionals about managing families hope and loss, was shown to assist staff to develop a greater degree of confidence in supporting people who are distressed and greater understanding and permission to not feel pressured to ensure the families entire psychological adaptation to the situation occurs during the person's admission.

Chapter Five showed that when healthcare professionals ($n = 21$) are facilitated to reflect and think about their work, they share a sense of constantly striving to achieve balance in their work between the needs of the injured person, the family,

their own needs and the requirements of the organisation/funding authorities. Importantly, the healthcare professionals' observations support the families' experience of ambiguous loss. Professionals have regular contact with families that they believe is part of their role, yet few receive specific skills training to deal with complexly distressed families and refer to stage based grief models that are less helpful in understanding the family experience. Professionals also report feeling challenged in the interactions with families.

Chapter Six, showed working with neurological conditions in general differed to the normative data of healthcare workers and that complex neurological care in general may be difficult for healthcare professionals ($n = 78$). Elevated levels of work related burnout and personal burnout were found. This study suggests supporting staff that work in PDoC is important to manage work related burnout and improve compassion satisfaction. This study further added to the findings of previous research that had suggested the time spent with people with PDoC (Gosseries et al., 2013; Leonardi et al., 2013) was a core factor in burnout. This study suggested that the nature of the professional's role (task or process focused) was also important, not just the time spent, and PDoC staff may actually spend less time with the injured person than colleagues working with complex neurological care conditions.

Professionals reported that working with families of people with PDoC could be challenging, personally confronting, and this population can be associated with burnout, and low levels of compassion satisfaction. Chapter Seven investigated the impact of a psychoeducational training session on staff confidence to support psychologically distressed families ($n = 60$). This showed that professionals were

able to gain increased confidence in their perceptions of their ability to work with families when provided with a framework to understand family needs and strategies to interact with psychologically distressed families.

8.2 Implications for clinical practice

A number of key findings point to the requirement to reconsider how services for people with PDoC could be better delivered. A general observation through the qualitative research in this thesis showed there is a paradigm conflict in how families and healthcare professionals think about recovery in PDoC. Families report a belief that getting their relative to specialist neuro-rehabilitation services, will mean that the professionals will be able to facilitate recovery. That is, what is done to the person with the PDoC by the clinician, will be the mechanism of recovery. This belief, leads to wanting intensive input as believing doing more will help recovery, and the need to strongly advocate and fight for the services that they understand will be the change agent to enable recovery. When this does not happen, and indeed the person does not recover during the neuro-rehabilitation admission, families report feeling abandoned themselves as the professionals input decreases. In complete contrast to this model of recovery, healthcare professionals talk of a disability management approach, whereby their role is accurate diagnosis, management of complex underlying medical conditions (such as contractures, postural management, nutrition, neuro-cognitive fatigue) and expect the mechanism of change to be optimizing conditions for the brain to spontaneously recover. This suggests that the purpose of admission to specialist neuro-rehabilitation is often different for families and professionals. The difference of understanding of how recovery may occur creates points of conflict (such as “why

aren't you doing more?", "how can he be discharged when he is not recovered?"). Conflict between families and professionals has previously been reported in the literature (Edgar, Kitzinger, Kitzinger, 2014; Rodrigue, Riopelle, Bernat & Racine, 2013) and that families have attached differing meanings to therapy tasks than the professionals (Latchem, Kitzinger, Kitzinger, 2016). However, this is a new finding which adds that family and healthcare professional conflict may stem from fundamentally differently held ideas of mechanisms of recovery and has not previously been reported. An interesting extension of the research would be to discuss this observation in a focus group to reveal the extent this finding reflects the wider experience of staff and families.

This highlights a clear area for service development, getting shared expectations and understandings of the purposes of an admission and the likely recovery process right prior to an admission. The sponsor site for this research has already begun to implement this finding. The medical consultants now meet with families prior to admission at the acute referring hospital to begin education about PDoC with the family and educate the referring team. This covers the purposes of the admission and the limited range of outcomes of the admission (a diagnosis of VS, MCS or emergence, disability management and planning for longer term care). In an acute setting, families are often surrounded by other people with neurological injury who are getting better. Now, pre-admission families are invited to visit the neuro-rehabilitation setting to see the nature of the programme. This means often for the first time families are seeing multiple people with PDoC, not just their own family member. This can be an emotionally confronting experience but this pre-admission visit is important to help the families begin to contemplate the reality that PDoC can be chronic and set expectations for the programme. Further research to

formally evaluate how these new clinical processes may influence families is important.

Further, a second general observation was families reported limited resources to understand information about PDoC and that internet searching can be devastating or hope raising. Professionals acknowledge families often do not have much understanding of PDoC, unrealistic hope and that the referral hospital staff could unintentionally be fostering unhelpful expectations (such as suggesting that transfer to a place with experts for this condition will help). Enabling families to access quality information and develop understandings about PDoC and rehabilitation is especially important in the context of the reports of the families in this thesis and the understandings of the healthcare professionals, that families do not appear to want peer based support groups at this point in the injury pathway. Commonly it is assumed that there are helpful benefits of sharing experiences and exchanging information with others in a similar position and whilst this may occur naturally and informally, there can be barriers to take-up of formal programmes of peer support (Taylor, Gutteridge & Willis, 2015). There is a need for more information as to what constrains families in PDoC from group based peer support. Future research to explore with families the perceived barriers to group based peer support could be useful.

The identified need to provide accurate and helpful information for families has begun to be developed at the research sponsor site. The hospital is a national specialty service and is well placed to create quality information that can be accessed on the internet and families can be signposted to. Studies in other rare conditions have shown that availability and accessibility of a comprehensive

resource with key information is an important means of supporting families (Jones, et al., 2017). However, more could be developed. Neuro-rehabilitation wards for people with PDoC would also benefit from the development of a clearly displayed clinical pathway, perhaps displayed on the wall or noticeboard that would show the different tasks in an admission (such as SMART assessment, seating assessment, seating prescription, seating delivery, 24 hour postural management plan, diagnosis meeting etc.), the different roles of staff and the range of places people are discharged to. This would help families understand how their relative is progressing through this process and explicitly that discharge is approaching.

Professionals were found to regularly interact with families and considered it part of their role, yet whilst specialist in their own area of practice, few had specific skills training to support families. Professionals held unhelpful models of understanding family distress and what they could do to assist it. The training session for staff (described in Chapter Seven) was shown to be helpful to staff, enabling them to consider other ways to understand the family experience. This clearly needs to be done regularly, as staff on these specialist wards change as part of the rotational post-graduate training system and other researchers have suggested turnover in PDoC can be high (Leonardi et al., 2013). It also seems important to ensure new staff are supported to develop their understandings. The sponsor site organisation now includes teaching on post-modern models of loss and grief during the induction period when new healthcare professionals join the organization, to help staff develop a framework for thinking about the work they do with families. In addition, the organisation's Chaplaincy Team met to discuss the research and how they can integrate the concept of Ambiguous Loss in their practice. However, as highlighted in Chapter Seven, it is important when developing a new practice skill to

be supported in the implementation of it. Development of reflective practice groups and practice supervision groups could be valuable as professionals think about the dynamics of their interactions in supporting families. This is an area for further research, particularly in evaluating how these groups support practice from the professionals' perspective (such as gains in confidence and skill), from the family perspective (such as feeling more recognized by professionals and satisfied with admissions) and potentially at an organizational level (such as the number of complaints received from families relating to care).

This research has developed a preliminary model for understanding the experience of families and this Preliminary Model of Chronic Uncertainty indicates how healthcare professionals can use this to intervene and support families. The basis of this intervention is to create a shared psychological formulation with families to enable a framework for sense making of their feelings and to have techniques to live with difficult thoughts, feelings, memories and sensations that arise as a result. This research also adds that families and staff find a single meeting helpful, and that this meeting could have utility in differentiating who may need further support and could be a route to opening willingness to attend further psychologically supported sessions to facilitate skill development in coping with a situation that is beyond their ability to change. In future studies, it would be useful to expand the sample in order to explore if this proposed Preliminary Model of Chronic Uncertainty is applicable to a wider range of family members than the primary carer and males. This preliminary model of understanding family distress and how to intervene to enhance coping, may be useful with other populations where families are also faced with situations that do not change rapidly and where the change is outside of their control. An example of a possible wider use of this concept for intervention to

enhance meaning making, is with families experiencing the opposite form of ambiguous loss where the person is physically absent but seems psychologically present. In missing persons' situations, families have to cope with the physical absence of the person and ambiguity until there is confirmation that they dead or found. This life event could disrupt situational meaning made and one's sense of global meaning (Holland, 2015).

Crucially, families reported that at a time of such confusing loss and uncertainty, interactions with healthcare professionals had at times been very distressing and their needs were not being met. Healthcare professionals also reported interactions with some families to have been distressing to them. Families understandably take on advocacy roles and believe that they should assume a level of responsibility for directing care. However, this is not their position in law. Whilst professionals report recognizing the value of families and their importance, they are also legally required to work within confidentiality limitations and make decisions on behalf of the person in their best interests, as in PDoC the person lacks mental capacity to consent to care and treatment. The current service delivery approach is typical in adult care, and is patient centred not family centred. In services for children, families are validated, included and trained by staff to be able to perform tasks and understand the condition. This alternative approach seems important to consider for adults with PDoC, where families will become the "expert" on the person's care and management, advocate for services for them, monitor services the person receives, and be able to assess changes in the person's condition. If a family centred approach were adopted, the way services are constructed would need to change. By viewing the family unit as the focus of care,

this would alter the way information is shared with families, the way they are included and the sense of validation and importance they feel.

The lack of a family centred model of care is further highlighted by comments regularly raised by families during the research programme, which have been shared with the sponsor site, related to their need for the organisation to recognize the needs of the wider family in the provision of spaces.

- an outdoor children's play area that the wider family can use so injured parents can watch and join with the children in the children's world,
- indoor children's activity space including the use of computer gaming
- creation of a family space where children can do their own activities nearby and the adults can still supervise this from a distance whilst spending time with the injured person
- A guest room that enables families to stay together as a family to mark key life events, such as birthdays, wedding anniversaries with the intensive nursing and care support available
- Development of the organisation website to include information provided by families for families about tips and strategies for the admission; such as items to bring in, clothing that is useful to have, places to go together, things to do together

Professionals' involvement with people with PDoC is time limited. However, as PDoC is a chronic condition, families are the constant that typically maintain a level of contact with the person over the long-term. It is therefore important that families are adequately educated, skilled and aware of the issues arising in PDoC. All services caring for people with PDoC would benefit from reappraising the way

they support the relationships between professionals and the family, as well as the family and the person with PDoC.

8.3 Limitations and directions for future research

As shown in Chapter One, research on families of people with PDoC has been limited by an a priori approach to the research and as such as relied on the same variables and measures. The field has been limited by small sample sizes in the quantitative literature, ranging from 16 (Chiambretto et al., 2001) to 53 (Elvira de la Morena & Cruzado, 2013) with the exception of the Italian national study of 487 participants (Leonardi et al., 2012). Focus on the primary caregiver, long recruitment periods and cross sectional design have been used. These quantitative studies have been conducted in two countries, Italy and Spain. The qualitative literature has also included the experiences of families in Italy, Israel and Iran. The basis of funding, religion, health and social care is likely to differ from the UK experience in these countries. The studies reported in this thesis were designed with the intention to overcome some of the existing limitations in the research to date, by beginning the research from an exploratory and discovery orientated approach (Barker, Pistrang & Elliot, 2016) seeking to understand and contextualize the psychological distress and prolonged grief previously reported from the perspectives of the family. By focusing the research in a national tertiary referral centre specializing in PDoC and employing online data collection to enable wider national participation, it was intended to be able to access participants with a broader range of relationships to the injured person and be able to establish a better understanding of the impact of time post injury.

Research on healthcare professionals has relied on measuring burnout in this population without examining the issues that may contribute to burnout. Research has compared professionals working PDoC with the general experience of other healthcare professionals and not professionals working with similar clinical populations, such as complex neuro-disability. This thesis therefore attempted to further understand factors that may contribute to professional burnout with people with PDoC and to make comparisons of their experiences with a more similar control group.

However, despite these intentions, Part One of this thesis is limited in generalizability resultant from the methodologies employed and sample size. The aim in interpretative phenomenological analysis (Chapter Two) is to establish homogenous, small sample sizes to enable depth of understanding and theoretical generalizability in relation to existing professional and experiential knowledge (Smith, Flowers & Larkin, 2009). The findings of Chapter Two when combined with the existing knowledge, led to the development of a preliminary theoretical model (The Preliminary Model of Chronic Uncertainty) of what may underpin the distress observed in families in PDoC. It is intuitively a reasonable model, but should be viewed as tentative and one that requires further assessment, particularly with a wider and more heterogeneous sample of PDoC families to confirm it. In particular, this was developed with female participants, primary caregivers and its applicability to males and members of the wider familial network needs further investigation. One of the six studies in this thesis (Chapter Three) is limited by the small sample recruited. Whilst family experience is an under-researched area and they are clearly distressed, obtaining sufficient sample sizes to have sufficient power in the findings and confidence in generalizing these was not possible. Nonetheless this

approach is justified in formative and exploratory research and has the potential to inform the new research directions. Larger sample sizes have been recruited in the nationwide study in Italy, and this shows that future research on families in the UK is likely to require a similar approach in order to obtain a sample size to enable adequate power. Online data collection techniques were not successful in recruitment and this suggests that in line with the international research, face to face data collection (Leonardi et al., 2012) is important for people in high distress in PDoC. Although recruitment was challenging in one study (Chapter Three) and the development of a theoretical model was made with a small sample, this thesis has proposed a preliminary model for understanding family distress and theoretically guiding how best professional can intervene. This thesis does add to the understandings about the nature of family experience of a small group of families of people with a rare condition. It is important to take these tentative and partial findings and determine if it is possible to replicate within a larger sample.

Another limitation identified in this thesis related to measurement and reliance on self-report measures in the studies (Chapter Three, Four, Six and Seven). A lack of measures for this specific population of both families and healthcare professionals, is problematic and some variables such as ambiguous loss and acceptance are not associated with measures that have not been validated with this population. This has also meant that the wording of some items had to be changed to fit the participant's situation, which limits the psychometric properties. The analysis in this thesis is limited by the sensitivity of these standardized measures with this population especially for detecting clinical change. Other measures were developed for this research, but were not able to be piloted informally to address reliability and a possible factor analysis. Future areas of research focused on

development of specific measures, for this population is needed. This seems important to try to establish, in order to advance efficacy trials of the intervention.

