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An exploration into the lived experiences of informal caregivers of people with prolonged disorders of consciousness- Occupational engagement patterns, role change and perceptions of the care needs of their loved one.

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Declaration

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Mile Buiochas.

Summary

The purpose of this study was to explore the lived experiences of informal caregivers of people with prolonged disorders of consciousness (PDOC) following severe acquired brain injury (ABI). The study aimed to explore the role of the informal caregiver, the impact of caregiving on time use, roles and occupational engagement patterns. Study objectives included an exploration of the preparation received by family members to take on a caregiving role and the support available to assist with managing the role. Mixed methods embedded sequential design in an overall qualitative framework was used to gather descriptive data over two phases. Purposive convenience sampling was used to obtain a sample of the Next of Kin of 37 patients admitted to a tertiary rehabilitation hospital between the years 2000 and 2013. A postal questionnaire was used to obtain quantitative data relating to the prevalence and context of informal caregiving during phase one. Mixed methods including the completion of self-rating questionnaires of caregiver strain and quality of life, along with individual, semi-structured interviews, and a time diary were used in phase two. Basic descriptive statistics and descriptive content analysis were used to analyse quantitative data and interview data was analysed using qualitative description.

The postal questionnaires yielded a 54% (n=20) response rate. The majority of respondents were providing care in residential care units (residential caregivers). The mean time since onset of severe brain injury among care recipients was 6.2 years. Almost half of the respondents had taken on caregiving in addition to working in paid employment. Eighty two percent of residential caregivers visited their relative daily or several times per week with visits ranging one to seven hours. Sensory stimulation was the most frequently carried out care task. Home caregivers (n=3) reported providing from between 75% to 100% of the necessary care for their relative with tasks ranging from personal care to advocacy. Seventy percent of all caregivers reported receiving some or a lot of preparation from the rehabilitation hospital to take on their caregiving role.

Four main themes emerged from the qualitative data obtained from ten interview participants in phase two. 'Centrality of Caregiving': caregiving was a central feature in the daily routines of all close family members. 'Self as Secondary': participants described placing the needs of others, particularly the care recipient ahead of their own needs. Caregiving impinged upon the participants' self-care, work, social and leisure activities and occupational imbalance was described among the majority of participants. 'Abandonment and isolation': Participants described their *wilful* abandonment of previous social and leisure activity on adopting the caregiving role. *Imposed* abandonment was described with a lack of follow up and support from healthcare experts over the lifetime of the care recipient. The 'constant caregiver': Caregiving was seen as a relentless and life-changing role and participants described feeling obliged to take on the care. Dealing with the 'system' and having to 'fight' for services were main causes of strain among caregivers.

The findings reflect the trend towards long-term residential care placement for severe acquired disability in Ireland (Dwyer *et al.*, 2017). The amount of time spent engaged in caregiving among the sample was often in excess of national daily averages of informal caregiving (Central Statistics Office 2012). The findings of this study add to a small existing body of literature (Goudarzi *et al.*, 2015) that specifies the informal caregiver role for people with PDOC, spanning practical and intimate care to financial management and decision making. Caregiving was often juggled with other roles including paid employment. The feeling of abandonment by formal care services was consistent with other studies of informal caregiving for people with PDOC (Giovannetti *et al.*, 2015; Covelli *et al.*, 2014). Caregiving for a relative with PDOC resulted in many hidden losses for the participants including loss of autonomy over time use and loss of other meaningful occupations in their lives. The enduring nature of caregiving described in the current study impacted upon quality of life experiences and caregiver strain was experienced over prolonged periods of time.

Areas for further research highlighted by this current study include an exploration of the hidden costs associated with long-term care provision for people with PDOC and a need for a longitudinal study of occupational adaptation amongst informal caregivers

of people with PDOC. The sensitive issue of alternatives to long-term care such as the withdrawal of life sustaining treatments was not addressed in this study. The prevalence of informal caregiving for people surviving with PDOC most likely reflects the fact that there is no alternative option but to provide ongoing care. However, further scrutiny is warranted explore this hypothesis and, with consideration of best interests' decision making, to develop the care pathway to include a range of options for the care and management of people with PDOC. Implications of the findings for professional practice include the need for a comprehensive approach to training and preparation of informal caregivers to adopt and manage the caregiver role over the life time of the patient so as to assist with managing caregiver strain and expedite a move towards occupational balance.

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Abbreviation List

ABI- Acquired Brain Injury
ADL- Activities of daily living
BSRM- British Society of Rehabilitation Medicine
CANH- Clinical Artificial Nutrition and Hydration
DOC- Disorder of Consciousness
EAT- Electronic Assistive Technology
EEG- Electroencephalography
EMCS- Emerging Minimally Conscious State
GP- General Practitioner
HSE- Health Service Executive
ICF- International Classification of Functioning, Disability and Health
MCS- Minimally Conscious State
MCSI- Modified Caregiver Strain Index
MOHO- Model of Human Occupation
NOK- Next of Kin
NTBI- Non-traumatic Brain Injury
OT- Occupational Therapy
OQ- Occupational Questionnaire
PDOC – Prolonged Disorders of Consciousness
PEG- Percutaneous Endoscopic Gastrostomy
PHN- Public Health Nurse(ing)
PMP- Per Million Populations
PVS- Persistent Vegetative State
QOL- Quality of life
RCP- Royal College of Physicians
SMART- Sensory Modality Assessment and Rehabilitation Technique
SLT- Speech and Language Therapy
TBI- Traumatic Brain Injury
UWS- Unresponsive wakefulness syndrome
VS- Vegetative state
WHO- World Health Organisation
WHO QOL-BREF- World Health Organisation Quality of Life BREF

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1. CHAPTER 1.0 INTRODUCTION

1.1. Overview

In this chapter the background to the current study is provided, along with an overview of acquired brain injury (ABI), and specifically of the phenomenon of disorders of consciousness. The ongoing care needs of people with prolonged disorders of consciousness (PDOC) will be outlined. The rationale for the study will be provided together with the study aims and objectives and definitions of key operational terms. Limitations from the outset will be acknowledged.

1.2. Background and need

Medical advances have resulted in a growing number of people surviving with severe ABI resulting in profound disability and complex, long-term care needs. Acquired Brain Injury Ireland (ABI Ireland) estimated that there are currently approximately 50,000 to 80,000 people living with traumatic brain injury in Ireland and 30,000 living with stroke (ABI Ireland, 2015). ABI will affect each individual differently with severity ranging from very mild, whereby patients make good functional recoveries through to very severe, resulting in life-limiting and life-long impairments and disability.

Moderate to severe ABI is often associated with loss of consciousness which can vary in duration from seconds and minutes, to weeks and months. In some cases, the person will never fully emerge from a state of 'unconsciousness'. The term 'disorders of consciousness' (DOC) is used as an umbrella term for a spectrum of 'states' of altered consciousness, which become 'prolonged' (PDOC) if the person fails to fully emerge to normal levels of consciousness after four weeks of onset. The duration of altered consciousness is an important clinical outcome measure (Ono *et al.*, 2001), with those who are slow to recover from unconsciousness presenting with greater levels of long-term disability and complex care needs (Royal College of Physicians (RCP) 2013; Multi-society Task Force on PVS 1994).

Figures from the United Kingdom estimated that moderate to severe brain injury occurs in 25/100,000 people per year with 2-4 (10-20%) likely to have severe disability or prolonged coma (British Society of Rehabilitation Medicine (BSRM) 2003). A smaller proportion of the overall population presenting with ABI will survive with PDOC and there is an international trend towards improved mortality rates in this population (Strauss *et al.* 1998). Information relating to the numbers of people living specifically with PDOC in Ireland is limited. Crude data extrapolated from admissions to the Irish national tertiary specialist rehabilitation hospital with a dedicated PDOC services indicates that approximately 135 people have been admitted and discharged since the service commenced in 2000.

Due to the complex and enduring needs of people with severe ABI, spending on health and social services for this group is costly to the State (Cooney and Carroll 2016). Family members play an important role in providing ongoing care to relatives surviving with ABI (Department of Health & HSE 2011) and recent national surveys suggest an upward trend in provision of care by family members for aging and disabled Irish people (Central Statistics Office 2012). The contribution of informal caregiving within society is often poorly understood and under-appreciated (Department of Health 2012). Little is known of the experiences of family members who provide care for people with PDOC in Ireland. This study aims to explore the extent of family involvement in providing care for relatives with PDOC and the impact that caregiving has on their occupational engagement, roles and routines.

1.3. Consciousness

Severe ABI frequently causes temporary interruptions to normal consciousness. Consciousness is a phenomenon that does not have a simple definition, yet it is core to our being. Fundamentally, it is the factor that differentiates the state of being in dreamless sleep from being awake (Damasio and Meyer 2009) and is considered “*the essence of personhood*” (Kaufman 2003; p. 224). Consciousness has two major components, wakefulness (or arousal) and awareness of the environment and of the self (Chawala-Schlegel and Schabus 2012; The Multi-task Force on PVS 1994, Part 1). The behavioural signs characteristic of normal consciousness include wakefulness,

primary emotions (e.g. sadness, happiness) and social emotions (e.g. embarrassment, guilt); attention- the ability to focus and sustain attention or demonstrate interest in stimuli in the environment, and purposeful behaviour including communicative behaviours and goal-orientated object-related behaviours (Damasio and Meyer 2009).

1.4. Disorders of Consciousness

Disorders of consciousness (DOC) are generally defined by what is absent rather than present such as wakefulness which is absent in the coma state. It is helpful to consider consciousness and its disorders as existing along a continuum with full and intact consciousness at one end and with death (or brainstem death) i.e., the total absence of any level of responsiveness, at the other. In between are the states that patients may experience as they recover from severe injury to the brain. These include coma, the vegetative state (VS) and minimally conscious states (MCS), moving through to severe, moderate and mild impairment towards 'full' or 'intact' cognitive function. Patients may progress through some or all of these states towards recovery. Some may regress over time from a level of consciousness to unconsciousness (e.g. from MCS to VS or coma). Similarly, some people may fluctuate on a daily or hourly basis from being more alert and aware to having minimal or no awareness (see Figure 1.1). The brainstem and its associated structures such as the thalamus play key roles in consciousness and as such, injuries to these parts of the brain are likely to result in difficulties with the pathways to higher cortical (or conscious) areas of the brain rendering the patient with significant global impairments.

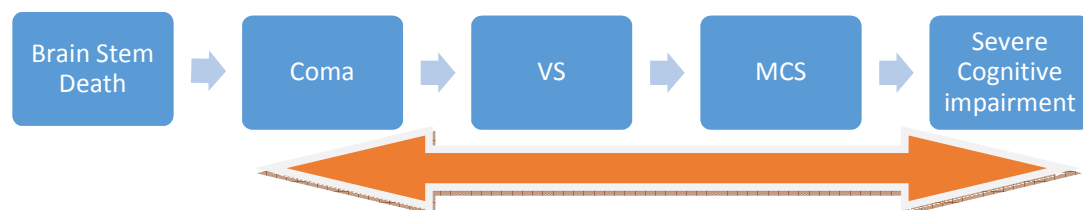


Figure 1.1 Continuum of Consciousness

The impact of providing care for a person remaining in a prolonged state of altered consciousness following coma resulting from non-progressive brain injury is the subject of this study.

1.4.1. *Brain Stem Death*

Brain stem death may occur with severe brain injury and has been described as the deepest possible coma (Bernat 2009). Brain stem death is typically irreversible and the person is completely unresponsive to all forms of stimuli. It results in complete paralysis, a sleep-like state and patients are unable to breathe on their own, thus requiring a mechanical ventilator to support their breathing. The test to confirm brain stem death involves stimulating normal reflex responses triggered in the brain stem. When these reflexes are absent, the person is deemed to be clinically dead (Bernat 2009). Reflex activity is motor activity that occurs without conscious control, such as blinking, swallowing, pupillary responses to light and other motor activity that occurs without voluntary effort. Reflexive responses are generated in the spinal cord and brain stem, and therefore are different from purposeful, voluntary movements which require conscious initiation and control from cortical areas of the brain.

1.4.2. *Coma*

Coma is described as a temporary state of “*unarousable unconsciousness*” resulting from damage to the alerting system in the brainstem. The person is unable to open his or her eyes and will demonstrate exclusively reflexive motor responses with no verbalisations or other means of communicating (Young 2009, p.138). The outcomes from coma are variable with some injuries so severe that it eventually results in death. Emergence from coma (typically defined by spontaneous eye opening) may vary from persisting alterations of consciousness such as VS and MSC to full recovery of consciousness (Young 2009).

1.4.3. *Vegetative State (VS)*

People presenting in ‘vegetative state’, sometimes referred to as ‘unresponsive wakefulness syndrome’ (Brukamp 2012; Bruno *et al.*, 2011) will have spontaneous eye opening along with periods of eye closure. Movement patterns are generally reflexive

in nature (RCP 2013; Jennett 2002; Giacino *et al.*, 1997; Giacino and Kalmar 1997). Sometimes these reflexive behaviours can be misinterpreted as being meaningful, such as the grasp reflex whereby caregivers may perceive that the person is wilfully gasping their hand or the blink reflex or facial grimaces, sometimes interpreted as attempts to communicate (Jennett 2002). There is a complete absence of behavioural signs of awareness (Giacino and Kalmar 1997). The person will at times appear awake but will be unable to interact or respond to their surroundings. They are unable to communicate and will demonstrate no evidence of language comprehension, such as ability to follow a simple command. They are fully dependent and require 24 hour care.

1.4.4. *Minimally Conscious States (MCS)*

MCS is defined as states of altered consciousness whereby the person is no longer unconscious yet not fully conscious (McCann *et al.*, 2012; Giacino *et al.*, 2002). The person has an ability to demonstrate clearly discernible behavioural signs of awareness of themselves and their environment. These behaviours are typically inconsistent but reproducible and purposeful thus, requiring conscious processing by the cortex, the part of the brain that controls voluntary movement, thinking skills and emotions (RCP 2013; Giacino and Schiff 2009; Giacino *et al.*, 2002; Giacino *et al.*, 1997). Recently it has been proposed that, rather than there being one 'state' of minimal awareness, there are three sub classifications of MCS (Bruno *et al.*, 2011; RCP 2013; Giacino and Schiff 2009) including 'MCS-' where the person is capable of non-reflexive movement but is unable to communicate or interact with their environment; 'MCS+' with patient demonstrating more complex behaviours such as command following, and finally, Emerging MCS (EMCS) whereby either reliable and consistent interactive communication or functional object use is possible (RCP 2013; Bruno *et al.*, 2011; Giacino and Schiff 2009). Despite having inconsistent levels of awareness, people with MCS will have significant levels of functional disability and will require 24 hour care.

1.5. Aetiology of PDOC

A range of disorders may cause coma which in turn may emerge to VS or MCS. These include brain lesions, metabolic disorders, seizures, toxicity, septic illness and trauma (Young 2009).

1.6. Ongoing care needs of people with PDOC

People with PDOC are profoundly disabled and will have long-term complex care needs and are the most dependent survivors of ABI. Residual impairments may include tetraplegia, incontinence of bowel and bladder, difficulty with feeding, breathing and communicating. They are highly susceptible to medical complications and secondary co-morbidities including pressure sores, contractures, limb deformity due to immobility and spasticity, chest infections due to immobility and swallowing difficulties, seizures and difficulty regulating their temperature and other autonomic functions.

People surviving with PDOC will require around the clock care in a special environment, which is usually a residential care unit or long-stay hospital setting (RCP 2013). A minority will be cared for in the family home (RCP 2013). In some countries however, if it is established that it is in his or her best interests (RCP 2013), or if the person has a living will or an Advanced Healthcare Directive that states a wish not to be kept alive in a state of permanent VS, or where their life has been deemed futile (Duttge 2012), the life is not artificially maintained using Clinical Artificial Nutrition and Hydration (CANH) and other measures. Therefore the issue of long-term caregiving may not be as relevant in some jurisdictions as it is in Ireland as the legislative and ethical framework has not advanced to accommodate such measures. A move in this direction would involve considerable constitutional, social, legal and ethical debate, but if legislated for, would mitigate the need for long-term care in such circumstances. For now, however, long-term care remains the only option available in the care pathway for people surviving with PDOC in Ireland.

Caregiving for people with PDOC is associated with significant family caregiver burden (Giovannetti *et al.*, 2012), distress (Cruzado and Elvira de la Morena 2013) and burnout among healthcare staff (Leonardi *et al.*, 2013; Gosseries *et al.*, 2012). There are few specialist services dedicated to the care and management for people with PDOC in Ireland. The most recently published clinical guidelines from the United Kingdom emphasise the need for specialist services and skilled experts to provide appropriate longitudinal assessment and management of care for people with PDOC (RCP 2013).

A decade of experience working with people with PDOC in clinical practice has provided abundant evidence of the deeply traumatic and life-changing scenario that unfolds for the family of a person with PDOC. Families experience a sense of grief, often referred to in the literature as 'ambiguous loss' (Boss 1999). The patient is alive, yet unable to 'live', to do, and often, even to communicate. It is further compounded by uncertainty of prognosis (Huber and Kuehlmeier 2012). Families have often reported waiting for months for the patient to either die or to wake up. Furthermore, a hope for recovery is evident in families who have been observed to embark on a relentless quest to find solutions and cures for their relative.

Such clinical observations of family responses are the impetus for this study as anecdotally it appeared that many families seem to put their lives on hold in the aftermath of the injury occurring. Furthermore, in recent years, an increasing number of families have taken their relative to the family home for long-term care rather than the traditional route to a residential care unit. Additionally, family members are increasingly involved in caregiving in the post-acute rehabilitation phase. The impact of family involvement in the long-term care and support of people with PDOC has not been systematically studied from an Irish perspective. There is little known about how intensively family members continue to care for relatives in VS and MCS following discharge from rehabilitation facilities or about the impact that this 'informal caregiver' role has on the caregivers time use, occupations and quality of life. The overall aim of this study was to explore the prevalence and lived experiences of informal caregiving for people with PDOC and the impact of this on the lives of family caregivers within an Irish context.

1.7. Aims of study

The aims are to explore the lived experiences of informal caregivers of people with prolonged disorders of consciousness in relation to their time use and routines, roles and their quality of life. In addition, this study aims to identify levels of strain amongst informal caregivers as well as their perceptions of their relatives' future care needs.

1.7.1. Study objectives

Phase One:

- To examine the prevalence of informal caregiving for people with PDOC, including the type and patterns of informal care provided
- To explore informal caregivers' perceptions of preparation they received from specialist healthcare professionals to enable them to adopt and manage caregiving roles.

Phase Two:

- To explore the lived experience of informal caregivers of persons with PDOC and the impact caregiving has on caregivers occupational engagement, roles and routines
- To explore perceptions of quality of life and levels of caregiver strain among informal caregivers of people with PDOC.

1.8. Limitations at outset of the study

At the outset of the study, the main limitation is the small size of the potential sample from which to recruit participants to the study. The recruitment of a study sample is limited to one tertiary rehabilitation site that specialises in treating this group of patients. Further, the researcher works at this site; however efforts are made, as outlined in Chapter 3.5.1 to reduce any possible coercion in recruitment or bias in interpretation of the study findings. Despite these limitations it remains an important area for study given the complexity of the care needs of this group and the ongoing nature of their care requirements.

1.9. Operational definitions

Prolonged Disorders of Consciousness (PDOC): refers to failure to recover full consciousness, remaining in coma, a vegetative state or the minimally conscious states, some for the rest of their lives, following acquired brain injury. Collectively, these states are referred to as disorders of consciousness and are *prolonged* if they persist longer than four weeks (RCP 2013).

Informal caregiver: relates to the provision of care, support and assistance to another person in the absence of payment for that care. It relates to care that is generally provided by family members and friends as opposed to 'formal' care in which is care provided by a person who is paid for carrying out a caregiving role (Care Alliance Ireland 2015; Goodhead and McDonald 2007).

Residential care unit: refers to an institution or an organisation that provides 24 hour care to patients residing within the facility. This care is generally funded by the patient themselves, their family or the state. In Ireland, care provision at a residential care unit is funded privately by the patient and family or by the Health Services Executive (HSE).

Occupation: refers to the broad range of goal-related activities that humans engage in. Occupations generally fall within three main categories-daily living tasks, leisure/play and work. Occupations involve 'doing' and they provide meaning and structure to time and are driven by various needs or motives (Kielhofner 2008). Engaging in a range of occupations has a positive impact upon one's wellbeing (Yerxa 1998). However, some occupations may have a negative impact on wellbeing (Kielhofner 1997). Occupational balance, that is, engaging in a variety of activities with relatively equal amounts of leisure or play and work facilitates optimal wellbeing (Christiansen *et al.*, 2009).

2. CHAPTER 2.0 LITERATURE REVIEW

2.1. Overview

A literature review exploring the lived experiences of informal caregivers for people with prolonged disorders of consciousness was conducted in order to inform the current study. This review aimed to discover what is already known about the impact that caregiving for a person with PDOC has on the lives of the informal caregiver, particularly their experiences of work, social and leisure activities. The search strategy and selection criteria used to identify relevant studies will be outlined. The literature review will be presented in two sections. In section one, an overview of the epidemiology, the functional outcomes, care needs and models of long-term care for people with PDOC is provided so as to contextualise informal caregiving within the social, cultural and economic milieu. The impact of caregiving on the lives of informal caregivers is addressed in section two with a particular focus on occupational participation and quality of life.

2.1.1. Literature search

Data was sourced from comprehensive searches of databases including Medline, PubMed, PsychINFO, Allied and Complimentary Medicine Database (AMED) and Cumulative Index to Nursing and Allied Health Literature (CINAHL). The search terms included 'informal caregiver', 'carer', 'family caregiver(s)'; combined with 'occupational'- 'engagement', 'lives', 'work', 'social', 'leisure', 'time use', 'routine', 'quality of life', 'strain', 'caregiver role(s)', 'role change' combined with '(prolonged) disorders of consciousness', 'vegetative state', 'minimally conscious state'. 'Grey data' such as government policy and reports, newspaper and online media were also accessed, along with manual searches of reference and bibliography lists. Due to the relatively few papers identified, the search period was not restricted. However, only papers published in English and with cohorts that included caregivers of people experiencing VS or MCS for longer than four weeks were reviewed.

2.2. Section One: Epidemiology, care needs and models of care

2.2.1. Epidemiology of PDOC

Although numbers of people surviving with PDOC are relatively small compared to other clinical groups, literature indicates that survival with PDOC is a growing phenomenon due to advances in emergency and neurosurgical medicine, presenting unique challenges across health, social and bioethical domains. There is a dearth of information from Ireland and at an international level regarding the specific incidence and prevalence of PDOC perhaps partially due to a lack of consensus on the diagnostic criteria for DOC (Beaumont and Kenealy 2005; Andrews 1996). Contemporary databases are essential to facilitating accurate epidemiological information (Beaumont and Kenealy 2005), and currently there is no national database for PDOC in Ireland. Further, with few valid diagnostic tools and clinicians with the relevant skills, misdiagnosis between the states of disordered consciousness is often high (McCann *et al.*, 2012; Wijdicks 2006). Misdiagnosis of VS has been as high as 41% (Schnakers *et al.*, 2009) and 56% for VS and MCS combined according to a recent Irish study (McCann *et al.*, 2012). Incidence rates of PDOC in the literature are scant, dated and primarily related to VS exclusively, due to the relatively recent confirmation of the defining criteria for MCS by Giacino *et al.*, (2002). Furthermore the majority of epidemiological studies report exclusively on populations with traumatic aetiologies (Seel *et al.*, 2013; Whyte *et al.*, 2013) and this is a widely recognised limitation of available published data (Bernat 2009; Estraneo *et al.*, 2014).

Jennett in 2002 estimated the annual incidence of VS in the UK at 14 PMP (per million populations) at one month, eight PMP at three months and five PMP at six months (Jennett 2002). It is not clear as to whether reduced numbers from one to six months indicate mortality rate or recovery rates in this acute phase. However, given that this estimation is over 10 years old, figures are likely to be higher in line with advances in medical and diagnostic procedures.

Crude data from Irish services was reported by Ni Lochlainn *et al.*, (2013) who summarised retrospective findings relating to patients with PDOC admitted to post-acute rehabilitation or long-term care beds in three hospitals. Their data described 51 patients, nine of whom were VS, 38 in MCS and four with an unknown diagnosis. Non-traumatic injuries were the most common aetiology in this group (67%) with TBI being the cause of onset for 33% (n=17) of cases (Ni Lochlainn *et al.*, 2013). However, this data was limited to three sites within the Dublin region and as such gives no indication of the national incidence or prevalence, and the data is also based on admission information to services and not survivorship rates.

The International Working Party on the Management of VS (1996) estimated that between two and ten per 100,000 of the world population were in VS (Andrews 1996). A prevalence rate of 315,000 Americans living with DOC, 35,000 in VS and 280,000 in MCS was reported in 2009 (Patrick 2009). Clinically it is difficult to predict the prognosis for PDOC although it becomes more predictable over time (Whyte and Nakase-Richardson 2013) with the likelihood of recovery reducing as time passes (Bernat 2009; Giacino and Kalmar 2005). The Multi-Society Task Force on PVS (1994) argued that it is wise to consider 'recovery' as having two dimensions- consciousness and function. People may recover consciousness yet remain severely disabled; however one cannot recover function without prior recovery of consciousness (The Multi-Society Task Force on PVS 1994 part 2).

Recovery of consciousness after 12 months is unlikely in adults who have had traumatic brain injuries (TBI), and is rare after six months in adults who have had non-traumatic brain injuries (NTBI) (RCP 2013; Giacino and Kalmar 2005) and VS is considered permanent after six months for NTBI and 12 months following TBI (RCP 2013). As the pattern of recovery tends to vary more for MCS than for VS, serial testing to re-evaluate consciousness is recommended annually until the person emerges from PDOC or dies (RCP 2013).

Those who emerge from MCS tend to do so within the first two years with a smaller percentage recovering after two years (Luaute *et al.*, 2010; Lammi *et al.*, 2005) and

recovery later than five years is rare (RCP 2013; Voss *et al.*, 2006). In many 'late recovery' cases 'recovery' relates to consciousness rather than function, with people continuing to have long-term care needs (Estraneo *et al.*, 2014; Fins *et al.*, 2007; Wijdicks 2006; Voss *et al.*, 2006; Beaumont and Kenealy 2005;). A disorder of consciousness is described as prolonged (PDOC) when the person remains in VS or MCS for longer than four weeks from the onset of injury (RCP 2013).

Acquired Brain Injury (ABI Ireland) Ireland estimated that there are currently approximately 50,000 to 80,000 people living with TBI in Ireland and 30,000 living with stroke (ABI Ireland, 2015). There is no information available relating to the survival rates of patients presenting specifically with PDOC in Ireland. The general trend reported in the literature is that people are surviving longer with PDOC (Strauss *et al.*, 1999) but with a shorter life expectancy than their healthy peers due to secondary medical co-morbidities (The Multi Society Task Force 1994 (part 2). Leonardi *et al.*, (2013) reported that 2.6% of VS patients and 4.8% of MCS patients had survived longer than ten years in their cross sectional study of 600 Italian people surviving with PDOC. This same study would suggest that those with non-traumatic brain injuries were more likely to survive longer than their TBI counterparts with 64.3% to 77% of those who lived longer than ten years presenting with non-traumatic aetiologies.

Numbers of people surviving with PDOC are likely to vary across international jurisdictions depending upon the medico-legal perspective on treatment withdrawal. In England and Wales for example, the Mental Capacity Act sets out a legal framework for those over 16 years old lacking the ability to self-determine what is in their best interests. The recent RCP guidelines on care and management of people with PDOC outlines that physicians must inform the Court of Protection if a consensus has been reached by the family and the treating team that it is not in the persons' best interests to continue to receive active life-sustaining interventions in cases of permanent vegetative state. If the Court of Protection, having scrutinized the case, particularly the approach to diagnosing permanent VS, is in agreement that any further treatment is futile and not in the patients' best interests, clinical artificial nutrition and hydration (CANH) can be ceased and other measures such as a neuro-palliative approach to

caregiving is adopted. In some cases the Court takes the view that it is 'assault' to continue to provide life sustaining measures in such circumstances (RCP 2013).

Over 40 applications made to the Court of Protection in the UK have resulted in life sustaining interventions being withdrawn on the basis of best interests decision making (RCP 2013). This system illustrates an alternative 'care' pathway for people with PDOC which impacts upon survival rates and indeed the necessity for the provision of on-going long-term care. In the Republic of Ireland there has been one case only in the history of the State whereby, the Irish Supreme Court took a decision that the life of a lady presenting in a 'near-persistent vegetative state' for 23 years should be ended. The outcome of the case, in 1995, known as re: '*a Ward of Court*' (re *A Ward of Court* (1996) 2 IR 79), was based on best interests taken from the viewpoint of the patients' parent (Hospice Friendly Hospitals 2017; Cusack *et al.*, 2000). As noted, this has been the only such case in Ireland to date and 20 years ago it presented as one of the most contentious for Irish Citizens, sparking national debate on issues surrounding the status of CANH and other life sustaining measures (Hospice Friendly Hospitals 2017).

The Irish Medical Council and Nursing Board were strong in their view that use of CANH was a humane, ordinary and necessary intervention. In 2009, the Medical Council of Ireland changed their statement somewhat from the absolute necessity to maintain all 'reasonable and practical efforts' to provide CANH to a viewpoint of the need to consider the wishes of the patient if known, the risks and burdens, and any benefit that might be achieved in using CANH. They also advocated for the involvement of family in such best interests' decision making (Medical Council of Ireland, 2009). Despite this change in perspective, no further cases of people with PDOC have presented to the Courts. The National Policy and Strategy for the Provision of Neuro- rehabilitation in Ireland (Department of Health & HSE 2011) does not make any provisions for the option of ending life-sustaining interventions based on best interests' decision making, as an alternative to ongoing, long-term care.

People with PDOC present with considerable disability resulting in “*a living body but the person is absent or questionable*” (Kaufman 2003, p. 2259). Functional recovery, irrespective of improvement in awareness is generally poor for people who have experienced PDOC (Kitzinger and Kitzinger 2014A) even with a period of early intensive neuro-rehabilitation (Eilander *et al.*, 2013). A number of older studies, such as Dubroja *et al.*, (1995) reported that 12 of 19 patient’s regained consciousness after experiencing coma of 190 days mean duration. Of the 12 patients, seven (58%) presented with moderate disability and five (42%) with severe disability following rehabilitation (Dubroja *et al.*, 1995). A US study reported that 56% to 86% of a population of patients with traumatic disorders of consciousness had regained some functional independence by five years post-injury and patients who recovered consciousness later were likely to remain more disabled (Whyte *et al.*, 2013).

2.2.2. PDOC and the International Classification of Functioning, Disability and Health (ICF)

The International Classification of Functioning, Disability and Health (ICF) aims to measure health and disability in individuals and across populations. ICF offers a biopsychosocial perspective on health, a broader view than the traditional medical model (WHO 2002) and it is a useful tool for describing the needs and challenges faced by individuals with severe ABI (Scarponi *et al.*, 2009; Leonardi *et al.*, 2014). Strong parallels can be drawn between the theoretical basis for ICF and the fundamental theoretical underpinnings of occupational therapy (Stamm *et al.*, 2006). ICF facilitates a way of communicating how changes in body function (impairments) resulting from injury or illness impact upon an individual’s capacity to carry out activities (activity limitations) and participate in their physical and social environments and life roles (participation restrictions) (WHO 2002). Figure 2.1 illustrates the interaction between ICF components.

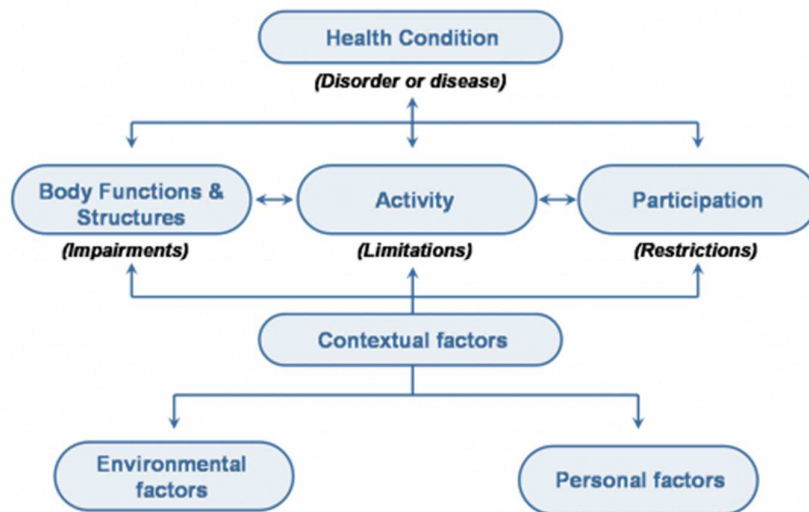


Figure 2.1 WHO ICF Model: Interaction between ICF Components.

Source: <http://www.rehab-scales.org/international-classification-of-functioning-disability-and-health.html>.

The body functions of a person with VS and MCS, particularly those requiring voluntary control will be affected as a result of damage to sub cortical and cortical areas of the brain. Typically they are immobile, incontinent of bowel and bladder and have swallowing difficulties requiring clinical artificial nutrition and hydration fed through a naso-gastric or percutaneous endoscopic gastrostomy (PEG) tube. Many will have developed secondary complications such as musculoskeletal changes and contractures resulting from spasticity (RCP 2013).

People with PDOC have multiple activity limitations and are reliant on maximum assistance from caregivers for all self-care tasks. People in VS and MCS- are unable to communicate, and people in emerging MCS may have established crude methods of communication. Overall, patients surviving with PDOC present with significant levels of physical and functional disability and will have high nursing, care and therapy needs (RCP 2013).

People with PDOC typically require care in adapted environments with maximum supports from health and social care services in addition to a requirement for specialist equipment and technology to meet their complex care needs. Finally, personal factors, which WHO defines as those aspects about a person that influence how they experience a disability such as their cultural background, personality, age and coping styles (WHO 2002) will depend upon the level of awareness that the patient presents with and this can range from no awareness of self or one's environment as in VS to fluctuating but generally inconsistent levels of awareness in MCS.

Relatives of people with PDOC will often describe them as “*present but absent*”, “*living but dead*” (Kitzinger and Kitzinger 2014, p240), a paradoxical situation whereby the person is still alive but unable to interact with their surroundings (Elliott and McVicar 2016). Gray *et al.*, (2011) established that healthy participants viewed survival in a vegetative state following a road traffic accident as being worse than death (m=4.74, SD: 1.36) for themselves (m=3.22, SD 1.41; p<0.005) and also that being in VS (m=5.04, SD-1.11) would be a worse outcome than death (m=4.00, SD= 1.57) for their family. The emotional response to having a relative survive in a state that may be perceived by some as worse than death itself results in emotional responses similar to bereavement (Kitzinger and Kitzinger 2014A; Crawford and Beaumont 2005; Kaufman 2003; Chiambretto *et al.*, 2001; Boss 1999; Tzidkiahu *et al.*, 1994). Family members frequently maintain vigil at the bedside and relatives sustain a hope for recovery many months and years after the injury (Crawford and Beaumont 2005). People who survive with PDOC have significant long-term care needs (RCP 2013) of which family caregivers are often involved in providing, resulting in significant disruption to their own lives (Elliott and McVicar 2016; Covelli *et al.*, 2014).

2.2.3. Long-term care provision for PDOC

Information is lacking relating to the care locations and provisions of care for people with PDOC in Ireland and internationally. Many studies exploring long-term outcomes of patients in VS and MCS and their caregivers suggests that care for adults with PDOC mostly occurs at residential nursing homes or long-term rehabilitation facilities rather than in the patients' own home (Ni Lochlainn *et al.*, 2013; Seel *et al.*, 2013; Whyte and

Nakase-Richardson 2013; Leonardi *et al.*, 2012; Luautte *et al.*, 2010; Wilson *et al.*, 2002). A Northern Irish study found that the majority of PDOC subjects sampled resided in residential settings including acute and rehabilitation hospitals, and residential care units. A small minority (two subjects of 35) were residing at home with care (Wilson *et al.*, 2002).

Ni Lochlainn *et al.*, (2013) does not address long-term care provision for the PDOC patients in the Republic of Ireland however it is generally recognised that the model of healthcare funding in Ireland favours residential care over community/home based care for people with significant disability and age-related infirmity (O'Shea and Monaghan 2016). This has been the focus of recent media attention as the government has been criticised for directing resources out of community care and into institutional care when legislation and policy prevents patients and their families from freeing up assets to support them in the community (O' Regan 2017; Westin 2017). Consequently, State funded home care tends to provide for basic personal and domestic care in very limited quantities and is heavily subsidised by family members either paying for private care or providing the care themselves (O' Regan 2017; Westin 2017). Residential nursing facilities designed mostly for older adults have been criticised for inadequately meeting the needs of younger people with acquired brain injury (Dwyer *et al.*, 2017; Ryan 2013; Cameron *et al.*, 2001).

Access to specialist rehabilitation services for people with PDOC is very limited in the Republic of Ireland and only provided for in one tertiary rehabilitation hospital. Typical duration of this specialised assessment and intervention is approximately three to four months after which the person is usually discharged to long-term care facilities around the country. The recommended pathway of care in the UK and the US highlight the need for slow stream rehabilitation facilities, or other specialist longer term facilities that are equipped to cater for the complex needs of people with chronic neurological disability (RCP 2013, Berube *et al.*, 2006). Continued access to rehabilitation and periodic reviews from specialists is recommended as an ongoing requirement for this client group, however such longer term services are lacking in the UK (RCP 2013).

Similarly in Ireland such specialist long-term care facilities are seriously lacking and often the staff lack the specialist skill set required for this complex client group.

Many researchers advocate the need for long-term inter-disciplinary follow-up and support for patients with PDOC and their families due to the dynamic nature of their condition (Whyte and Nakase-Richardson 2013; Wilson *et al.*, 2013), the need to manage clinical complications over time (RCP 2013) and continued monitoring for any changes or improvement in awareness (Whyte and Nakase-Richardson 2013) although generally the chance of improvement in awareness and function tends decrease over time. The survey from Northern Ireland concluded that it was likely that a number of participants received sub-optimal care placements and long-term follow-up interventions based on initial diagnosis and a lack of recognition by clinical teams of the dynamic nature of the diagnosis (Wilson *et al.*, 2013).

Decision-making processes regarding care and management for people with PDOC tends to require consideration of best interests and the effectiveness and health outcomes of interventions typically measured through analysis of functional gains, measurable quality of life and goals achieved (Rodrigue *et al.*, 2011; Martone 2006; Borgonovi 2004). Internationally, the growth in the number of people surviving with life limiting injuries has placed considerable demands on the provision and the distribution of resources across the healthcare system, creating an ethical and social dilemma for those responsible for healthcare service allocation (Congedo and Zullo 2012). The outcomes of these decisions for people surviving with PDOC can range from the withdrawal of life sustaining treatments such as clinical artificial nutrition and hydration in some countries, if ongoing treatment is not deemed to be in their best interests (RCP 2013; Huxtable 2012; Borgonovi 2004) to decisions about the quantity and duration of provision of ongoing therapy and formal care support (Whyte and Nakase-Richardson 2013; Huber and Kuehlmeier 2012; McCann *et al.*, 2012; Martone 2006; Leri 1995).

In addition, the increasing emphasis on economics in healthcare resulting in rationing of services and a focus on cutting costs has added pressures to how care and

rehabilitation programs for people with ABI operate in terms of high turnover rates and less access to follow-up and longer-term support (Leri 1995). Whyte and Nakase-Richardson (2013) note a “*vicious circle of fatalism*” that exists in relation to healthcare and treatment options for people with PDOC (Whyte and Nakase-Richardson 2013; p.1853). The consequence of this general lack of specialised long-term care and rehabilitation for people with PDOC is that the burden of care falls onto the family members to fill the gaps in service provision and to advocate for continued services and supports (Martone 2006). This burden of care and role of the caregiver is present irrespective of whether the person resides at home or in residential care (Leonardi *et al.*, 2012).

2.2.4. *Informal caregiving for people with PDOC*

Informal caregiving may be over or under-reported in official documents and research as it is generally poorly defined (Stacey *et al.*, 2016) and is very heterogeneous in nature encompassing many different aspects of care (O’Reilly *et al.*, 2008; Dilworth-Anderson *et al.*, 2002). There is a growing culture and dependence upon informal caregivers to support the practical needs of aging and disabled people in Ireland (Care Alliance Ireland 2015), with data from the previous three Census showing an upward trend in the provision of unpaid care by family members equating to 4.1% of the total population in 2011 providing care for another without payment (Care Alliance Ireland 2015; Central Statistics Office 2012). However the available data on informal caregiving is likely to be limited exclusively to care provision that occurs in the family home (Department of Health 2012) and not take account of care provided by unpaid family caregivers who assist, supplement and provide essential top up care to relatives and friends in hospitals, rehabilitation and residential care units.

Informal caregiving usually falls to one family member (Medalie 1997) and in Ireland women are more likely to be caregivers than men (Care Alliance Ireland 2015) with the majority of caregivers aged 40-55 years for both males and females (Care Alliance Ireland 2015; Central Statistics Office 2012 A). These trends are consistent with patterns of informal caregiving in other countries including Canada where 62% of informal caregivers were aged 45-54 years and 51% were female (Hollander *et al.*,

2009). Informal caregivers recruited into studies of psychological responses to caregiving for patients with PDOC would also confirm a trend of female dominance in the caregiving role, aged in their early 50's (Giovannetti *et al.*, 2015; Cruzado and Elvira de la Morena 2013; Giovannetti *et al.*, 2012; Guarnerio *et al.*, 2012; Leonardi *et al.*, 2012).

Of the 187,112 people who identified themselves as informal caregivers in Census 2011, 43% (80,891) provided up to two hours of care per day with 21% of the total number of caregivers providing fulltime care to a relative (i.e. 43 hours or more per week) (Central Statistics Office 2012 B). Caregiving for a person with PDOC was not specifically reported in the census. The average number of hours spent providing informal care for a person with advanced stage dementia in Ireland in the family home was estimated to be 13.15 hours. In economic terms this equated to 570 Euro per day to replace this care with formal caregivers (Trepel 2011).

Anecdotal evidence from clinical practice indicates that caregiving for people with PDOC is least likely to take place in the family home due to the complexities of the patients care needs, their high dependency levels and a scarcity of health and social care resources to support home discharges. The majority are transferred to residential care settings for long-term care. Although there are gaps in the evidence base from Ireland, the heavy investment by family members to meeting the ongoing care needs of people with PDOC residing both at home and in residential care facilities has been recognised in the literature from other countries (Goudarzi *et al.*, 2015; Covelli *et al.*, 2014; Guarnerio *et al.*, 2012; Leonardi *et al.*, 2012; Chiambretto *et al.*, 2001).

A large Italian study provides insights into the extent of caregiving into residential care settings by unpaid family caregivers. This observational, multi-centre cross sectional study of 487 informal caregivers for adults and children with PDOC found that over 60% of participants spent more than three hours per day with their relative. Participants providing care across a range of settings were included in the study including hospitals, post-acute rehabilitation units, long-term care facilities and the family home. Interestingly, 60.3% of the home caregivers reported providing 24 hour

care to the care recipient with 3% of the long-term residential care unit caregivers providing 24 hour care to their relative despite the presence of formal care staff to attend to the patient. Almost 20% of the informal residential caregivers spent between four to six hours in residential care facilities providing care for relatives (Leonardi *et al.*, 2012). A similar trend towards relatively high intensity caregiving was found in an earlier study of patients in long-term residential care by Chiambretto *et al.*, (2001). In this quantitative study of caregiver attitudes and reactions to having a relative in PDOC, informal caregivers spent up to three hours per day with the care recipient (mean: 3.25; range: 2-5 hours per day) five days per week (mean 4.75; range 1-7) (Chiambretto *et al.*, 2001). Being cognisant of the cultural differences that may exist between Ireland and Italy with regards to social values and norms in caring for ill or infirm family members, these studies highlight a potential prevalence of informal caregiving into residential care settings for people with PDOC. The time commitment to caregiving is intense given the availability of formal care staff to attend to needs of the care recipient.

Whilst studies show that family members spend many hours per day with their relatives regardless of care location, little research exists on the role that family members play in the provision of care for people with PDOC. How do informal caregivers spend their time a person with PDOC? A search of the literature found one study, that by Goudarzi *et al.* (2015) which offers an insight into the role of informal caregivers of patients with PDOC in Iran. Of the 16 participants, 13 were informal caregivers, mostly female and immediate family members who participated in an interview. Three professional caregivers reported their observations of the informal (family) caregivers engaging in caregiving tasks. The care provided was comprehensive and relatively specialised and included tasks such as personal hygiene, pressure area management, positioning, sensory stimulation, drug and fluid therapy, insertion of intravenous lines, management of tracheotomy and suctioning, bowel and bladder care, management of nutrition and checking of vital signs. Although this study provided some rich data illustrating a range of caregiving tasks undertaken, the sample was restricted to mainly female caregivers providing care in the home only and some had been caregiving for a relatively short period of time (mean length caregiving=

20.35 months; range 1.5- 108m). The results may not be generalizable to male informal caregivers and those providing care for relatives in residential care units due to the availability of skilled nurses and other professionals who would be more likely to carryout personal care and clinical tasks.

Caring for a family member in a vegetative state has been described as being “*dually complicated*” because of the sense of loss for person and the chronic nature of the situation (Guarnerio *et al.*, 2012, p.66). Love, affection, a feeling of responsibility, needing to protect one’s relative and avoiding feelings of guilt experienced when not present with the person may be drivers for high levels of informal caregiving among family members of people with PDOC (Huber and Kuehlmeier 2012). Additionally, perceptions of gaps in care due to subordinate care provision by the State or private services may result in families perceiving the need to provide care. Ireland has a greater reliance on informal care than the United Kingdom due to differences in government funding for formal care across the two jurisdictions, with far greater investment in National Health Service care provision, social services and in residential care in the UK (Trepel 2010). Family caregiving is the most common source of help for people with disabilities in Ireland, followed by assistance from friends and neighbours (Watson and Nolan 2011). Whilst many reasons may exist for high levels caregiving by family members including social and cultural norms and values, there is no empirical information mapping the prevalence and contexts of informal caregiving for people in PDOC in Ireland.

2.3. Section Two: Lived experiences of caregiving for a person with PDOC

2.3.1. Theoretical underpinnings informing occupational engagement

The Model of Human Occupation (MOHO) is concerned with how people organise occupations in to daily patterns and routines and engage in occupations in a range of physical, social and cultural environments (Kielhofner 2008, Kielhofner 1997). ‘Doing’ occurs within the structure of time resulting in occupational engagement becoming a

reference for time- the past, present and future, and the purpose of time resulting in cyclical patterns of 'doing' or routines (Kielhofner 2008). Occupational engagement and one's capacity for engagement alters in response to changing life circumstances such as the onset of illness or a change in one's physical or social environment. Constructs of MOHO assist with conceptualising the changes to occupational engagement patterns brought about by for example, the onset of severe brain injury in the lives of informal caregivers and the occupational adaptation that may have to occur as a result. Kielhofner (2008) described occupational adaptation as being able to meet one's own needs and desires through occupation whilst dealing with expectations from one's environment (Kielhofner 2008). Adopting a caregiver role places demands on the time use of the caregiver which will change roles, routines and patterns of occupational engagement. By exploring the constructs of volition, habituation and environment, MOHO provides a theoretical perspective for the occupational engagement patterns and adaptation of informal caregivers.

2.3.1.1. Volition

Volition is influenced by a range of feelings and thoughts such as interests, values and sense of effectiveness (personal causation) in 'doing' and relates to the innate motivation to engage in occupations (Kielhofner 2008, Kielhofner 1997). Having an interest in certain activities tends to result in these activities being preferred or prioritised. Engagement in activities that one finds interesting results in feelings of satisfaction (Kielhofner 2008). Values relates to a sense of what is important or meaningful to do. Values, often linked with moral beliefs and cultural viewpoints, tacitly influence a sense of how one should act or conform. When one does not act or conform to cultural or personal values, feelings of guilt, failure, inadequacy or lack of belonging emerge (Kielhofner 2008). Personal causation relates to capacity for doing and a sense of satisfaction and effectiveness in doing. An appraisal of one's mind-brain-body subsystem and associated skills and abilities is pertinent to one's sense of capacity for doing. Further, life experiences and events can influence and change one's sense of capacity. Self efficacy is a vital component of personal causation, relating to how effective one feels in using their personal capacities to engage in occupations,

achieve goals and influence the outcomes of tasks performed (Kielhofner 2008; Kielhofner 1997).

2.3.1.2. *Habituation*

Habituation relates to the organisation of occupations into routines. The effectiveness of routines influences experiences of satisfaction and success. With repetition, patterns of occupational behaviour become consistent and internalised into routines. These are influenced by habits, roles and the social, physical and temporal environment (Kielhofner 2008, Kielhofner 1997). Habits relate to automatic and consistent ways of engaging and are a type of internalised set of rules formed over time to guide the ability to respond in changing environments and circumstances. They are a regulating and guiding force for behaviour (Kielhofner 2008; Clark 2000). Kielhofner (2008) emphasised the importance of people, objects and events (environmental factors) in the development of habits. Habits contribute to familiar patterns of time use with well-learned habits facilitating automatic actions as well as the ability to do two or more actions or tasks at any one time adding to efficiency of time use. However, negative habits can be barriers to effective routines and can impact upon performance capacity and indeed well-being. Life events such as the onset of illness in a family can directly affect performance capacity which in turn disrupts habits. People who are faced with adversity are required to restructure habits as they begin to find ways to re-engage in meaningful daily activities, work and leisure (Kielhofner 2008).

Roles explain the status that one holds within social systems, such as 'parent', 'caregiver' or 'team-member'. Internalising a role involves adopting a set of attitudes, beliefs, actions and identity. Roles dictate how one is expected to behave, with a direct relationship existing between the roles one holds and the occupations associated with that role (Kielhofner 2008). Role identity is developed when others recognise and respond to one's actions and attitudes in a way that affirms that one holds a particular status in society (Kielhofner 2008, Kielhofner and Forsyth 1997). In order to identify with a role, one must internalise an interpretation of what the role entails and also what societal views are attributable to the role. Role identity may differ among people

who hold the same role. This is particularly true when roles do not have clearly defined social status or, are 'informal' in their nature (Kielhofner 2008), such as the roles held by informal caregivers. One caregiver may see the scope of his her role as exclusively advocating for the care recipient. Another caregiver may see his or her role as assisting with personal care or helping with therapy programmes. Further, roles can begin and end over one's lifetime, as happens for example when a woman adopts the role of wife when she marries, or a caregiver experiences role loss when a care recipient dies. Role reversal may be experienced for example, when a child takes on caregiving of a parent. Role change involves change to one's identity, relationships, lifestyle and occupations and can involve significant reorganisation for people. Having too many roles can result in 'role strain' and having too few roles can be equally negative, impacting on one's sense of purpose, identity and structure to time use (Kielhofner 2008).

Central to the concept of habituation is the idea of routine. Routine behaviour required by roles is regulated by habits, and further habits and roles are woven together to produce organised routine behaviours (Kielhofner and Forsyth 1997). Temporal (relating to time) cycles such as day and night and weekday and weekend, provide structure for routines. The places in which occupations are carried out routinely are also an important consideration, with familiar environments supporting routines and demanding less conscious effort with task performance. Similarly when behaviours are repeated in constant environments, the actions that make up habits and roles are strengthened (Kielhofner 2008). The environment may afford (facilitate) or press (present a barrier) occupational engagement (Kielhofner 1997). For example, care-giving, as an occupation, may occur in a range of social, physical, cultural and political environments. The experience of informal caregiving may be very different depending on how variables in the environment afford or press the engagement in this and all other occupations.

2.3.2. Informal caregivers of PDOC: Occupational engagement

The experience of having a relative survive with an acquired brain injury results in significant upheaval within the family unit, as families are challenged unexpectedly to adjust their lives to a "new normal" (Peterson and Sanders 2015). There is a growing

body of research to show that the more severely impaired a care recipient is, particularly in terms of cognitive and behavioural domains, the greater the level of restriction to the informal caregivers occupational participation (Caulfield and Jackson 2014; Contador *et al.*, 2012). ABI results in unique caregiving demands and research shows that family members of people with ABI experience levels of stress and burden that do not dissipate with time (Degeneffe 2001) regardless of whether one has a direct caregiving role (Goudarzi *et al.*, 2015). In this section, literature pertaining to how caregiving impacts upon the lives of informal caregivers will be explored in terms of their routines, roles and occupational engagement patterns. The impact of caregiving on the occupational lives of the caregiver of persons with PDOC has been sparsely studied with only a handful of papers published on the topic.

A recent study from the UK explored the impact of prolonged disorders of consciousness on the occupational lives of family members at six months and 12 months post-injury. The authors proposed that the impact on occupations would be sequential in nature. Firstly the person with PDOC would impact upon the family member, in turn this would impact upon occupation and eventually, due to the chronic nature of the condition, occupational adaptation would occur. This would be the point whereby the response to caregiving would be accommodated in day-to-day life rather than caregiving consuming the life of the family member (Elliott and McVicar 2016). Mixed methods including a time diary, questionnaire and individual interviews were used to gather comprehensive details about the daily routines and occupational choices of the six participants.

'Change' was a dominant theme identified over the 12 month period, experienced in occupations and roles of the participants and the environments and the medical status of the patient. Family members committed considerable amounts of time on a daily basis to caregiving with a decrease in work and leisure particularly at six months post-injury. Occupational balance was considerably affected, however at the 12 month point there was evidence that the caregivers had begun to move towards occupational adaptation and improved sense of balance. An important outcome from this study was the identification of key 'catalysts for change' for achieving improved balance through

occupational adaptation. Such catalysts included measures to reassure family caregivers that their relative was being cared for in a safe and supportive environment; medical stability and support with understanding the prognosis over time. The researchers recommended that healthcare professionals assist and support family caregivers of people with PDOC in creating the opportunity for 'catalysts for change' in their responses to caregiving commitments, to facilitate improved occupational balance and adaptation among family caregivers.

People generally do not choose to become caregivers when a family member experiences severe ABI, but rather circumstances tend to govern whether people adopt the role (Elliott and McVicar 2016). The time consuming nature of caregiving can impact on other occupations, roles and routines particularly in areas of work (Elliott and McVicar 2016; Care Alliance Ireland 2015; Goudarzi *et al.*, 2015); leisure and social activity (Giovannetti *et al.*, 2015; Goudarzi *et al.*, 2015; Covelli *et al.*, 2014; Leonardi *et al.*, 2012; Chiambretto *et al.*, 2001).

2.3.2.1. Work

Most informal caregivers in Ireland are of working age and thus are challenged to juggle care commitments with work (Care Alliance Ireland 2015). Informal caregiving frequently results in interruption to, or termination of participation in paid employment (Giovannetti *et al.*, 2015; Goudarzi *et al.*, 2015; Caulfield and Jackson 2014; Trepel 2011). The decision to forego work or education is a challenging decision to make. Future career progression and employability may be jeopardised by giving up work to provide informal care (Care Alliance Ireland 2015; Gourdarzi *et al.*, 2015). Care Alliance Ireland reported that 64% of those caring for a person with neurological illness in Ireland reported a fall in family income since the onset of the condition and 42% of 170 family caregivers had to give up work to care for a family member (Care Alliance Ireland 2014). Female gender and having multiple caregiving commitments are associated with greater risk of interruption, including termination of paid work roles (Lee and Tang 2015).

In a study of 270 informal caregivers of patients with dementia in Ireland, 63% of respondents to a survey were below the age of retirement and of this subgroup, half had stopped working to provide care. Of those who continued to work in full time employment, 61% reduced their hours, and of those in part-time employment 71% reduced their hours to less than 20 hours per week (Trepel 2010). This highlights the high numbers of informal caregivers who take on caregiving for a person with dementia in addition to their paid employment with a significant impact on their time investment to employment. No comparable Irish study relating the impact on work due to the provision of informal care for people with PDOC exists.

In the study by Leonardi *et al.* (2012) cited earlier, more than one third of the sample had to resign from their job to facilitate caregiving. Little difference was found between informal caregivers who provided care at home versus caregivers for care recipients in residential care, with comparable figures across both groups continuing in employment. Just under half (47.5%) of the residential care caregivers were employed, compared with 39.7% of the home caregivers. Similarly, Gourdarzi *et al.*, (2015) found that informal caregivers of patients with VS often put their careers on hold to provide care and additionally, family members who were not principal caregivers experienced an impact upon their careers or education. The time-consuming nature of caregiving for a person with VS was a reason for having to give up work. Whilst this qualitative study provided some rich information from the 16 participants who were interviewed, some had been caregiving for relatively short periods of time, (e.g. 1.5 months) and it is arguable that this may not be long enough for the full impact of caregiving on one's life to be felt.

Studies have highlighted that by continuing to engage in paid employment, informal caregivers experienced better interpersonal relationships and sense of social support (Scharlach 1994); feelings of fulfilment resulting from familiar activities that offer opportunities to develop knowledge and expertise (Eldh and Carlsson 2010) and sense of self efficacy and accomplishment (Scharlach 1994). The support of flexible employers has been found to be one of the most helpful factors in facilitating the juggling of caregiver roles with paid employment roles (Eldh and Carlsson 2010;

Scharlach 1994). Narrative interviews with 11 informal caregivers of ageing parents in Sweden illustrated the challenge to balance caregiving with work as participants alluded to feeling guilty about not being engaged in caregiving tasks when at work. However, despite these challenges, they described work as their “*sanctuary*”, a “*haven*” where they were free to develop themselves individually and professionally, and a reminder of “*life outside their caring responsibilities*”. Work helped to facilitate a sense of balance in their lives (Eldh and Carlsson 2010: p. 290). Caregiver burden is reduced if a balance can be achieved between paid work and informal caregiving (Carmichael and Ercolani 2016).