A further possible limitation is that this research was conducted at one site and this has also meant the sample is derived from essentially the same time point in the neuro-rehabilitation pathway post injury. The cross sectional online recruitment was intended to circumvent this (Chapter Three) but was unfortunately not as successful as a methodology as expected. Clearly it remains important to investigate the longitudinal experience of families. At present when people with PDoC are discharged to long-term care and general practitioner medical management, there is no follow up from specialist services. This makes identifying and recruiting participants who were at a different time post injury problematic. The UK is in the process of establishing a national register of people with PDoC which will enable future research to maintain contact with families and determine the impact of the effects of time. As the longitudinal experiences of families and staff were not able to be studied in this thesis, the findings therefore may be related to this setting and/or time point and not representative or generalizable to the wider experience of supporting people with PDoC. This research now requires further investigation in other sites and the longitudinal experience of this chronic condition. However, in broad terms findings of this thesis are consistent with the wider international experience, which enables a degree of confidence in findings.

In relation to Part Two of this thesis, the healthcare professionals that informed Chapters Five and Six, were from one site. It would be useful to replicate the findings with healthcare professionals on other sites and at different points on the care pathway of people with PDoC. This would enable examination of any site

specific factors and longitudinal issues. Finally, the evaluation of the psycho-educational training session would be enhanced if the design incorporated a pre, post and additional follow-up measurement. Further, future design would be enhanced by having an objective measure of knowledge, rather than self rated knowledge perception.

8.4 Conclusions

A complete understanding of how best to support families of people with PDoC is beyond the scope of this research programme. This thesis nonetheless adds to understandings that in order to support families well, you also need to support the professionals who work with them and a broader systemic and multifactorial approach is required. This occurs at a systems level (policy; design of services; processes prior to admission and during admission to neuro-rehabilitation settings), at an educational level (staff in acute hospitals who make referrals to neuro-rehabilitation and set expectations and hope in families; for families; for neuro-rehabilitation staff), at a professionals level (developing understandings of the family experience and their role in this and skills training to perform interactions with families in a helpful way) as well as at a family level and the individuals within the family unit. Advances are being made in understandings of the neuroscience of people with PDoC (Crone et al., 2015). Their families have been neglected in the research until recently and advances are equally needed in the support of the families of people with PDoC. Critically, this thesis has described a new way of understanding what may be precipitating and perpetuating the distress families experience with PDoC, which has led to the tentative development of The Preliminary Model of Chronic Uncertainty, of understanding their distress that provides a new direction for psychological interventions with families. This

research contributes to the developing foundation of an evidence base that is still in its infancy of understanding family experiences in PDoC. This field is evolving and more comprehensive investigations of family experiences are important and needed.

Chapter Nine

Reflections on the research experience and considerations for future research design

Reflections on conducting this research has highlighted four key areas that maybe of value for future researchers to consider when planning research with this clinical population and healthcare professionals. These areas are; ethics, design, measures and recruitment.

1. Ethics

- Locating appropriate families of people with PDoC, requires identifying people with suspected PDoC in order to approach their families. Protecting the confidentiality of the injured person who is unable to consent to research is a key consideration. In this research study it was required by the sponsor site and NRES ethics panel, that clinical staff at the sponsor site would be responsible for matching the inclusion and exclusion criteria in identifying potential participants, in order to maximise the confidentiality of the injured person and prevent the researcher from seeing information about them. However, in practice this meant that recruitment was slow and prolonged. It was not clear if this was because amongst a busy clinical case load the research projects were forgotten or less of a priority with the limited time staff

have, or if the consultant considered additional factors that were not part of the formal exclusion criteria (such as feeling the family member was too distressed or had too much going on to ask if they also wanted to participate in research). This process also meant that the research was seen as an “extra” rather than integral to the clinical programme. It would be recommended that in future research, families are made aware that the sponsor site has a clinical teaching programme and hence staff in training may be present and it also has an active research programme and they may be invited to participate in research. In this way it sets out the culture of the sponsor site and alerts families to the potential of involvement.

- As described, the invitation to participate in this research was made by the clinical staff. The research was also designed in this way to prevent families from feeling pressurised to participate if they did not want to, without breaching their own confidentiality. This unfortunately meant that they did not get to meet the researcher unless they expressed interest to know more about the project. Balancing feeling pressurised with having informed consent is needed. For example, had the families met the researcher, it would be potentially more concrete an option for them – such as I would meet “that” lady and talk to her as opposed to wondering about a theoretical “researcher”. How to achieve balancing a sense of feeling pressurised to participate with feeling clear and comfortable with the researcher needs further consideration. One route to this could be to host a “meet the researcher” afternoon and be available to discuss the research with families. This may require additional ethical approval as it could be viewed as advertising.
- Use of social media and social marketing to reach the target population maybe of benefit and would require specific ethical approval, such as asking other brain injury organisations (for example Headway or NHS NeuroNavigators or British Association

of Brain Injury Case Managers) to highlight the research and signpost potential participants to it.

- In the course of detailed interviews, invariably it means that the nature of discussions will raise very personal details of the family and of staff who may be identifiable through research. Consideration is needed on how to report this and protect confidentiality, and this is very well addressed in the Saunders, Kitzinger and Kitzinger (2015) paper and this paper is highly recommended to future researchers.

2. Design

- To obtain sufficient numbers of participants to enable appropriately powered statistical analysis is critical to design of the research. This may mean prolonged data collection periods, needs for changes in the way data is collected and considerations to multi-site research designs.
- Whilst it seemed sensible to use online data collection approach in this thesis, particularly as this was through a community organisation with access to the wider population, this was not borne out in obtaining a sufficient number of participants this research. Online recruitment was ineffective and no apparent “snowballing” occurred. It is likely to be helpful to alert the online community to the research, but it is unlikely to be useful as a recruitment source.
- It seems likely that there is importance of rapport with the researcher and face-to-face data collection with families of people with PDoC, and this is the method used in the Spanish and Italian literature on family experiences.
- Regional centres for specialist assessment, rehabilitation and care mean many families will travel long distances and may have already returned to work and taken on new roles post injury. Research flexibility to meet their needs and maximise their

ability to participate such as out of hours', weekend meetings and travelling to them should be considered.

- The families speak to each other informally in the settings that the person with PDoC resides, this could potentially make trying to allocate families to different intervention arms difficult within one project site.
- Using a particular location (such as a rehabilitation centre or care home) where it is known people with PDoC are located increased the opportunity to access more families. Even so, this is still a very limited population.
- To obtain sufficient sample sizes it is likely to be necessary to have a multi-site research designs, however this introduces a level of possible bias as the nature of the sites are so varied in relation to time post injury, the number of other people with PDoC, the funding arrangements and projected admission times, the organisation culture and working practices, as well as the families contact and relationships with staff and other families. For example, during this research I have spoken with families who describe very different experiences in different locations. Consideration to these biases is needed when using a multi- site design.

3. Measures

- It is important to record the number of clients healthcare professionals treat with PDoC and their level of experience with the clinical group (not just years qualified).
- There are no specific measures for families of people with PDoC. A number of standardised questionnaires reviewed as part of this research highlighted items that could be upsetting to families already coping with a great deal and at a time of heightened emotions or items that were just irrelevant given the nature of the person's severity of impairments. Consideration of the face validity of measures

seems particularly important and may indicate the need for development of bespoke measures for this clinical population.

4. Recruitment

- It is important to consider how families of people with PDoC are approached. Recruitment via a clinician working with their family member and not directly from the researcher has challenges and benefits. Online and no doubt postal surveys may limit recruitment.
- In these studies it proved challenging to recruit nursing staff because it was very difficult for them to be released from their clinical roles to participate in research. It may be particularly helpful to address this with lead nursing staff ahead of the study starting.
- It was a challenge to obtain sufficient numbers of participants, even when extending the time frames of data collection. Some of the points identified above will go some way to addressing this, but careful consideration of realistic participant numbers is needed when designing studies in this field and the issues this creates for statistical power.
- Recruiting multiple members of the same family has been used by some researchers in Spain and Italy. This has the advantage of locating people with different relationships to the injured person (such as sibling, parent, child, cousin etc) and different genders.
- The RCP guidelines recommended that development of a national database which may should this occur, greatly assist in design and identification of potential participants in the future particularly possible identification of people with PDoC who are not resident in rehabilitation units or care homes who may have families

with different experiences of living with people with PDoC in a domiciliary setting.

This potential database would also be useful to help identify possible participants at different time points post injury.

Families of people with PDoC are a hard to reach population with specific needs and addressing this in the research design is important in order to maximise recruitment and develop the evidence base for how best to support them.

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Appendices

10.1 Appendix A: Clinical features of Disorders of Consciousness

Coma (absent wakefulness and absent awareness)	<p>A state of unrousable unresponsiveness, lasting more than 6 hours in which a person</p> <ul style="list-style-type: none">• Can not be awakened• Fails to respond normal to painful stimuli, light or sound• Lacks a normal sleep-wake cycle, and• Does not initiate voluntary actions
Vegetative state (VS) (Wakefulness with absent awareness)	<p>A state of wakefulness without awareness in which there is a preserved capacity for spontaneous or stimulus-induced arousal, evidenced by sleep-wake cycles and a range of reflexive and spontaneous behaviours.</p> <p>VS is characterized by complete absence of behavioural evidence for self – or other environmental awareness.</p>
Minimally conscious state (MCS) (wakefulness with minimal awareness)	<p>A state of severely altered consciousness in which minimal but clearly discernible behavioural evidence of self – or environmental awareness is demonstrated.</p> <p>MCS is characterized by inconsistent, but reproducible, response about the level of spontaneous or reflexive behaviour, which indicate some degree of interaction with their surroundings.</p>

Note. Reprinted from *Prolonged disorders of consciousness: national clinical guidelines* (p. 3), by Royal College of Physicians, 2013, London, RCP.

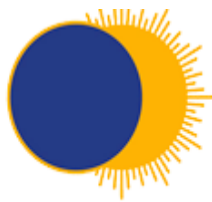
10.2 Appendix B: Differential Diagnosis in Disorders of Consciousness

Condition	Vegetative State (VS)	Minimally Conscious State (MCS)	Locked In Syndrome	Coma	Brain Death confirmed by brain stem tests
Awareness	Absent	Present	Present	Absent	Absent
Sleep-wake cycle	Present	Present	Present	Absent	Absent
Response to noxious stimuli	+/-	Present	Present in eyes only	+/-	Absent
Motor function	No purposeful movement	Some inconsistent verbal or purposeful motor behavior	Volitional vertical eye movements or eye blink preserved	No purposeful movement	None or only reflex spinal movement
Respiratory function	Typically preserved	Typically preserved	Typically preserved	Variable	Absent
EEG Activity	Typically slow wave activity	Insufficient data	Typically normal	Typically slow wave activity	Typically absent
Cerebral Metabolism (PET)	Severely reduced	Intermediate reduction	Mildly reduced	Moderately to severely reduced	Severely reduced or absent
Prognosis	Variable: if permanent, continued VS or death	Variable: if permanent, continued MCS or death	Depends on cause but full recovery unlikely	Recovery, or vegetative state or death within weeks	Organ function can be sustained only temporarily with life support

Note. PET = Position emission tomography, EEG = electron encephalography. Reprinted

from *Prolonged disorders of consciousness: national clinical guidelines* (p. 15), by Royal College of Physicians, 2013, London, RCP.

10.3 Appendix C: Participant Information Sheet (Chapters Two and Four)



Royal Hospital for
Neuro-disability

A national medical charity
Registered Charity No. 205907



INFORMATION ABOUT THE RESEARCH

Disorders of Consciousness and the experience of families

A Royal Holloway University of London and
Neuro-disability Research Trust-funded research project.

We would like to invite you to take part in this research study. You are welcome to keep this information sheet for your own reference.

Before you decide if you are interested in getting involved, we would like you to understand why this research is being done and what it would mean for you.

Please take time to read the following information carefully. Talk to others about the study if you wish. We are happy to go through the information sheet and answer any questions you may have.

Part 1 tells you the purpose of this study and what this will mean for if you choose to take part.

Part 2 gives you more detailed information about the conduct of the study.

Please ask us if there is anything that is not clear or if you would like more information.

Part 1

What is the purpose of the study?

People who have a family member with a disorder of consciousness after a brain injury face many challenges. For example, having to suddenly learn a lot about the injury and medical teams, cope with the uncertainty of the diagnosis and future, juggle the changes to home life and cope with the impact of the injury on their own lives.

The aim of this study is to investigate the experiences of family members of people who have a disorder of consciousness in the Royal Hospital for Neuro-disability and to find out whether an intervention is helpful in supporting families cope with the situation they have suddenly found themselves in.

Why you have been approached?

You have been approached because we aim to offer everyone with a family member with a disorder of consciousness the chance to take part and have their say.

Do you have to take part?

No. It is up to you to decide to join the study. We will describe the study and go through this information sheet, which we will then give to you to take away. Take your time to decide whether or not you wish to take part. You do not have to take part in this study if you don't want to. If you agree to take part, we will then ask you to sign a consent form.

If you do decide to take part you may withdraw at any time without having to give a reason. Your decision not to take part at all or to withdraw along the way will not affect your family members treatment and care in any way at the Royal Hospital for Neuro-disability.

What will happen if you agree to take part?

There are several different things you may be invited to do:

- (1) To speak with the researcher, Sonja Soeterik, answering questions and discussing your experience of what it is like having someone close to you with a disorder of consciousness after brain injury. Interviews should last between one to one-and-a-half hours depending on how much you have to say. We will aim to conduct the interview at a time and place that is most convenient to you. The interview needs to take place in a quiet uninterrupted environment. This could either be in the comfort of your home or at the hospital in a private office in the psychology department. All interviews will be audio taped and notes will be taken during the course of the interview. You will also be asked to complete several questionnaires that ask about your general feelings and thoughts and how you are coping.
- (2) To fill out a range of questionnaires.
- (3) To come with your family to several meetings to try out some ideas that families facing other difficulties have found useful in helping them cope with

difficult times. You will then be contacted 6 months later and invited to fill out some more questionnaires.