2.3.2.2. *Leisure and social activities*

Several studies highlight how informal caregivers for patients with PDOC experience significant changes to their participation in leisure and social activity (Giovannetti *et al.*, 2015; Goudarzi *et al.*, 2015; Covelli *et al.*, 2014; Leonardi *et al.*, 2012; Chiambretto *et al.*, 2001). The findings from these studies, four from Italy and one from Iran (Goudarzi *et al.*, 2015) bear striking similarities. The largest study was an observational, multi-centre cross sectional study carried out in Italy. Participants (n=487) were caregivers for relatives with PDOC living in a range of residential settings including the family home. The study used quantitative measures, including self-rating forms to establish burden and needs of the caregivers. The majority (n=411 of 487) of participants reported reduced engagement in leisure activities since commencing caregiving, particularly meeting with friends (67.6%) and taking exercise such as walking or riding a bicycle (50%). Participants reported reading and watching television considerably less often than prior to assuming a caregiving role. Over half of participants (61%) reported never going to the theatre or cinema and 54.4% reported that they never attend social events. More than half of the participants spent longer than three hours per day engaged in caregiving and just under half of the total sample were in paid employment (Leonardi *et al.*, 2012).

This study illustrates extensive interruption to the caregivers’ social and leisure participation. However as the methodology was quantitative in nature, there was a lack of qualitative detail obtained regarding specific reasons for reduced participation

in these activities and the lived experience of this occupational deprivation. Leonardi *et al.* (2012) hypothesised that informal caregivers possibly dedicated their former leisure time to caregiving with the belief that they could provide better care for their relative compared to care provided by the formal caregivers, or perhaps support available with caregiving was limited.

Similar findings have been reported by Giovannetti *et al.*, (2015); Covelli *et al.*, (2014); Chiambretto *et al.*, (2001). A qualitative study exploring the lived experiences of informal caregivers of patients with PDOC in Iran found that participants viewed the vulnerability and the dependence of the patient as reasons for investing considerable time towards caregiving. This impacted upon relationships, resulted in feelings of isolation, and limited time for relaxation, recreation and time to themselves (Goudarzi *et al.*, 2015). Similar feelings of loneliness, social isolation and feeling “*stuck*” were also described by participants in studies by Giovannetti *et al.*, (2015) and Covelli *et al.*, (2014). Participants described how they felt cut off from previous relationships and they had perceived that their friends had withdrawn from them, with one stating “*these situations make others run away*” (Covelli *et al.*, 2014).

A small phenomenological study of three informal caregivers of patients with dementia being cared for in the family home found that two of the three participants reported occupational imbalance and deprivation. Losing contact with people and not being able to do anything for themselves’ led to feelings of burden. Support from family members and access to respite were key to facilitating occupational participation among the caregivers (Caulfield and Jackson 2014). These studies (Caulfield and Jackson 2014; Covelli *et al.*, 2014) would suggest that home caregivers may be particularly susceptible to social isolation, perhaps due to being unable to leave the home without support from others. Small sample sizes and the diagnosis of the care recipient in the latter study reduce its generalisability to PDOC populations and to caregivers of patients in residential settings.

Loss of leisure has been associated with significantly more stress and higher levels of burden among informal caregivers of stroke patients (Kniepmann 2014). Lack of

opportunity to engage in social activities significantly correlated with anxiety and depressive symptoms ($P=0.01$) among caregivers of patients in a vegetative state (Chiambretto *et al.*, 2001). These findings were echoed in the later, larger study by Leonardi *et al.*, (2012). They concluded that caregivers of people with PDOC are more likely to experience higher levels of distress, burden and depression due to difficulty balancing caregiving with other demanding roles and their own self-care (Leonardi *et al.*, 2012). This study did compare quantitative measure scores of psychological functioning with normative data and it included a large heterogeneous group of caregivers, both strengths of the study. Inadequate support for caregivers may lead to social exclusion and occupational deprivation for caregivers (Caulfield and Jackson 2014).

2.3.2.3. *Impact on roles*

Significant role change among informal caregivers of patients with ABI is reported in the literature. Parents of adults with ABI will often experience role regression, described by Degeneffe as “*extended parenthood*” at a time when they should be looking forward to retirement (Degeneffe 2015, p.6; Degeneffe 2001). Caregiving for a spouse or partner involves significant redefining of the relationship (Degeneffe 2015; Hamama-Raz *et al.*, 2013). Siblings often play a significant role in supporting the principal informal caregiver and become “*forgotten victims*” in the sphere of family caregiving and ABI (Degeneffe and Olney 2010, p: 1416).

Some interesting studies are emerging that illustrate responses to caregiving based on gender and relationship to the care recipient. For instance, women have been found to assume a wider range of caregiving tasks than men with husbands experiencing greater challenges in their caregiving role than wives (Calassanti and Bowen 2006). A study of informal caregiving by spouses of patients with Alzheimer’s disease and dementia suggest that women in society as a whole are synonymous with doing a greater array of household and self-care tasks than men, thus facilitating greater preparation for an informal caregiving role. When faced with providing care for a relative, gender becomes insignificant and both men and women had to assume responsibility for all tasks. However males were more likely to report having to ‘learn’

tasks that were traditionally carried out by their female spouse, such as housework and also a range of gendered caregiving tasks such as applying makeup and attending to intimate personal hygiene. Men were more likely to both ask for and accept support from other family members and friends in completing aspects of their caregiving roles (Calassanti and Bowen 2006) indicating that the role is more challenging for men, as it is not a typical gender role (Chiambretto *et al.*, 2001).

Female caregivers have described feeling 'engulfed' by the role compared to males who were found to have a greater ability to strike a balance between caregiving duties, other roles and making time for themselves (Boeije and van Doorne-Huiskes 2003). The feeling of 'engulfment' among female participants in a study of 13 spousal caregivers of patients with advanced Multiple Sclerosis being cared for at home may explain why more women than men will forego their careers to assume caregiving roles and why they experience greater levels of perceived burden than male counterparts. Spouses/partners are often forced to redefine their relationships with their partner, the care recipient, often being challenged to make complex decisions on their behalf (Degeneffe 2015; Degeneffe 2001).

A qualitative study using grounded theory methodology to explore perceptions of changes in the lives of female caregivers (n=15) of patients with PDOC found that participants experienced role reduction- whereby all of life's roles were reduced to one role, that of caregiving. Caregiving became the principal priority in the lives of the women, reflecting somewhat the findings of Boeije and van Doorne-Huiskes (2003), as work-related roles and other roles became subordinate to the caregiving role. One participant reported "*I hardly have time to breathe because I'm handling so many things*" (Covelli *et al.*, 2014 p.6). Mothers spoke of the role regression associated with caregiving for adult children with PDOC- "*it's like having another child*" and they perceived their children as being helpless. Interestingly, role identity as a caregiver was not strong among the women, but rather the relational role, i.e. of mother or a partner and the duty or responsibility that comes with this relationship was more dominant for the women (Covelli *et al.*, 2014 p.5).

Similar findings were reported by McDougall *et al.*, (2014) among caregivers of adults with intellectual disability whereby there was a sense of obligation to care that stemmed from personal morals associated with relationships and kinship. Furthermore, caregiving resulted in significant occupational adaptation, with negative adaptation experienced including lack of balance in caregivers' lives and occupational deprivation as caregivers stopped certain activities so as to dedicate time to caregiving. Some positive adaptations were reported including learning new skills through caregiving and developing a new sense of meaning to their lives. There is a dearth of research on caregiving from the discipline of occupational therapy with many of the studies emerging from the realms of social science and psychology. McDougall *et al.* (2014) and Elliott and McVicar (2016) offer a refreshing perspective on caregiving from an occupational therapy perspective, linking the impact of caregiving to occupational adaptation and engagement. The generalisability of findings by McDougall *et al.*, (2014) are limited due to the significant differences in the needs of patients with PDOC compared with intellectual disability, but nonetheless they offer insight into how caregivers experience occupational adaptation.

Role change is a significant feature of the informal caregivers' experience. The role of caregiver is not only a new role but further role adjustment within family life is required (Greenwood *et al.*, 2009). Siblings for instance very often become actively involved in caregiving for a brother or sister with ABI due to the strong emotional bond that exists with the person from childhood and an expectation that they will provide ongoing care for their sibling in the absence of parental caregivers into the future (Degeneffe 2015). Sibling caregivers for adults with ABI report a number of duties including guardianship, providing financial support, advocacy, and respite for parent caregivers, companionship and transport (Degeneffe and Olney 2010).

Results of a study by Degeneffe (2015) exploring perspectives of siblings on adopting the future care of their brother or sister with a brain injury found that half of the respondents reported reluctance and resentment towards the role and were angry about the future planned assumption of the caregiver role. Moreover, having a sibling with ABI can profoundly alter the lives of siblings, introducing chaos, unexpected

changes and a sense of loss. Significant negative life events have been reported in the lives of sibling caregivers resulting from caregiving commitments including divorce, mental and physical illness and breakdown in family relationships (Degeneffe and Olney 2010). These studies illustrate the profound impact that ABI has on family life, with the caregiving role often extending beyond a parent or a partner and resulting in significant life changes for the informal caregiver. Informal caregivers often feel disconnected from society due to lack of recognition for their caregiving role (Department of Health 2012; Boeije and van Doorne-Huiskes 2003) and the need to make sacrifices and adjustments to home, family and work life (Department of Health 2012).

2.3.2.4. *Impact on routine*

No studies were found that specifically looked at the routines of caregivers of patients with PDOC. Some studies exploring the psychological impact of caregiving suggest that caregiving places considerable demands on caregivers time as they are often challenged to juggle the role with other commitments resulting in occupational imbalance, feelings of burden, and limited time for oneself (Giovannetti *et al.*, 2015; Covelli *et al.*, 2014; Leonardi *et al.*, 2014). A recent qualitative study of informal caregivers of patients who were undergoing diagnostic assessment reported that they had difficulty thinking about the future and could only deal with the present day to day routine (Giovannetti *et al.*, 2015). A possible limitation of this study is that the sample were recruited during the clinical assessment phase and as such, participants may have been experiencing expectations and hope for recovery, and were fearful of viewing caregiving as a feature of their future lives. Nonetheless, the uncertainty of the situation and the fear of looking to the future '*just in case*' was evident.

Temporal space (e.g. morning, afternoon etc.) and the environmental contexts in which activities are conducted (e.g. home, residential care unit, work environment) are important aspects of daily routine (Kielhofner 2008). Studies of caregiving routines are thus strengthened if they include methodologies that capture details of time use and the context in which habitual behaviours are carried out in order to obtain detailed description of the experience of the caregiving routine. Routine and balance in life

activities are inextricably linked (Kielhofner 2008) and it is well recognised that having an imbalance between too much work and too little leisure time leads to stress (Christiansen *et al.*, 2009) and illness (Yerxa 1998). Having a greater understanding of how informal caregivers spend their time and the demands on their time would assist occupational therapists in designing interventions to improve occupational participation and balance for caregivers (Caulfield and Jackson 2014).

2.4. Quality of life experiences of informal caregivers

Whilst informal caregiving may be seen to save the State money (Trepel 2011), it does not come without costs. These include the costs of opportunities associated with caregiving, particularly when the caregiver has had to forego work to provide care (O'Shea and Monaghan 2016). Further, there may be secondary health cost associated with informal caregiving as duration and intensity of caregiving is often an attributing factor in experiences of caregiver burden and burnout (Giovannetti *et al.*, 2012), emotional distress (Hamama-Raz *et al.*, 2013; Chiambretto *et al.*, 2001; Tzidkiahu *et al.*, 1994), poor health (Carmichael and Ercolani 2016; Jowsey *et al.*, 2013; Guarnerio *et al.*, 2012) and increased risk of mortality (O'Reilly *et al.*, 2008).

In a study of caregiver burden among 487 informal caregivers of people with PDOC, 66.5% of whom resided in residential care units and 10% at home, those caring for patients for longer than 4.9 years reported higher levels of social isolation and anxiety compared to those who had been caregiving for less than one year. Intensity, measured in daily hours of caregiving was the only factor that associated significantly with overall perceived levels of burden. Interestingly, this study found that it was time away from the care recipient that seemed to increase feelings of burden, with caregivers who spent less than three hours per day with the care recipient experiencing the greatest feelings of burden (Giovannetti *et al.*, 2012). Whilst capturing a large sample of principal family caregivers, the researchers used an exclusively quantitative methodology involving the completion of a range of self-rating forms. The choice of methodology failed to provide an opportunity to gather rich

qualitative information from participants about the types of caregiving tasks and the lifestyle changes that most impacted upon sense of burden.

Caregiving for a person with PDOC is a highly stressful experience regardless of their level of awareness. No significant difference has been found when comparing caregivers of VS and MCS patients on severity and frequency of symptoms of depression, post-traumatic stress disorder and prolonged grief disorder (Guarnerio *et al.*, 2012).

It has been argued that informal caregivers can eventually become hidden 'patients' with specific needs of their own due to the high risk of burden, burnout and the impact upon their occupational and social lives and wellbeing (Roche 2009; van Heughten *et al.*, 2006;). This may have particular relevance when the condition of the care recipient is complex, highly dependent and unlikely to improve but rather to be kept alive artificially over many years with little chance of full functional recovery. Further, the experience of caregiving for a person in vegetative or minimally conscious state may be further compounded by a relentless grief for that person- a paradoxical grief as the person is still alive but unable to interact with the world around them. This feeling of loss has been referred to as ambiguous loss (Boss 1999) and is prevalent among family members and informal caregivers of people with PDOC (Giovannetti *et al.*, 2015).

Although the literature is dominated by the negative impacts of caregiving, some studies have reported positive effects on the lives of informal caregivers. A systematic review of 17 studies of informal caregivers of stroke patients being cared for at home reported that caregiving contributed to feelings of inner strength, a feeling of mastery and a means of learning new skills. Other positive effects of caregiving, some which may be less directly generalizable to PDOC include evidence of progress and recovery, feeling appreciated by the care recipient and by the community and improved family relationships facilitated through caregiving (Mackenzie and Greenwood 2012). Caregivers of patients with PDOC in Giovannetti *et al.*, (2015) reported realisation of personal inner strengths and increased self-esteem brought about by caregiving (Giovannetti *et al.*, 2015).

2.5. Chapter summary and limitations of current evidence base

In summary, studies illustrate an international trend towards increased prevalence of PDOC. Similarly there is a trend towards increased family involvement in the provision of care for people with chronic disabilities. Studies have demonstrated that caregiving can impact upon all occupational domains, with informal caregivers often giving up their work or reducing engagement in social and leisure activities to provide care. Little is known about the role of informal caregivers in providing care to people with PDOC. However role changes brought about by assuming a new caregiver role are commonly reported in the literature. Time use studies relating to caregiving are also sparse. However the existing literature indicates that caregiving can become an all-consuming role, and caregivers often experience occupational imbalance. Significant stress, burden and prolonged grief have been reported which impacts upon quality of life for caregivers with few positive experiences such as feelings of mastery and inner strength being reported.

No studies were found that were published in Ireland relating to PDOC and caregiving. Many of the existing studies from other jurisdictions relate predominantly to the experiences of female caregivers. This may be related to social and cultural aspects of traditional gender roles. There is reliance on the use of quantitative measures in the research to explore the impact of caregiving with many existing studies reporting the experience from a psychological perspective. There is a dearth of literature focusing on the occupational and time use impacts of caregiving. Some studies report the experiences of caregiving over relatively short timeframes. Due to the increasing survival times of patients with PDOC and to allow time for roles and routines to become habitual, there is a need for a longitudinal perspective of the lived experience of informal caregiving for patients with PDOC.

2.6. Contribution to the evidence base

This is the first Irish study to explore the lived experiences of informal caregivers of patients with PDOC. It takes a longitudinal perspective of the experience and a focus on occupational engagement, roles, routine and time use. Having a greater understanding of how caregivers spend their time, both when caregiving and apart from caregiving will assist occupational therapists in designing interventions to improve caregivers occupational participation and quality of life, and offer support to them in their caregiving roles. Further, identifying the needs of informal caregivers will inform the development and implementation of a comprehensive care pathway for patients with PDOC in Ireland in line with the National Policy and Strategy for the Provision of Neuro-rehabilitation Services (Department of Health and HSE 2011) and clinical care guidelines (RCP 2013).

3. CHAPTER 3.0 METHODOLOGY

3.1. Introduction

This study is designed to explore the lived experiences of informal caregivers of people with prolonged disorders of consciousness (PDOC). The study is conducted in two phases. Phase one is designed to gather a range of descriptive information relating to people surviving with PDOC, their informal caregivers and their care environments. In phase two, information will be gathered on individual participants' perspectives regarding the experience of informal caregiving with a particular emphasis on exploring changes in occupational engagement patterns brought about by caregiving.

3.2. Aim of the study

This study aims to explore the lived experiences of informal caregivers of people with PDOC in relation to their time use and routines, roles and quality of life. In addition, it aims to identify levels of strain amongst informal caregivers as well as their perceptions of their relatives' future care needs.

3.2.1. Phase one objectives

1. To examine the prevalence of informal caregiving for people with PDOC, including the type and patterns of informal care provided
2. To explore informal caregivers' perceptions of the quality of preparation they received from specialist healthcare professionals to enable them to adopt and manage caregiving roles.

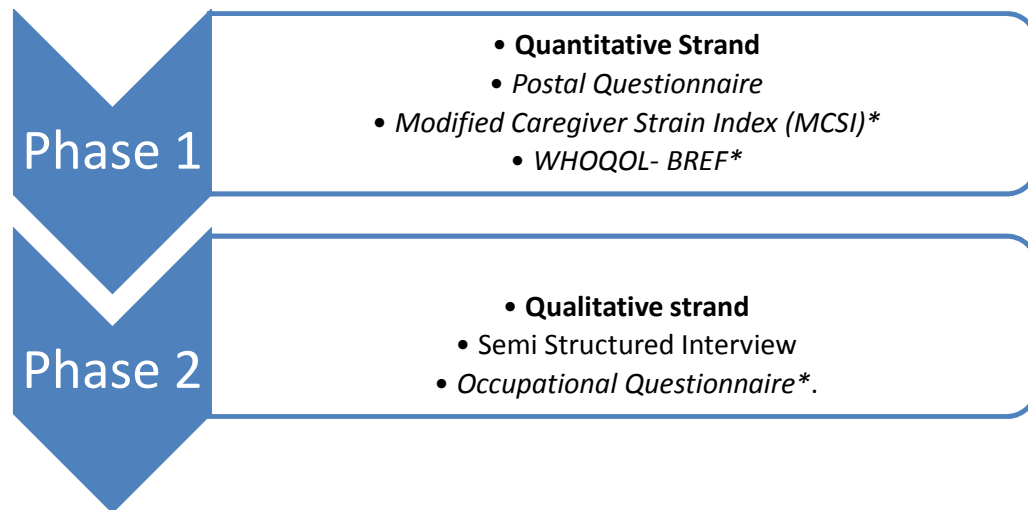
3.2.2. Phase two objectives

1. To explore the lived experience of informal caregivers of persons with PDOC and the impact caregiving has on their occupational engagement, roles and routines
2. To explore perceptions of quality of life and levels of caregiver strain among informal caregivers of people with PDOC.

3.3. Study design

A mixed method research design, using a descriptive, non-experimental approach was selected to best meet the overall study aim. This design is useful when attempting to illustrate a situation and gain information that will inform practice (Drummond 1996). Mixed methods designs are particularly useful when a combination of quantitative and qualitative data is required to give an in-depth and thorough understanding of a problem or an experience (Creswell and Plano- Clarke 2011). Using mixed methods of data collection and analysis offers a recognised way of bridging qualitative and quantitative research designs to provide a more complete understanding of the phenomena being explored (Creswell 2013).

A mixed methods design was chosen in this instance because a sole reliance on either quantitative or qualitative measures would not enable an in-depth exploration of the occupational engagement experience of informal caregivers. The use of multiple data collection tools is not uncommon in mixed methods research as it facilitates gathering a range of perspectives to assist with gaining a real-life understanding of a particular phenomenon (Creswell *et al.*, 2015). Multiple methods including self-rating scales, questionnaires and interviews, were chosen to measure family involvement in caregiving, to obtain narratives of the lived experience, to add richness and to enhance the meaning of the data obtained (Plano-Clarke and Ivankova 2016; Creswell and Plano-Clarke 2011). Figure 3.1 illustrates the multiple methods employed over two phases to gather a mix of quantitative and qualitative data to inform the research aim and objectives.



**Completed by interview sample in phase two.*

Figure 3.1 Data Collection Process

Mixed method designs are also particularly useful when the focus of a study is on examining aspects of service delivery, the experience of service users and the study of outcomes of service provision (Creswell *et al.*, 2015). One aspect of the current study involves exploring the caregiver experience of preparation by healthcare staff for the role of caregiving, as well as establishing caregiver views of the support structures that would assist them in fulfilling that role.

Quantitative measures are used in the current study to generate descriptive data relating to the prevalence of informal caregiving, demographic information of caregivers, and measures of time use, caregiver strain and quality of life. Qualitative methods are used to facilitate in-depth, individual interviews exploring the participants' lived experiences of caregiving for a person with PDOC.

3.3.1. *Embedded, sequential mixed methods design*

An embedded sequential design was selected as most appropriate typology for the current study. In embedded mixed methods designs, the data collection and analysis of both qualitative and quantitative data are combined within the framework of a traditional qualitative or quantitative research design (Plano-Clarke and Ivankova 2016; Creswell and Plano-Clarke 2011). This design is suitable for use when a number of research questions requiring different kinds of data collection are needed in order

to comprehensively address the overall purpose of the study (Creswell and Plano-Clarke 2011). It is a flexible design in which the collection and analysis of the 'second data set' (or the less dominant set of data in relation to the overall research question), may occur before, during, or after the data collection and analysis associated with the larger, overarching design (Creswell and Plano-Clarke 2011). In order to explore and describe the 'lived experience' of informal caregivers, a phenomenological approach to the experiences of subjects within their own social worlds rather than a mapping of trends or a calculation of rigid correlations is required (Mason 2002). A predominately qualitative design offers the opportunity to do this. Data is collected sequentially, with quantitative data (the 'second data set') collected in the first phase of the study, followed by qualitative data, the predominant data (the 'first data set') in the second phase. Figure 3.2 illustrates the embedded nature of quantitative data collection within an overarching qualitative data collection and analysis framework.

It is common when using embedded mixed methods design to consider the timing and analysis of both sets of data in relation to each other, and relative to the predominant study design (Creswell and Plano-Clarke, 2011). Mixing of methods can occur at both the design and data collection stages. In phase one, quantitative data collection will be embedded within a qualitative data collection and analysis framework. A study by Mayoh *et al.*, (2012) used a questionnaire containing both closed and open-ended questions. The authors described their questionnaire as "quanqual" in design, whereby primarily quantitative information was gathered and supplemented with qualitative open-ended questions. This description matches the questionnaire design used in the current study. This initial quantitative element will be used to identify an appropriate sample group for phase two (Plano-Clarke and Ivankova 2016). Furthermore, quantitative measures are required because qualitative measures alone (semi-structured interviews) would not be sufficient to gather the breath of information required to provide a contextual background upon which to build narrative descriptions in phase two.

Establishing the contextual background, including the prevalence of informal caregiving for PDOC patients in Ireland and the time spent engaged in caregiving in

relation to other occupations is essential as it will provide the context for relevant information relating to the lived experience of caregiving to be further explored in the qualitative phase of the study. Therefore, the quantitative data is directly linked to the primary, overarching question. This data not only informs the overall study findings, but also assisted in the design of the qualitative phase, thereby reflecting the interactive nature of this mixed methods design, whereby results from one phase are used to enhance the design of another phase (Plano-Clarke and Ivankova 2016; Creswell and Plano-Clarke 2011; Kaul Nastasi *et al.*, 2010;). In addition, completing the quantitative questionnaires may also help prepare and motivate participants to engage in the qualitative phase to follow.

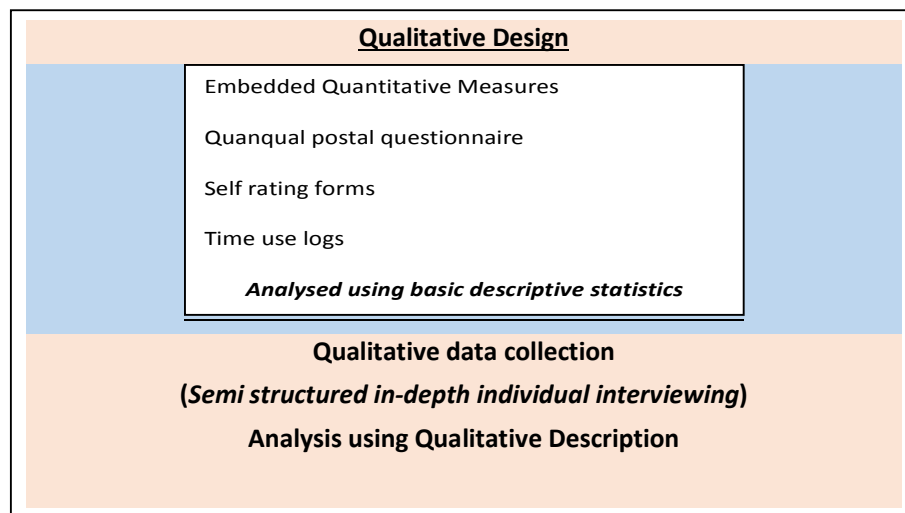


Figure 3.2 Embedded Sequential Mixed Methods Design

In this study, the phases of data collection occur sequentially. At a basic level, this involves a sequential Quan → QUAL design (Plano-Clarke and Ivankova 2016, Creswell and Plano-Clarke 2011; Kaul Nasti *et al.*, 2010). Quantitative and qualitative phases are employed in sequence, culminating in the use of qualitative data collection methods to elaborate on, confirm or explain results obtained from initial quantitative measures (Plano-Clarke and Ivankova 2016). During phase one, quantitative measures are used to obtain descriptive data on the prevalence of informal caregiving for PDOC patients, the demographic profile of caregivers and patients, the pattern of typical caregiving duties, and the experiences of caregiver strain and quality of life. In phase two, qualitative, semi-structured interviews will be used to explain and confirm data

obtained from questionnaires relating to time use, experiences of strain and quality of life and to elaborate on the impact of caregiving on other occupations, routines and roles.

Data analysis will also occur sequentially at different time stages, however results from both phases will be interpreted together in order to provide rich information relating to the experiences of caregiving. This sequential data analysis design will afford an opportunity for unexpected results or specific trends identified in the quantitative strand to be explored in more detail during the qualitative phase (Plano-Clarke and Ivankova 2016; Creswell and Plano-Clarke 2011).

Embedded mixed methods designs pose the challenge to integrate the data gathered during the analysis and discussion phases so as to address different research questions adequately. Creswell and Plano-Clarke (2011) argued that the aim of an embedded design at the analysis stage is not to merge the results, as would be common with a convergent mixed methods design, but rather to use the data from one phase to complement and enhance the other, with the results often being reported separately. Furthermore, Plano-Clarke and Ivankova (2016) suggest that a benefit of the sequential Quan → QUAL design is that the chronological sequence of data collection and analysis of quantitative followed by qualitative data makes it a straightforward design to implement for a lone researcher, as was the case in this study (Plano-Clarke and Ivankova 2016).

A philosophy of pragmatism will guide the development of the mixed methods design for this study, as the objectives of both phases require different methods of data collection and analysis – a case of considering ‘what might work best?’ whilst acknowledging that views about the reality of the phenomena in question may be diverse. Ontological assumptions guide the qualitative phase of the research whereby the nature of reality of the phenomenon of caregiving and its influence on daily life of the respondents is central whilst recognising that there may be multiple realities. The aim is to report these multiple realities and different perspectives as themes emerged (Creswell 2013). Furthermore, the researchers’ values and experiences are important

in relation to identifying the research questions and drawing conclusions from the data (Plano- Clarke and Ivankova 2016; Creswell 2013). These are outlined later in relation to reflexivity.

3.4. Theoretical framework

Human beings have an innate desire to 'do', i.e. to be actively engaged in goal orientated activity (Hocking and Wright-St. Clair 2011; Kielhofner 2008; Wilcock 2002, Yerxa 1998; Kielhofner 1997). A theoretical conceptualisation, the Model of Human Occupation (MOHO) (Kielhofner, 1998; 1997) is used to guide the development of data collection tools and data analysis. Additionally, the core concepts of MOHO assist with developing an understanding occupational engagement among informal caregivers of patients with PDOC in this study.

Human occupation is a broad concept referring to activities of daily living, productivity (work and play) and leisure that occur in physical, social and temporal contexts (Kielhofner 2008, Kielhofner 1997). MOHO is a holistic, occupation-focused model that offers a unique perspective on human occupational behaviour. It conceptualises motivation and performance as interrelated rather than viewing them as separate entities in their contribution to human occupation. Physical performance components such as musculoskeletal ability, and the cognitive, emotional and drive components required to engage in an occupation are integrated to provide a holistic understanding of the occupational being (Kielhofner 2008). Kielhofner referred to this as the 'mind-brain-body performance subsystem' (Kielhofner 1997).

The interplay between the mind-brain-body subsystem is relevant in this study of informal caregivers as feelings of physical well-being or frailty, emotional strength or feelings of burden and strain, as often reported by informal caregivers may influence motivation and drive and subsequent occupational choices, routines and sense of effectiveness (personal causation) of caregivers. In addition, MOHO offers a means to explain how occupational choices and aspects of one's routine and time use can contribute to negative experiences of health and well-being (Kielhofner 2008, 1997).

3.4.1. *Volition*

Volition relates to the innate motivation to engage in occupations and is influenced by a range of feelings and thoughts such as interests, values and personal causation in 'doing' (Kielhofner 2008, Kielhofner 1997). The concept of volition is used to assist in the design of the postal questionnaire in phase one of the study. Caregiving occupations are explored and feelings of satisfaction in one's ability to complete them are obtained. Additionally, during the interview in phase two, aspects of the broader occupational engagement of participants is explored. The interview is designed to establish a description of occupational engagement relating to values, satisfaction and interests and the changes experienced as a result of caregiving.

3.4.2. *Habituation*

Habituation relates to how one engages consistently and repetitively in occupational behaviours that eventually become internalised as routines. Routines are structured by cycles of time (temporal cycles) such as day and night and are influenced by habits, roles and the social and physical environment (Kielhofner 2008; 1997). Roles explain the status that one holds within social systems and internalising a role involves adopting a set of attitudes, beliefs, actions and identity. Roles dictate how one is expected to behave, with a direct relationship existing between the roles one holds and the occupations associated with that role (Kielhofner 2008). Role identity is developed when others recognise and respond to one's actions and attitudes in a way that affirms that one holds a particular status in society (Kielhofner 2008, Kielhofner and Forsyth 1997). The concept of habituation is used in the design of this study to facilitate an exploration of time use by adopting the Occupational Questionnaire (Riopel-Smith *et al.*, 1986). In addition, the occupational engagement patterns associated with the roles and routines of caregivers are explored by incorporating trigger questions in the interview schedule to explore both the caregiver role, and changes in other roles, experienced as a result of adopting caregiving commitments.

Concepts of MOHO will be used to assist with the analysis of results and presentation of discussion from an occupational therapy theoretical perspective. MOHO, as a

holistic conceptual model recognises the heterogeneous nature of human occupation (Kielhofner 2008; Kielhofner & Forsyth 1997). This is reflected in the descriptive accounts of the occupational experiences of informal caregivers as their patterns of occupation are illustrated within the context of individual physical, social and cultural environments, their roles, values and interests.

3.5. Sampling

The study was conducted within an Irish tertiary rehabilitation hospital that specialises in brain injury rehabilitation and includes a programme for people with prolonged disorders of consciousness. The High Dependency/PDOC Service predominantly provides specialist assessment and intervention to people presenting with PDOC however some patients are admitted with severe physical and sensory disability or Locked-in Syndrome and some are so complex that definite diagnosis of their level of awareness is difficult to establish (McCann *et al.*, 2012). Purposive, convenience sampling is used to recruit participants. Convenience sampling involves identifying participants who may be interested in participating and are accessible and available to the researcher (Acharya *et al.*, 2013, Sarantakos 2013; Morse and Richards 2002; Drummond 1996). This sampling method has been criticised for reducing credibility and narrowing options for information gathering. However it is useful when time and resources are limited (Drummond 1996, Creswell 2013) as in this study. Further, it facilitates the identification, from an already small sample group of a specific target population, those most relevant to the research topic (Sarantakos 2013; Creswell and Plano- Clarke 2011). This sampling method has been used in similar related studies (Covelli *et al.*, 2014; Sit *et al.*, 2004).

As rules of probability do not apply to this form of sampling, the focus of the research is not to ensure representativeness but to explore a topic and reflect findings through qualitative analysis (Sarantakos 2013). Qualitative research aims to uncover individual experiences from subjects who have rich information about the identified phenomenon of interest and provide an in-depth exploration of experiences, rather than produce findings that necessarily apply beyond the study participants (Creswell

and Plano-Clarke 2011). Convenience sampling is a useful way to select an “*explicitly biased*” sample that have particular characteristics, with defined inclusion and exclusion criteria being helpful in minimising too many different variables so that the end result is a relatively select homogenous sample defined by the phenomenon of interest (Hultsch *et al.*, 2002, pg. 345).

Sample sizes are thus usually small (Creswell and Plano-Clarke 2011) and determined by the specific research question and the researcher’s belief that saturation has been reached or that no new findings are emerging (Pope *et al.*, 2000). Whilst the Irish population surviving with PDOC is growing, numbers remain relatively low compared to other clinical populations. As such it is challenging to recruit a large number of participants as they simply do not exist. ‘Lived experience’ is inherently challenging to generalise as it is unique to each individual. The Irish experience of caregiving, and particularly caregiving for this unique group, may be difficult to generalise to other countries or indeed to other patient/caregiver groups due to the psychological, social, cultural and socioeconomic factors that may influence the specific experience of caregiving for a relative with PDOC.

3.5.1. *Phase One: Sampling procedures*

The recruitment of a purposive convenience sample is outlined in the steps below:

- 1) Healthcare records of patients admitted to the High Dependency/PDOC service in a Rehabilitation hospital, between the years 2000-2013, were accessed by the researcher.
- 2) Deceased patients were excluded from the study. This was evident from healthcare records and follow-up contact with general practitioners.
- 3) An ethical challenge in clinical research is the risk of collusion, persuasion and introducing sampling bias if the researcher has worked at the sample site or with the target population as in this case. It may influence participants’ decision to engage in the study or the amount and type of information they choose to share with the researcher (Sanders and Wilkins 2010). Thus, a gatekeeper was appointed at the sampling stage to minimise the risk of coercion and persuasion to participants. The Occupational Therapy Manager, who had no

previous clinical contact or relationship with the service user, acted as gatekeeper. The gatekeeper made initial contact with the next of kin (NOK) of those who met the inclusion criteria (see Table 3.1) to explain the study. Potential participants were assured that information provided would be managed in the strictest confidence, a factor that can positively influence response rates (Oppenheim 1992).

Table 3.1 Inclusion Criteria

Inclusion Criteria

- The NOK of persons alive at the time of sampling and who received care in the High Dependency/PDOC service between 2000-2013
 - 18 years or older and capable of giving informed consent to participate in the study
 - Fluency in English
- 4) The gatekeeper provided the details of those who were interested in participating in phase one to the researcher.
 - 5) The researcher mailed an Information Pack (see 3.6.1) to potential participants along with a stamped addressed envelope for return of completed postal questionnaires. Consent to participate in phase one was assumed by return of completed anonymous questionnaires.
 - 6) A reminder letter along with a copy of the postal questionnaire was forwarded to the sample three weeks after the initial questionnaire was sent. Those who had returned their questionnaire were asked to ignore the reminder. This strategy may improve response rates (Fowler 2014).
 - 7) Respondents who returned anonymous, completed postal questionnaires made up the sample for phase one of the study.

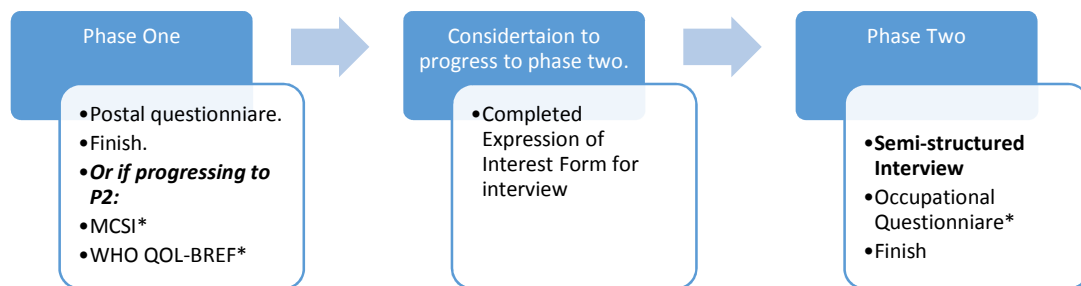
3.5.2. Phase Two: Sampling procedures

Those invited to participate in phase one received a form in the Information Pack inviting them to consider participating in an interview in phase two of the study. The following procedure was carried out to create the phase two sample group:

- 1) The researcher contacted individuals who had expressed an interest in participating in an interview, to provide an opportunity to receive more information and to ask questions in relation to participation in phase two of the study.
- 2) On confirming their interest in continuing with the interview, a date and location was arranged and an Information Pack for phase two (see 3.6.1) of the study was mailed to potential participants.
- 3) Interviews were continued until saturation in findings was reached. Those who participated in the interview made up the sample for phase two of the study.

3.6. Data Collection Procedures: Overview

The collection of data occurred in two sequential phases and involved a quantitative phase (phase one), followed by predominantly qualitative data collection involving individual semi structured interviews, in phase two. Results were analysed sequentially and some findings from phase one informed the development of the interview schedule for phase two. Figure 3.3 illustrates the process and methods of data collection.



**Completed with interview participants only*

Figure 3.3 Sequential stages of data collection.

The data collection process occurred in the following sequence:

- 1) A convenience sample of potential participants was identified using the sampling procedures outlined in 3.5.1.
- 2) A postal questionnaire (Appendix 2) was forwarded to the NOK who met the inclusion criteria and who had indicated to the gatekeeper that they were interested in receiving information about the study. Completed and returned questionnaires were taken as consent to participate in phase one of the study.
- 3) Respondents to the Expression of Interest to Participate in Interview Form (Appendix 3) were contacted by the researcher. A date and time was arranged to conduct the interview at a location convenient to them and an Information Pack for phase two was forwarded to participants.
- 4) Quantitative measures, the Modified Caregiver Strain Index (MCSI) (Appendix 8) and the WHO Quality of Life-BREF (WHOQOL-BREF) (Appendix 9) were completed prior to commencing the interview and collected at the point of interview. This was intended to provide context to the interview and focus the participant on 'their experience' rather than that of the person to whom they provided care.
- 5) Individual semi-structured interviews were completed gathering qualitative information relating to the lived experience of caregiving and its impact on occupational patterns, roles and routines.
- 6) Interview participants were asked to complete the Occupational Questionnaire (Appendix 10) for one weekday and one weekend day and return it in the stamped addressed envelope provided.
- 7) Audio recordings were transcribed and then destroyed in accordance with data protection policy.
- 8) Following analysis of the qualitative data emerging themes were summarised and forwarded to participants for member-checking (Appendix 11). At this point, a reminder to return completed Occupational Questionnaires was sent to participants along with a stamped addressed envelope.

3.6.1. *Participant information packs*

The Participant Information Pack was sent to subjects who expressed an interest in receiving more information about the study. It contained:

- Participant Information Leaflet (Appendix 1). This outlined the rationale for the study including what participating in both phases of the study entailed, along with information about how data would be managed and stored to ensure confidentiality.
- An Anonymous Postal Questionnaire (Appendix 2) was included and subjects were invited to complete and return it in a stamped addressed envelope.
- An Expression of Interest to Participate in Interview Form (Appendix 3) was included, along with a separate envelope to return it in. This was to ensure that both questionnaire and expression of interest forms were not returned together, thus impacting on the anonymity of the respondent. By signing this form, respondents were expressing an interest in receiving more information about phase two of the study and were giving permission to the researcher to make contact with them to provide further information.
- A reminder letter to return completed postal questionnaires was forwarded three weeks after the initial postal questionnaire was sent to prompt return of completed questionnaire (Appendix 4).

Participants for phase two received the following Information Pack in advance of the Interviews:

- A cover letter confirming the arrangements for interview (Appendix 5)
- A Consent to Interview form (Appendix 6)
- An Interview Schedule to help with preparing for interview (Appendix 7).

3.7. Phase One: Study design and procedures: Quantitative strand

3.7.1. Design rationale

In phase one, the quantitative strand of the study, a survey was used. Surveys are a useful method of gathering information from which patterns can be identified and characteristics of a group of individuals can be described (Drummond 1996; Bell 1993). One of the main purposes of using surveys is to establish the extent of a problem (Drummond 1996). This was a key aim of utilising a postal questionnaire in phase one of the study, as little was known about the survival rates and the long-term care arrangements for people with PDOC in Ireland. Furthermore, little was known about the extent to which family members provided caregiving to people with PDOC. A postal survey is also useful as it facilitates access to a large number of people over an expansive geographical area (Drummond 1996), as was the case with this study.

3.7.2. Phase One Data Collection Tool: Anonymous postal questionnaire (survey)

An anonymous postal questionnaire (see Appendix 2) was sent to the convenience sample. The objectives of the questionnaire were:

- To gather demographic information relating to people discharged from the High Dependency/PDOC service over a 13 year period
- To gather information relating to the persons current care environment, hours of informal care provided and to find out how well prepared the person was for taking on their caregiving role.

3.7.2.1. Design of questionnaire

The questionnaire survey was designed to review a sample of clients discharged from the High Dependency/PDOC service between the years 2000-2013. Patients admitted to and discharged from this service comprise predominantly of those with PDOC, however, in some cases people with emerged awareness and those with Locked-in Syndrome or severe acquired physical and sensory disability following ABI may be admitted to this service. Typically there is limited, if any, medical review of patients

following discharge from the service. Therefore the survey was designed to account for those who may have emerged over time since discharge from the service to states such as emerging MCS, full awareness and Locked-in Syndrome, and indeed to account for those who may have deteriorated to lower levels of awareness since discharge. The questionnaire was designed in consultation with expert clinicians at the research site so as to gather relevant information that may influence the future improvement of services in-keeping with the broad aims of the study. It included open ended and closed-ranked questions designed to gather factual and descriptive information. Multiple drafts of the questionnaire were revised upon feedback from expert clinicians to ensure the relevance of each question. Re-drafting involved changing terminology; sentence structure; omitting or adding questions and changing formats to improve presentation. Guidelines for Accessible Documents (Trinity College Dublin 2015) were used to aid in design of the layout and the language used. A glossary of terms was provided at the beginning to assist with interpreting any jargon which was used sparingly.

The broad focus of the questionnaire was to establish the extent and nature of informal caregiving for people with PDOC in Ireland. In a study by Rodrigue *et al.*, (2011), a questionnaire was used in a similar way to gather demographic and other information relating to caregiving experience of formal care-providers for people with prolonged disorders of consciousness.

Demographic information relating to the care recipient and the informal caregiver was gathered in Section 1. The extent and nature of informal caregiving for patients in residential care was established in Section 2. Section 3 was designed to gather information relating to the extent and nature of caregiving for patients in the family home. Finally, a series of Likert scales, open-ranked questions and closed questions were designed to establish details of preparation for caregiving in Section 4. Following piloting, further revisions were made. Sections are illustrated in Table 3.2 below.

Table 3.2 Anonymous Postal Questionnaire: Content

Section	Content
Section 1	<p><i>Demographic information:</i></p> <p>Caregiver demographics, including age, gender, employment status.</p> <p>Demographics of patient including gender, age, level of awareness, and current care environment.</p>
Section 2	<p><i>Residential care: (Option 1)</i></p> <p>Completed only by participants with family member being cared for in long term care. Questions included length of stay in residential care, frequency of visits and contact, type of caregiving tasks completed by participants, availability and access to a range support services and therapy.</p>
Section 3	<p><i>Caring for the person at home: (Option 2)</i></p> <p>Completed only by participants with caregiving for family member residing in the family home. Questions asked about important supports and resources supporting care in the home, number of formal care hours available each day/week, caregiving tasks that participants assisted with and frequency of provision of assistance, frequency of access to support services.</p>
Section 4	<p><i>Preparation for caregiving:</i></p> <p>Questions included level of caregiver involvement in decision making relating to care; provision of, and usefulness of care plans provided by the rehabilitation hospital on discharge; views on most suitable care environment for person with PDOC; level of support provided with preparing for caregiving role; involvement in advocacy; and self-rating scales of participants health before injury occurred to their family member, health now.</p>

3.7.2.2. *Piloting of questionnaire*

The questionnaire was piloted with five pilot participants to improve face and content validity and inter-rater reliability. Convenience and snowball sampling was used to

recruit participants. The anonymous questionnaire was given to two informal caregivers of patients with PDOC who are not included in the main sample. Both were involved in caregiving for relatives in MCS residing in residential care settings. One of the pilot participants had been discharged from the rehabilitation hospital outside of the dates suitable for inclusion in the main study. The other participant volunteered to assist with piloting the tools. A third participant, an informal caregiver of a person with dementia who is being cared for in her own home was recruited. It is important to select pilot subjects who are similar to the sample population (Drummond 1996; Oppenheim 1992) but due to the small convenience sample numbers for this study, a caregiver of a person with end-stage dementia was recruited. The questionnaire aimed to establish the experience of informal caregiving for patients both in their homes and in long-term care facilities. Therefore it was important to include relevant pilot subjects to test these variables (Oppenheim 1992).

Two experts in the area of PDOC also assisted with piloting the questionnaire. The first was based at the study site and the second was an expert involved in conducting research with family members of people with PDOC in the United Kingdom. Following the pilot, wording and answer selection options changed, questions were re-ordered and added and some were omitted due to inadvertent bias.

3.7.2.3. Questionnaire procedures

Subjects were required to complete three of the four sections with approximately 30 minutes required for completion. A stamped addressed envelope was provided for return of the questionnaire. A letter of reminder and a copy of the questionnaire were sent to the sample 3 weeks after the original questionnaire was sent. They were asked to ignore the reminder if they had already returned a completed questionnaire.

3.7.3. Phase one data analysis

Returned anonymous surveys are coded using a letter and number combination from details provided by the respondent regarding their relationship with the care recipient and the care location. An example is: "R3MR" as follows "R"= respondent, '3'= the third survey returned, 'M'- mother and 'R'= residential care unit. This is useful in

assisting with identifying different groups of respondents based on residential care environment. Further, the anonymous codes are helpful in identifying and linking content from open questions to the anonymous respondent. Closed questions are analysed using descriptive statistics including percentages and mean. This is suitable as the scope of the study is not broad enough to draw inferences, correlations or comparisons.

Conventional content analysis (Hsieh and Shannon 2005) is used to systematically identify categories and themes from open-ended questions included in the questionnaire. This type of data analysis is useful when the aim is to describe a phenomenon (Hsieh and Shannon 2005). Themes and patterns are counted so as to establish how frequently the themes present in the data.

3.7.4. *Validity*

Piloting and pre-testing instruments assisted in testing the content validity that is, the extent to which the instrument extrapolates the information it was designed to (Brink *et al.*, 2012). Following piloting, a number of amendments were made to improve content validity. Face validity is a subjective view that the tool has been designed in such a way that will adequately obtain the information it was intended to obtain (Brink *et al.*, 2012). Experts in the area of research and care provision for people with PDOC provided feedback on the face validity of the questionnaire. The process of piloting the questionnaire also improved the reliability of the tool. Redrafts of the questionnaire were made to improve the internal consistency of the questionnaire.

3.8. Phase Two Study Design and Procedures: Quantitative strand

3.8.1. *Design rationale*

Mixed methods were used to collect data in phase two of the study. Two self-administered quantitative measurement tools were used prior to the subjects engaging in individual qualitative semi-structured interviews, the Modified Caregiver

Strain Index (Onega 2013, see Appendix 8) and the World Health Organisation Quality of Life-BREF (WHO 2004) (see Appendix 9). Following the individual interviews, the Occupational Questionnaire (Smith et al., 1986) (see Appendix 10) was provided to participants to complete. Using a range of tools to explore variables such as the nature of caregiving, the impact of caregiving on how one spends ones time and quality of life domains assisted in contextualising the interview for the participants and ultimately in providing complimenting evidence to enrich the data obtained from interviews (Plano-Clarke and Ivankova 2016).

3.8.2. Data Collection Tools: Phase two quantitative strand

3.8.2.1. Modified Caregiver Strain Index (MCSI)

As reported in the literature, caregiving can induce burden and stress on both formal and informal caregivers (Hamama-Raz *et al.*, 2013; Giovannetti *et al.*, 2012; Chiambretto *et al.*, 2001; Tzidkiahu *et al.*, 1994). Strain is the combination of perceived burden and stress (Onega 2008). Strain has a negative influence on quality of life. The Modified Caregiver Strain Index (Onega 2013, 2008) (see Appendix 8) was chosen as it is quick and easy to administer, taking approximately 10 minutes to complete (Thornton and Travis 2003). The tool which is derived from the original Caregiver Strain Index (Robinson 1983) has been validated for use with informal caregivers of any age providing care to older people with chronic disability (Onega 2008, 2013; Thornton and Travis 2003). It was used in this study to explore the extent to which caregiving occupations contributed to strain.

The MCSI outlines a range of scenarios that caregivers frequently report and asks participants to rate how regularly they experience these feelings and situations. Themes include the effect of caregiving on sleep, time use, and finances, as well as feelings that may arise relating to caregiving such as being confined or overwhelmed (Onega 2013, 2008). Participants rate each of the 13 statements on a three point scale of 0-2. Higher scores indicate higher caregiver strain. As the tool was designed for use primarily with older people, some of the examples of the caregiving activities and care

recipient behaviours linked to the trigger statements were not applicable for caregivers of people with PDOC. Minor adjustments were made to the examples including:

My Sleep is disturbed: “the person I care for is in and out of bed or wanders around at night” was changed to “I wake to check on the person”.

Some behaviour is upsetting: “incontinence, drooling and grimacing” were added to the example provided.

Such changes to the examples would not alter the scoring or validity of the tool, however a request to make these modifications was made to the authors as courtesy (Appendix 8). Scoring is straightforward with sum scores ranging from 0 to 26. The higher the sum of the scores in category 1 and 2, the higher the level of caregiver strain experienced. A score of 0 indicates no perceived caregiver strain, 26 indicates extreme caregiver strain (Onega 2008). The MCSI has demonstrated test-re-test reliability (.88) in a study of 158 family caregivers (average age 61 years) of older people discharged from hospital. This study also demonstrated that the modified tool had better internal reliability than the original Caregiver Strain Index (Onega 2013; Thornton and Travis 2003).

3.8.2.2. World Health Organisation Quality of Life-BREF (WHOQOL-BREF)

Quality of life is influenced by one’s health, psychological state, relationships, environments, belief systems and goals. It concerns perceptions of self in relation to these factors and how one lives in the broad context of our culture and values (WHO, 1995). Quality of life therefore, is a complex phenomenon involving the interaction of many variables that will effectively influence how a person views themselves as a functional being, but also, how aspects of one’s health and environments can, in turn influence one’s perceptions of quality of life. The WHOQOL- BREF (WHO 2004) (see Appendix 9) is an abbreviated version of the WHO QOL-100 and is quick and easy to complete taking less than 10 minutes (WHO 1996). It was developed across 15 different centres worldwide, which makes it comparable across cultures and it has

been shown to be a reliable and valid tool. This self-administered tool was designed for use in a range of ways including clinically and also in research to capture subjective experiences of quality of life and well-being (WHO 2015). When dealing with sensitive issues such as caregiver strain and one’s quality of life, it has been argued that self-administered questionnaires are a superior way to gather data, as participants do not have to disclose directly to the researcher negatively valued information (Fowler 2014). Thinking about the past four weeks, the WHOQOL-BREF requires participants to rate how they feel about their quality of life. Four domains of QOL (see table 3.3) are rated on a series of Likert scales.

Table 3.3 World Health Organisation Quality of Life- BREF: Summary

World Health Organisation Quality of Life- BREF: Summary

Domain

Physical:

Activities of daily living, energy & fatigue, mobility, pain & discomfort, sleep & rest, work capacity, dependence on medical substances and medical aids.

Psychological:

Body image & appearance, negative feelings, positive feelings, spirituality, self-esteem, thinking, learning, concentration & memory.

Social relationships:

Personal relationships, sexual activity, social support.

Environment:

Home environment, financial resources, freedom, safety, security, opportunities for gaining information and skills, participation in recreation & leisure, transport.

How would you rate your **quality of life**?

How satisfied are you with your **health**?

How often do you have **negative feelings** such as blue mood, despair, anxiety, depression?

When scoring the tool, four domain scores can be generated, as well as separate scores relating to the persons overall perception of their quality of life, and of their health. Higher domain scores indicate positive perceptions of one’s quality of life (WHO 1996). The WHOQOL-BREF has demonstrated “*good discriminant validity, content validity and test re-test reliability*” (WHO 2015, p.4). The WHOQOL-BREF can

discriminate very well between people who are healthy and those who are ill (Chronister *et al.*, 2010). Chui *et al.*, (2006) studied the reliability and validity of the WHOQOL- BREF with a population of n=199 participants who had experienced TBI. They identified that the WHOQOL-BREF had excellent internal consistency, good content validity, good responsiveness and good reliability and interpretability (Polinder *et al.*, 2015). The tool has been used in a number of studies involving informal caregivers of people with severe brain injury including a studies by Chronister *et al.*, (2010) and Jackson *et al.*, (2009).

3.8.2.3. Occupational Questionnaire

The Occupational Questionnaire (Smith *et al.*, 1986) (see Appendix 10) was designed for use by occupational therapists as a structured method to gather information relating to time use and activity participation and the theoretical basis of its design is the MOHO (Kielhofner 1997). The tool provides detailed information about habits and routines, i.e. how people spend their time (Kielhofner 1997), useful in assisting with achieving the aims of this study. Further, the tool is unique in that it illustrates the 'experience' of occupational engagement in terms of personal causation, the value of occupation for the person and informs the researcher about the person's broader occupational interests and engagement patterns (Kielhofner 1997) which allows one to appraise occupational balance.

Informal caregiving is demanding of time, and this can result in a disproportionate amount of time being allocated to caregiving tasks, often to the detriment of other occupations such as paid employment, leisure and social contact (Caulfield and Jackson 2014, Giovannetti *et al.*, 2012, Guarnerio *et al.*, 2012). The aim of the Occupational Questionnaire which is essentially a time diary (Newton Scanlan and Bundy 2011) was to capture the numbers of hours that participants spent engaged in caregiving. Participants were asked to record how they spent their time over half hour intervals for one typical weekday and one weekend day from 5am to 12 midnight. Further, they were asked to categorise each activity according to five headings: work, daily living work, recreation, rest and the fifth 'caregiving', added with permission from the authors (see Appendix 10). In addition, they were asked to rate on a Likert scale how

well they executed the activity; how important the activity was to them and how much they enjoyed the activity. Whilst this information is valuable in analysing satisfaction in occupational engagement, it was not the pertinent focus for this study, thus the OQ was used exclusively to decipher how much time was spent engaged in caregiving on an average day and weekend day. It was scored by adding up total times spent engaged in the 5 occupational domains. The results were presented descriptively to demonstrate how much time was being allocated to caregiving. There is a dearth of empirical literature on the use of the OQ with caregivers however Newton-Scanlan and Bundy (2011) noted that it has been used in a number of small scale studies mainly in the area of mental health research. It has demonstrated good concurrent validity and acceptable test-retest reliability in a study by Smith *et al.*, 1986, cited by Newton Scanlan and Bundy (2011).

3.8.3. *Phase two quantitative procedures*

Prior to engaging in the semi-structured interviews, the MCSI and WHOQOL-BREF were self-administered by the participants. Instructions for completion of each tool were given. They were provided with an opportunity seek clarification as required. Following the interview, the Occupational Questionnaire was provided. The form was explained and participants were asked to complete it for one weekday and one weekend day, returning it within three weeks in the stamped addressed envelope provided.

3.8.4. *Phase two quantitative data analysis*

The data collected from the quantitative data collection tools is analysed and presented as follows:

Modified Caregiver Strain Index: The sum score from each of the completed self-rating forms give a figure between zero and 26. Each participant's score is reported individually along with a participant profile summary in the Chapter 4 (4.7.2). Statistical analysis is not conducted as the aim is to describe the participants' experience of the phenomenon. Scores approaching 26 indicate significant levels of perceived strain. Scores closer to zero indicate minimal experiences of strain.

WHO Quality of Life-BREF: Raw scores for each of the four domains are calculated and the method outlined in the administration and scoring guidelines provided by WHO

(1996) to is followed. Transformed scores from zero to 100 are presented. Domain scores are scored in a positive direction, thus the higher the score, the better the quality of life experience within each domain (WHO 1996).The transformed scores for each domain, for each participant are presented along with a participant profile in Chapter 4 Results (section 4.7.2). Information obtained regarding participants' experiences of overall quality of life, satisfaction with health and frequency of negative feelings are presented descriptively using the Likert rating identified by the participant and are reported in individual participant profiles.

Occupational Questionnaire: A sum of the total hours spent engaged in caregiving over two days, one weekday and one weekend are presented descriptively in participant profiles in Chapter 4 Results (4.7.2).

3.8.5. Validity

Pre-testing the MCSI, the WHOQOL-BREF and the Occupational Questionnaire provided an opportunity for the researcher to practice scoring and interpreting the data and allowed one to test how feasible and valid the tools were to the study. Studies have illustrated the reliability and validity of the self-administered tools used in the study as summarised in Table 3.4 below.

Table 3.4: Validity and Reliability of Self-rating Tools.

Tool	Content validity	Concurrent Validity	Test reliability	re-test	Internal consistency
MCSI			.88 <i>Thornton & Travis 2003, Onega 2003</i>		
WHOQOL-BREF	Good <i>Polinder et al. 2010</i> Excellent <i>Chiu et al. 2006</i>		Good <i>Polinder et al. 2010</i> Very good <i>Chiu et al. 2006</i>		Excellent <i>Polinder et al. 2010</i> Very good <i>Chiu et al. 2006</i>
OQ		Good <i>Newton Scanlan & Bundy 2011</i>	Acceptable <i>Newton Scanlan & Bundy 2011</i>		

3.9. Phase Two Study Design and Procedures: Qualitative strand

Respondents who expressed an interest in progressing to phase two of the study participated in a qualitative semi-structured interview. Interviews were completed until saturation of findings was reached. Principles of qualitative description influenced the design of the qualitative phase of the study.