- (4) To come with your family to meet other families who have someone they care about in a low awareness state too and to be part of an information day at the Royal Hospital for Neuro-disability where you can hear about some ideas to try out on your own that may make coping with the situation easier. You will then be contacted 6 months later and invited to fill out some more questionnaires.

Expenses and payments

Unfortunately, no payments can be made to you for your time.

Procedures

The only requirement is to talk and fill in the questionnaire, no samples will be taken nor any drugs administered.

What are the potential benefits of taking part?

The potential benefits of the research are that you may have the chance to feedback on your experiences and services, which may help to identify better ways of meeting the needs of relatives.

You may learn about some new ways of coping with the situation you have found yourselves in as a family. Some of these techniques can be helpful in dealing with other stress in your life.

In the longer-term, it is my intention that the findings of this study will inform future support services for families provided within neurorehabilitation settings at the Royal Hospital for Neuro-disability and in other places where people in low awareness states receive treatment.

What are the potential disadvantage and any risks of taking part?

Whilst you may find that discussing issues of concern is helpful, it is possible that some people might find it distressing to talk about their problems and experiences. If you get upset you can skip questions, take a break or decide not to continue with the intervention or interview.

At the end of your participation we will spend some time to talk about how you are feeling, if you are very distressed we will offer you some sources of support. Further psychological support and counselling, can be arranged within the Hospital at any stage (alternatively, arrangements can be made for you closer to home) by speaking to the researcher or Dr Sophie Dupont, the Research Department Associate Director.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed by contacting Dr Sophie Dupont, the Associate Director of Research on 0208 780 4500 ext 5142.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. All audio tapes will be erased once transcribed. All notes will be kept in a locked filing cabinet and the data kept for 8 years. Storage of data is strictly in line with the Data Protection Act 1998. The details are included in Part 2.

Sometimes people like their own GP to know that they are participating in research, we are happy to tell your GP about this study if you wish and let us know your GP contact details.

This completes Part 1. If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

You are free to withdraw at any time and without giving a reason, even if that is during an interview or meeting.

A decision to withdraw, or a decision not to take part, will not affect the standard of care or treatment for you or your relative at the Royal Hospital for Neuro-disability.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (020 7837 3611 ext 3821). If you remain unhappy and wish to complain formally, then any member of staff can direct you to the hospital complaints procedure. Alternatively, please contact the Head of Quality & Risk Management on 0208 780 4500.

Insurance

This project is fully insured through the Royal Hospital for Neuro-disability indemnity policies.

Will my taking part in this study be kept confidential?

Yes. All information about your participation in the study will be kept confidential. Any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised. The procedures for handling, processing, storing and destroying data are compliant with the Data Protection Act 1998. Your name will be swapped for a participant ID number (such as on the questionnaires, the audiotape of the interview and the interview transcript). If you have participated in an interview, the tape will be erased once it has been transcribed. Information about you will be stored securely and will be available only to members of the Research

Department who want to check that the study is being carried out correctly. It will be used only for the purposes of the current study. Data from this study will be retained for 8 years and subsequently disposed of securely.

When the study is written up and published we will use some quotes from the interviews as examples of what people have said. If we use any extracts from your interview they will not contain your name or anything that identifies you as an individual (e.g. your town or workplace) it will be completely depersonalized and anonymous.

What will happen to the results of the research study?

The results will be used to determine the unique needs of families of people with a disorder of consciousness and to help the researchers understand whether an intervention is useful for families of people in a low awareness state. The study may also be written up for publication in scientific journals and may be presented at scientific conferences. Any quotes that are being used in reports or in presentations will be completely depersonalized and anonymous. If you would like to know the results you can be provided with a summary sheet.

Who is organising and funding the research?

This research has been developed by the Psychology Department at Royal Holloway, University of London in conjunction with the Institute of Neuropalliative Rehabilitation (based at the Royal Hospital for Neuro-disability) and is funded by a grant from Royal Holloway, University of London and the Neuro-disability Research Trust.

Who has reviewed the study?

This proposal has been reviewed by researchers and lay representatives within and outside The Royal Hospital for Neuro-disability and presented to Hospital staff at a research seminar. The project was approved by the National Research Ethics Service Committee London - Bloomsbury. It was also reviewed and approved by the Royal Holloway, University of London Ethical Committee within the Psychology Department.

Contact details for further information

If you would like to discuss your potential involvement in this research further please contact:

Sonja Soeterik Tel: 07515523227 Email: Sonja.Soeterik.2012@rhul.ac.uk
Post Graduate Research Student, Department of Psychology, Royal Holloway,
University of London, Egham Hill, Egham, Surrey TW20 0EX

Thank you for taking time to read this information sheet.

10.4 Appendix D: Participant Consent Form (Chapter Two)

CONSENT FORM

Project Title: **Disorders of Consciousness and the Experience of Families**

Please initial

Name of Researcher: Sonja Soeterik

1. I confirm that I have read and understand the information sheet dated 13 th May 2013 (v2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I have had enough time to consider whether or not I want to be involved with this study. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. I understand that if I decide to stop taking part at anytime, this will not affect the medical care or treatment my family member receives at the Royal Hospital for Neuro-disability.	
3. I understand that relevant sections of my relatives medical notes and data collected during the study, may be looked at by individuals from the Royal Hospital for Neuro-disability where it is relevant to my taking part in this research (such as checking the diagnosis of my relative). I give permission for these individuals to have access to my relatives records.	
4. I understand that anonymised quotations maybe used in the research reports.	
5. I understand my GP will not be notified I am participating in this study unless I request this to happen and provide my GP's contact details. <i>GP contact details (please provide this only if you wish your GP to be notified):</i> <i>Name of GP and Surgery:</i> <i>Address:</i> <i>Post code:</i>	
6. I would like to receive a summary of the study.	
7. I agree to take part in the above study.	

Your Name (Participant)

Date

Signature

Name of Person taking consent

Date

Signature

10.5 Appendix E: Herth Hope Scale

© 1988 Kaye Herth

Study No. _____

HERTH HOPE SCALE

Listed below are a number of statements regarding hope. Read each statement and decide whether it applies to you personally. There are no right or wrong answers. Place a check [X] in the appropriate box indicating how often the statement has applied to you in the past week or two.

	Never applies to me	Seldom applies to me	Sometimes applies to me	Often applies to me
1. I am looking forward to the future.				
2. I sense the presence of loved ones.				
3. I have deep inner strength.				
4. I have plans for the future.				
5. I have inner positive energy.				
6. I feel scared about my future.				
7. I keep going even when I hurt.				
8. I have a faith that gives me comfort.				
9. I believe that good is always possible.				
10. I feel at a loss, no where to turn.				
11. I feel time heals.				
12. I have support from those close to me.				
13. I feel overwhelmed and trapped.				
14. I can recall happy times.				
15. I just know there is hope.				
16. I can seek and receive help.				

HERTH HOPE SCALE (cont)

	Never applies to me	Seldom applies to me	Sometimes applies to me	Often applies to me
17. I am immobilized by fears and doubts.				
18. I know my life has meaning and purpose.				
19. I see the positive in most situations.				
20. I have goals for the next 3-6 months.				
21. I am committed to finding my way.				
22. I feel all alone.				
23. I have coped well in the past.				
24. I feel loved and needed.				
25. I believe that each day has potential.				
26. I can't bring about positive change.				
27. I can see a light even in a tunnel.				
28. I have hope even when plans go astray.				
29. I believe my outlook affects my life.				
30. I have plans for today and next week.				

10.6 Appendix F: Work & Social Adjustment Scale (Chapters Two and Three)

Rate each of the following questions on a 0 to 8 scale:

0 indicates no impairment at all and 8 indicates very severe impairment.

Because of my loved ones injury...	0 No Impairment	1	2	3	4	5	6	7	8 Very Severe Impairment
my ability to work is impaired. 0 means not at all impaired and 8 means very severely impaired to the point I can't work.									
my home management (cleaning, tidying, shopping, cooking, looking after home or children, paying bills) is impaired.									
my social leisure activities (with other people, such as parties, bars, clubs, outings, visits, dating, home entertainment) are impaired.									
my private leisure activities (done alone, such as reading, gardening, collecting, sewing, walking alone) are impaired.									
my ability to form and maintain close relationships with others, including those I live with, is impaired.									

10.7 Appendix G: Hospital Anxiety & Depression Scale (HADS)

HOSPITAL ANXIETY & DEPRESSION SCALE (HADS)

Please read each item below and tick the box that comes closest to how you have been feeling this past week.

			SCORING
★ I feel tense or 'wound up'	Most of the time A lot of the time Occasionally Not at all	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<div style="border: 1px solid black; padding: 2px; display: inline-block;"> 3 2 1 0 </div>
★ I still enjoy the things I used to enjoy	Definitely as much Not quite so much Only a little Hardly at all	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<div style="border: 1px solid black; padding: 2px; display: inline-block;"> 0 1 2 3 </div>
★ I get a sort of frightened feeling as if something awful is about to happen	Very definitely & quite badly Yes, but not too badly A little, but it doesn't worry me Not at all	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<div style="border: 1px solid black; padding: 2px; display: inline-block;"> 3 2 1 0 </div>
★ I can laugh and see the funny side of things	As much as always Not quite so much now Definitely not so much now Not at all	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<div style="border: 1px solid black; padding: 2px; display: inline-block;"> 0 1 2 3 </div>
★ Worrying thoughts go through my mind	A great deal of the time A lot of the time Not too often Very little	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<div style="border: 1px solid black; padding: 2px; display: inline-block;"> 3 2 1 0 </div>
★ I feel cheerful	Never Not often Sometimes Most of the time	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<div style="border: 1px solid black; padding: 2px; display: inline-block;"> 3 2 1 0 </div>
★ I can sit at ease and feel relaxed	Definitely Usually Not often Not at all	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<div style="border: 1px solid black; padding: 2px; display: inline-block;"> 0 1 2 3 </div>
★ I feel as if I am slowed down	Nearly all the time Very often Sometimes Not at all	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<div style="border: 1px solid black; padding: 2px; display: inline-block;"> 3 2 1 0 </div>
★ I get a sort of frightened feeling like 'butterflies' in the stomach	Not at all Occasionally Quite often Very often	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<div style="border: 1px solid black; padding: 2px; display: inline-block;"> 0 1 2 3 </div>
★ I have lost interest in my appearance	Definitely I don't take as much care as I should I may not take as much care I take just as much care as ever	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<div style="border: 1px solid black; padding: 2px; display: inline-block;"> 3 2 1 0 </div>
★ I feel restless as if I have to be on the move	Very much indeed Quite a lot Not very much Not at all	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<div style="border: 1px solid black; padding: 2px; display: inline-block;"> 3 2 1 0 </div>
★ I look forward to enjoyment to things	As much as I ever did Rather less than I used to Definitely less than I used to Hardly at all	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<div style="border: 1px solid black; padding: 2px; display: inline-block;"> 0 1 2 3 </div>
★ I get sudden feelings of panic	Very often indeed Quite often Not very often Not at all	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<div style="border: 1px solid black; padding: 2px; display: inline-block;"> 3 2 1 0 </div>
★ I can enjoy a good book or radio or TV programme	Often Sometimes Not often Very seldom	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<div style="border: 1px solid black; padding: 2px; display: inline-block;"> 0 1 2 3 </div>
TOTAL SCORES		A <input type="checkbox"/>	D <input type="checkbox"/>

10.8 Appendix H: Warwick Edinburgh Mental Wellbeing Scale (WEMWBS)

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

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10.9 Appendix I: Boundary Ambiguity Scale #6 (BAS6) – adapted for this thesis
for caregivers of people with dementia – adapted for this study.

The following statements are about your relationship with your injured family member. As you read, imagine their name in blank space in each sentence. Choose the number that best shows how you feel and place a cross underneath it. There are no right or wrong answers. It is important that you answer every item, even if you are unsure of your answer.

BAS6	STRONGLY	DISAGREE	AGREE	STRONGLY	UNSURE
	DISAGREE			AGREE	HOW I FEEL
	1	2	3	4	5
I feel guilty when I get out of the house and do something enjoyable while _____ remains in hospital.					
I feel it will be difficult if not impossible to carve out my own life as long as _____ needs my help.					
I feel incapable of establishing new friendships right now.					
I feel I cannot go anywhere without first thinking about _____'s needs.					
I feel like I have no time to myself.					
Sometimes I'm not sure where _____ fits in as part of the family.					
I will never be satisfied until _____ recovers.					
I often feel mixed up about how much I should be doing for _____.					
I put _____'s needs before my own.					
My family and I often have disagreements about my involvement with _____.					
When I'm not with _____, I find myself wondering how s/he is getting along.					
Family members tend to ignore _____.					
_____ no longer feels like my spouse/parent/sibling/child.					
I think about _____ a lot.					

Pauline Boss, Jan Greenberg and Wayne Caron © 1990 Minnesota Agricultural Experiment Station, University of Minnesota

10.10 Appendix J: Family Needs Questionnaire- R (Chapter Two)

FAMILY NEEDS QUESTIONNAIRE-R

Name: _____

Date: ____ - ____ - ____

I

INTRODUCTION: Family and/or friends of persons who have had a traumatic injury often find they have their own special needs. These needs may or may not have been met during the patient’s rehabilitation. Often, these needs change over time. We are interested in seeing whether or not your needs have been met. The information you provide will help us to understand the needs of your family as well as other families of persons with serious injuries.

DIRECTIONS: For each of the following questions please use the scale described below to tell us whether a need has been met or not. **Circle Y (Yes)** if the need has been met, **Circle P (Partly)** if the need has only been partly met, and **Circle N (No)** if the need has not been met at all.