3.9.1. Design Rationale: Qualitative description

Qualitative description, originating in the tradition of qualitative research is concerned with the investigation of human experiences of phenomena (Sandelowski 2010; Neergaard *et al.*, 2009; Magilvy and Thomas 2009). The exploration of experiences using qualitative description involves the answering of “who”, “what” and “how” questions (Neergaard *et al.*, 2009). Qualitative descriptive studies by nature, echo philosophical attributes of naturalistic enquiry (Sandelowski 2010, 2000) and although less theoretically driven than other forms of naturalistic enquiry such as grounded theory or phenomenology, the researcher may draw on elements of these forms of enquiry to describe the lived experience of phenomena (Sandelowski 2000). The analysis is not so concerned with interpretation, as is the case with phenomenological methodology, but rather with providing rich and detailed descriptions of the experience as outlined by the participant using their words and terminology and in doing so, ensuring that the researcher stays close to the ‘surface’ of the data gathered (Magilvy and Thomas 2009; Neergaard *et al.*, 2009; Sandelowski 2000).

Qualitative description was chosen for this study as it provides a very useful way to obtain an initial insight into views of participants related to particular phenomena (Magilvy and Thomas 2009; Neergaard *et al.*, 2009; Sandelowski 2000) to illustrate the experience rather than draw concrete inferences or interpretations. As the experiences of Irish caregivers for people with PDOC have never been explored before, this descriptive approach was suitable to obtain preliminary insights that may lead to further empirical investigation involving interpretative analysis in the future. The

'who', 'what' and 'where' of the occupational engagement patterns of caregivers and the influence of caregiving on occupation, roles and routines of the caregivers is examined. Additionally, qualitative description is a useful methodology to employ in mixed methods research where a pragmatic approach to data collection and analysis is indicated and particularly when an element of the research is to explore intervention development or needs assessment of clinical groups (Neergaard *et al.*, 2009). Qualitative description is believed to be a suitable way of analysing data when the views of service-users/patients (or their caregivers) and professionals is required to explore experiences of the organisation of the healthcare system in order to inform change or service development (Magilvy and Thomas 2009; Neergaard *et al.* 2009). Gleaning an understanding the caregiver experiences of the healthcare system in preparing them to adopt and manage the role of caregiver is an aspect of the broad aims of this study.

Qualitative description is useful methodology to employ when exploring the lived experience of phenomena if time and resources limit the use of more detailed, interpretative methodology such as phenomenology. Qualitative description is a flexible approach and whilst "*hues*" and "*tones*" of phenomenology (Sandelowski 2000, pg. 337) influenced the employment of qualitative description in this study, the researcher is careful to avoid 'posturing' the research as an in-depth qualitative interpretative study (Sandelowski 2000), which indeed it is not. It is descriptive in nature. The characteristics of qualitative description that guide the design of this study are illustrated in Table 3.5.

Table 3.5 Characteristics of Qualitative Description (Sandelowski 2000) used in Study Design- Qualitative Strand

Study Design	Characteristics of Qualitative Description
Philosophy	Pragmatic approach
Theoretical Framework	Naturalistic enquiry
Sampling	Purposive techniques Samples are composed of individuals who are “information rich” (Sandelowski 2000, p. 338).
Data Collection	Individual interviews Aim to explore the “who”, “what”, “where” of events and experiences (Sandelowski 2000, p. 338).
Data Analysis	Qualitative content analysis. Codes generated from the data itself are applied. Low levels of interpretation. Focus is to describe and ‘stay close’ to the data.
Data Re-presentation	Results are presented as “straight descriptive summaries”. Different experiences of the same phenomena are presented. The “surface” of the data is presented rather than deep interpretations (Sandelowski 2000, p.338).

3.9.2. *Data Collection Methods: Semi-structured interview*

Individual semi-structured interviews were conducted during phase two of the study and the aims were:

- To explore the role of informal caregivers in the long-term care provision for people with PDOC
- To identify the impact of informal caregiving on the occupational engagement patterns, roles and routines
- To explore relationships between caregiving and perceptions of quality of life and caregiver strain.

Semi-structured individual interviews were the chosen in preference to other suitable methods of data collection such as focus groups because the experience of having a family member survive with PDOC may be very distressing, and participants may not

have been comfortable talking about their experiences in a group situation fearing becoming upset or feeling cautious about expressing their emotions. This is a common limitation of focus groups (Brink *et al.*, 2012). Further, in-depth interviewing is particularly useful in qualitative occupational therapy research, assisting with the exploration of the meaning of occupation in people's lives. Its purpose is not to test hypothesis but to learn more about the effect of phenomena on participant's experience of the world, by uncovering meanings, views and perspectives with the interviewee acknowledged as the expert imparting this knowledge to the researcher (Valiant Cook, 2001).

Semi-structured interviewing is a common method of data collection in qualitative descriptive studies (Magilvy and Thomas 2009; Neergaard *et al.*, 2009; Sandelowski 2000) with elements of both structured and unstructured interview styles employed (Sarantakos 2013). Closed and open-ended questions can be used (Sarantakos 2013, Brink *et al.*, 2012) along with probes to expand the discussion and help with development of rapport and trust between researcher and participant. Probes can also indicate to the participant that the researcher is interested in what they have to say (Brink *et al.*, 2012). Individual interviewing has many advantages and it is one of the best ways to collect "high quality data from a population sample" (Fowler, 2014, p. 66). Interviews are often considered a less demanding method of data collection for participants compared with complex questionnaires for example. The interview process affords an opportunity to observe non-verbal behaviour and to correct any misunderstandings, as well as the opportunity to present complex questions. Response rates tend to be high with interviews (Sarantakos 2013).

Some limitations to using interviewing are acknowledged. Interviewing is time-consuming and less convenient than other methods and interviewer bias may be high (Sarantakos 2013). To counteract this, openly acknowledging personal interests and experiences relating to the topic with participants (reflexivity) and keeping field notes to record feelings and thoughts that may bias results has been recommended (Conneeley 2002). Despite these limitations, interviewing is used widely in studies relating to experiences of caregivers with PDOC and other chronic conditions. An

important study conducted recently involved interviewing 51 relatives of people surviving with prolonged disorders of consciousness in the United Kingdom (Edgar *et al.*, 2014; Kitzinger and Kitzinger 2014a, 2014b). Results from this vast quantity of data resulted in the development of content for an on-line resource (www.healthtalk.org.uk) to support other families in similar situations. A semi-structured interview has been used to explore healthcare professionals' perspectives on end-of-life decision-making with people with PDOC (Rodrigue *et al.*, 2011) and perceptions of life changes experienced by informal female caregivers of patients with PDOC in Italy (Covelli *et al.*, 2014); and experiences of ambiguous loss with informal caregivers of people with PDOC (Giovannetti *et al.*, 2015).

3.9.3. *Design of interview schedule*

The design of the interview schedule was directed by the broad aims of the study, existing similar studies relating to caregiving for persons with PDOC (Hamama-Raz *et al.*, 2013; Covelli *et al.*, 2014; Gourdarzi *et al.*, 2015) and the guiding theoretical underpinnings of MOHO. Interview questions relating to time use, roles, routine, and satisfaction in occupational engagement were influenced by insights offered by MOHO regarding human occupational behaviour, to comprehensively explore the lived experience of caregiving and its influence on the broader occupational lives of the participants. Further, themes arising from the scaled responses and categories in the self-administered questionnaires were elaborated on during the interview in an effort to illustrate their full meaning. This is a very common data collection strategy used in mixed methods design (Bryman 2006, cited in Bazeley 2010). This type of *sequential* mixed methods relates to the use of qualitative and quantitative measures in a consecutive way, with subsequent questions emerging from earlier methods used (Kaul Nastasi *et al.*, 2010). In keeping with the ethos of qualitative description, the questions were open-ended, emphasising the 'who', 'what' and 'where' of the phenomena (see Table 3.6).

Table 3.6 Sample questions from Interview Schedule

	Question/ trigger statement	Reference from existing literature that contributed to question formation
Daily routine	Describe your daily routine. Is your routine the same every day?	A qualitative study on perceptions of changes reported by caregivers of patients in vegetative and minimally conscious state: The 'Time Gap Experience' (Covelli et al., 2014)
Roles	Tell me about your roles in life and how has your relative's illness influenced the roles you play? Describe the role you have with your relative.	From Hope to Despair, and Back: Being the wife of a patient in a persistent vegetative state. (Hamama-Raz et al., 2013) Multiple victims: The result of caring for patients in vegetative state. (Goudarzi et al., 2015)*
Caregiving	Tell me about how you spend time with your relative... has your caregiving role changed over time? What are the most/least satisfying caregiving tasks	Goudarzi et al., 2015*.
Well-being and quality of life	What makes you think it has been a good day/ bad day? Tell me about your QOL...what contributes positively/negatively to your wellbeing? Tell me about social contacts and relationships.	Patients in a persistent vegetative state: caregiver attitudes and reactions. (Chiambretto et al., 2001) Coping and distress in caregivers of patients with disorders of consciousness. (Cruzado & Elvira de la Morena 2013)
Preparation	How prepared did you feel for taking on care-giving role? What would have been beneficial in helping you to be more prepared?	Prolonged Disorders of Consciousness National Clinical Guidelines: Report of a working party. (RCP 2013)
Future care needs	What influences your feelings about care being provided? Thoughts regarding the future care needs of your relative?	Grief, anger and despair in relatives of severely brain injured patients: responding without pathologising. (Kitzinger & Kitzinger 2014)

3.9.4. *Piloting of interview schedule*

The interview schedule was piloted with two conveniently sampled pilot subjects- an informal caregiver of a person with PDOC who is being cared for in residential care and a caregiver of a person with late-stage dementia who is being cared for at home. An expert clinician was invited to critically appraise the interview schedule and asked to provide suggestions for further themes to explore or questions to omit. Whilst not a substitute for a pilot sample, an expert can be useful to “*to pick your questions to pieces*” (Oppenheim 1992 p. 63). The pilot interviews provided an opportunity for the researcher to practice interview skills, including taking a consistent approach to the interviews, to practice probing, gathering field notes and reflection (Drummond 1996). Minor adaptations were made to the interview schedule following the pilot to improve content and face validity.

3.9.5. *Procedures for Data Collection: Qualitative strand*

Respondents to the Expression of Interest in Interview Forms were contacted by the researcher and arrangements were made for the interview to take place. Two weeks prior to the interview, participants received a copy of the interview schedule. Interviews took place at locations and times convenient for participants and were audio-recorded. Audio-recording can help to reduce frequent interviewing errors including selective hearing, too early or too late registration of responses, and incomplete, faulty or illegible responses (Sarantakos 2013). Following each interview, audio data was transcribed and recordings were deleted in accordance with data protection guidelines.

3.9.6. *Qualitative data analysis*

Transcripts were read and re-read by the researcher. Codes were marked in the margin of each transcript to assist with describing the data and organising it in to categories (Miles and Huberman 1994). Data was examined descriptively to find common patterns and differences in the material (Magilvy and Thomas 2009). The data was then imported into QSR Nvivo software (QSR International, 2016) and further analysis occurred to identify relationships between the content in the categories to identify themes (Magilvy and Thomas 2009).

3.9.7. *Methods to ensure trustworthiness*

Techniques outlined in a model proposed by Guba (1981) and Guba and Lincoln (1989) were employed to strengthen the trustworthiness of methodology used in phase two.

The four elements to the model are:

- a) Credibility- this relates to how confident one is in the 'truth' of the findings.
- b) Transferability- relating to the ability to demonstrate that the findings may be applied in other contexts (Robert Wood Johnston Foundation 2008). This was not relevant due to the descriptive nature of the study. The data holds descriptive value in and of itself (Krefting 1991) and is not broadly generalizable outside of the target population.
- c) Dependability- measures taken to ensure that the research was carried out in a consistent way and may be repeated
- d) Confirmability- this relates to the neutrality of the findings and the extent to which findings are based as exclusively as possible on the information gathered from participants rather than the influence of researcher bias, motivations or interests (Robert Wood Johnston Foundation 2008; Krefting 1991; Guba and Lincoln 1989; Guba 1981).

Strategies (see Figure 3.4) relating to each element of the model are used to ensure that the research is carried out with rigour and trustworthiness.

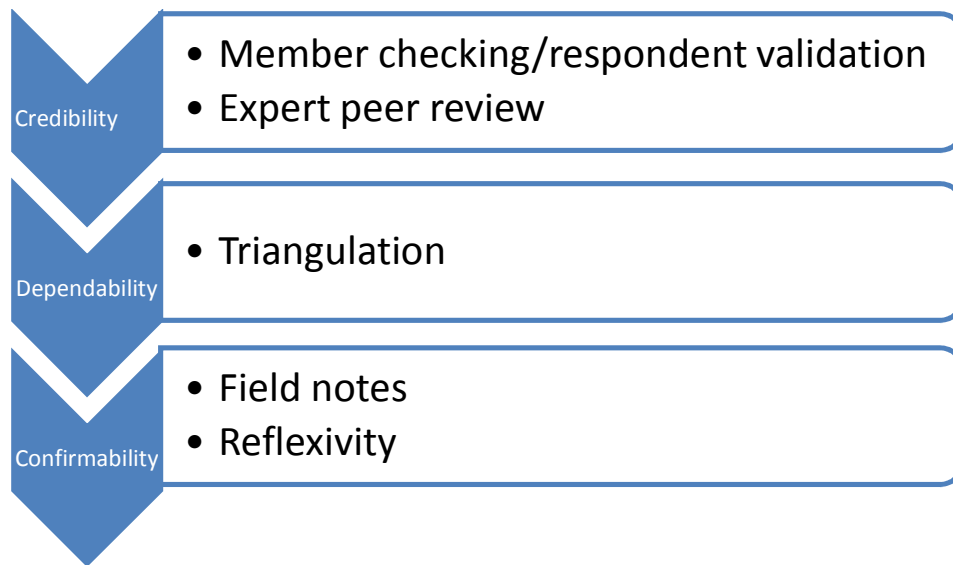


Figure 3.4 Strategies used to establish trustworthiness (Krefting 1991; Guba & Lincoln 1989; Guba 1981)

3.9.7.1. Member checking/Respondent validation

Member checking is commonly used in qualitative studies and has been described as one of the most important measures to improving the trustworthiness of the findings (Sarantakos 2013; Brink *et al.*, 2012; Shenton 2004). It can help to avoid some common evaluation errors including the projection effect when personal prejudice of the interviewer is projected on to the respondents, and the central tendency effect which occurs when the researcher avoids recording extreme responses (Sarantakos 2013). There are a number of ways in which member checking can be conducted. In this study, broad themes emerging from all of the interviews were summarised (see Appendix 11) and sent to all of the interview participants to check the ‘truth value’, to verify that the themes illustrated the collective experience. Data holds ‘truth value’ and is credible when the descriptions presented are recognised immediately by others who hold that same experience (Krefting 1991).

3.9.7.2. Peer review

This is similar to member checking however it involves sharing and discussing qualitative findings with colleagues or experts who are impartial to the study (Burke Johnson 1997; Krefting 1991). The process can involve elements of debriefing and also

reflection on the process and themes emerging, an action that Krefting argued can lead to deeper reflexive analysis and assist with keeping the researcher honest (Krefting 1991). Periodic meetings with the research supervisor involved an opportunity to discuss and review categories and themes. In addition, two colleagues with experience in the field of brain injury rehabilitation and working with PDOC reviewed transcripts and identified broad themes which were checked against the themes identified by the researcher. This corroborative process assisted in strengthening of the credibility of the findings.

3.9.7.3. *Triangulation of methods and data*

An inherent advantage to mixed methods research is the need to use a range of data collection and analysis techniques to obtain rich information relating to the variables being studied. This process of using several tools within the same study is called triangulation (Sarantakos 2013). Triangulation and mixed methods research are inextricably linked and with mixed methods design emerging from earlier use of triangulation in research (Johnson and Gray, 2010). Inter-method triangulation (Sarantakos 2013) was used in this study, including postal questionnaires, self-rating tools and interviewing. Data analysis was also triangulated, involving the use of descriptive analysis and basic content analysis. Use of multiple methods of data collection and analysis can help to ensure a thorough approach to exploring a topic, by increasing the amount of data, thus adding to the breadth of knowledge collected. Moreover, data collection methods can compensate for each other as the weaknesses of one are strengthened by use of a supplemental method, adding to dependability (Krefting 1991). Corroboration of results across the methods used strengthens the credibility of the findings (Collins 2010). The benefits of triangulation include enrichment of data (Sarantakos 2013), improved credibility of results (Guba 1981), improved validity and enhanced research utility. A limitation noted in the literature is that triangulated studies can be difficult to replicate (Sarantakos 2013).

Triangulation is particularly useful in this study due to the complexity of the phenomenon being studied- the lived experience of informal caregiving for people with PDOC. A number of variables that influence this lived experience such as

caregiver strain, other demands on one's time, the severity of the care recipients condition and the care environment to name but a few. The scope of the project is broad, thus requiring a range of tools to capture relevant information that enrich an understanding of the lived experience. The goal was to obtain 'divergent results' which can provide richer detail and insights into complex phenomenon, resulting in an in-depth study of the issues (Teddlie and Tashakkori 2010). Furthermore, if results happen to be congruent between more than one methods of data collection, this can allow for greater confidence in the outcome and the conclusions drawn from the study (Greene and Hall 2010; Krefting 1991).

Triangulation during the data collection and analysis phase allowed the researcher to use findings from quantitative tools to inform qualitative measures. An example is when patterns of interval and scaled responses provided by the questionnaires were identified and reflected to the participants during the interview to provide a platform for greater elaboration and description of the meaning of these responses. This is a common practice with mixed methods research (Bryman (2006) cited by Bazeley (2010)), and it is typical of sequential mixed methods design (Teddlie and Tashakkori 2010). It helps to strengthen the trustworthiness of the information obtained as it provides an opportunity for respondent validation/member checking of information received at an earlier stage of the study.

3.9.7.4. Reflexivity

Positioning oneself in the research, acknowledging one's subjective views and experience with the topic being investigated, acknowledging how this experience led to and shaped the research from the initial question to the results and inferences made thereafter is a process known as reflexivity (Creswell 2013; Sarantakos 2013; Shenton 2004; Burke Johnson 1997;). Reflexivity, common to qualitative studies (Mason 2002), is a self-awareness exercise, and an attempt to make one's bias explicit from the outset. In the analysis phase reflexivity involves taking into consideration the implications of the researchers' prior knowledge on the research outcomes (Sarantakos 2013). Reflexivity was embedded throughout the research with the

researcher outlining prior to interview one's interest and experience with the topic. A personal statement is provided to document these influencing factors.

3.9.7.5. *Personal statement*

Observations from clinical practice of family responses to having a relative survive with PDOC, is the impetus for this study. I am an occupational therapist working in a national hospital for neuro-rehabilitation. There are three beds dedicated to the assessment and rehabilitation of patients with PDOC. I have worked for 12 years in acquired brain injury rehabilitation and have undertaken specialist training in the assessment and treatment of low awareness states including training in the use of the Sensory Modality Assessment and Rehabilitation Technique (SMART) (Gill-Thwaites and Munday 2008). I have engaged in a number of benchmarking and audit studies relating to PDOC (Delargy *et al.*, 2013; Royal College of Physicians, 2013).

The role of an occupational therapist with patients with PDOC is broad, ranging from the assessment of awareness, postural management, and maximising functional engagement for those who emerge to the minimally conscious state. I am involved in supporting and educating families regarding the patients ongoing care needs with most requiring considerable care for the rest of their lives. Observations from clinical practice are that family members assume a considerable role in caregiving or care co-ordination and appear to put their own lives 'on hold'. Recently, a mother of a young man in a vegetative state informed me that she had seen her four month old grandchild once as she spends all of her time with her son, as he is "*my baby again, he is my life now*".

Conversations such as these have led me to enquire further about the extent of occupational change for informal caregivers of patients residing both in long-term care (as this man was) and those living in the family home. Furthermore, there are a number of initiatives developing in other international centres to support adjustment and assist family members to transition towards the role of caregiver. To this end, a gap in our service exists. The National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011- 2015 emphasises the role of the hospital (study

site) as a tertiary service for complex acquired brain injury, with expert staff having a role in training formal and informal caregivers of patients with severe brain injury including PDOC into the future, the 'hub and spoke model' (Department of Health and Health Services Executive 2011). Occupational therapists are required to understand their role in educating and training informal caregivers regarding providing care in a safe and supported way and to assist them in finding ways to care for themselves. An important pre-requisite to developing such an initiative is to firstly understand the role of family members in providing care to a relative with PDOC; the impact upon their time use and occupational engagement patterns; the caregiving tasks they undertake and their perceptions of the support they need in order to be effective in their caregiving role.

As a researcher who continues to work clinically in this field, and whose clinical practice has informed the study it is important to make my own assumptions and bias known throughout and to indicate when relevant, how clinical practice informed the study design and analysis of findings. Hammersley and Atkinson (1995), cited by Creswell (2003) argued that the researcher who makes their biases and experiences known and explicit in the research will serve to enhance the quality of it (Creswell 2003).

Initial assumptions relating to caregiving for people with PDOC are that it most likely results in significant caregiver strain, and one assumes that it has life changing consequences in terms of occupational engagement patterns for caregivers. The quality of life of caregivers is likely to be significantly negatively impacted upon, particularly in terms of capacity to continue in paid employment, social and leisure participation. Occupational balance is likely to be affected. My own assumptions and bias informed through clinical practice and personal experience of assisting with caregiving for aged relatives is that there is limited training and support available particularly for those caregiving in the family home. Recent economic challenges for the Irish Health service has resulted in reduced staffing in hospitals and care homes. Anecdotal evidence indicates increased time being dedicated by family members to assisting with daily care, therapy programmes and a rise in those seeking to provide

care in the family home instead of the traditional route to residential care. The extent and impact of personal commitments by family members to be involved in caregiving for patient with PDOC is the focus of this study and theories underpinning occupational therapy particularly MOHO may well assist with understanding the lived experience of caregiving for people with PDOC.

3.9.7.6. *Field notes*

Field notes will be kept throughout the data collection phase to record personal thoughts and reactions to the information being gathered. This helps to protect against the projection effect, i.e. when personal prejudices of the interviewer are projected on the interviewee, (Sarantakos 2013). Brief notes are gathered during the interview including thoughts on emerging themes, ideas to probe for expanded information during the interview and observations of the mood, environment and personal reactions to the content. This material will be used later for reflection. Recording field notes provides a means to analyse one's own role in the evolvment of the study (Mason, 2002). Reflection on the field notes gathered after the interview will help the researcher to challenge and minimise the impact of bias.

3.10. Ethical considerations

3.10.1. *Ethical approval*

Ethical approval to undertake this study was granted from the Research Ethics Committee at Trinity College Dublin (see Appendix 12) and the Ethics Committee at the rehabilitation hospital (see Appendix 13).

3.10.2. *Informed consent*

Consent for phase one is assumed on return of completed postal questionnaires. Written consent for phase two will be obtained prior to the interview using the Consent to Interview Form (Appendix 6), which accompanies the Confirmation of Interview Letter (Appendix 5) in line with the National Consent Policy (HSE 2013).

3.10.3. *Confidentiality and anonymity*

Respondents are requested to complete questionnaires anonymously. On return, they will be coded to assist with basic content analysis of any qualitative data obtained in open-ended questions. Interviews will be transcribed and the names of interview participants and family members including the patient are omitted. A combination of numbers and letters to indicate the order of interview, the relationship of the respondent to the care recipient and the care location of the patient are used to ensure anonymity of the participant on the transcripts.

3.10.4. *Data storage*

Electronic data will be stored on a password encrypted computer in a locked cabinet with sole access by the researcher. Hard copies of data including self-rating forms will be kept in a locked cabinet and then shredded following analysis and when no longer required.

3.11. Chapter summary

The aim of this descriptive, non-experimental study is to explore the extent to which informal caregivers are involved in the provision of long-term care for people with PDOC and the impact of informal caregiving on occupational engagement patterns including roles and routines. Embedded sequential design involving quantitative data collection in phase one, and predominantly qualitative data collection in phase two, is used with a purposive convenience sample. The theoretical framework, MOHO, is used to guide the choice and development of data collection tools and to inform analysis of the findings. Qualitative Description is used to analyse data obtained from semi-structured interviews so as to describe the lived experience of caregiving. Qualitative description offers a pragmatic, non-interpretative approach to qualitative data analysis and is suitable for preliminary or early studies of a phenomenon. Mixing of methods occurred in both the data collection and the analysis phase of the study to provide rich and detailed descriptions of phenomenon, as outlined in the next chapter.

4. CHAPTER 4.0 RESULTS

4.1. Introduction

The broad aims of this study are to explore the extent to which informal caregivers are involved in the provision and coordination of care for people with prolonged disorders of consciousness. A further aim is to illustrate the impact of informal caregiving on the occupational engagement patterns, roles, routines and time use of informal Irish caregivers. The findings of data collected using mixed methods over two phases will be outlined in this chapter.

4.2. Phase One: Quantitative findings

The findings from the postal survey are summaries in this section.

4.2.1. Sample

Patients who attended the High Dependency/PDOC service between the years 2000 to 2013 were identified from the Rehabilitation Hospital records (n=87). The next of kin (NOK) of patients who were known to be deceased (n=29) were automatically excluded from the study, representing a mortality rate of 33% over the 13 years. A further 21 were excluded as they did not meet the inclusion criteria (see Figure 4.1).

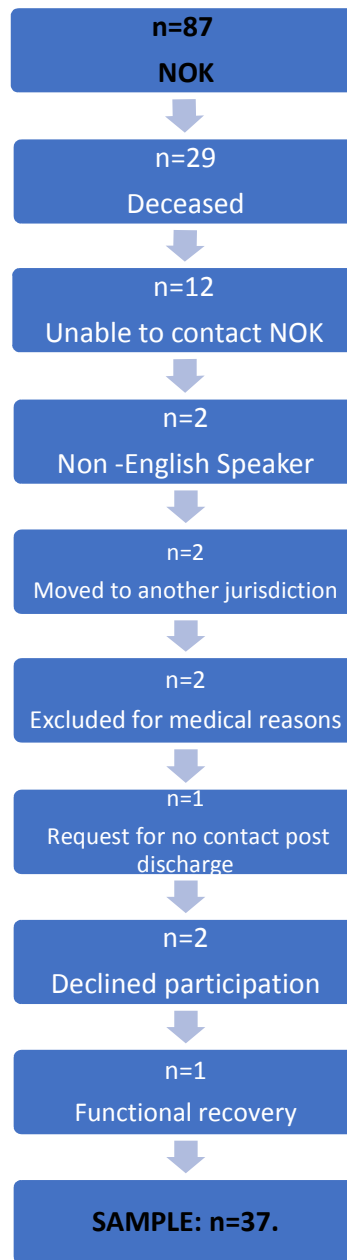


Figure 4.1 Phase One Sample

Postal questionnaires were distributed to the NOK of the 37 of the sampled patients. The sampled group were NOK of patients who were between three and 18 years post injury, 19 (51%) had sustained TBI, and 18 had mixed aetiology including hypoxia, stroke, and tumour. At time of discharge from the rehabilitation hospital 26 of these patients (70%) were classified as MCS, six (17%) were VS, and five (13%) classified as Locked-in syndrome or emerging awareness. Upon discharge, 23 patients (62%) were discharged to residential care facilities, six (16%) were discharged home, the

remainder were discharged to an acute hospital or other rehabilitation facility. Completed questionnaires were returned by 20 NOK/informal caregivers representing a 54% response rate.

The findings of the survey will be presented under the following sections:

- Demographic information informal caregivers and care recipients
- Informal caregiving for relatives in residential care
- Informal caregiving for relatives at home
- Preparation for caregiving, caregiver needs and wellbeing.

4.3. Demographic information of informal caregivers and care recipients

Demographic information relating to the respondents (caregivers) and the care recipients is summarised in this section.

4.3.1. Demographic information of survey respondents

Completed questionnaires were returned from 20 respondents (12 female (60%), eight male (40%)). Three respondents (15%) were caregiving for the patient at home ('home caregivers'), whilst 17 (n= 85%) provided care to a relative who was residing in a residential care facility ('residential caregivers').

The majority, (n=17, 85%) of the respondents were 46 years or older (see Figure 4.2). With the exception of one, (a sister) all respondents were either parents (n=11, 55%) or spouses (n=8, 40%) (See Table 4.1).

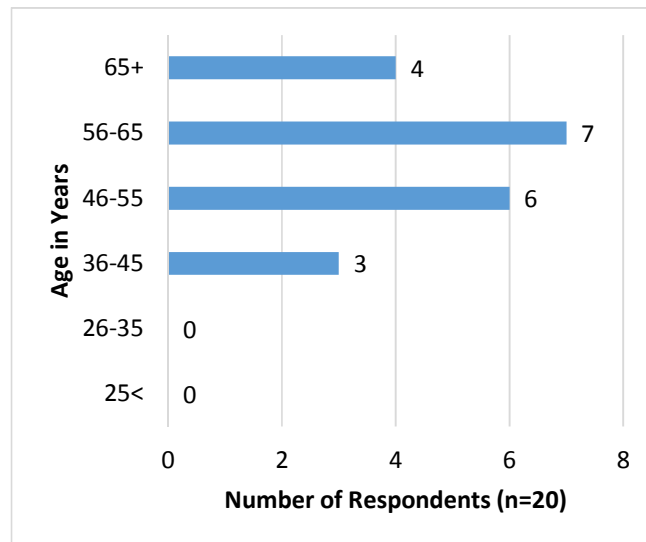


Figure 4.2 Age of Respondents (n=20)

Table 4.1 Relationship of Caregiver to Care Recipient (n=20)

Relationship	N
Mother	6
Wife	5
Father	5
Husband	3
Sister	1

4.3.2. *Employment and income of respondents*

All of the respondents were involved in providing care for their relative and none of them received payment for providing this care thus fulfilling the definition of ‘informal caregiver’. Less than half of the respondents were in paid employment (n=8, 40%), six worked full time and two worked part-time and they fitted in caregiving duties around their paid employment schedule (see Figure 4.3). The mean number of hours worked was 35.75 (range: 10-50 hours). Of those who were in paid employment, six (75%) were residential caregivers and two (25%) were home caregivers.