I NEED	HAS THIS NEED BEEN MET?		
	YES	PARTLY	No
1. to be shown that medical, educational or rehabilitation staff respect the patient's needs or wishes.	Y	P	N
2. to be told daily what is being done with or for the patient.	Y	P	N
3. to give my opinions daily to others involved in the patient's care, rehabilitation, or education.	Y	P	N
4. to be told about all changes in the patient's medical status.	Y	P	N
5. to be assured that the best possible medical care is being given to the patient.	Y	P	N
6. to have explanations from professionals given in terms I can understand.	Y	P	N
7. to have my questions answered honestly.	Y	P	N
8. to be shown that my opinions are used in planning the patient's treatment, rehabilitation or education.	Y	P	N
9. to have a professional to turn to for advice or services when the patient needs help.	Y	P	N
10. to have complete information on the medical care of traumatic injuries (e.g. medications, injections, or surgery).	Y	P	N
11. to have complete information on the patient's physical problems (e.g. weakness, headaches, dizziness, problems with vision or walking).	Y	P	N
12. to have complete information on the patient's problems in thinking /e.g. confusion, memory, or communication).	Y	P	N
13. to have complete information on drug or alcohol problems and treatment.	Y	P	N
14. to be told how long each of the patient's problems is expected to last.	Y	P	N
15. to be shown what to do when the patient is upset or acting strange.	Y	P	N

HAS THIS NEED
BEEN MET?

I NEED	YES	PARTLY	No
16. to have information on the patient's rehabilitative or educational progress.	Y	P	N
17. to have help in deciding how much to let the patient do by himself/herself.	Y	P	N
18. to have enough resources for the patient (e.g. rehabilitation programs, physical therapy, counselling, job counselling).	Y	P	N
19. to have enough resources for myself or the family (e.g. financial or legal counselling, respite care, counselling, nursing or day care).	Y	P	N
20. to have help keeping the house (e.g., shopping, cleaning, cooking, etc.)	Y	P	N
21. to have help from other members of the family in taking care of the patient.	Y	P	N
22. to get enough rest or sleep.	Y	P	N
23. to get a break from my problems and responsibilities.	Y	P	N
24. to spend time with my friends.	Y	P	N
25. to pay attention to my own needs, job or interests.	Y	P	N
26. to have my significant other understand how difficult it is for me.	Y	P	N
27. to have my partner or friends understand how difficult it is for me.	Y	P	N
28. to have other family members understand the patient's problems.	Y	P	N
29. to have the patient's friends understand his/her problems.	Y	P	N
30. to have the patient's employer, coworkers or teachers understand his/her problems.	Y	P	N
31. to discuss my feelings about the patient with someone who has gone through the same experience.	Y	P	N
32. to discuss my feelings about the patient with other friends or family.	Y	P	N
33. to be reassured that it is usual to have strong negative feelings about the patient.	Y	P	N
34. help getting over my doubts and fears about the future.	Y	P	N
35. help in remaining hopeful about the patient's future.	Y	P	N
36. help preparing for the worst.	Y	P	N
37. to be encouraged to ask others to help out.	Y	P	N
28. to have other family members understand the patient's problems.	Y	P	N
29. to have the patient's friends understand his/her problems.	Y	P	N
30. to have the patient's employer, coworkers or teachers understand his/her problems.	Y	P	N
31. to discuss my feelings about the patient with someone who has gone through the same experience.	Y	P	N
32. to discuss my feelings about the patient with other friends or family.	Y	P	N
33. to be reassured that it is usual to have strong negative feelings about the patient.	Y	P	N
34. help getting over my doubts and fears about the future.	Y	P	N
35. help in remaining hopeful about the patient's future.	Y	P	N
36. help preparing for the worst.	Y	P	N
37. to be encouraged to ask others to help out.	Y	P	N

Developed by the Rehabilitation Psychology & Neuropsychology Service, Department of Physical Medicine and Rehabilitation, Virginia Commonwealth University, Richmond. Revised 2/08

10.11 Appendix K: Interview Guide (Chapter Two)

Interview Guide *Version 1*

- Thank person for agreeing to participate
- Explain how long it will take^[1]_{SEP}
- Remind them of their right to withdraw and confidentiality^[1]_{SEP}
- State that they do not have to answer any questions and we can stop at anytime
- Remind that this is about them and their experience, there are no right or wrong answers
- Ask if there are any questions before we begin
- Start tape and check it is recording

1. I wanted to start by doing a family tree with you. This gives me an idea of the important people in your life and also makes sure I know who you are talking about during the interview.

2. What do you understand about X 's condition (diagnosis, treatment, prognosis) at the moment?

Example prompts: What can they do? What can't they do? What do you believe they can understand now? What do you believe the reasons are for their non-responding?

Probe: How have you found out information (Internet, other families, Headway, ward staff)

3. What does their condition mean for you?

Example prompts: Can you give me any examples of things in your life you've had to change since their injury? How did that feel? What bothers you most about the situation you've found yourself in?

Ask about thoughts and feelings (mood, work, finances, childcare, role changes).

4. What is visiting them like for you?

Example prompts: What do you do when you are visiting? What do you think about? How do you feel when you visit? How often do you visit? Do you do anything to make it easier to come?

5. How do you see things will be in the future?

Example prompts: What, if any, certainty about the future is there? How do you see their longer term outcomes impacting on your life and future? What type of relationship do you see with them going forward?

6. What have you done to cope with this situation?

Example prompts: What help have you had that has made a real difference for you? What do you think would have been or would be helpful for you now? Thoughts, feelings and Uncertainty?

7. What do you think might be important for other people in your position to know and do to help them cope?

8. Is there anything we haven't talked about that you think is important?

**9. I'm wondering how you are before we stop (check if onward referral needed) ^[L]_[SEP]
What made you decide to take part?**

- Thank them for participation ^[L]_[SEP]
- Discuss what will happen to results and study, remind of confidentiality and in order to keep the information confidential I will use a pseudonym/other name. This means no one will know who you are
- Remind them of my contact details ^[L]_[SEP]
- Ask if they want to receive details of the study when finished and how to contact them for that
- Switch off tape ^[L]_[SEP]
- Check recording
- Ask them to complete demographic information sheet ^[L]_[SEP] and questionnaires

Participant's characteristics (responses to the standardized questionnaires)

Participant	WEMWBS*	BAS6	HHS*	WSAS	HADS (A)	HADS (D)	HADS TS
Anna	41	45	49	24	10	10	20
Kate	66	30	82	11	5	1	6
Jean	64	38	68	30	11	7	18
Imogen	56	31	78	6	6	0	6
Samantha	55	41	76	4	8	5	13
Rebecca	52	30	77	20	6	2	8
Bronwen	43	37	51	25	16	12	28
Zoe	46	45	61	29	13	4	17
Jessica	45	31	65	20	9	2	11

Note. **BOLD** scores reflect clinically significant impairment in functioning, * higher scores reflective of wellbeing, higher levels of hope



10.12 Appendix L: Transcript extract to illustrate the IPA analytic process

Quote (Rebecca)	“You know, is this 2 years?, is this 3 years?, is this 20 years? That I find hard, um, ugh.... So I yeah, I guess at the moment because he's reasonably stable, I guess I kind of, at the moment I kind of envisage it going on like this, but, going to see him each day and um, but also I guess, as a what, I am aware that he's more vulnerable, so occasionally I have thoughts about, you know at some point, there probably will be phone calls about, "he's got an infection", or um, and that's going to be really hard too, and it will be, you know that would be like, losing... I know people with Alzheimer, say its almost like you lose the person twice, and I can absolutely see that because, um, because had he died in that first 10 days when he was in [acute hospital], when he was still in a coma, um, it would have been difficult, but he hadn't opened his eyes at that point”.
Exploratory coding	Lost twice. The old person and the new person lost. He has already gone. Window for physical death due to injury closed, but now eyes are open and he has survived he's different, he's stable but vulnerable = Uncertainty of prognosis, can't envisage the future. Death will be second loss (the body and eyes) it would be a new but different loss
Emergent theme	Uncertainty with death as only release
Superordinate theme	Holding on and letting go
Subtheme	Not a death
Main theme	Loss without a name

10.13 Appendix M: Table of themes

Super-ordinate Themes	Sub-Themes
"Who I know is gone, but there's a body there" Complex losses	<ul style="list-style-type: none"> • Multiple points of loss not just the initial injury • Not a death and worse than a death • Onesidedness of the relationship
"I don't quite know what I'm dealing with" Uncertainty Challenges	<ul style="list-style-type: none"> • Awareness of condition and the persons level of awareness • Prognosis and Quality of life • Medical stability
"This is how she is" Finding a new way of relating	<ul style="list-style-type: none"> • New relationship but honouring of the old • New routines • Coping and wellbeing
"I will never rest until I've done everything I can possibly do" Ensuring quality care and rehabilitation	<ul style="list-style-type: none"> • Advocacy • Abandonment • Professionals versus family battles

10.14 Appendix N: Participant Information and Online Consent Form(Chapter Three)

 <p>Royal Hospital for Neuro-disability <small>A national medical charity Registered Charity No. 208627</small></p>	 <p>ROYAL HOLLOWAY UNIVERSITY OF LONDON</p>
DoC and Families Experiences	
Welcome! You are invited to participate in a research study.	
The experiences of families of people with disorders of consciousness.	
This study is being done by Sonja Soeterik from the Department of Psychology at Royal Holloway, University of London. You were selected to participate in this study because you have accessed the Brain Injury is BIG information and support charity.	
What is the purpose of the research study?	
People who have a family member with a disorder of consciousness after a brain injury face many challenges. For example, having to suddenly learn a lot about the injury and medical teams, cope with the uncertainty of the diagnosis and future, juggle the changes to home life and cope with the impact of the injury on their own lives.	
The aim of this study is to investigate the personal experiences and impact of having a family member with a disorder of consciousness.	
Do you have to take part?	
Your participation in this research study is completely voluntary and you can withdraw at any time. You are free to skip any question that you choose.	
You are able to choose not to participate. If you decide not to participate in this study or if you withdrawal from participating at any time, there are no consequences for you.	
What will happen if you agree to take part?	
You will be asked to fill in an online survey that will take approximately 15 – 30 minutes.	
Will my taking part in this study be kept confidential?	
Yes. To help protect your confidentiality, the surveys will not contain information that will personally identify you. We do not collect identifying information such as your name, email address or IP address. All data is stored in a password protected electronic format.	
What are the potential benefits of taking part?	

You have the chance to feedback on what your family members injury has meant for you and your own experiences.

In the longer-term, it is intended that the findings of this study will inform future support services for families provided within neuro-rehabilitation settings and in other places where people with disorders of consciousness receive care, assessment and treatment.

What are the potential disadvantage and any risks of taking part?

It is possible that some people might find it distressing to think about and focus on their experiences. If you find that some aspects of the study triggered distress and upset, you can skip questions, take a break or decide not to continue.

As researchers we will not be following up with you after this study and we are not able to provide counselling services. If you feel upset after completing the study, or find that some questions or aspects of the study triggered distress, talking with a qualified clinician may help, additional support can be arranged for you. Please contact BIG who will help coordinate this.

What will happen to the results of the research study?

The results will be used to determine the unique needs of families of people with prolonged disorders of consciousness and to help the researchers understand whether an intervention is useful for families of people with this condition. The study may also be written up for publication in scientific journals and may be presented at scientific conferences. Any information used in reports or in presentations will be completely depersonalized and anonymous. If you would like to know the results you can be provided with a summary sheet.

DoC and Families Experiences

Welcome! You are invited to participate in a research study.

Who is organising and funding the research?

This research has been developed by the Psychology Department at Royal Holloway, University of London in conjunction with the Institute of Neuropalliative Rehabilitation (based at the Royal Hospital for Neuro-disability) and is funded by a grant from Royal Holloway, University of London and the Neuro-disability Research Trust.

Who has reviewed the study?

It has been reviewed and approved by the Royal Holloway, University of London Ethical Committee within the Psychology Department (Ref 2015/067R1).

Expenses and payments

Unfortunately no payments can be made to you for your time.

Contact details for further information

If you have any questions or would like to discuss your potential involvement in this research further please contact:

Sonja Soeterik
Email: Sonja.Soeterik.2012@rhul.ac.uk
Tel: 020 8780 4500 x5141

Post Graduate Research Student
Department of Psychology
Royal Holloway, University of London
Egham
Surrey
TW20 0EX

* 1. Clicking on the "I Agree" button below indicates that:

- you have read the above information
- you are over 18 years of age
- you voluntarily agree to participate in the research study

Clicking on the "I Do NOT agree" button means you do not wish to participate in the research study

I agree I do not agree

10.15 Appendix O: Continuing Bonds Scale (CBS)

Continuing Bonds Scale (CBS)

Statement	Not true at all ----- Very true				
	1	2	3	4	5
1. I seek out things to remind me of my loved one	1	2	3	4	5
2. I keep items that belonged to or were closely associated with my loved one as a reminder of them	1	2	3	4	5
3. I like to reminisce with others about my loved one	1	2	3	4	5
4. I have inner conversations with my loved one where I turn to them for comfort or advice	1	2	3	4	5
5. My loved one continues to be a loving presence in my life	1	2	3	4	5
6. I am aware of having taken on many of my loved one's habits, values or interests	1	2	3	4	5
7. I am aware of the positive influence of my loved one on who I am today	1	2	3	4	5
8. I attempt to carry out my loved one's wishes	1	2	3	4	5
9. I have fond memories that bring joy to me	1	2	3	4	5
10. When making decisions, I imagine my loved one's viewpoint and use this as a guide in deciding what to do	1	2	3	4	5
11. I experience my loved one as continuing to live on through me	1	2	3	4	5

10.16 Appendix P: Prolonged Grief (PG-12) Caregiver Version

Prolonged Grief Disorder (PG – 12) Caregiver Version ©

Holly G. Prigerson, Ph.D., Paul K. Maciejewski, Ph.D.

PGD is a newly defined mental illness that is a specific reaction to the serious illness of a significant other. There are a particular set of PGD symptoms – feelings, thoughts, actions – that must be associated with significant functional impairment in order for a person to meet criteria for PGD.

I

INSTRUCTIONS

Below lie instructions for how to score (diagnose) Prolonged Grief Disorder (PGD).

Each of the requirements for Criteria A-G must be met for an individual to be diagnosed with PGD.

A. Event Criterion: In order to complete the PG-12, we assume the respondent is caring for a significant other with serious illness.

B. Separation Distress: The respondent must experience PG-12 questions #1 or 2 at least daily.

C. Cognitive, Emotional, and Behavioral Symptoms: The respondent must experience 5 of the PG-12 questions #3-11 at least “once a day” or “quite a bit”.

D. Impairment Criterion: The respondent must have significant impairment in social, occupational, or other important areas of functioning (e.g., domestic responsibilities). That is, PG-12 question #12 must be answered as “Yes”.