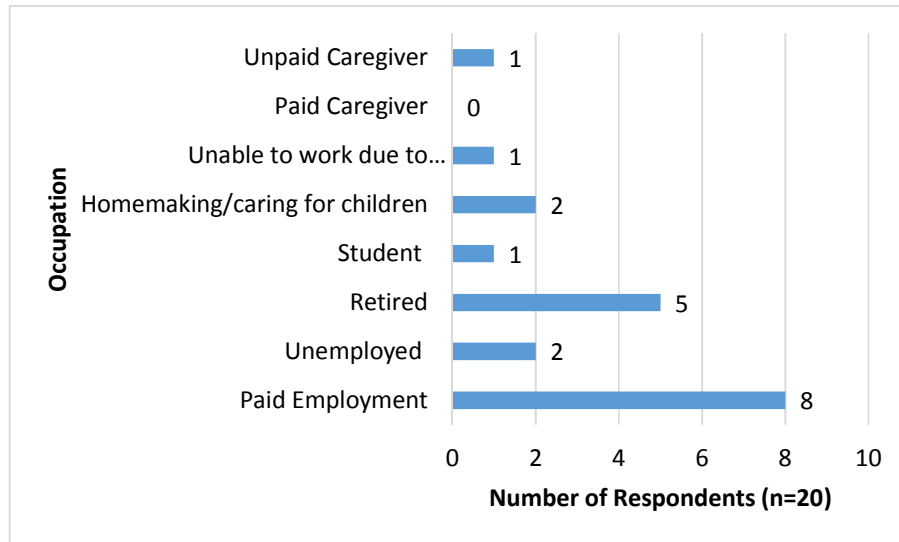


Figure 4.3 Employment Status of Respondents (n=20).

4.3.3. Changes to employment

Change in employment status upon commencement of caregiving roles was reported by seven (35%) of respondents (see Table 4.2). All were female relatives of the patient (three wives, three mothers, one sister). Six of these women were providing care to their relative who was residing in residential care and one was providing care to a relative residing in the family home.

Table 4.2 Change to Employment Status with Commencing Caregiving Role

How did employment status change?	(n=7)
Part-time paid to <i>fulltime</i> paid	1
Fulltime paid to <i>part-time</i> paid	2
Fulltime paid to fulltime <i>student</i>	1
Fulltime paid to <i>fulltime unpaid caregiver</i>	1
Fulltime paid to <i>retirement</i>	2

Paid employment or pension payments were the main sources of income for 75% (n=15) of respondents (see Figure 4.4).

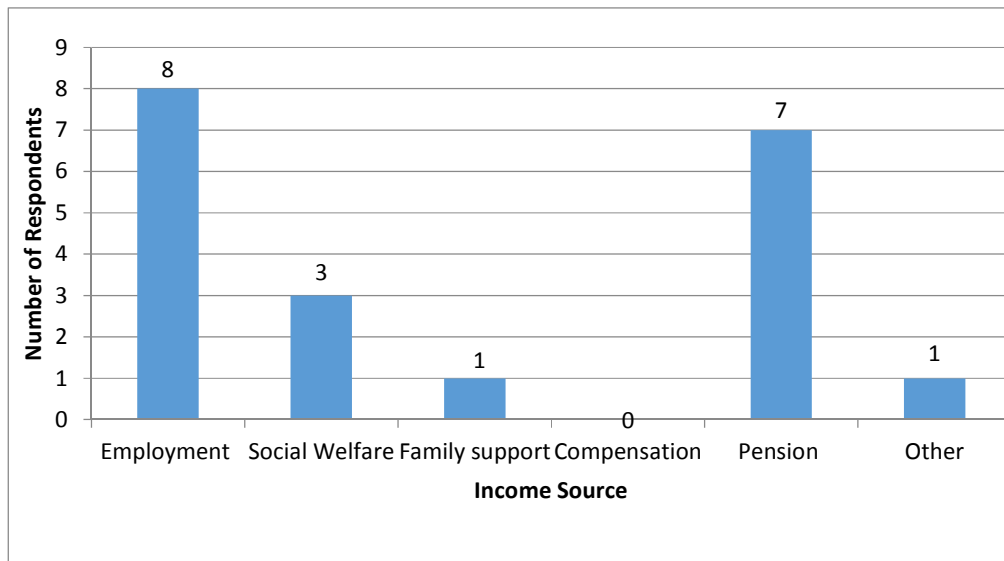


Figure 4.4 Income Source of Informal Caregivers (n=20)

4.3.4. *Living arrangements and other dependents*

The majority of caregivers (n=14, 70%) lived with a relative or a partner, four (20%) lived alone and two (10%) lived with others. Almost half (n= 9, 45%) of the respondents had other dependent children, young adults or elderly relatives living with them.

The three home caregivers reported that the care recipient lived with them on a full time basis, receiving 24 hour care in the family home. Of the 17 residential caregivers, two reported that the care recipient ‘sometimes’ visited the family home to stay overnight (e.g. at weekends or special occasions e.g. Christmas).

4.3.5. *Demographic information of care recipients*

Respondents were providing informal care to 14 male (70%) and six female (30%) care recipients. Three (15%) were being cared for at home and were all children of the respondents. Seventeen (85%) care recipients resided in residential care settings.

The mean age of care recipients was 40.7 years (age range of 23-72 years). The mean time since onset of injury or illness was 6.2 years (range: 3-14 years) (see Table 4.3).

Table 4.3 Demographic information of Care Recipients

Demographic Information		
Age	n	Mean (Years), (Range Years)
Current Age	20	40.7; (23-72)
Age at injury/illness onset	20	32.1; (17-67)
Age of patients living at home	3	31.6; (31-33)
Age of patients living in residential care	17	43.9; (23-72)
Survival times	Mean (Years), (Range Years)	
Time since injury/illness onset	20	6.2; (3-14)

4.3.6. Current diagnosis: Level of consciousness

Definitions from *Prolonged Disorders of Consciousness National Clinical Guidelines* (Royal College of Physicians, 2013) were provided to respondents to assist them with describing their relatives' current level of consciousness. Respondents were more likely to describe relatives in residential care units as having lower levels of awareness (see Table 4.4).

Table 4.4 Level of Consciousness (n=20).

Level of Awareness	n, (%)	Care environment	
		Home (n)	Residential Care (n)
No awareness (<i>Vegetative State</i>)	4, (20)	0	4
Minimal/Intermittent (<i>Minimally Conscious State</i>)	10, (50)	2	8
Full awareness (<i>Locked-In Syndrome or emerged awareness</i>)	5, (25)	1	4
Not indicated/No answer provided	1, (5)	0	1

4.3.7. *Care facilities*

Of the 17 care recipients in residential care, 12 (60%) were being cared for in nursing homes (mix of private and publicly funded facilities) and five (25%) were receiving care at a district care unit (publicly funded), none were receiving care at acute hospitals or rehabilitation units. The type of care provided was predominantly nursing focused, regardless of whether the care recipient was receiving care at home or in a residential facility. Only two respondents (10%) reported that care was a mix of nursing care and therapy. The duration of stay at residential facilities varied from one year to 11 years (mean: 4.5 years) with the majority of care recipients having received care at an average of four different care facilities before moving to their current care location (range: 1-6 facilities).

4.4. Informal caregiving for care recipients in residential care

Of the 17 residential caregivers, 15 (88%) visited their relatives daily or several times per week. They spent an average of 2.6 hours per visit (range= <1 hour – 7 hours per visit) (see Figure 4.5). Daily visitors spent an average of 21 hours per week visiting. This figure does not account for travel time to and from the residential care unit. There were eight parental residential caregivers and all visited their children daily (n=6, 75%) or several times per week (n=2, 25%). The mean length of each visit by parental caregivers was three hours (range: 1.5 – 7 hours).

A further eight of the caregivers were spouses visiting partners. The frequency of spousal visits varied with over 75% (n=6) visiting daily or several times per week. The remaining two spouses visited once per week (n=1) or several times per month (n=1). The mean length of visiting time by spousal caregivers was two hours (range: 0.25 hours- 4 hours).

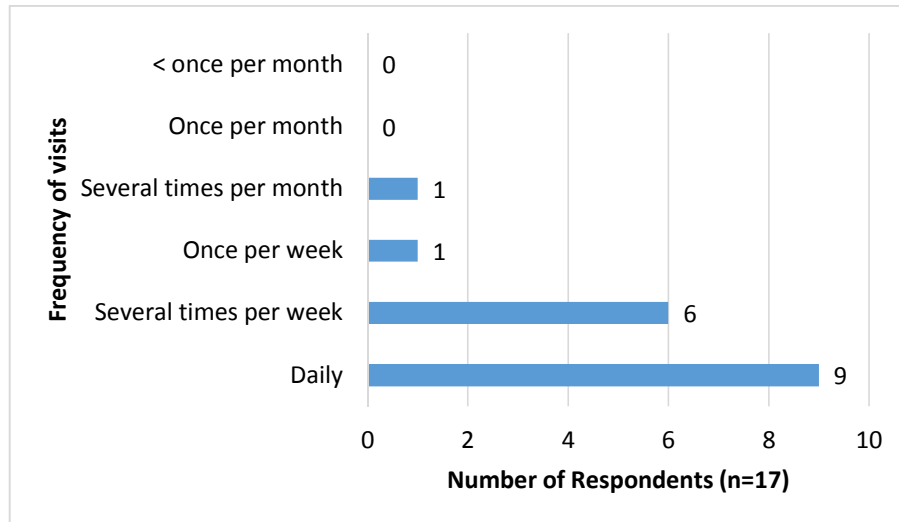


Figure 4.5 Frequency of Visits by Informal Caregivers - Residential Care Facilities (N=17)

4.4.1. Caregiving activities of residential caregivers

Seven residential caregivers (41%) reported feeling that they provided more than half of the everyday care needed by their relative even though the care recipient was in a residential care setting, as illustrated in Figure 4.6.

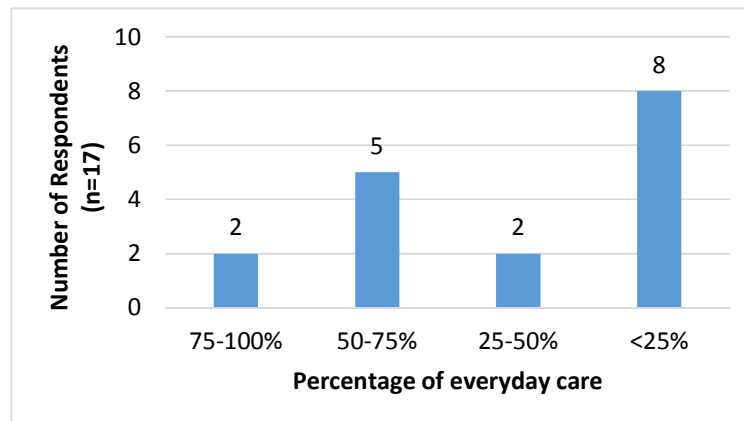


Figure 4.6 Contribution to Everyday Care: Residential Caregivers (n=17)

Respondents were asked how frequently they carried out various caregiving tasks. Responses were categorised using dichotomous pairing. 'Frequently' refers to 'every visit' and 'occasionally'; 'less frequently' refers to 'rarely/never' and 'just started'. Tasks that were carried out most frequently included sensory stimulation, talking with

and watching TV with the care recipient. Almost half (n=8, 47%) of residential caregivers assisted their relatives with personal activities of daily living (ADL's) such as washing and dressing on a frequent basis. More than half (n=11, 65%) reported frequent outings to the family home. A small number of respondents carried out therapy programs (Occupational Therapy (OT), Speech and Language Therapy (SLT) and Physiotherapy) (see Table 4.5).

Table 4.5 Type and Frequency of Care-giving Activities: Residential Caregivers

Activity	Frequently (every visit & occasionally) (n, %)	Less Frequently (rarely/never or just started) (n, %)
Activities of daily living		
Replenishing care necessities	n= 14, 82%	n=3,18%
Laundry	n= 10, 59%	n=7,41%
Personal ADL's (washing, dressing etc.)	n= 8, 47%	n=9, 53%
Feeding- Oral feeding or PEG care	n= 5, 30%	n= 12, 70%
Therapy related caring		
Massage, aromatherapy or other complimentary care	n= 7, 41%	n=10, 59%
Stretching exercises	n= 6, 36%	n=11, 64%
Transfers & Positioning	n= 6, 36%	n=11, 64%
Sensory Stimulation		
Talking, telling stories, reading or singing	n= 16, 94%	n=1, 6%
Watching TV or listening to music with patient	n= 14, 82%	n=3, 18%
Sensory Stimulation	n= 11, 65%	n=6, 35%
Visits to the family home (day or night leave)	n= 11, 65%	n=6, 35%
Outings around facilities/grounds/ trips out	n= 10, 59%	n=7, 41%

4.4.2. Quality of care provision

Respondents rated their perceptions of the overall care provided at the residential care facility with Likert scale increments grouped to establish categories: Inadequate (1-2), Adequate (3-5), Good (6-8) and Excellent (9-10). Sixteen respondents provided a rating with the overall majority (n=14, 88%) describing the care being provided as 'good' or 'excellent' (see Figure 4.7).

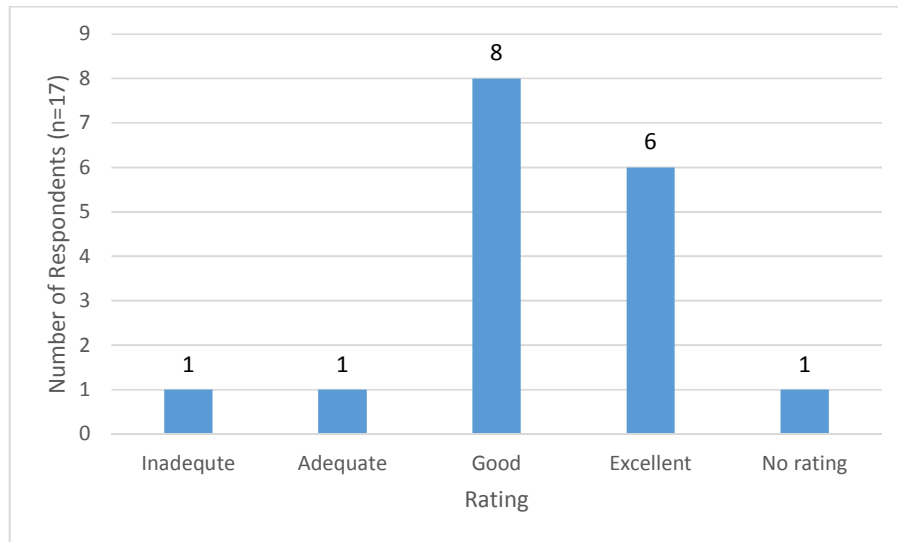


Figure 4.7 Perceptions of Overall Care Provision at Residential Care Facilities (n=16)

Frequency of access to allied health services was low as illustrated in Table 4.6. Physiotherapy was the most routinely accessed therapy with 47% (n=8) reporting routine access. Fewer patients had routine access to OT (n=5, 29%). A quarter of respondents reported having access to OT on a review basis only (n=4, 25%) and almost half, (n=7, 44%) reported that their relative never had access to OT at the facility. None of the care recipients or caregivers had access to psychology services.

Table 4.6 Frequency of Access to Allied Healthcare Services.

Therapy Discipline	Routine Access n, (%)	Review Only n, (%)	Privately Organised by Family n, (%)	Never by n, (%)
Occupational Therapy	5, (29)	4, (24)	0	8, (47)
Physiotherapy	8, (47)	3, (18)	2, (11)	4, (24)
Speech and Language Therapy	1, (6)	4, (24)	2, (11)	10, (59)
Psychology	0	0	0	17, (100)
Dietician	1, (6)	5, (29)	0	11, (65)
Music Therapist	5, (29)	0	0	12, (71)

4.5. Informal caregiving for care recipients at home

Three respondents (15% of total respondents) provided 24 hour care for a relative with PDOC at home. Respondents reported that having purpose built facilities (n=2); training (n=2), access to night nursing (n=1), and equipment (n=1) were the most important resources that facilitated care-giving at home.

4.5.1. Caregiving activities at home

Respondents provided information regarding the frequency of carrying out a range of caregiving tasks. Responses were categorised using dichotomous pairing. 'Frequently' refers to 'every visit' and 'occasionally'; 'less frequently' refers to 'rarely/never' and 'just started'. All respondents reported frequently assisting care recipients with ADL's, feeding (including PEG feeding), transfers, and sensory stimulation everyday. Physiotherapy programs including passive ranging and stretching was completed by two of the three caregivers on a daily basis. Regular outings were reported by all home care respondents (see Table 4.7).

Table 4.7 Type and Frequency of Caregiving Activities: 'Home caregivers' (n=3)

Activity	Frequently (<i>Everyday/occasionally</i>)	Less Frequently (<i>Rarely/never/just started</i>)
	n, (%)	n, (%)
Activities of daily living		
Replenishing care necessities	n=3, 100%	0
Laundry	n=3, 100%	0
Personal ADL's (washing, dressing etc.)	n=3, 100%	0
Feeding- Oral feeding or PEG care	n=3, 100%	0
Therapy related caring		
Stretching exercises	n=3, 100%	0
Transfers & Positioning	n=3, 100%	0
Massage, aromatherapy or other complimentary care	n=2, 67%	n=1, 33%
Sensory Stimulation		
Talking, telling stories, reading or singing	n=3, 100%	0
Watching TV or listening to music with patient	n=3, 100%	0
Sensory Stimulation	n=3, 100%	0
Other: "Music therapy"	n=1, 33%	0

4.5.2. Support with caregiving

In addition to informal care provided by the respondent and other family members all three home caregivers reported that their relative received support from formal (paid) caregivers however the number of hours of formal care provided to the patients varied. Only one reported receiving support from formal caregivers seven days per week, a second received support six days per week, and the third, five days per week. The hours of formal care received varied from between 22 and 84 hours per week. The HSE provided formal care to two of the care recipients and family sourced private care for the third. Two of the three respondents reported daily support from private therapists. This included allied health professionals such as physiotherapy, as well as

complementary therapy such as reflexology, and creative therapists such as Music Therapists. None of the respondents reported receiving support from state funded allied healthcare professionals such as those affiliated with Primary Care Teams or Community Rehabilitation Teams. None of the home caregivers accessed day care services, home-help services or inpatient respite services. Public Health Nursing (PHN) services provided input to two care recipients either daily (n=1) or weekly (n=1). Infrequent contact with General Practitioners (GP) was reported with one respondent identifying support from the GP, on a monthly basis.

4.6. Preparation for caregiving and caregiver needs

A summary of the preparation received by respondents to take on and manage the role of caregiver is summarised.

4.6.1. Care plans

All but one of the respondents (n=18) reported that their relative was discharged from the Rehabilitation Hospital with some advice or a clear care plan (n=17, 95%). Seventeen respondents reported on the frequency of implementation of care plans with 59% (n= 10) reporting that care plans were followed half of the time or more frequently. The remaining respondents (n=7, 42%) reported that care plans were followed occasionally or rarely.

4.6.2. Preparation for caregiving

Results highlighted inconsistencies in preparation received for caregiving prior to discharge from the Rehabilitation Hospital. Seventeen of 20 respondents provided information by scoring on a Likert scale (3 broad categories- No preparation (1-3), some preparation (4-7) and a lot of preparation (8-10)). Twelve (70%) reported receiving some or a lot of preparation from the Rehabilitation Hospital for caregiving. Two of the three home caregivers received no preparation from the Rehabilitation Hospital and one receiving a lot of preparation. Less than half of respondents (n=9, 45%) outlined details of caregiving training provided by the Rehabilitation Hospital. Conventional content analysis was used to analyse this descriptive data. Three main

categories emerged: Nursing Care, Physical Care and Opportunities for Experiential Learning with training limited broadly to physical care (see Figure 4.8).

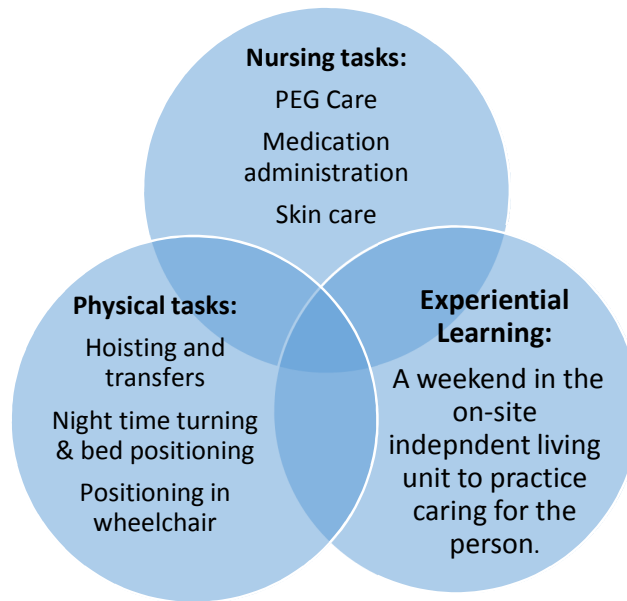


Figure 4.8 Caregiving preparation provided by Rehabilitation Hospital (n=9)

4.6.3. Confidence with caregiving

Respondents (n=16, 80%) indicated their confidence with carrying out caregiving tasks using a 10 point Likert scale with scale points grouped to create three main categories- not confident (1-3), somewhat confident (4-7) and very confident (8-10). Home caregivers (n=3) were the most confident with all three reporting feeling 'very confident' with carrying out care-giving tasks. Fewer than half of the 13 residential caregivers who responded (n=5, 38%) reported feeling very confident with caregiving. The remaining eight residential caregivers (62%) reported feeling 'somewhat' or 'not confident' with their role. The most challenging tasks included physiotherapy exercises, washing hair, engaging with the patient, oral hygiene, bed transfers, showering and dressing.

4.6.4. Caregiver needs

Just over half (n=13, 65%) of the 20 respondents provided information about how the Rehabilitation Hospital and the healthcare system could have assisted in preparing

them for their role as caregiver. Three main areas emerged: therapy, ongoing support and follow up and funding, as summarised in Table 4.8.

Table 4.8 Recommendations to Improving the Care Pathway for Relatives with PDOC.

Category 1: Therapy Recommendations

- *“Long-term therapy provision, with annual programmes offered”- R3MR.*
- *“Better understanding of the therapy required”- R4WR.*
- *“New directions.. research” and “best practice on the therapy and care frontier” and “ideas on therapy from outside of Ireland, such as Germany”- R4WR*
- *Greater availability of “therapy on a regular basis”- “provision of SLT and Physio at least once per week; more nursing care and physiotherapy” –R19FH.*

Category 2: Ongoing Support and Follow-up Recommendations

- *Access to information and advice: “more information about what to expect”-R15MR.*
- *A forum to avail of support from others: “links with people who have gone through this before”- R4WR.*
- *Support and follow up post-discharge from the Rehabilitation Hospital: “More support to families after discharge and should have the best interests of the patient as a priority.” R18FH”Follow up”- R12HR.*
- *Access to “qualified specialists”, “to help with ongoing therapies”; “home based training with hands-on care tasks”- R18FH*

Category 3: Funding Recommendations

- *More resources to assist with caregiving: “HSE assistance with funding caregiving”- R18FH.*
- *Improved government funding for residential care facilities: “Units need more Government funding, but some families are willing to pay for services”- R20MH*
- *Equity of service provision: “In (residential care unit), my son gets 100% care and doesn’t need for anything. Others may not have this experience”- R16MR.*

Respondents rated a number of initiatives on a three- point scale as to how useful they feel each may be in supporting their caregiver role with the highest score of ‘3’ equating to ‘Useful’, 2- ‘Somewhat useful’, 1 - ‘Not useful’. When scores for both caregiver groups were combined, a yearly review by specialists from the Rehabilitation

Hospital was perceived by respondents as the most useful in supporting their role (see table 4.9).

Table 4.9 Perceived Usefulness of Initiatives to Support Informal Caregivers

Initiative	Total	Total	Total Scores Combined
	Scores	Scores	
	Residential	Home	
Yearly review for patient by specialists from Rehabilitation Hospital	39*	7†	46*
Update on diagnosis and prognosis	35†	8*	43†
Online information to support PDOC caregivers	34	7†	41
Practical training in care-giving tasks	31	6	37
PDOC Caregiver Support Group	30	7†	37
Annual PDOC caregivers day	28	7†	35
Education & training booklet to guide caregiving tasks	30	5	35
Lifestyle Design Programme	27	7†	34

*Highest ranked initiative per group †2nd highest ranked initiative per group

4.7. Phase Two: Qualitative findings

The findings from the qualitative data obtained during semi-structured individual interviews and analysed using qualitative description will be presented below.

4.7.1. Introduction

Expressions of interest to participate in the qualitative interviews were received from 13 people. Ten were successfully contacted and interviews were conducted in their homes or at residential care units. Each participant will be referred to using a code:

- 'P' referring to 'participant',
- a number- the order interviewed,
- a letter to indicate their relationship with the care recipient (e.g. F- father, M- mother, H-husband, W-wife, S-sister)
- the care location (e.g. H-home, R-residential care unit).

Each participant is introduced along with results from the MCSI and the WHOQOL-BREF which were completed prior to the interviews.

Four men and six women with a mean age of 50 years (range 37-69y) were interviewed. One was providing care at home (home caregiver) and nine cared for relatives in residential care (residential caregivers). Participants had been providing care for between three and nine years (range: 3-9 years, mean: 5.3 years). The participants were related in a variety of ways to the care recipient – spouses (n=5), parents (n=4) and siblings (n=1). Duration of interviews ranged from 56 to 105.69 minutes with an average time of 84.39 minutes per interview.

4.7.2. Participant Profiles

Participant 1 (P1FR)

P1FR is a 51 year old father who works full-time running his own business. He assists in providing care to his 26 year old son who lives in residential care a short walk from the family home. His son sustained a traumatic injury three years ago and he is fully dependent and unable to communicate. P1FR described his son’s level of awareness as minimally conscious state. P1FR reported that other family members, particularly the patient’s mother provide up to nine hours of caregiving daily as reported in the interview.

Table 4.10 MCSI & WHOQOL-BREF Participant 1

Participant 1 (P1FR)			
MCSI*	Score: 24/26		
	Physical	56	Overall Quality of Life rating- Very Poor
WHOQOL-	Psychological	44	Satisfaction with health- Dissatisfied
BREF**	Social	56	Frequency of negative feelings- Very Often
	Environment	75	

**Higher scores denote higher levels of strain **Higher scores denote better quality of life*

Participant 2 (P2MR)

P2MR is a 54 year old lady who retired to care for her 27 year old son, who sustained a traumatic brain injury four and a half years ago. Her son has emerged MCS and can communicate using technology. He requires assistance with all activities. He lives in a residential care unit six kilometres from the family home. P2MR reports that she assists with his care in the residential unit on a daily basis. Her husband and other adult children support in providing care. Every weekend the family take him home to stay overnight. P2MR spends on average 6.5 hours engaged in tasks that she perceives as caregiving on a weekday and four hours caregiving on a an average weekend day.

Table 4.11 MCSI & WHOQOL-BREF Participant 2

Participant 2 (P2MR)			
MCSI	Score: 16/26		
	Physical	44	Overall Quality of Life rating -Neither poor nor
WHOQOL-BREF	Psychological	69	good
	Social	75	Satisfaction with health - Satisfied
	Environment	81	Frequency of negative feelings - Quite Often

Participant 3 (P3HR)

P3HR is a 62 year old man, caring for his 61 year old wife who resides in a residential care unit following a traumatic brain injury four and a half years ago. P3HR works fulltime and he visits his wife to provide care five days per week which involves travelling a fifty kilometre round trip to the residential care unit. His wife is fully dependent and unable to communicate. P3HR describes her as being in a minimally conscious state. Two other family members assist P3HR with caregiving. P3HR spends two hours on a weekday and three hours on a weekend day doing tasks he perceives as caregiving.

Table 4.12 MCSI & WHOQOL-BREF Participant 3

Participant 3 (P3HR)			
MCSI	Score: 19/26		
	Physical	50	Overall Quality of Life rating-Poor
WHOQOL-BREF	Psychological	44	Satisfaction with health- Dissatisfied
	Social	50	Frequency of negative feelings- Seldom
	Environment	56	

Participant 4 (P4MH)

P4MH is a 64 year old lady who has been caring for her 32 year old daughter for five years at home following a traumatic brain injury six years ago. Her daughter is fully dependent and unable to communicate and P4MH describes her as being in a minimally conscious state. Five other family members assist P4MH with caregiving including her son who is the full-time caregiver, along with thirty minutes of ‘home-help’ per day. P4MH had planned to retire shortly before her daughter’s accident. She now spends four and a half hours on an average weekday and four hours on an average weekend day engaged in tasks she perceives as caregiving.

Table 4.13 MCSI & WHOQOL-BREF Participant 4

Participant 4 (P4MH)			
MCSI	Score: 12/26		
	Physical	75	Overall Quality of Life rating-Very good
WHOQOL-BREF	Psychological	94	Satisfaction with health- Very satisfied
	Social	100	Frequency of negative feelings- Seldom
	Environment	81	

Participant 5 (P5WR)

P5WR is a 52 year old lady who provides caregiving for her 70 year old husband who lives in a residential care unit following a non-traumatic brain injury four years ago. She describes her husband as being in a vegetative state. P5WR works full-time and travels a five kilometre round trip to the residential unit a number of times per week.

She reports that she spends two hours on an average weekday and weekend day engaged in tasks she perceives as caregiving.

Table 4.14 MCSI & WHOQOL-BREF Participant 5

Participant 5 (P5WR)			
MCSI	Score: 11/26		
	Physical	63	Overall Quality of Life rating-Good
WHOQOL-BREF	Psychological	68	Satisfaction with health Neither satisfied nor
	Social	44	dissatisfied
	Environment	81	Frequency of negative feelings- Quite often

Participant 6 (P6SR)

P6SR is a 40 year old woman who is the main caregiver for her 43 year old brother who sustained a traumatic brain injury nine years ago. She works part-time, and is also mother to two young children as well as providing care to her elderly mother. P6SR describes her brother as being in a minimally conscious state, fully dependent and unable to communicate. He lives in a residential care unit and has short day visits fortnightly to the family home. Visiting to provide care involves a 32 kilometre round trip for P6SR, however her workplace is a short walk away from the residential care unit which allows her to visits at lunchtimes and after work. She spends one and a half hours on an average weekday and half an hour on a weekend day engaged in caregiving related tasks.

Table 4.15 MCSI & WHOQOL-BREF Participant 6

Participant 6 (P6SR)			
MCSI	Score: 12/26		
	Physical	56	Overall Quality of Life rating-Good
WHOQOL-BREF	Psychological	69	Satisfaction with health- Satisfied
	Social	75	Frequency of experiencing negative feelings-
	Environment	69	Seldom

Participant 7 (P7WR)

P7WR is a 37 year old woman who has been caregiving for her 41 year old husband since his traumatic brain injury four and a half years ago. P7WR is a fulltime post-

graduate student and she is also caregiving her young daughter. P7WR is supported in caregiving by her husband’s family and a group of committed friends. She describes her husband as having minimal awareness and is fully dependent upon others for all activities. She estimated that she spent four and a half hours providing care twice per week to her husband in the residential care unit and in addition, she takes her husband home for day leave every weekend whereby a schedule of private therapy is undertaken in the family home.

Table 4.17 MCSI & WHOQOL-BREF Participant 7

Participant 7 (P7WR)			
MCSI	Score: 23/26		
	Physical	69	Overall Quality of Life rating -Good
WHOQOL-BREF	Psychological	81	Satisfaction with health - Very satisfied
	Social	44	Frequency of negative feelings - Seldom
	Environment	69	

Participant 8 (P8HR)

P8HR is a 69 year old man who provides care for his 70 year old wife who sustained a traumatic brain injury five years ago. He is retired however he does odd jobs for his previous employer. P8HR visits his wife twice every day and described in the interviews, spending up to two hours with her per visit. He occasionally takes her to their home, a 64 kilometre journey. P8HR describes his wife as being in a minimally conscious state. She can communicate inconsistently, uttering a couple of words every few weeks. She is fully dependent, requiring assistance with all tasks.

Table 4.18 MCSI & WHOQOL-BREF Participant 8

Participant 8 (P8HR)			
MCSI	Score: 17/26		
	Physical	56	Overall Quality of Life rating -Very poor
WHOQOL-BREF	Psychological	38	Satisfaction with health - Neither satisfied nor
	Social	56	dissatisfied
	Environment	31	Frequency of negative feelings - Quite often

Participant 9 (P9MR)

P9MR is a 53 year old lady who provides care to her 23 year daughter who sustained a non-traumatic brain injury resulting in a vegetative state five years ago. P9MR gave up her work shortly after her daughter became ill. However, she recently commenced child -minding part-time. Her daughter is fully dependent and unable to communicate. P9MR visits to provide care to her daughter daily. Other family members including P9MR's partner, sister and adult children assist with providing care on a frequent basis. P9MR engages in tasks that she perceives to be caregiving for four and a half hours per weekday and seven and a half hours on an average weekend day.

Table 4.19 MCSI & WHOQOL-BREF Participant 9

Participant 9 (P9MR)			
MCSI	Score: 21/26		
	Physical	38	Overall Quality of Life rating -Neither satisfied nor dissatisfied
	Psychological	44	
WHOQOL-BREF	Social	69	Satisfaction with health - Neither satisfied nor dissatisfied
	Environment	44	
			Frequency of negative feelings - Quite often

Participant 10 (P10HR)

P10HR is a 69 year old retired man who provides care to his 70 year old wife who resides in a residential care unit. Since retiring, P10HR engages in voluntary work in his community. His wife sustained a non-traumatic brain injury eight years ago and P10HR describes her as having minimal awareness. She is dependent for all activities and unable to communicate. P10HR reported visiting daily to provide care, with visits on week days and weekend days lasting on average 30 minutes. He is supported in caregiving by his daughter who lives close by. The residential care unit is a short walk from P10HR's home.

Table 4.20 MCSI & WHOQOL-BREF Participant 10

Participant 10 (P10HR)			
MCSI	Score: 9/26		
	Physical	69	Overall Quality of Life rating-Good
WHOQOL-BREF	Psychological	69	Satisfaction with health- Satisfied
	Social	31	Frequency of negative feelings- Seldom
	Environment	75	

4.7.3. Themes

Following the process of transcribing, coding and analysing the data using qualitative description four main themes emerged:

- a) The Centrality of Caregiving: Roles and routines of the informal care-giver
- b) Self as secondary: The impact of caregiving
- c) Abandonment and Isolation
- d) The 'Constant Caregiver'- The enduring and perpetual nature of caregiving.

Themes and subthemes (Figure 4.9) were interlinked with strong relationships between themes identified.

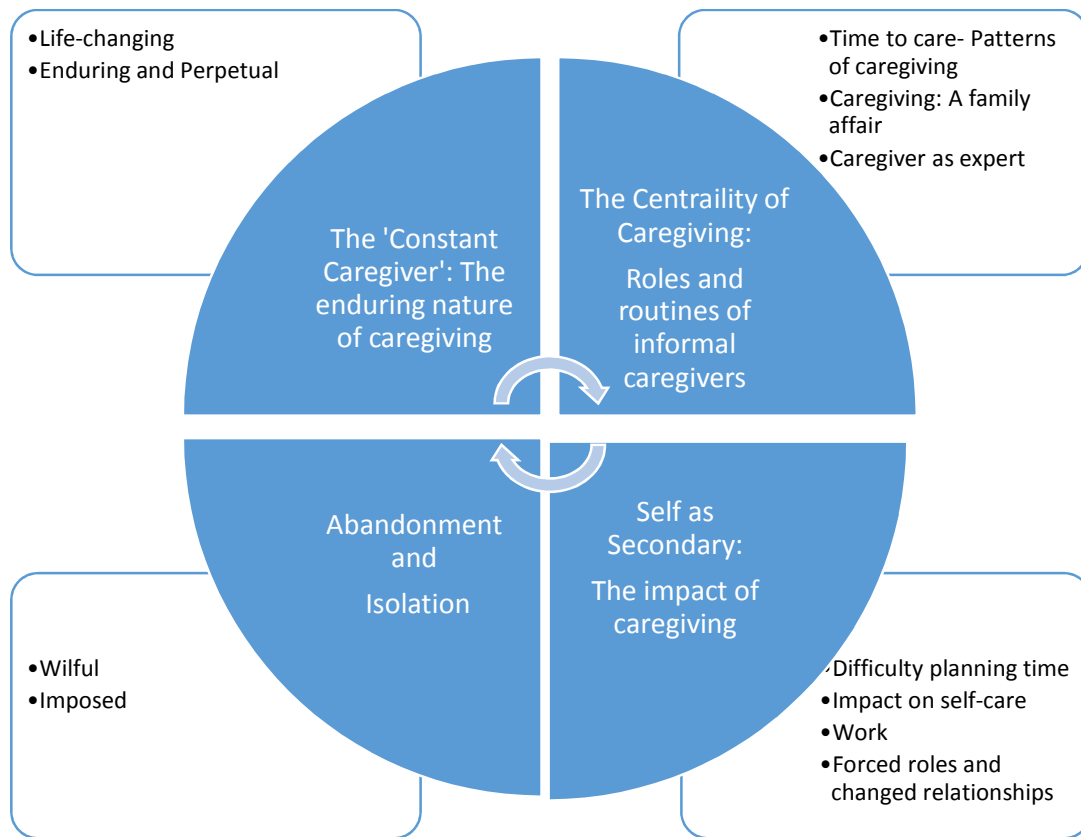


Figure 4.9 Themes and Subthemes

4.7.4. Member checking of themes

A summary of the main themes that emerged from the interviews was collated and sent to the interview participants for member checking. Participants were invited to review, verify and provide any additional information to the themes and main points that had emerged from data analysis. Responses were received from five of the 10 participants (50%) all of whom confirmed that the themes illustrated the essence of their experience (see Appendix 11).

4.8. The Centrality of Caregiving: Roles and routines

A common theme within the interviews was the centrality of caregiving in the lives of the participants. Caregiving became the focus point around which daily routines were structured. Caregiving was prioritised regardless as to whether the participant was

providing care to their relative at home or in a residential care unit. Caregiving routines were individual to each of the participants and varied depending upon family and work commitments, proximity to the care environment, relationship with the care recipient and the involvement of other family members in providing care. Three subthemes emerged that illustrate the centrality of caregiving in the lives of the participants:

- a) Time to care- The patterns of caregiving routines
- b) Caregiving: A family affair
- c) Informal caregiver as expert.

4.8.1. *Time to Care: Patterns of caregiving*

"I do what needs to be done and then we decide who's going up to (son)...There's always someone with (son)...you're constantly thinking ahead of possible problems that are going on, while in the meantime thinking all the time of what we need to be doing with (son), he's the centre of attention all the time"- P1F R.

Findings from the interviews and the Occupational Questionnaires indicated that participants spend immense amounts of time engaged in practical caregiving regardless of whether they are providing caregiving in the home or in residential care units. The majority of the participants dedicated some time each day to the needs of the care recipient. Caregiving dictated the daily routines for the majority of participants as other activities were scheduled around caregiving. Caregiving in the family home involved "24/7" input from family caregivers with some support from formal caregivers who were generally employed privately. A number of residential caregivers went to the care unit early in the morning to take over the care of their relative or visited in the evening to assist with putting their relative to bed, often not leaving until late at night.

"A typical day is that my husband and I get up at 7.30am and we have an hour before the carer arrives at 8.30am. So the bed has to be stripped down to the rubber mattress as (daughter) is bed bathed. And we medicate (her) ourselves.

If she needs to be changed, we do that and then we'd have a quick breakfast and the Home Help comes and they're here for half an hour. They get (her) washed, they may have to change her again and they get her dressed, and then I give her breakfast the minute they leave and I do her teeth. And then she's in the bed on her own, well when I say on her own I'm about but I'm doing my housework"- P4MH.

"Ok. I get up in the morning and my first thought is I get organised for (residential care unit), make my lunch- bring my packed lunch with me, so I have that ready... Then I would usually leave here around 11 or so, sometimes maybe 11.15...So I get there usually around 11.15, sometimes 11.30 or 11.45; ... I stay usually until about 6.30pm most days and that can vary... I don't get home 'til 7.30" – P2MR.

The centrality of caregiving in the routines of the majority of caregivers often reflected the time commitment one might give to a fulltime job. Some residential caregivers visited multiple times a day, every day of the week to carryout care tasks.

"As soon as I wake up 'oh daylight, let's go, coming up here to see my (wife). Go then and maybe get something in the local shops for dinner or a bit of a lunch or something. ... So that happens and then around six or seven o'clock there might be a mug of tea or a sambo and by the time that happens, it's time to go back up again and stay here (with wife) until about eleven or thereabouts and be home about half eleven, quarter to twelve, bed then. That's the average, practically every day"- P8HR.

Caregiving duty prevailed through the night, with all participants reporting disturbed sleep. The home caregiver described getting up several times during the night to check on their relative. A number of residential caregivers feared that their relative might become unwell during the night resulting in broken sleep as they checked their mobile phones frequently.

"I'm on edge all the time expecting that phone to ring to say there's something wrong with her. There's no way I could sleep. I'd be doing well to get to bed by two o'clock in the morning... and eventually when I'd get the head down, I have the phone beside me and come daylight I'm awake again. I'd be doing well to get four maybe five hours sleep at night. It's not easy no, when you have something like that on the mind."- P8HR.

The home caregiver described a less intensive caregiving routine at weekends as they were not required to fit caregiving tasks around their work commitments or confined to the schedule of formal caregivers who came to help on weekdays.

"The routine is different at weekends. We opted from the beginning not to have Home Help at the weekend. We opted for that ourselves because it means that you can go around in your pyjamas or you don't have to be dressed when somebody comes. So it's more relaxed at weekends. We get up a bit later, maybe half an hour later. We don't have to strip the bed immediately, and then on Saturday (daughter) is given what we call a 'big wash' and we do shaving and personal things, plucking and things like that"- P4MH.

For residential caregivers, caregiving became a central focus to the routine at the weekends. It was usually the time when they brought their relatives for day leave to the family home or in one case where the care recipient stayed overnight at home. Day leave required considerable levels of organisation and planning. Participants described a sense of obligation to make efforts to have the person spend some time at home as they did not want to feel as if they had 'abandoned' the person.

"(Brother) also visits at home once a fortnight...She (mother) likes him coming. I think she likes to tell people he's been and that's important to her. I think that behind it all she thinks that they think that she's just left her son high and dry or something like that and she likes to say 'oh no, I have him home' and stuff like that..."- P6SR.

4.8.2. Caregiving: A family affair

"We have, we've all done it together. I haven't done it on my own. We often talk about it- myself and (husband) and (son) and my other son, and my sister, all of us who are heavily involved with (daughter)"- P4MH.

It became clear within the interviews that providing ongoing care for relatives with PDOC was a task that was central to the lives of all family members, although it tended to be the females, particularly mothers who were the principal caregivers. This 'team' approach involved mainly close family members and trends emerged within the interviews in relation to the distribution of tasks and roles among members of the caregiving team.

"(My husband) does all of the showering and dressing. I'd only be in the way, and it gives him his time with (son). Sometimes (daughter) helps a little. If I had to bring him to the bathroom I'd always use the proper hoist. I wouldn't leave anything to chance. Sunday is the family day. His brother comes over. So (my husband) does the personal care and I'm cooking"- P2MR.

"My husband and I get up at 7.30am-we have an hour before the home-help arrives at 8.30am. The bed has to be stripped down to the rubber mattress for obvious reasons. We give her a bed bath. We medicate her. If she needs to be changed- we do that. I give her breakfast and I do her teeth. Then my son, or my husband, but mostly my son is here and we put her on the tilt-table and he spends three hours with her and does her physio with her. Then he gives her medication...and at 3pm my sister comes and does music therapy with her and that brings us to 4.30pm and she has a quiet hour then. Then I give her the evening meal"- P4MH.

Principally, but not exclusively, the females were involved in providing personal and intimate care both at home and in residential care units. Some participants described how male family members, despite not initially wanting to, had to provide intimate

care for female relatives. Male caregivers were more likely to complete the physically demanding tasks such as exercise programmes, moving and handling and transport of the patient.

“The first time I went to wash (daughter) in her private areas I remember my son-he said ‘No, I can’t do this, I can’t. And I said ‘(son), you have to, now you have to think about this very carefully; if you are going to be doing this, you have to be able to do everything’. I said ‘we don’t want to be doing it. Do you think (daughter) wants me to be doing it?’ Now there’s nothing I feel I shouldn’t be doing and (son) would be the same, and (husband) would be the same, (other son) would be the same. There is nothing we feel we shouldn’t be doing, because we have to do it. It’s as simple as that”- P4MH.

Rotas and schedules were frequently referred to as a strategy to assist with co-ordinating the ‘team’ of family caregivers. Both the home caregiver, along with the majority of residential caregivers described using rotas frequently. Six participants described their need to make sure that there was always somebody, usually a close family member, present with the care recipient regardless of whether the person was in residential care or at home.

“We decide who’s going up to (son)... You just, you know get a structure so someone is there with him. I go up, (wife) goes up, (wife) comes down, I go up whatever it is. There is always someone with (son)”- P1FR.

When participants were not directly involved in providing care themselves, they were ‘behind the scenes’ co-ordinating the rota. Managing the rota was labour intensive and involved much co-ordination as part of the caregivers’ role.

“I generally go two times per week, maybe three, but (husband) has at least one therapist, privately funded and one visitor a day. I manage his rota. So even when I don’t go to visit him I’m doing work- co-ordinating, sourcing, linking”- P7WR.

Rotas were also used to help with organising care schedules to ensure that everyone who was involved had a break at various times and to prevent duplication of 'resources' for the care recipient. The rota facilitated some sense of control over the consistency of care being provided regardless of the care environment. Other life activities had to be planned around the delegated tasks scheduled on the rota.

"When I go on holidays someone else just takes over. He (brother) says 'I'll go in and out. You just go'. They encourage me to go away and break out of the routine"- P6SR.

"I have a rota going on- people checking in. So even when you're not there, you're still involved"- P7WR.

Other reasons cited for having rotas included concerns about how vulnerable the care recipient was perceived to be and concerns that their needs might not be met in a timely or effective way by formal caregivers. Whilst people from outside the family unit offered to help, not all offers of assistance were accepted. Some participants described how they preferred the privacy to manage the care needs within the close family unit. It was also evident in the interviews that practical care was generally restricted to close family members and tasks involving being present with the care recipient were distributed among 'trusted' others who displayed certain qualities or were seen to have a 'certain way' with the care recipient.

"But at the same time (wife) needs a break and (daughter) can't do it. So it's great to have someone else going in, the likes of (friend) who reads to him and she's just a lovely person, she knows how to talk to him. It's great, like last night (wife) was away, I was up there with (son) all evening. She came in around eight o'clock and stayed there with him until ten o'clock last night"- P1FR.

"His dad visits every weekend. His sister helps a lot on the medical side, working with his therapists. We have a group of his friends who do a weekly rota to

spend time with him and my friends are involved in that too. We have a group of us running his Trust Fund. So it's not just me- it's his friends as well- having a rota makes it easier" – P7WR.

4.8.3. Caregiver as expert

"So I get there usually around 11.15. When the activities are over we go back to (son's) room and he usually needs to go to the bathroom before lunch. And we might do that or we might have a little cup of coffee if there's time or we might do a little bit of speech practice before lunch, therapy wise. So he goes to lunch as 12.30pm and I help to give him his lunch...I try to encourage him to do as much as possible of the self-feeding...so that brings us up to 1.15..we go back to his room and then he needs to go to the bathroom for the bowels...So at 2pm then...I massage his hands with cream, or sometimes I give him a foot massage. Sometimes he dozes off for 15 minutes...I set him up on the bike and he can do the arms and then the legs...the other things we do during the day before tea would be speech therapy, because I've been taught by the speech therapist how to do the speech therapy with (son).. We'd go out to the courtyard for a bit of sun...I stay usually until 6.30pm most days"- P2MR.

Adopting a central role in the care of the patient resulted in the participants and other family caregivers developing a range of skills that facilitated their ability and confidence in providing care. The participants described developing expertise in four broad task domains involved in caregiving (see Figure 4.10):

- a) providing practical care
- b) supplementing therapy
- c) advocacy
- d) monitoring and teaching.

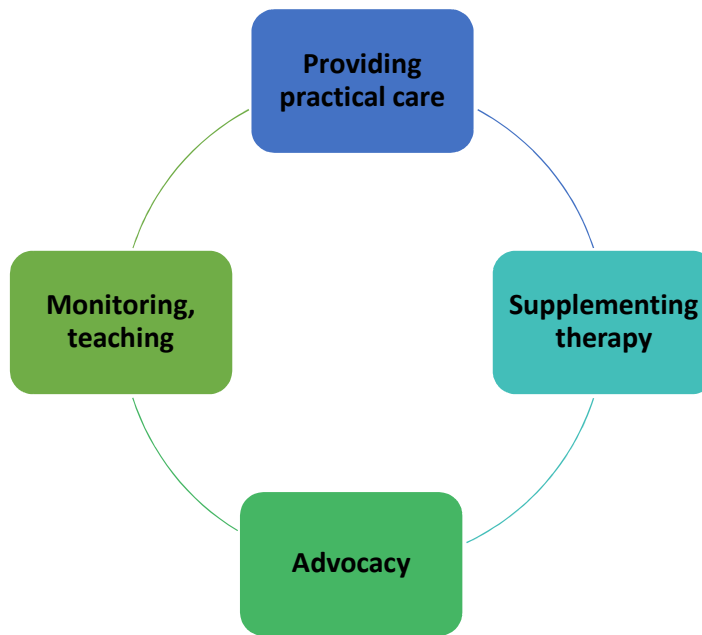


Figure 4.10 Caregiving role

4.8.3.1. Practical care

Practical caregiving involved tasks such as helping with medical and nursing care and contributing financially to the cost of care, particularly for home caregivers, but not exclusively so. Whilst home caregivers were very involved in providing practical “hands-on” care, some residential caregivers took over all aspects of their relative’s care when they visited and also contributed to the cost of sundry care items such as transport for appointments, hairdresser and chiropody services.

“He comes up, he has his little routine...He checks that her nose is clean. He checks all the numbers (settings) on her chair. He checks her feet- takes her stockings off and cleans between her toes and then he checks that her straps are on right. It’s his little routine. Then he gets out cotton buds and has his little light, he checks her ears, cleans her ears, cleans her nose and cleans her mouth with Listerine, does all that. And when that’s all done, he brings her back out and they sit there for a while. Then she goes to bed at one o’clock and he’d sit in the room with her and then she gets up at three and he makes sure the chair is right again and then off he goes home and has his dinner. That’s his whole day, and then he stays at home and I come back down in the evening”- P9MR.

Participants described a sense of confidence in the skills of close family members to complete caregiving tasks with attention to detail and expertise that many seemed to find lacking in formal care staff. This lack of trust in formal care along with a sense of belief in their own abilities to complete the tasks to a desired acceptable standard resulted in caregiving becoming central to their routine to ensure that tasks were done properly.

“And I know they’re busy and most of the care staff, they’re so you couldn’t fault them. But you always get one. There’s always one and there’s always someone rushing...they dress her in the mornings in the winter with a t-shirt, things like that. Just put your bloody self in (daughter’s) position-it’s not rocket science, you don’t need no big degree, it’s just a bit of empathy for people. It’s such a small thing to ask”- P9MR.

Some participants, particularly home caregivers, had developed a level of expertise in carrying out clinical tasks such as changing catheters, progressing with oral feeding and managing medications. All were keen to receive training from professionals develop their expertise in a range of skills as it facilitated their confidence and sense of control over providing the best care for their relative.

“We change the catheter ourselves. It’s a supra-pubic catheter. Myself, (husband) and (son) were trained to do that...we still give her the liquid through the Mickey...it’s like a little button and it’s fantastic. We also change that I think twice a year is recommended. My son does that because he was trained to do that”- P4MH.

All participants reported a role in assisting with financing care which involved tasks such as arranging fundraising events, managing trust funds, dealing with the cost of transport (for visits home etc.) and arranging and paying for private therapy. Helping to finance the cost of care was challenging particularly for those who have lost the second income of their relative in supporting the family and for those who are retired.

Activities relating to financing care were viewed as being as important as practical 'hands-on' care. In some cases caregivers were managing large compensation settlements on behalf of the care recipient. The responsibility of managing the financing aspect of care was perceived as a heavy burden to bear.

“Every year we look at it and you say I’m doing a great business, but when the bottom line comes, when we see like I can distinguish thirty five, forty thousand Euros a year that has gone directly towards (son’s) care. We don’t get any assistance other than what we have ourselves”- P1FR.

4.8.3.2. *Supplementing therapy*

“(Husband), my guess is, is doing a lot better than many in his situation. He doesn’t get sick often. He doesn’t get huge chest things- so he’s healthy- because of all the therapy and movement we’re doing with him”- P7WR.

Most participants, particularly those caregiving for less than five years believed that their relative still had potential for recovery. However the majority were very frustrated and angry with the lack of ongoing therapy and stimulation that was provided for their relatives following discharge from rehabilitation hospitals. They believed that their own intervention to supplement therapy was essential to keeping their relative healthy, a further drive to centralise caregiving in their routines. Participants described feeling a duty and an obligation to fill the gaps in this aspect of care by carrying out passive stretching and massage; using therapy equipment such as the 'Motomed'; sensory stimulation including using music and alternative therapies. A number of residential caregivers felt confined by HSE regulations and policies preventing them from doing therapy themselves with their relative, despite feeling competent having received training from therapy staff at other facilities. This was a source of anger and stress for participants.

“When you know they need movement therapy and nothing is giving it to them, you feel the guilt to give it to them..He’ll come home (on weekend)..we’ll do therapy with him- I’m trained up. We do physio, massage, stimulation and then some relaxation...He comes from 11.30am to 3.30pm.. if we have a therapist, the therapist will work for two hours- so we probably do two hours of therapy and two hours of non-therapy, relaxing”- P7WR.

“When I was above in (rehabilitation hospital), the guys showed me a bit of it. But I was doing it here one night with the bedclothes off and they said ‘what are you doing? That is inappropriate’. I was stretching (wife’s) leg. I said ‘this is my wife you’re talking about’. ‘But that’s inappropriate, you shouldn’t be doing it’. And I was stretching her legs and she asked me not to do it...So I’m in a no-win situation. So I try to do it in the chair even though (rehabilitation staff) told me it was better off to do it on the bed”- P8HR.

Some residential caregivers described a feeling of failing their relative by not being able to provide therapy and some were concerned that the care recipient had deteriorated as a result. Obeying the ‘rules’ of the care facility was challenging and they felt their role was confined.

“It frustrates me to see that she’s not getting the proper physio or the way we were asked to do it. But that hasn’t happened since day one. So that’s the frustrating thing...I think she has deteriorated in the last couple of years...Going forward there’s not a lot to be optimistic about I guess”- P3HR.

Generally the home caregiver completed therapy themselves with their relative and this was a central part of the daily caregiving routine. Access to community based services was limited and often involved travelling to outpatient departments or clinics which the home caregiving participant viewed as impractical.

“My son and my husband put (daughter) on the tilt table because it takes two, and we’re particular about that. It really does take two for safety and (son) spends three hours every day with (daughter). He does the physio with her and gives her a break in between”- P4MH.

The quest to find a solution or a cure also occupied much of the participants’ daily lives, particularly those caregiving for less than five years. It resulted in a range of therapies being trialled with the patient. A small number of participants who had been caregiving for longer than five years, described how a certain amount of acceptance of their relatives condition had resulted in a transition in their role away from a constant searching and striving for more and better therapies to ensuring that their relative was comfortable and safe.

“I was throwing homeopathy at him, reflexology, Kinesiology, Feldenkrais, anything I could think of and nothing seemed to make a difference...I didn’t see any benefit to him of anything that was being done really”- P5WR.

“Because I know that he is not going to make a recovery and I know the day will come when he’ll die and that will change things again. I’ll just keep an eye on him, make sure his positioning is good or that he’s comfortable, and I’ll put on music for him and sit with him and talk to him and tell him what’s going on. And that’s really all I can do...I feel that my role has changed completely now to just giving him love in the only way that I can”- P5WR.

4.8.3.3. Advocacy

“You wouldn’t get them (services) unless you fight for them. Everything we get here, we have to fight for it. You have to go down and challenge them and ask them when they’ll do it”- P8HR.

As well as feeling a duty to supplement therapies, participants described how as part of the caregiver role they had a responsibility to be a strong advocate for their relative

to ensure that they were getting the best care. The majority of the participants were conclusive that accessing services and supports was a struggle and added to a sense of strain. They described in the interviews feeling 'unheard' by formal care services and professionals.

"At the beginning he had a catheter that he didn't need. His body was resisting it. No one would listen to me about it. I spent six to eight months with him getting UTI's (urinary tract infections) and me fighting saying "does he need it?" I think it was placed wrongly in (rehabilitation hospital). And then people were saying 'Oh, he doesn't feel pain' and his body was like this (tenses up her body, flexing her arms and grimaces as if in pain), and I'M SORRY LIKE (angry)" – P7WR.

Advocacy was time consuming and resulted in increased intensity to the caregiving routine. As time passed, some residential caregivers described how there had been a shift away from practical hands-on caregiving to advocacy and care co-ordination. This shift did not change the centrality or the priority of caregiving in their routine, but instead the tasks they carried out changed.

"I think now I spend a lot less physical time with him. So fundraising or training therapist, when you're working with therapists or linking in with therapists or new ideas. So instead of being physically in with (husband). I would say I spend a similar amount of time, but in a different way. So even today, talking to you-it's for (husband) and for other families and its something (husband) would want, to know that other families benefited from his experience"- P7WR.