PART I: INSTRUCTIONS. FOR EACH ITEM, PLACE A CHECK MARK TO INDICATE YOUR ANSWER.

1. In the past month, how often have you felt yourself longing or yearning for _____ (patient) to be healthy again?

Not at all	- 1
At least once	- 2
At least once a week	- 3
At least once a day	- 4
Several times a day	- 5
REF	- 7
DK	- 8

2. In the past month, how often have you had intense feelings of emotional pain, sorrow, or pangs of grief related to _____ (patient's) illness?

Not at all	- 1
At least once	- 2
At least once a week	- 3
At least once a day	- 4
Several times a day	- 5

3. In the past month, how often have you tried to avoid reminders that _____(patient) is ill?

- Not at all - 1
- At least once - 2
- At least once a week - 3
- At least once a day - 4
- Several times a day - 5
- REF - 7
- DK - 8

4. In the past month, how often have you felt stunned, shocked, or dazed by _____(patient's) illness?

- Not at all - 1
- At least once - 2
- At least once a week - 3
- At least once a day - 4
- Several times a day - 5
- REF - 7
- DK - 8

PART II: FOR EACH ITEM, PLEASE INDICATE HOW YOU CURRENTLY FEEL. CIRCLE THE NUMBER TO THE RIGHT TO INDICATE YOUR ANSWER.	Not at all	Slightly	Somewhat	Quite a bit	Overwhelmingly
5. Confusion about your role in life or a diminished sense of self (i.e., feeling that a part of yourself has died)?	1	2	3	4	5
6. Have you had trouble accepting _____(patient's) illness?	1	2	3	4	5
7. Has it been hard for you to trust others since _____(patient's) illness?	1	2	3	4	5
8. Do you feel bitter over _____(patient's) illness?	1	2	3	4	5
9. Do you feel that moving on (e.g., making new friends, pursuing new interests) would be difficult for you now?	1	2	3	4	5
10. Do you feel emotionally numb since _____(patient's) illness?	1	2	3	4	5
11. Do you feel that life is unfulfilling, empty, or meaningless since _____(patient's) illness?	1	2	3	4	5
PART III: FOR EACH ITEM, PLACE A CHECK MARK TO INDICATE YOUR ANSWER.					
12. Have you experienced a significant reduction in social, occupational, or other important areas of functioning (e.g., domestic responsibilities)?					
_____ No _____ Yes					

10.17 Appendix Q Integration of Stressful Life Experiences Scale (ISLES)

Holland, Currier, Coleman & Neimeyer (2010)

Please indicate the extent to which you agree or disagree with the following statements with regard to (the most stressful life event you experienced in the past two years). Read each statement carefully and be aware that a response of agreement or disagreement may not have the same meaning across all items.

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1. Since this event, the world seems like a confusing and scary place.	1	2	3	4	5
2. I have made sense of this event.	1	2	3	4	5
3. If or when I talk about this event, I believe people see me differently.	1	2	3	4	5
4. I have difficulty integrating this event into my understanding about the world.	1	2	3	4	5
5. Since this event, I feel like I'm in a crisis of faith.	1	2	3	4	5
6. This event is incomprehensible to me.	1	2	3	4	5
7. My previous goals and hopes for the future don't make sense anymore since this event.	1	2	3	4	5
8. I am perplexed by what happened.	1	2	3	4	5
9. Since this event happened, I don't know where to go next in my life.	1	2	3	4	5
10. I would have an easier time talking about my life if I left this event out.	1	2	3	4	5
11. My beliefs and values are less clear since this event.	1	2	3	4	5
12. I don't understand myself anymore since this event.	1	2	3	4	5
13. Since this event, I have a harder time feeling like I'm part of something larger than myself.	1	2	3	4	5
14. This event has made me feel less purposeful.	1	2	3	4	5
15. I haven't been able to put the pieces of my life back together since this event.	1	2	3	4	5
16. After this event, life seems more random.	1	2	3	4	5

10.18 Appendix R: Short Form of the Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS)

Below are some statements about feelings and thoughts. Please tick the box that best describes your experience of each over the last two weeks.

Statements	None of the time	Rarely	Some of the time	Often	All of the time
1. I've been feeling optimistic about the future					
2. I've been feeling useful					
3. I've been feeling relaxed					
4. I've been dealing with problems well					
5. I've been thinking clearly					
6. I've been feeling close to other people					
7. I've been able to make up my own mind about things					

10.19 Appendix S: Integration of Stressful Life Experiences – Short Form (ISLES-SF)

Please indicate the extent to which you agree or disagree with the following statements with regard to (the injury of your loved one). Read each statement carefully and please note that for these statements, a response of 1 indicates that you “strongly agree” and a response of 5 indicates that you “strongly disagree”.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1. I have difficulty integrating this event into my understanding about the world	1	2	3	4	5
2. This event is incomprehensible to me	1	2	3	4	5
3. I am perplexed by what happened	1	2	3	4	5
4. Since this event happened, I don't know where to go next in my life	1	2	3	4	5
5. I don't understand myself anymore since this event	1	2	3	4	5
6. This event has made me less purposeful	1	2	3	4	5

10.20 Appendix T: Acceptance and Action Questionnaire – II (AAQ-II)

Below you will find a list of statement. Please rate how true each statement is for you using the scale below to make your choice.

Statement	Never True	Very seldom true	Seldom true	Sometimes true	Frequently true	Almost always true	Always true
1. My painful experiences and memories make it difficult for me to live a life that I would value	1	2	3	4	5	6	7
2. I'm afraid of my feelings	1	2	3	4	5	6	7
3. I worry about not being able to control my worries and feelings	1	2	3	4	5	6	7
4. My painful memories prevent me from having a fulfilling life	1	2	3	4	5	6	7
5. Emotions cause problems in my life	1	2	3	4	5	6	7
6. It seems like most people are handling their lives better than I am	1	2	3	4	5	6	7
7. Worries get in the way of my success	1	2	3	4	5	6	7

10.21 Appendix U: Feasibility and Acceptance Questionnaire

POST MEETING QUESTIONS:

How much do you disagree or agree with the following statements by circling how you feel right now.

1. I think that the way I feel about life right now is completely normal for anyone going through what I am going through

Strongly agree-----agree-----neither agree nor disagree-----disagree-----strongly disagree

2. I think I have greater sense of certainty about my situation.

Strongly agree-----agree-----neither agree nor disagree-----disagree-----strongly disagree

3. I feel I have a framework to make sense of what I am experiencing since the injury.

Strongly agree-----agree-----neither agree nor disagree-----disagree-----strongly disagree

4. I think I have a better understanding of what I feel is important to do.

Strongly agree-----agree-----neither agree nor disagree-----disagree-----strongly disagree

5. I have a way to manage things when I feel overwhelmed.

Strongly agree-----agree-----neither agree nor disagree-----disagree-----strongly disagree

6. The injury has made me feel less purposeful.

Strongly agree-----agree-----neither agree nor disagree-----disagree-----strongly disagree

7. I feel my needs are less important than helping my injured family member with their needs.

Strongly agree-----agree-----neither agree nor disagree-----disagree-----strongly disagree

8. My feelings don't make sense to me as _____ has not died.

Strongly agree-----agree-----neither agree nor disagree-----disagree-----strongly disagree

Thinking about the meeting today, how much do you agree or disagree with the questions below:

1. Do you think that the meeting with the researcher was helpful for you?

Strongly agree-----agree-----neither agree nor disagree-----disagree-----strongly disagree

2. Do you think you would recommend this kind of meeting to others in similar situation?

Strongly agree-----agree-----neither agree nor disagree-----disagree-----strongly disagree

3. Do you think you would benefit from more of these type of meetings?

Strongly agree-----agree-----neither agree nor disagree-----disagree-----strongly disagree

4. Would you have preferred this meeting to have been with other families coping with a similar situation?

Strongly agree-----agree-----neither agree nor disagree-----disagree-----strongly disagree

5. How important is it to you to take care of yourself as well as your injured family member?

Very important-----important-----neutral-----not important -----really not important

6. Do you think this meeting has helped to think about ways you can cope with the situation you are in?

Strongly agree-----agree-----neither agree nor disagree-----disagree-----strongly disagree

7. Is there anything else you think is important to share about this meeting?

10.22 Appendix V: Participants Materials to accompany the intervention described in Chapter Four

Ambiguous Loss

Loving and caring for someone who has had a devastating brain injury, lots of medical intervention and been very unwell is very stressful and difficult. Even though the brain injury happened to only one person, the whole of the family gets affected.

The injured person has been through so much and they are still alive and physically here. But, they are no longer able to interact or be with you in the same ways as before their injury. Even though no one has died, some families talk about feelings like grief and loss, and because the person has not got better, the situation has no ending.

The stressful part of this condition is the ambiguity that the person you love is still here and alive but is no longer here in your life in the way they used to be. They are here but not here. It is not their fault or yours. It is caused by the injury to their brain. It can help coping with the ambiguity of this condition by giving it a name. This unique type of complicated loss was first recognized by Pauline Boss and is called Ambiguous Loss.

Living with Ambiguous Loss is hard and creates a sadness that can make families freeze, put parts of your life and friendships on hold, cancel family gatherings and rituals that were the glue of enjoyable family life, decisions get put on hold and tasks pile up. It can lead to feelings of doubt, confusion, helplessness, hopelessness, exhaustion and even the strongest family members can feel anxious and depressed.

Living with ambiguity means moving forwards, despite the stress of not knowing what lies ahead. It can help to practice thinking “both” & “and” instead of extremes like “either/or.” This means balancing two different ideas at the same time—here and also not here. Both/and thinking is less stressful than continuing to search for an absolutely perfect solution.

Here are some examples:

“I am both his caregiver—and a person with my own needs.”

“I take care of both him—and myself.”

“I both wish it was over—and that my loved one could keep on living.”

“I am both sad at my loved one’s illness—and joyful with my daughter.”

“I am both sad about my lost hopes and dreams—and happy about some new plans and goals.”

Sometimes well meaning friends and family don’t offer the support you may need. Know who you can count on, as it helps to have certainty and predictability at a time of so much ambiguity. Who can you count on for help and support? Who can share information with all the people who want to know things? Who can help so you can take time away to do other things? What resources do you have or does your community offer?.

A Compassionate Hand

Find a comfortable position, straighten your back and press your feet lightly into the floor. Feel the flow of gravity flowing down through your head, down your spine and body and into your feet.

Bring into your mind what you are struggling with, take a second to remember what has happened and consider how it is affecting you and impacting on your future. Tap into those difficult thoughts and feelings associated for you with this painful and difficult time.

You will notice with those difficult thoughts and feelings showing up, perhaps they are fearful, worrying, anger, sadness ...

Take one of your hands and gently hold it in your other hand. Imagine this is the hand of someone very kind, very caring, and very compassionate. Perhaps in the past you have had a person reach out to you with genuine love, care and compassion. See if you can put that same sense of warm and kindness and caring into your own hand.

Place this warm loving hand on whichever part of your body hurts the most – perhaps you feel the hurt most in your chest, or head or neck or your tummy, wherever it is most intense, lay your hand there

If you feel it all over your body, then pick the part of your body and place your hand where it feels most intense. If you feel numb, place it where you feel the most numb. If you're not feeling anything in particular, place your hand on your chest over your heart area.

Allow your hand to rest lightly and gently and feel it against your skin and clothes, feel the warmth flowing from the palm of your hand into your body

Now imagine your body loosening up around this pain, softening up and making space. If you're numb, then soften and loosen around that numbness, and making space.

As you feel that warmth flowing around the space, see if you can hold your pain or numbness very gently, hold it lightly. Hold it as if it is a crying baby, or a whimpering little kitten, hold it like its a fragile butterfly. Feel the warmth flowing from your hand flowing into and around your pain, this sadness, the numbness or simply flowing into your heart.

Imagine in a magical and special way, your heart is opening up and making room for this sadness, this pain, this hurt or this numbness. It is expanding around it and taking it in.

See if you can Infuse this gentle action and with caring and warmth – as if you are reaching out to someone you truly care about. If somebody that you really love or care about were in similar pain to what you are going through right now, and if you wanted to reach out to this person with warmth and kindness, see if you can do the very same thing to yourself right now in this moment, as it you can reach out with similar kindness flows from your fingers into your body.

Now use both of your hands in one kind gesture. Use both of your hands, place one on your chest over your heart and one on your tummy – let them just rest there, gently and hold yourself kindly, infusing your body with kindness. Feel the comfort and kindness that caring warmth, connecting with yourself, caring for yourself, contributing comfort and support.

Drop your Anchor

Take five to ten seconds when difficult and very painful thoughts and feelings show up.

Drop your anchor. Push your feet into the floor hard.

Notice and feel the ground beneath you.

Straighten your spine.

Feel the chair beneath you. Notice your back supporting you.

Drop your anchor. Slowly press your fingertips together, as you do that gently move your elbows and shoulders. Feel your arms pressing all the way from your shoulders to your finger tips.

Take a moment to acknowledge there's a lot of pain here, difficult feelings, urges and sensations that you're struggling with...you didn't ask for it ... but here it is....it's challenging and it's difficult and you want it to go away, and yet its not going....acknowledge and notice what type of pain this is "here's sadness", "here's worry", "here's fear", "here's a painful memory".

Allow them to flow through you – you don't have to like or want these feelings – just make room for them and allow them to be there even though they're unpleasant. You're not going to struggle and fight them, you're not going to run from them or hide from them. You are going to quickly expand and make room for them.

Drop your anchor. As you do this take a slow deep breath into your tummy. Make room for these difficult feelings and sensations.

Take a slow deep breath.

Now notice that as well as this pain that you're struggling with, there is also a body around that pain, that you can move and control.

Now also look around the room and notice five things you can see.

Take a slow deep breath.

Also notice three things you can hear – sounds coming from you or the room around you.

Tree Metaphor



10.23 Appendix W: Focus Group - Topic guide (Chapter Five)

Topic: The experience of staff working with patients with disorders of consciousness and their families.

Welcome & Introduce self

During this focus group I will ask questions and facilitate a conversation about your experiences as a staff team of working with people with a disorder of consciousness and their families. Please keep in mind that there are no “right” or “wrong” answers to any of the questions I will ask. The purpose is to stimulate conversation and hear the opinions of everyone in the room. I hope you will be comfortable speaking honestly and sharing your ideas with us.

We're recording this session, to ensure we adequately capture your ideas during the conversation, so please try to have one person speaking at a time!. Comments from the focus group today will remain confidential and your name will not be attached to any comments you make.

The results from today will be used for understanding the key issues for staff and their perception of the service needs. All findings will be anonymised and are intended to be used in future publication.

You were selected because of the work you are doing within the brain injury service at the Royal Hospital

Do you have any questions before we begin?

Topic guide

1. Let's do a quick round of introductions. Can each of you tell the group your name, your clinical discipline and how long you have been working here at RHN?
2. What are the main issues you get involved with here in dealing with patients families? What is it you think relatives need or benefit from? Is there a team approach to this type of work?
3. Are there any aspects of providing support to families that are beneficial and you enjoy? What types of successes have you had?
4. What are the difficulties and limitations you face in working with patients families? Are there any specific skills you think are needed for this type of work? Are there any organizational barriers or challenges you face in working with families?
5. How do you feel about the staff interactions with families here? (helpful to the families?, not helpful to them? Takes too much staff time?).
6. How do interactions with families affect your work (not enough time for patient, emotional drain, stress etc..). How and where do you draw the line,

know what is for support within RHN vs external referral? Are there any differences you perceive in the way different professionals deal with families?

7. What is it about working with this client group, people with a disorder of consciousness that is particularly stressful? During the past 12 months have you had interactions with patients families that you have found upsetting, distressing?

8. What factors do you notice that contribute to your own or colleagues work stress?

9. What support do you receive or can you access?

10. Now imagine that you are part of a committee of people designing the service – what would be important for the service to have, look like?

11. Is there anything else we haven't discussed yet that you think is important me to know about what it is like to work in the Brain Injury Service?

THANK YOU for participating and sharing your experiences. Remind anonymised findings in publication. Remind findings will be shared in a Lunchtime Takeaway Research Presentation in the future.

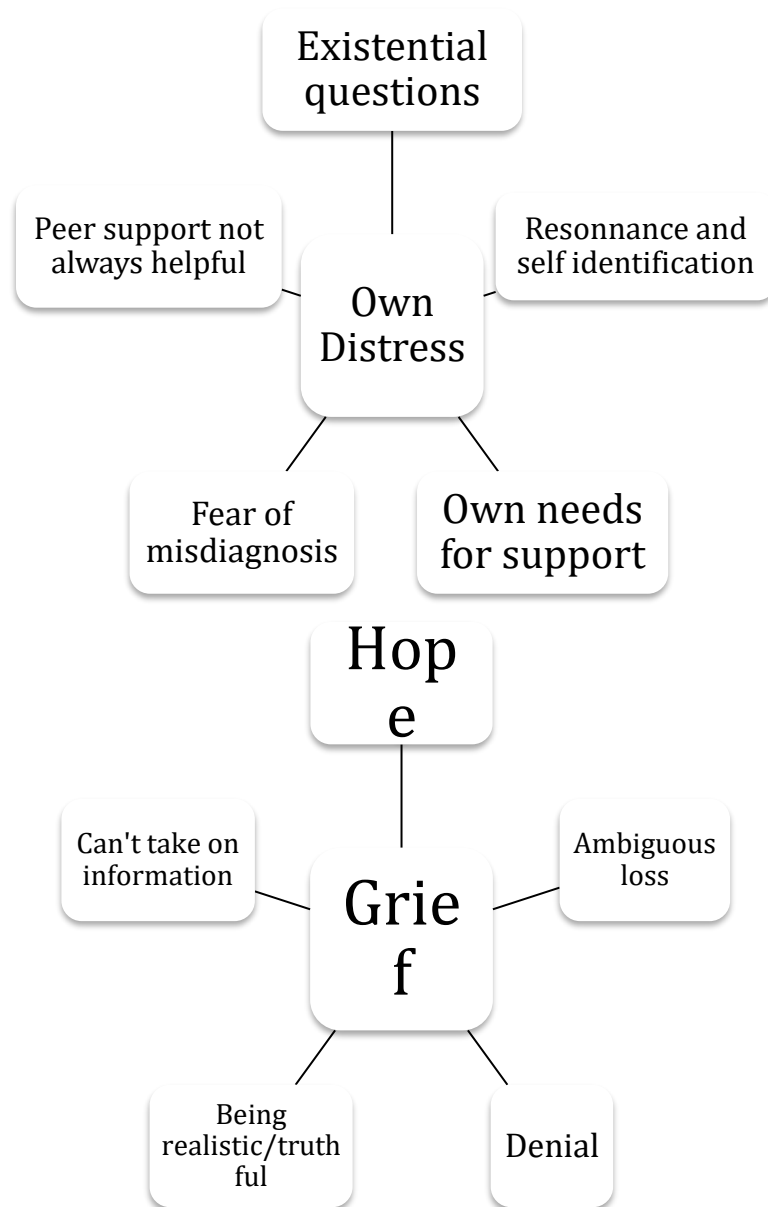
10.24 Appendix X: Focus Group Questionnaire

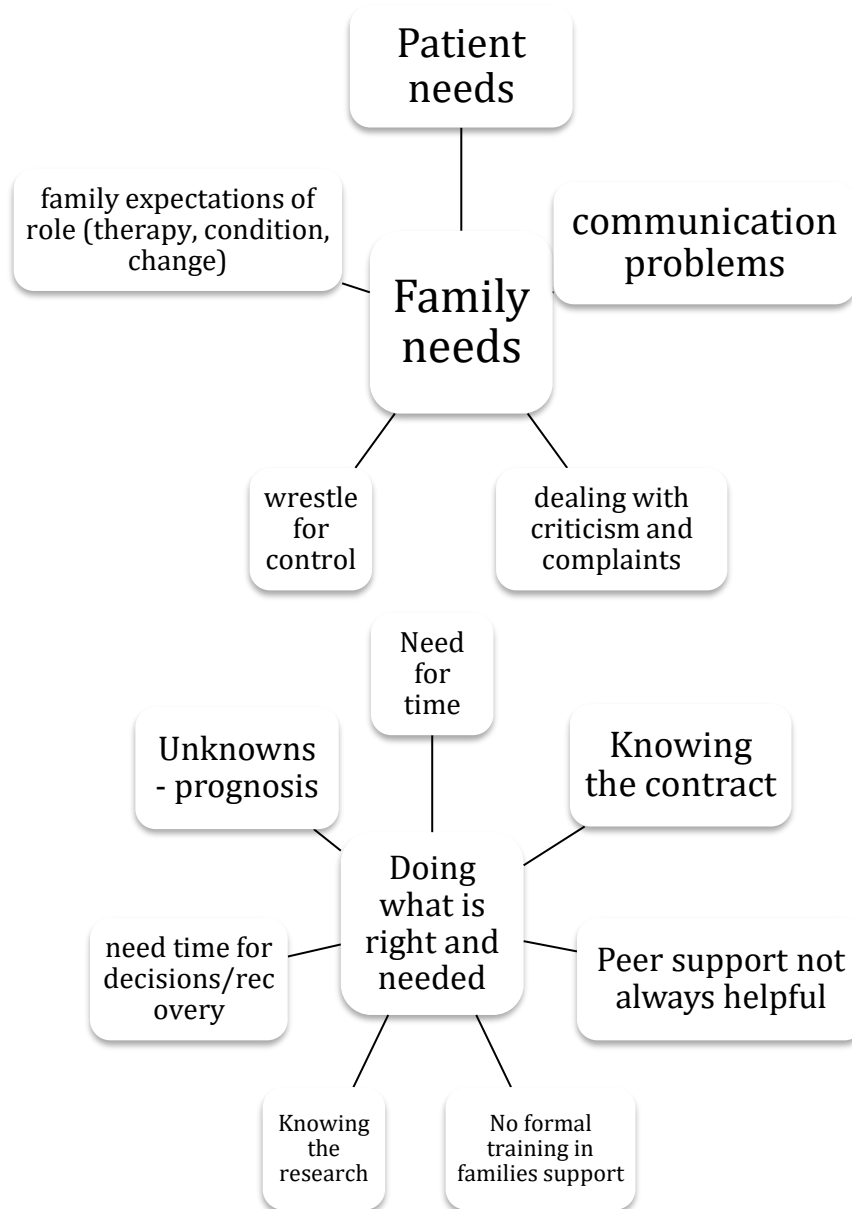
Your discipline	<input type="checkbox"/> Nursing <input type="checkbox"/> Health Care Assistant <input type="checkbox"/> Medical <input type="checkbox"/> Psychiatry <input type="checkbox"/> Occupational Therapy <input type="checkbox"/> Clinical Psychology <input type="checkbox"/> Social Work <input type="checkbox"/> Music Therapy <input type="checkbox"/> Physiotherapy <input type="checkbox"/> Speech and Language Therapy
In the last fortnight, in your role have you done things that support families?	<p style="text-align: center;">Yes No</p>
Did the support you provided feel like it was within your own job role?	<p style="text-align: center;">Yes No</p>
Was this support the result of:	<input type="checkbox"/> Preplanned family / MDT meeting <input type="checkbox"/> Preplanned timetabled session initiated by you <input type="checkbox"/> Preplanned timetabled session requested by the family <input type="checkbox"/> Ad hoc needs led initiated by you (ie you saw them in the day area and started talking about something you wanted to catch them about) <input type="checkbox"/> Ad hoc needs led initiated by family <input type="checkbox"/> Verbally – they saw you <input type="checkbox"/> Verbally they asked for you or called <input type="checkbox"/> Email <input type="checkbox"/> Other reason _____
What was the nature of your support?	<input type="checkbox"/> Informational (RHN, meetings etc) <input type="checkbox"/> Practical (finances, locations of things) <input type="checkbox"/> Educational (BI education, Trache, feed, wheelchairs, positioning etc) <input type="checkbox"/> Emotional support <input type="checkbox"/> Dealing with concerns / complaints about rehab or care <input type="checkbox"/> Other _____
How has information to the family been provided?	<input type="checkbox"/> In Family/ Team Meeting verbally <input type="checkbox"/> In key worker conversation <input type="checkbox"/> Formal (pre-organised) timetabled meeting <input type="checkbox"/> In therapy session where family are present <input type="checkbox"/> Handouts/ leaflets

	<input type="checkbox"/> Email correspondence <input type="checkbox"/> Verbal Face to Face in public area <input type="checkbox"/> Verbal Face to Face in private area <input type="checkbox"/> Verbal Telephone <input type="checkbox"/> Other: _____
What specific training have you done around therapeutically supporting families?	<p style="text-align: center;">Yes No</p> <p style="text-align: center;">Please write what training you have done:</p>
What support do you get for this task in your current role?	
Have you in the past fortnight had interactions with families they have been upsetting or abusive at times to you?	<p style="text-align: center;">Yes No</p>
Whose role do you see supporting families to be?	<input type="checkbox"/> Nursing <input type="checkbox"/> Health Care Assistant <input type="checkbox"/> Medical <input type="checkbox"/> Psychiatry <input type="checkbox"/> Occupational Therapy <input type="checkbox"/> Clinical Psychology <input type="checkbox"/> Social Work <input type="checkbox"/> Music Therapy <input type="checkbox"/> Physiotherapy <input type="checkbox"/> Speech and Language Therapy <input type="checkbox"/> External person / agency (please describe what)
Who do you think should take the lead on working with families who are the most challenging?	
Is this happening at the moment? If not, why do you think that is not happening at present?	
What support do you know the RHN currently provides for families of people with a DOC?	
What support do you know of that is available to families outside of RHN?	
Are there things you believe the RHN could do better to support families?	<p style="text-align: center;">Please suggest:</p>
Thank you for all your time and participation today.	

10.25 Appendix Y: Focus Group Themes

- (1) managing the professionals own self care versus care for the family in distress
- (2) use of clinical time spent with the patient versus their wider networks
- (3) managing families hope versus their grief
- (4) knowing what is contracted versus the sense of what is right or required





10.26 Appendix Z: Focus Group - Annotated Transcript Excerpt

SLT	The <u>emotional effect</u> the family point of view I think the <u>fatigue effect</u> , <u>the time</u> , a <u>lot of emotion comes on to you</u> I feel as well I think, if you have a family member that is distressed, and not even if they are unhappy it could be that stressed about their family member, or they can sometimes <u>get quite personal</u> sometimes I mean if they are <u>criticizing you</u> it can start to feel sometimes that they are not criticizing from a professional point of view but from a more <u>personal point</u> of view sometimes as well so that more emotional aspect of it which is quite <u>challenging to deal with</u> really	<i>Emotional work</i> <i>Tiring work</i> <i>Emotionally charged situation</i> <i>Family conflict and challenge- personal attacks</i> <i>Dealing with families challenging</i>
Interviewer	I hear lots of mms coming from over here?...	<i>General agreement</i>
PT	I start to <u>question my communication</u> skills sometimes because I think that I communicate well, but I don't have any specific skills in communicating with people who are in a <u>really complex grieving process</u> really so relatives will come to me <u>complaining</u> or asking about splints or stretches or something and I <u>continually generate the same information</u> and I wonder if there is any training available or <u>anything for me</u> to put the onus back on them and try and to work out what their perception of what they're expecting, what I've said	<i>Need for information</i> <i>Complex grief</i> <i>Family complaints</i> <i>Repetitive communication</i> <i>Need training</i>
Interviewer	So its not just having to have expertise in working with these patients but also a level of expertise in dealing with people who are complexly distressed?	
OT	Yeea, because <u>they are just not ready</u> to perceive the information and that's why you find yourself repeating, because you will have an hour conversation with someone so you will explain why they cant communicate because they are not aware, they are asleep so we need to get that sorted out first blah blah blah blah blah, and then they'll say ok so we are working on yes and no? No, I've just been trying to explain that now, and you can <u>have that conversation multiple times a day</u> and its just, we are having to be that support to guide them through <u>the grieving process on top of dealing with the patient</u> as well	<i>Families need time</i> <i>Repetitive communication</i> <i>Family need AND patient needs</i> <i>Unrealistic expectations of change</i> <i>Families grief</i>
SLT	And I think you are right we are doing that <u>without any training really</u> , and it is a <u>heavy burden and load emotionally</u> and you start to question yourself, you must have been in the situation where you wonder if you had said that in a different way, done things differently if that situation would be better, I think we don't have any...	<i>Emotional work</i> <i>Lack of training for level of family distress/needs</i>
MT	Hmm in our music therapy training we spend a lot of time on psychotherapy training in our training, and we have been thinking about <u>running workshops for you guys on transference and counter transference</u> etc it is needed I mean we find it <u>hard on the background of having years of training in that</u>	<i>Even with some psychotherapy training this difficult – need workshops</i>
SLT	I think having <u>more psychology on the ward</u> would be great but there is still going to be an <u>onus on us</u> as therapists to we are delivering the therapy	<i>Need psychology AND MDT – part of the job</i>

10.27 Appendix AA: Copenhagen Burnout Inventory (CBI) (Chapters Five and Six)

CBI Item	Always	Often	Sometimes	Seldom	Never/ almost never
How often do you feel tired?					
Do you have enough energy for family and friends during leisure time?					
Do you feel worn out at the end of the working day?					
How often are you physically exhausted?					
Are you exhausted in the morning at the thought of another day at work?					
Are you tired of working with clients?					
How often do you feel weak and susceptible to illness?					
How often are you emotionally exhausted?					
How often do you think: "I can't take it anymore"?					
Do you feel that every working hour is tiring for you?					
How often do you feel worn out?					
Do you sometimes wonder how long you will be able to continue working with clients?					

Please use these new categories for your answers below:	To a very high degree	To a high degree	Somewhat	To a low degree	To a very low degree
Does your work frustrate you?					
Does it drain your energy to work with clients?					
Do you feel burnt out because of your work?					
Do you find it frustrating to work with clients?					
Is your work emotionally exhausting?					
Do you find it hard to work with clients?					
Do you feel that you give more than you get back when you work with clients?					
Do you work (please circle)	Full time	Part time			

10.28 Appendix AB: Healthcare Professionals Participant Information Sheet and Consent Form (Chapter Six)



The experiences of healthcare professionals supporting people with complex neuro-disability

Welcome! Thank you for considering participating in this important research survey.

This study is being conducted by Sonja Soeterik from the Department of Psychology at Royal Holloway, University of London and the Institute of Neuropalliative Rehabilitation.

You were selected to participate in this study because you are a member of staff at the Royal Hospital for Neuro-disability and work with people who have a neurological injury and complex neuro-disability.

What is the purpose of the research study?

Complex neuro-disability can require healthcare professionals to work with clients and the clients' wider family network for a long time and to think about their work in a different way.

The aim of this study is to investigate what the personal impact of helping people with these complex conditions is like for healthcare professionals.

Do you have to take part?

Your participation in this research study is completely voluntary and you can withdraw at any time. You are free to skip any question that you choose.

You are able to choose not to participate. If you decide not to participate in this study or if you withdraw from participating at any time, there are no consequences for you.

What will happen if you agree to take part?

The procedure involves filling in an online survey that will take approximately 15 - 30 minutes.

Will my taking part in this study be kept confidential?

Yes. To help protect your confidentiality, the surveys will not contain information that will personally identify you. We do not collect identifying information such as your name, email address or IP address. All data is stored in a password protected electronic format.

What are the potential benefits of taking part?

You have a chance to feedback about what working with this client group means for you and what you find more challenging.

In the longer-term, it is intended that the findings of this study will inform future support services and training for healthcare professionals working with people with complex neuro-disability.

The experiences of healthcare professionals supporting people with complex neuro-disability

You are invited to participate in a research study:

Who is organising and funding the research?

This research has been developed by the Psychology Department at Royal Holloway, University of London in conjunction with the Institute of Neuropalliative Rehabilitation (based at the Royal Hospital for Neuro-disability) and is funded by a grant from Royal Holloway, University of London and the Neuro-disability Research Trust.

Who has reviewed the study?

It has been reviewed and approved by the Royal Holloway, University of London Ethical Committee within the Psychology Department (2015/067R1).

Expenses and payments

Unfortunately no payments can be made to you for your time.

Contact details for further information

If you have any questions or would like to discuss your potential involvement in this research further please contact:

Sonja Soeterik
Post Graduate Research Student
Department of Psychology
Royal Holloway University of London
Egham
Surrey
TW20 0EX

Email: Sonja.Soeterik.2012@rhul.ac.uk Tel: 020 8780 4500 x5141

1. ELECTRONIC CONSENT: Please select your choice below.

Clicking on the "I Agree" button below indicates that:

- you have read the above information
- you voluntarily agree to participate

If you do not wish to participate in the research study, please decline participation by clicking on the "I Do NOT agree" button.

I agree I do not agree

10.29 Appendix AC: Psycho-educational Training Session presented in Chapter Seven slides

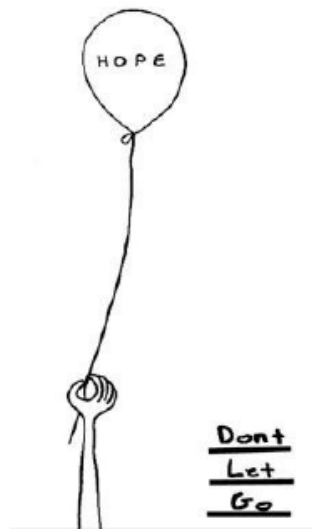


Research in
this area
needs you!

Please consider participating
now.

READ Information Sheet
SIGN Consent Form
COMPLETE Questionnaire

WE NEED YOU!



Working with families of people with PDoc: a time of complex loss and grief.

Sonja Soeterik C Psychol, AFBPSS, HCPC
Consultant Clinical Psychologist
PG Research Student RHUL
Research Fellow RHN

Dr Afsane Riazi - RHUL
Dr Sal Connolly - RHN



Plan:

- (1) Understand the nature of challenges facing families of people with Doc
- (2) Understand why conflicts with Healthcare Professionals and Families of people with Doc arise
- (3) Understand what can be done to improve working relationships with families in a rehabilitation setting
- (4) Reflect and revise the principles of supporting families and the tools needed to form collaborative working relationships



What does a DoC in the family mean?



- * Change
- * Loss and grief
- * Wellbeing changes (depressive & anxious symptoms++)
- * Burden
- * Coping
- * Time alone does not improve things
- * Little gender difference
- * Some will manage alone, others will need professional help
- * They will still be there long after your time with the patient has finished

Soeterik, S.M., Connolly, S., Playford, D., Dupont, S. & Riazi, A. In preparation. The experiences of families of people with a disorder of consciousness: A Systematic Review.

How can we understand their loss and grief?

THE 5 STAGES OF GRIEF



Denial



Anger



Bargaining



Depression



Acceptance

Loss research – Classical Grief Theories

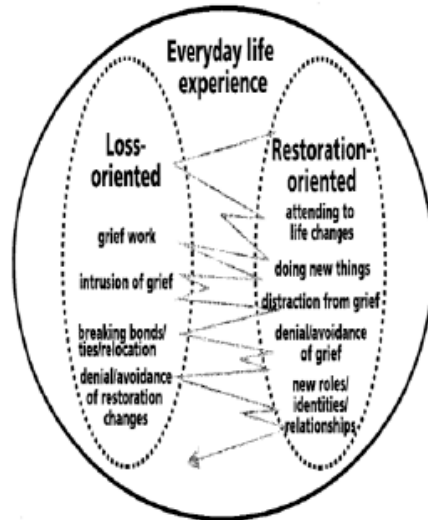
- * The Grief Work hypotheses (Freud): come to terms with loss by confronting it and working towards detaching from the lost person.
- * Grief does not automatically resolve with time
- * Grief work requires working through pain
- * Task based theory – the goal of grief is disengaging
- * Ongoing connection with the deceased pathological

Post modern grief theories



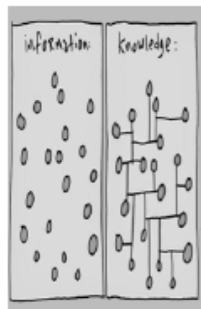
- * **The Dual Process Model**
(Stroebe & Schut, 1999)
- * **Meaning-Making in Bereavement**
(Neimeyer, 2006)
- * **Continuing Bonds Theory**
(Klass, Silverman & Nickman, 1996)
- * **Ambiguous Loss**
(Boss, 1999)

The Dual Process Model (Stroebe & Schut, 1999)



- * Examined what bereaved individuals actually do when coping with grief.
- * Moves between times of actively experiencing the grief and focusing on the loss ("loss-orientation") to times of avoiding the grief through focusing on daily activities and functioning ("restoration-orientation").
- * This oscillation allows the bereaved individual to both recognize the loss and experience the grief, and time away from active grieving to focus on rebuilding one's life.

Meaning-Making in Bereavement (Neimeyer, 2006)

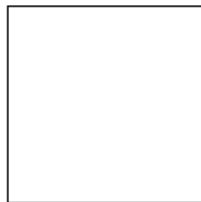


- * The process of making meaning involves imposing a structure on life so it is coherent, organized, understandable, and predictable.
- * The grieving process is essentially a way to make meaning of the loss and thus integrate the loss into a new way of being in the world.
- * Neimeyer (2000) stated that meaning restructuring includes:
 - (1) finding or creating meaning in the death of the loved one and in the life of the bereaved,
 - (2) integrating and constructing meaning within a framework of life beyond the death,
 - (3) an interpersonal process, and
 - (4) a cultural process

Continuing bonds theory

Klass, Silverman, and Nickman (1996)

- * Based on attachment theory grief can be seen as a reaction to having lost someone with whom there was an attachment
- * Resolving grief challenges the notion that disengagement from the deceased is a part of successful mourning, suggesting that the relationship to the deceased does not end with death.
- * Current research is embracing the idea that **one can remain emotionally connected** to a deceased loved-one through a **continued and transformed relationship that still recognizes and acknowledges** the death.



Ambiguous Loss

Pauline Boss (1999)



"A goodbye without leaving"

- * Physically present – but psychologically absent creates a “Frozen Grief”
- * No death - Uncertainty about what one is supposed to adjust to, Unclear how to adjust, seems premature to grieve
- * The grief is unending, the uncertainty drags out and there is little ability for resolution
- * Few social supports (support people are confused about whether to express sympathy or maintain a stoic sense of normalcy or hope)
- * The irrationality of life is on display, it is hard to feel that there is a rational world when nothing seems clear or rational

What families describe	Post modern grief/loss theory
Coping with someone they love who is there but – not there	Ambiguous Loss (Boss, 1999)
Everything is different and they are moving between loss and having to keep on keeping on	The Dual Process Model (Stroebe & Schut, 1999)
Finding a new way of remaining bonded	Continuing Bonds Theory (Klass, Silverman & Nickman, 1996)
Trying to make sense of what has happened and what this means	Meaning-Making in Bereavement (Neimeyer, 2006)



A lot to do for families...

- * They will still be there long after your time with the patient has finished

Family
WHERE LIFE BEGINS
& LOVE NEVER ENDS

Aren't they just “normal”?

- * “... personal and family problems – not because of flaws in the psyches ... but because of situations beyond their control or outside the constraints that block the coping and grieving response”



Pauline Boss (1999)



Encourage clinicians to respect the variety of ways families may cope with the injury and see these as normal responses to an abnormal and deeply distressing situation.

Kitzinger C, Kitzinger J. Grief, anger and despair in relatives of severely brain injured patients: responding without pathologising. Clin Rehabil 2014 Jun 11;28(7):627-631.

Why are staff – family relationships important?

- * Families are often with the patient a lot and therefore play a key role in the assessment and diagnosis of patients with DOC (RCP, 2013)
- * Many patients respond at an earlier stage to familiar people (RCP, 2013)
- * Can provide key insights into the patients pre-injury character, beliefs and wishes (RCP, 2013)

Why are staff – family relationships important?

- * Support families to be involved understanding the care and rehabilitation
- * Provide emotional support to the families as they adjust to the changes
- * Staff can contribute to the maintenance of the patient-family relationship
- * Makes it easier to resolve conflicts that may arise

Theoretical support for staff-family collaboration in DoC

BUT... this does not always translate into practice...

There can be a struggle for control over care and rehabilitation timings.

There can be tension.

People caring for people...



- * Burnout seen in HCP supporting DoC patients
- * This research is indicating the systemic work especially with families more challenging for HCP than their direct clinical role
- * HCP highly skilled in own role
- * HCP feel working with families is part of their clinical role
- * But HCP do not receive direct training on this in their professional training
- * HCP expectations about what = success and understanding of loss/ grief/adjustment

Healthcare Professional – Family tensions



- * limited specialist training on systems and family work, loss and trauma skills, dealing with distress etc
- * Many HCP task focused roles
- * Family distress doesn't lend itself to being "fixed"

Supporting families

Activity	Percentage of participants
Things to support families within last week	95%
Things done were within their professional role	68%
Received specific training to support families	27%
Interaction was upsetting to the healthcare professional	18%
Pre-planned contact with families over past week	53%
Ad hoc contact with families over past week	89%
Contact focused on emotional support to family	68%
Contact focused on educational support to family	58%
Contact focused on managing concerns raised by family	58%

Soeterik, S.M., Connolly, S., Playford, D., Duport, S., & Riazi, A. In preparation. The experiences of healthcare professionals working with people with disorders of consciousness.

What staff say about families...

- * Helpful source of information
- * Have their own coping and adjustment needs
- * Hard to satisfy
- * Unrealistic expectations
- * Lacking in knowledge
- * Unboundaried seeking out staff
- * Not able to take on information given about the diagnosis and prognosis

What families say about staff...

- * How the families can view staff:
- * Empathetic and understanding
- * Abandoning and giving up
- * Dismissive
- * Poor communicators (with each other) and no time to communicate with them
- * Offer little information spontaneously
- * Blockers
- * Untrustworthy

There can be
struggles...
whose patient is
it?

- For control over the care domain
- For rehabilitation input and durations
- For decision making power
- For information
- For trust



There can be struggles...

- * Staff perceive themselves to be in control of the patients care and rehab
- * Staff perceive there are legal and organisational barriers to establishing staff-family relationships
- * Family members perceive a primary part of their role to be monitoring the quality of the care
- * Families see themselves as having to take control and advocate to get rehab and care

There can be struggles...

- * Staff support the desire of family members to be actively involved but often assume control rather than promoting collaboration
- * work pressures interfere with the ability to provide the level of support and information families seek
- * Family members wish to be part of the decision making process and work in active collaboration with staff
- * Families need education and access to information about the RHN, DOC, the funding process, rehab and care

There can be struggles...

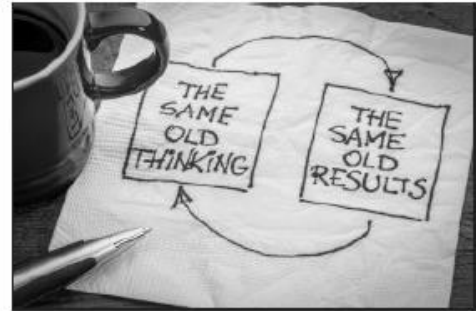
- * Poor communication and lack of recognition of contributions of each other contributes to unsuccessful relationships between staff and families
- * Relationships between family and staff are intertwined with family members perception of the quality of care “what happens when I’m not there?”
- * Relatives perceive person centered individuality of the patient to be an important aspect to quality of care
- * Family members value being recognised by staff
- * Relatives are more likely to initiate conversation with staff as they more often seek out information than have it provided

Magic formula vs principles



Improving working relationships

1. Information
2. Education
3. Support
4. Discuss and dissolve



How to connect with families and meet their needs

1. **“everybody knows your name”** Make a good first impression, know family members, introduce yourself to them
2. **“in my shoes”** Listen and show genuine interest in their story and feelings
3. **“It’s the little things that count”** Find out what is important to the family and their loved one
4. **“the chasm of Us vs them”** Let the family become aware of the value you place on their special knowledge and experience of patient
5. **“loss and laundry”** Provide openings and opportunities to communicate and collaborate about rehabilitation and care

“What should I say when”....

I've learned that people
will forget what you
said, people will forget
what you did, but
people will never forget
how you made them
feel.

Maya Angelou



It's THIS easy and THIS hard

- * Be a good listener – caring – I see you're in pain and I want to help
- * Ask about their feelings
- * Just sit with them
- * Acknowledge the pain
- * Let them feel sad
- * Resist moving to solutions and giving advice
- * Be available when you can
- * Do not minimize grief



An Acceptance and Commitment Therapy approach

1. **Hold yourself kindly** – self compassion and self care
2. **Drop the anchor** – ground self to take effective action amongst the painful emotional storm and waves of painful feelings
3. **Take a stand**- what do I want to stand for in the face of this, what dignifies the suffering and gives you the will to keep going on
4. **Find the treasure** – acknowledge pain and also appreciate all that life has to offer



Russ Harris (2011). *The reality slap: How to find fulfilment when life hurts.*

What can be tried with distress?

- * What does the person want or need you to do about their distress?
- * It is not likely to be something that you can “fix” or resolve in one conversation
- * Listening
- * Observe
- * Validate / Normalise
- * Any help you can offer to support them now
- * Focus on the present – looking after themselves
- * Schedule to help get through the day
- * Find supports in their life
- * Is it your specialism /role? Refer on?
- * <http://www.braininjuryisbig.org.uk>
- * <https://www.headway.org.uk>

Dealing with being shouted, criticism and questioning

- * Listen
- * Understand the crux of the concerns
- * Check you have the concern correct and if there are any more concerns
- * Show you understand the feeling behind the concerns (frustration, anger, worry, etc)
- * Thank them for their honesty, openness, willingness to talk about things that can be hard to raise, their advocacy for their family etc

"I can see this really is important to you and your family"

"have I understood right that X and Y really concerning to you? Are those the main worries or are there any other things that are also worrying you as a family?"

"Are there things that you think I do now that can help you with this?"

I hear what you're concerned about, leave it with me and I am going to talk to some others in the team about this "

"this sounds important to you and it is important to me too, I'd like us to have enough time and the right people around to really deal with this concern. Can you give me some times and dates you could meet with us?"

Principles

- * We are all different. Lots of different needs and different ways different families and different family members can respond
- * Relationships between staff and families are critically important
- * Staff roles with families:
 1. Information
 2. Education
 3. Support
 4. Discuss and dissolve
- * Leave people remembering how your interaction felt



3 more
questions
please....

and then....

LUNCH !!

10.30 Appendix AD: Family and Staff Relationship Attitude Tool (FASRAT)

Please indicate the extent to which you personally agree or disagree with each of the following statements by placing a tick in the corresponding box:

		Strongly Agree	Moderately Agree	Agree	Disagree	Moderately Disagree	Strongly Disagree	Don't know/ no opinion
1	Staff need to see patients as individuals in order to establish good relationships with families							
2	Tensions will occur if staff and families have different expectations about care							
3	Families should have the opportunity to be involved in decision making about their relatives care							
4	Families knowledge of day to day care needs should be acknowledged by staff							
5	Open communication between staff and families is necessary for the formation of good relationships							
6	Families should give feedback about the contribution staff make to their relatives care							
7	Cultural differences between staff and families can hinder their relationship							
8	Staff should be provided with training to work with families							
9	Good relationships between staff and families are more likely when they agree about patients individual needs							
10	Good relationships develop when staff and families share the same goal							

10.31 Appendix AE: New General Self Efficacy Scale (NGSES)

Please indicate the extent to which you personally agree or disagree with each of the following statements by placing a tick in the corresponding box:		Strongly Agree	Agree	No preference	Disagree	Strongly Disagree
1	I will be able to achieve most of the goals I set for myself					
2	When facing difficult tasks, I am certain I will succeed					
3	In general I think I can achieve outcomes that are important to me					
4	I believe I can succeed at most tasks to which I set my mind					
5	I will be able to successfully overcome many challenges					
6	I am confident I can manage well on many different tasks					
7	Compared to other people, I can do most tasks very well					
8	Even when things are tough I can manage quite well					

10.32 Appendix AF: Questionnaire (Chapter Seven)

PRE- Training session:



The experiences of healthcare professionals supporting families of people with disorders of consciousness.

A. Please tick your clinical background:

- | | |
|--|--|
| <input type="checkbox"/> Speech and Language Therapy | <input type="checkbox"/> Clinical Psychology |
| <input type="checkbox"/> Occupational Therapy | <input type="checkbox"/> Nursing |
| <input type="checkbox"/> Physiotherapy | <input type="checkbox"/> Healthcare Assistant |
| <input type="checkbox"/> Music Therapy | <input type="checkbox"/> Medical |
| <input type="checkbox"/> Dietetics | <input type="checkbox"/> Other (please say what) |
| <input type="checkbox"/> Social Work | |

B. What percentage of families of patients that you currently work with do you feel you have a constructive working relationship with?

_____ %

C. How aware do you feel of the range of experiences and ways of coping that families of people with disorders of consciousness use?

- | | |
|---|--|
| 0 | Not aware at all – most of my colleagues know more than me |
| 1 | Some awareness |
| 2 | Fairly aware – similar to most of my colleagues' knowledge |
| 3 | Highly aware |
| 4 | Very aware – I know far more than my colleagues |

D. How confident do you feel that you can manage a situation when you have to deal **ad hoc** with a distressed (crying and upset or agitated and angry) family member on the ward?

- | | |
|---|--|
| 0 | no confidence for almost every situation that I could encounter |
| 1 | slight confidence – do okay some of the time |
| 2 | moderate confidence – do okay most of the time |
| 3 | high confidence – do okay nearly all the time |
| 4 | very confident for almost every situation that I could encounter |

E. How confident do you feel that you can manage a situation when you have a **planned session** with a family member who becomes distressed (crying and upset or agitated and angry)?

- 0 no confidence for almost every situation that I could encounter
- 1 slight confidence – do okay some of the time
- 2 moderate confidence – do okay most of the time
- 3 high confidence – do okay nearly all the time
- 4 very confident for almost every situation that I could encounter

_____ POST SESSION QUESTIONS _____

Before today's presentation, had you thought about the relationships between families and staff in this way before?

- Yes
- No

How confident do you feel that you can manage a situation when you have to deal **ad hoc** with a distressed (crying and upset or agitated and angry) family member on the ward?

- 0 no confidence for almost every situation that I could encounter
- 1 slight confidence – do okay some of the time
- 2 moderate confidence – do okay most of the time
- 3 high confidence – do okay nearly all the time
- 4 very confident for almost every situation that I could encounter

How confident do you feel that you can manage a situation when you have a **planned session** with a family member who becomes distressed (crying and upset or agitated and angry)?

- 0 no confidence for almost every situation that I could encounter
- 1 slight confidence – do okay some of the time
- 2 moderate confidence – do okay most of the time
- 3 high confidence – do okay nearly all the time
- 4 very confident for almost every situation that I could encounter

Please feel free to leave any additional comments:

THANK YOU FOR YOUR TIME AND PARTICIPATION!

10.33 Appendix AG: Published papers and dissemination activity arising from work published in this thesis

The following paper includes material presented in Chapter One:

Soeterik, S.M., Connolly, S., Playford, E. D., Duport, S., & Riazi, A. (2017). The psychological impact of prolonged disorders of consciousness on caregivers: a systematic review of quantitative studies. *Clinical Rehabilitation*, Article first published online: March 14, 2017. <https://doi.org/10.1177/0269215517695372>

The following paper includes material presented in Chapter Two:

Soeterik, S.M., Connolly, S., & Riazi, A. (Submitted). "Neither a wife nor a widow": An interpretative phenomenological analysis of the experiences of female family caregivers in disorders of consciousness. *Neuropsychological Rehabilitation*.

The following poster includes material presented in Chapter Two:

Soeterik, S.M., Connolly, S. A. V., & Riazi, A. (2016, November). "Neither a wife nor a widow": An IPA investigation of the experience of women with disorders of consciousness. Poster Session presented at the meeting of British Psychological Society Division of Neuropsychology Annual Conference, London.

The following paper includes material presented in Chapter Five:

Soeterik, S.M., Connolly, S., Playford, E. D., Duport, S., & Riazi, A. (Submitted). Struggling to achieve balance: A focus group study of the experiences of multidisciplinary healthcare professionals in prolonged disorders of consciousness. *Disability and Rehabilitation*.

Dissemination Activity:

Soeterik, S.M., Connolly, S. A. V., & Riazi, A. (2012, November). "Neither a wife, nor a widow": Ambiguous Loss in families of people in Low Awareness States. Paper presented at the Post Graduate Research Forum (Cake Club), Royal Holloway University of London, Egham.

Soeterik, S.M., Connolly, S. A. V., & Riazi, A. (2012, December). "Neither a wife nor a widow": Ambiguous Loss and Low Awareness States. Paper presented at the Research Department Meeting (Lunch time takeaway), Royal Hospital for Neuro-disability, London.

Royal Hospital for Neuro-disability. (2012). Ambiguous Loss for the families of patients with disorders of consciousness following brain injury. *Brainwaves, Autumn/Winter*, Pg 2.

- Royal Hospital for Neuro-disability. (2013). Coming to terms. *RHN News, January*, Pg 4.
- Soeterik, S.M. (2014). *International Brain Injury Symposium 2014 Report*. *Advances in Clinical Neuroscience and Rehabilitation*, 14, 14. Published online 09/09/14. Retrieved from <http://www.acnr.co.uk/2014/09/international-brain-injury-symposium-2014-2/>
- Soeterik, S.M., Connolly, S. A. V., & Riazi, A. (2014, October). *“Neither a wife nor a widow”*: Prolonged Disorders of Consciousness, the experience of staff and families. Paper presented at the Research Department Meeting (Lunch time takeaway), Royal Hospital for Neuro-disability, London.
- Soeterik, S.M., Connolly, S. A. V., & Riazi, A. (2014, October). *“Neither a wife, nor a widow”*: The experiences of families and professionals of people with prolonged disorders of consciousness. Paper presented at the Psychology Department Post Graduate Research Convention, Royal Holloway University of London, Egham.
- Soeterik, S.M., Connolly, S. A. V., & Riazi, A. (2015, March). *Complex grieving and the role of staff*. Paper presented at The National Brain Injury Symposium: complexity and best practice conference, Royal Hospital for Neuro-disability, London.
- Soeterik, S.M., Connolly, S. A. V., & Riazi, A. (2015, June). *“Neither a wife nor a widow”*: Prolonged Disorders of Consciousness, the experience of staff and families. Paper presented at The Neurodisability and British Society of Disability and Oral Health Conference, Canterbury.
- Soeterik, S.M., Connolly, S. A. V., & Riazi, A. (2016, January). *Working with families of people with PDoc: a time of complex loss and grief*. Paper presented at Internal Prolonged Disorders of Consciousness Interdisciplinary Study Day, Royal Hospital for Neuro-disability, London.
- Soeterik, S.M., Connolly, S. A. V., & Riazi, A. (2016, March). *Working with families of people with PDoc: a time of complex loss and grief*. Paper presented at the External Prolonged Disorders of Consciousness Interdisciplinary Study Day, Royal Hospital for Neuro-disability, London.
- Soeterik, S.M., Connolly, S. A. V., & Riazi, A. (2016, September). *Complex coping and complex caring: The experiences of families and healthcare professionals supporting people with disorders of consciousness*. Paper presented at the Recent advances in the assessment, diagnosis and MDT management of people with disorders of consciousness Conference, Liphook, Hampshire.
- Soeterik, S.M., Connolly, S. A. V., & Riazi, A. (2016, November). *“Neither a wife nor a widow”*: An IPA investigation of the experience of women with disorders of consciousness. Poster Session presented at the meeting of British Psychological Society Division of Neuropsychology

Annual Conference, London.

Soeterik, S.M., Connolly, S. A. V., & Riazi, A. (2017, January). *Complex coping: the experiences of families of people with a disorder of consciousness and how healthcare professionals can help. Complex caring: the experiences of healthcare professionals supporting people with a disorder of consciousness and the effectiveness of an intervention on perceived competence.* Central England Rehabilitation Network. Warwick Medical School, Gibbet Hill Campus, University of Warwick, Coventry.

Soeterik, S.M., Connolly, S.A.V., Riazi, A. (2017, March). *Feeling our way forwards with families.* Prolonged Disorders of Consciousness Senior CPD Study Day. St Georges NHS Trust, London

Soeterik, S.M., Connolly, S.A.V., Riazi, A. (2017, June). *A time of complex change: The experiences of families after a disorder of consciousness and what healthcare professionals can do to help.* An Interdisciplinary Team Approach to the Management of Patients in Prolonged Disorders of Consciousness on 8th June at the Royal Hospital for Neuro-disability, London