4.8.3.4. *Monitoring and teaching:*

All participants described playing a role in monitoring formal care provision. Some participants worried that the care recipients' needs might not be adequately met or that care may not be completed properly by formal caregivers if a family member was

not there to oversee the care. Some residential caregivers described a feeling of having “no control” over who was involved in providing care to their relative. Both home and residential caregivers criticised a lack of consistency and continuity in the quality of formal care being provided and viewed this as a trigger for high levels of vigilance. They felt a responsibility to ensure that their relatives were receiving timely and responsive care. This resulted in participants feeling that they could not step away from caregiving to prioritise other tasks in their daily routines.

“It’s like having a member of staff that’s doing work and if you’re the boss you’re constantly checking that. You’re as well off not to have that person working for you because it’s twice the work in your head, and you’re constantly checking, checking, checking.”- P1FR.

“You are all the time watching. I have to keep on at the nurses. You don’t want to be doing that, but you just have to. Like the siren going off on the bed today- it was going off for 11 minutes- I timed it.”- P3HR.

As all of the care recipients were unable to summon assistance or express their needs, this perceived vulnerability heightened the level of vigilance on the part of the family caregivers. All residential caregivers were critical of levels of supervision and they expressed a preference for shared bedrooms over single bedrooms due to the increased likelihood that someone might summon help if their relative required it. A feeling of needing to “protect” their relative was described. This vulnerability resulted in high vigilance and an increased intensity of caregiving commitment.

“I would worry if he was in a single room-about the likelihood of checks by nurses- they might be low, just because of ratios. Those kinds of things- I would worry. So I’m quite happy where he is now with the numbers he’s in with someone noticing that something is wrong, so that minimises the worry” – P7WR.

“But at that point in time I would have been doing easy seven days a week for probably a couple of years, until I eventually realised it was ridiculous and that you couldn’t keep that going.. Protecting him – it was ridiculous”- P6SR.

A perception that participants had developed a level of expertise in caring for their relative was evident in the majority of the interviews. A knowledge of the care recipient before their injury and opportunities to observe specialists, along with considerable researching about brain injury contributed to this expertise. Many described feeling obligated to develop skills to be able to help their relative. There were mixed feelings about the extent of training and preparation received. The opportunity to have as much ‘hands-on’ practice with caring for the care recipient in hospital was valued by the home caregiver, and promoted a feeling of being well equipped to take on the caregiver role. However, some of the participants were unhappy with the level of training they had received to take on caregiving and they felt ill-equipped with aspects of the role.

“The nurse said ‘I want you to observe me when I’m bathing (daughter). She said ‘This is what you’re going to be doing when you take (daughter) home. So we took everything on board...we just used the shower chair and there was always two or three of us, myself, (sister) and even (husband)...and sure we thought it was fabulous using the hoist, and then they showed us how to put (daughter) into the chair...so we were trained to do all that before we left (rehabilitation hospital) so that was a huge help”- P4MH.

“I think the rehabilitation hospital is where it (training) should have been– I’m aghast...I was trained to be a nurse even though we knew that (husband) was never going to come home... all the articles point to good physical movement for (name) and as lovely as the physio team was, they spent three hours a day positioning him, telling me that the tilt table wasn’t necessary to (name), cycling wasn’t necessary to (name). They didn’t teach us any movement therapy. I’ve had to learn it from others”- P7WR.

A number of participants believed that many formal caregivers lacked the expertise, skill and experience required to manage the care of someone with complex brain injury. They described how formal caregivers often looked to them for guidance and assistance with problem-solving through practical aspects of the care. Despite feeling confident in this role, the majority of participants perceived taking on the task of training the formal caregiver in addition to their other caregiving roles an additional burden.

“They leave a bit of mash and veg there according to the instructions of the Speech and Language Therapist. I give it to her. She can’t take it herself. I observed what she (therapist) was doing and I said ‘Can I try that now?’ Reluctantly she let me, but now I actually do it all now. None of the staff here feed her. Actually one of the staff wouldn’t let me do it after she had a bad chest infection, and she wasn’t giving it to her the way (wife) is used to at all. So I said ‘Can I have it now?’ And I mixed it up the way she was used to and I gave her a little bitty on the spoon- no problem. The nurse thought she could take a big spoon of it and shove it down her throat. But she only takes a tiny bit for pleasure. So the nurse went away with herself”- P8HR.

Conversely, some participants believed that by training the formal care staff themselves, they experienced a sense of control over the care and reassurance that care tasks would be carried out consistently. Participants needed some assurance that they can ‘trust’ the formal caregivers to be able to provide care correctly and compassionately. Taking steps to maximise their trust in the care being provided such as supervising formal caregivers resulted in fewer concerns regarding the quality of care provided to the patient. Some believed that in the long run, the constant vigil involving checking and monitoring paid off.

“You need to be very careful who you allow to deal with her-who comes into the house, even from a caring point of view...when one of them (HSE formal caregiver) was absent I wouldn’t allow a sub for a long, long time...we’ll say if A was off and B would be on her own I always stepped in...I’ll allow a sub in now because I’m not going to worry about it...but I had to be convinced myself that that was ok. That only happened two years ago”- P4MH.

In summary, participants spent time each day involved in caregiving for their relative. The amount of time varied between participants and regardless of the care environment, the time spent caregiving was generally intensive. The scope of the caregiving role was broad and participants had developed a level of confidence and expertise in carrying out their role. As time progressed from the onset of the severe brain injury, caregiving became a central part of the participants’ lives, and a routine within itself. In all cases, caregiving duties were shared among close family members and rotas were essential to ensuring that therapies were supplemented and that there was always somebody with the care recipient. The routine of the care recipients’ became the dominant priority in the lives of the informal caregivers. In the next section, the impact of the centrality of caregiving on the lives of the participants is explored.

4.9. Self as Secondary: The impact of caregiving on the lives of caregivers

Caregiving duties dictated the lives of the majority of the participants, particularly those who had been caregiving for less than five years. The needs of the care recipient were prioritised over other commitments and activities and in essence, everything else, including the participants own needs were secondary to those of the person with PDOC. Participants described different demands on their time, changed personal routines, altered levels of engagement in activities and less autonomy over their own time use. They spent much of their waking hours either physically doing caregiving or thinking about caregiving. The impact on the occupational lives of the caregivers from

how they made choices about their time use and the activities they engaged in is encapsulated in the second theme- Self as Secondary.

Four subthemes emerged in the interviews (see Figure 4.11) that illustrated the wide impact of the centrality of caregiving on roles, routines and time use:

- a) Difficulty planning time
- b) Impact on self care
- c) Work
- d) Forced roles and changed relationships

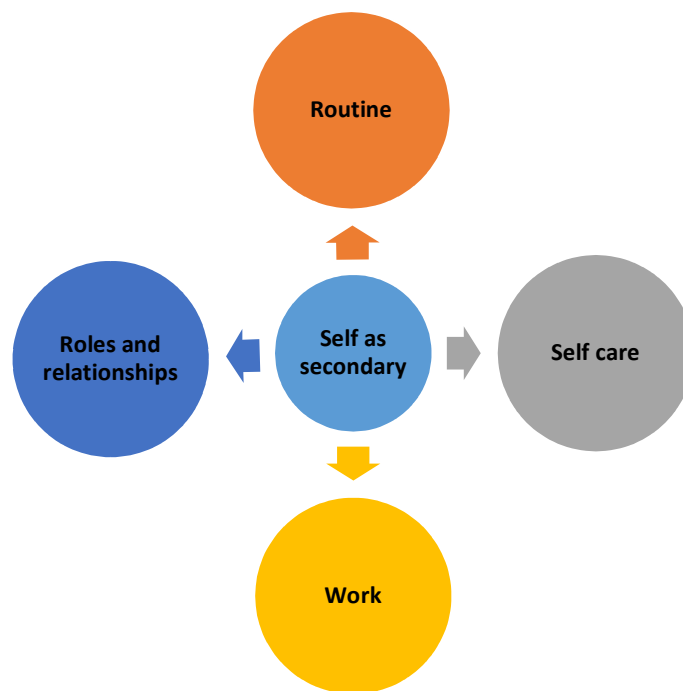


Figure 4.11 Self as Secondary

4.9.1. *Difficulty planning time*

Caregiving duties placed constraints on the time use of the participants with various experiences reported from having to keep very rigid schedules to having no routine whatsoever. Generally, the home caregiver and the residential caregivers who attended daily to take over the care of their relative were more likely to report having to stick to rigid schedules. Their own activities were planned so as not to interfere with

the care recipients' schedule. Spontaneity was absent from their lives, and unplanned events were challenging to deal with.

"A routine is very important from (daughter's) point of view and regardless of what we're doing, we basically keep to (daughter's) routine"- P4MH.

"I suppose we don't just go somewhere on the spur of the moment for an hour. It's something that we plan in advance."- P2MR.

A sense of chaos in routines also emerged in the interview, as participants described frantically trying to juggle competing demands on their time such as working and caregiving, or rushing to relieve other family caregivers. Some illustrated how they had had "no usual routine" and how "every day is different". Some described being unable to plan activities due to the changing demands of caregiving and needing to be available to respond to them or relieve other caregivers with little notice. There was a sense that this was frustrating and involved considerable personal sacrifice as participants placed their own needs secondary to those of others.

"I don't have a usual routine. The only usual daily routine is getting (daughter) to school and picking her up. Outside of that, it all depends"- P7WR.

"You just nearly feel that you have to come down (to the nursing home) and stay with her, to stick with her. So, it's no different to before (the accident), only that we had a good time together before the accident and it's just not good anymore. You just have to be as helpful, to keep her as comfortable as possible. Life is mostly confined to work 6.30am to 6.30pm and then I come down here (nursing home). It is 9pm before I'd be home"- P3HR.

Participants described feeling an imposed expectation to provide care. Participants described "feeling tied" and feeling that one's "wings had been clipped" and this resulted in less time to do things for themselves, even to respond to their own need for rest for instance.

"Sometimes I do be tired...You see (husband) is grand. (Husband) comes down in the day and he's finished, he goes home and he has the night to put his feet up and watch telly. I have my dinner, sit and watch the news and I'm starting to fall asleep and I'd say 'Oh God, I have to go down now, I have to go, I have to go'. And then (husband) would say 'Are you going to (daughter)? What time are you going to (daughter)?' 'I'm going now. I'm going in a minute'. And even if, not that I would, but you would never get away with sneaking off a night with (husband): 'Are you going down?' 'Yeah, I'm going in a minute'. But there are times when I feel like I really don't want to"- P9MR.

On the whole, the majority of participants, particularly residential caregivers acknowledged that they could choose how much time to devote to caregiving. They were keen to emphasise that they did not 'blame' or 'resent' the care recipient for the new demands that caregiving brought to the lives. Despite an awareness of this autonomy in relation to time use, a sense of duty and obligation to provide care prevailed and a feeling of guilt was associated with leaving their relatives to 'get on with (my) own life'.

"The one thing I don't ever feel is-I don't ever feel resentful of (wife). The fact that I have to go up every day-and I don't have to go up every day- she wouldn't know if I wasn't there, so I know there's no.., but it's just, there's a certain pressure on me- I feel I should go in everyday"- P10HR.

"Like, I think we feel guilty, like we're leaving him here and we're carrying on with our own lives"- P6SR.

Some participants, particularly those who had been caregiving for longer than six years reflected on the sense duty to provide care and how they had gradually begun to step back and feel empowered to do things for themselves again.

“I take time off now when I want, and I realise that I don’t have to be there. Like, I would arrive to (acute hospital) sometimes and they would say ‘it’s 10.40am. You should have been here at half ten’...I would be there at 10.30am every day and I would stay till twelve or one. And then I’d cycle home and I’d go back in then in the evening- it was incredibly rigid”- P5WR.

4.9.2. *Impact on self-care*

Caregiving had an impact on the participant’s self-care, domestic and family activities. Sleep, home-making and family life were frequently reported as being negatively impacted upon as a result of caregiving. The majority of participant’s reported that their sleep was affected at some point over the course of their relative’s illness. Waking a number of times during the night to check on the care recipient (home caregiver) or waking to check their phones for calls from the residential care unit and subsequently remaining awake worrying about the patient was reported by all of the residential caregivers. This added to the burden of the situation and had an impact on the participant’s wellbeing. Over half of the participants’ described having to take medication to assist with sleeping at some point since onset of their relative’s illness.

“I could go to bed at one and then I could be awake between two and six, awake and not being able to sleep... I’m sure this is true for anyone who’s thinking negative thoughts- if they’re lying in bed thinking about things, it’s not good...some of it would be worry and some of it would be like ‘oh if only it hadn’t happened, if only this hadn’t happened”- P2MR.

Some described how they had less time to do daily household tasks. Those who juggled their time between caregiving and paid employment were more likely to report challenges with fitting in home-making activities to their routine with housework usually completed early in the morning or late at night.

"It's 9pm before I'd be home most days. Tuesday I'd be home by 6.30pm which is lovely, because her daughter goes to the nursing home. I'd split a few sticks or do something useful on those days. I'd still be in bed by 9pm on those evenings"- P3HR.

A common theme among parents was an effort to minimise the impact of caregiving on other family activities. The majority of parents reported that this was challenging and they experienced a sense of guilt in recognising the challenge to be equally responsive to other family members needs as much as the care recipient's needs. They described trying to 'keep things as normal as possible' when with their other children.

"I've made a big effort not to focus too much on (son) when the other two children are around (long pause, tearful). I try to give them as much time as I ever gave them and always be there for them. I don't say 'Oh, I can't deal with this now because I'm thinking about (son).' No I do, I'm very conscious of that"- P2MR.

The majority of participants described a struggle with finding balance between work (paid employment, caregiving and other roles) and rest, with little time for oneself. The first two years of caregiving were described as particularly "frantic" and stressful with little lifestyle balance as prolonged periods of bedside vigil were kept. Generally taking time out had to be planned and co-ordinated, particularly for the home caregiver, but also for some residential caregivers who preferred that their relative was never alone. Some found it difficult to 'switch off' from caregiving for fear of something bad happening.

"So it's hard to find time for yourself...that's the thing you cut out, because everyone else's needs are more urgent" -P7WR.

"Even at that (going to the pub) you're not relaxed in my view- you can only go for a few pints because you don't know if the phone is going to ring. And it has happened like. You'd be in the pub and the phone would ring and the pint would

on the ground and I'm out the door...I don't have downtime... I find that well, I have to be with (son)"- P1FR.

Opportunities to have some time to oneself were rare and were very much valued by the majority of participants. Having an opportunity to take a short walk, to meet a friend or simply to be alone were activities that were reported as being important in helping to give respite to the participants.

"A good day is getting some time for yourself and getting in everything else. A good day is when you've gotten a few things done but also some time to switch off, to chat with a friend and catch up"- P7WR.

Holidays were significantly impacted upon for all participants particularly in the early years following their relatives' injury. Some participants, both residential and home caregivers, had never taken a break with a couple of days being the longest time away from the care recipient. The idea of taking a break from caregiving merely added to feelings of strain rather than reducing it with a fear that something would go wrong the most commonly cited reason not to travel.

"You can add up twenty three days in three years that she hasn't been with him. Oh yeah, constantly...Nah, look (wife) would be on the phone. You don't even say 'leave it', because what's the point? She can't turn off. When we came back from (rehabilitation) she said, 'look we'll go away now in October. October is here and we haven't a notion. We're further from holidays now and even if we were- where would you go? You can't get away from here" (taps his head as if to indicate thoughts in his head) – P1HR.

A small number of participants, particularly those who had been caregiving over longer periods of time, experienced a greater sense of balance. They described having 'to learn to step back', to entrust the care of their relative to others in order to take a break, however the process of reasoning with themselves about this was challenging as they had to deal with a sense of guilt in stepping back.

"It's like something bad is going to happen. Like, if I start living a normal life and doing what normal people do, something bad will come along and I'll have to deal with that.."- P5WR.

Reference was made to a number of facilitators to achieving a sense of balance, including encouragement from others to take a break; having a care rota, trust in the consistency and quality of care provided by others, proximity to the care environment, acceptance of their relative's condition and having another meaningful occupation such as paid employment, volunteering or leisure.

"When we're gone-I've a rota going on, people checking in. So even when you're gone you have to (co-ordinate care)...The first time I went was when he was in rehab. It's easier now because he has a good schedule. I trust the team he is with. I know what he's getting when I'm gone"- P7WR.

"I literally thought to myself, 'no, I can't leave (daughter). She'll die if I'm not there'. I mean people started saying to me 'you have to look after yourself. You have to get away from it, you have to let other people take on the task' and then gradually myself and (husband) said 'Yeah, we have to distance ourselves from it, there are other people who are capable'- so after two years, yeah, we finally decided that."- P4MH.

Six participants discussed the importance of having "something else to do". There was an acknowledgement that periods of time doing other things, apart from caregiving was important to one's well-being, and that this time away added to the quality of care that one can provide when they are with the care recipient. Some participants could 'switch off' when engaged in meaningful activity, when they had time alone, or when being productive in achieving a goal or that instilled a sense of self efficacy. These experiences were noted as facilitating a greater sense of balance. Re-engaging in previously enjoyed activities was seen as a symbol of 'normality'. A few participants,

particularly female caregivers described how engaging in social activity also helps with facilitating a sense of balance.

"I have a balance between work, visiting (brother), looking after my mum, social life and things like that. It's a busy week, it's ok. I don't let it-I've started doing some exercise in the past year or so and it's really beneficial. I've started cycling, walking and running as well. All of those things have been really positive 'cause now I make sure that I take time to do those things- it helps me control stress"- P6SR.

Participants also described feeling guilty about engaging in activities that brought a sense of enjoyment, seeing it as somehow "selfish" to engage in activities that enhanced their own feelings of satisfaction.

"I like doing the adult literacy or the other things and you'll do it because you see them coming on. 'God, you're suddenly getting something out of this'. Ok, that's the selfish side of things- that you feel you're doing something worthwhile"- P10HR.

4.9.3. Work

Financial pressures were reported by the majority of participants as a source of "sleepless nights". Financial strain was experienced as a result of three scenarios reported in the interviews: planned retirement, loss of a second income originating from the care recipients loss of earnings; and loss of a second income originating from a family member who had resigned from paid employment to adopt the caregiver role. Some who were retired described how their savings were "running out fast" as they attempted to supplement the cost of care. Almost half of the participants took on their caregiving role in addition to paid employment. The predominant challenge associated with this was a lack of rest and time to oneself. In order to facilitate both caregiving and paid employment, they were required to make changes to their working roles, responsibilities or routines. However, despite the challenge of dividing time

between both caregiving and paid employment, all concurred that remaining in paid employment had a positive influence on one's life.

"I have to work. We have to have the money to help (son) at any time. The cost is enormous. I'm working all of the time. I'm sitting here talking to you, I'm working. That phone could ring and that could be the end of it. I'm out the door so twenty-four hours a day I'd be at it. That's the job-Saturday, Sunday- it's the same thing. And (son) is still there. (Son) still has to be seen to."- P1FR.

4.9.3.1. Changes to working roles

In some situations, participants had planned to retire and the timing of this coincided with their relative's injury. However, for others, sense of duty to be with the care recipient when they were critically ill resulted in them foregoing work as it was just not possible to do both. Some of the retired participants found fulfilment in their new caregiving role and were grateful for the opportunity to be able to have dedicated time to their relative.

"When this happened to (daughter) I worked as a receptionist in...I didn't do much. I can't say (daughter) ended my sports career or my dancing days, there was none of that, but I do feel as my girls got older and moved on, that my life should be different to what it is now, and it's never going to be,"- P9MR.

Almost half of the participants worked in paid employment and had taken on caregiving in addition to paid employment. Some had increased their hours to supplement the loss of a second wage to the household or to supplement the cost of care; others had reduced their work hours and level of responsibility to free up time for caregiving. Continuing with paid employment whilst also caregiving, resulted in additional pressures on family life.

"I don't have down-time in my work. Before this happened to (son) I was probably more stressed in my work, but because this happened I have to be with (son) or at work. I'm either going into (son) or down to (son). If I'm doing a

job, (son) is always spoken about. 'How is (son)? How is he doing?' Downtime? There isn't any. I'm always working. It's not a 9 to 5, golf on a Saturday job"- P1FR.

A sense of duty to provide care resulted in family members making difficult choices and sacrifices in relation to their work and careers in the context of ensuring a commitment to care for one's relative. Three participants described how their other children had sacrificed their careers to become involved in caregiving rather than pursuing their original career path.

"My son said from the very beginning that he'd look after (daughter), but I put him off. This was when she was in the acute phase. I said 'No, you're too young. Absolutely not!' They had one child at that stage. He came home (from abroad) the following year for a year, but I still wouldn't let him come home permanently. He then went back. So, it was only last year that he came here and said that they were coming permanently but I made him consider it beforehand because it's a huge decision. He was teaching (abroad) and his wife was working for the government, so it was a huge decision" –P4MH.

4.9.3.2. Positive influence of work

"Work has a positive impact on my wellbeing. You don't have time to think, thinking about your problems and health and stuff like that. Too much free time might be a bad thing...I think I couldn't stay at home fulltime. I'd be thinking and going mad"- P3HR.

Despite the demands of working alongside caregiving, those participants who continued to work described how it had a positive influence on their lives. Work provided a routine, distraction, support and respite from caregiving as well as assisting with the financial pressures associated with caregiving and supplementing loss of earnings.

“It’s really very important because of the job I do which you really feel you are helping people...And that gives me a huge sense of satisfaction and I love my job. My employers are incredibly supportive. Anything that I want- if I want time off, yeah, absolutely no problem”- P5WR.

Some retirees described how they missed the structure and support that they had previously found in their paid employment. They did not experience the same feelings of being valued, self efficacy or feeling like they were part of a team in their caregiving role as they did from their former work role. Some had attempted to spend time doing other activities such as volunteering which seemed to support feelings of self-efficacy.

“I do miss it, I certainly miss the social aspect of work and I probably miss the routine of it as well, the routine of you have to be out of the house at such a time and then you’re in work. When you are in work it consumes all your thoughts. It’s like as though you’ve so many things to do you don’t have time to be thinking of other things. So, it does invade your space, so I’d like to have something like that that would stop me thinking about negative thoughts and I probably miss it in that, you know when you’re in a job, you’re part of a team and you’re expected to do so much. You’re needed. You’re required. And the stuff you do, you feel good because you did it. Whereas I don’t have that now.. In the beginning I didn’t miss it because I think I was still in shock. It’s only in the last year or so that I’ve been thinking about that, that I do miss it”- P2MR.

The support network that people experienced through their work colleagues was frequently referred to in the interviews. Those who continued to work described how it may not have been possible to both work and help with caregiving without the flexibility and understanding of their employers and the support from their colleagues.

“I love my job and my employers are incredibly supportive. Anything I want- if I want time off ‘yeah, absolutely no problem”- P5WR.

4.10. Forced roles and changed relationships

“No, it’s not something you want to do. No, I’m in my 30’s. I’m not meant to be a caregiver. The only satisfying thing is that (husband) is not getting sick”- P7WR.

‘Forced role change’ was a dominant theme in all of the interviews. Caregiving was a new, unexpected and unplanned role for all of the participants. Aspects of the caregiving role challenged their role identities across social domains and altered profoundly the social role that they had played with the person they provided care to.

Role regression was experienced by parental caregivers. They described how they perceived their child having changed from being an independent young person to someone who was once again vulnerable and in need of their care. The tasks involved in caregiving for their adult children were the same as they carried out when they were infants such as feeding them, changing them, in the absence of communication trying to establish their needs, and settling them to sleep. This role regression along with the level of dependence of the children was extremely upsetting for the participants.

“Oh he’s just like an infant again, a new born baby. It was just like somebody was so helpless and I used to think even he was even more helpless than a baby, because a new baby can scream their heads off when there is something wrong. For a long time, I felt he was helpless and he still is helpless”- P2MR.

“She’s taking more and more orally. She’s using a special beaker but we still give her liquid through the PEG too. Every second night she’s given a bottle of Ensure just in case she’s missing proteins and minerals. Normally at 10pm she’ll have dropped off to sleep, so we’ll stay with her ‘til about 11pm. She’s monitored throughout the night”- P4MH.

Some participants described how their roles within a range of contexts had been forced to change as a result of having a relative with PDOC. Role changes reported

included becoming a single mother as a result of the injury sustained by a partner or having to adopt roles that were formally held by the patient such as the person in the household who cooked the meals, completed the housework or paid the bills. Simply having to “to do everything now” added to a sense of burden with little time to oneself commonly reported among the participants. The opportunity to share duties no longer existed.

“Of course the responsibility falls on you when your husband is incapacitated so at the very beginning my day was just so full from beginning to end” - P5WR.

Participants who provided care to their partners described how their role with them had changed from the ‘usual’ husband-wife role with a ‘two-way’ nature to the relationship to a situation whereby they had to second-guess what their partners would want; to assisting them with the most basic tasks to meet their physical needs; and to giving them love without it being reciprocated.

“For (husband), you’re trying to come to a point where you are really unconditional with your feelings for them- where there is a lack of expectation for what they do or don’t do. So it’s a very different role to the usual husband and wife role, you know, because it’s not that ‘two-way’ relationship”- P7WR.

Some spousal caregivers described feelings of ambiguity in their relationship status and explained how they sometimes felt like “single” people again, particularly at social functions. Phrases like the loss of “my wingman” were used to describe the experience of going to an event without one’s partner. Some people described how they sometimes felt others may be expecting or thinking that they should “move on” to find other relationships, but that this was very challenging and upsetting as they continued to feel committed to their partner.

“And people are saying ‘it’s five years, you have to move on’. I’m coming up on seventy. What would I move on to? Get myself another partner? Can you imagine it? And even if I did- put yourself in that position that I was to ask you

out. I can't talk to you in the morning because I have to go to (wife) and we can't go out at night because I go up to (wife). So what do I do? Can you expect anyone to tolerate that sort of lifestyle and yet people are telling me 'oh move on, move on, move on'. I just turn away and smile"- P8HR.

All of the parental caregivers reported loneliness as a result of caregiving created by the lack of time with their partner, as one or the other was always with the care recipient. Having time together had to be planned. Residential parental caregivers carried out duties in 'shifts', often dove-tailing each other. The pressure to get home from work promptly to free up other family members who had been with the care recipient all day frequently resulted in meeting in the corridors of residential units as they relieved each other from caregiving duties. The home caregiver described how family members were more likely to work together in carryout caregiving.

"We'd literally meet on the corridor. If I was running late and (wife) had to get the bus it was like that"- P1FR.

The time commitment to caregiving impacted upon relationships whereby some partners felt lonely, neglected and resentful towards their spouse and in some cases, towards the care recipient.

"Oh yeah constantly (wife is constantly with son). And like that she'll stay there till ten o'clock tonight. You know, it's an empty house, big bloody house when its empty and you close the door, lock the gate at eight o'clock at night and that's it...(Wife) is up there with (son), she's away from home but she's with (son), whereas I'm at home alone, you know you just have that-you just feel it"- P1FR.

“You see, (husband) has a bit of OCD going on. I’d say to him ‘Ok, she’s in bed now, we can go for a walk’ and he won’t leave her. So I think he’s becoming a bit obsessed. I say, ‘she’s in bed now. She’s alright. We’ll go for a walk for an hour’ and I’d like that-it’s me that wants to pull him away from her. Now I want to walk. I want to go for a little walk but he’s all wrapped up in missy”- P9MR.

Some participants described how relationships had become critically strained as a result of the participant’s perceived need to prioritise caregiving for their relative over other family commitments. This centrality of caregiving in their lives was a direct cause of strain in their relationships as the participants put themselves and other relatives’ needs secondary to the needs of the care recipient.

“One of the days I was going and it was like ‘you’re going again?’ And I’m like ‘well, I go every day’. And it was kind of between me and my partner and he’s going ‘you can’t keep this up- you cannot keep going to the hospital everyday- you have to take some of your own life back’.. Things were difficult between him and I because he was at home with the kids. And at that point as well, my visiting times were very long”- P6SR.

In summary, caregiving was central to the lives of the participants and prioritised above many other important commitments, roles and responsibilities. Routines were scheduled around caregiving and participant’s needs were secondary to the needs of the care recipient. The time consuming nature of caregiving impacted upon lifestyle choices. Caregiving resulted in forced role change in a number of social domains. Work routines and responsibilities often changed to facilitate caregiving. Work and engagement in meaningful occupation enhanced perceptions of self- efficacy and provided structure and distraction for participants. The commitment of both parents to caring for a child often resulted in little time to spend with each other. Caregivers of spouses experienced a sense of loss of their partner and an expectation of them to provide unconditional love in the absence of it being reciprocated. Caregiving often resulted in loneliness and placed strain on relationships.

4.11. Abandonment and isolation

A theme of abandonment and isolation emerged in the interviews. Within this theme two subthemes emerged; firstly ‘wilful abandonment and isolation’ (see Figure 4.12), whereby participants made choices to abandon certain occupations or wilfully avoid social activities. Participants decided to disengage from social and leisure activities to make time for caregiving or to escape from talking about or thinking about caregiving. Secondly, all participants described a gradual withdrawal of services from the care recipient resulting in the family feeling that they and their relative had been abandoned by healthcare services. They described feeling isolated and alone in caregiving. This ‘imposed abandonment and isolation’ manifested from perceived failings in the current care pathway for people with PDOC due to gaps identified in service provision and follow up.

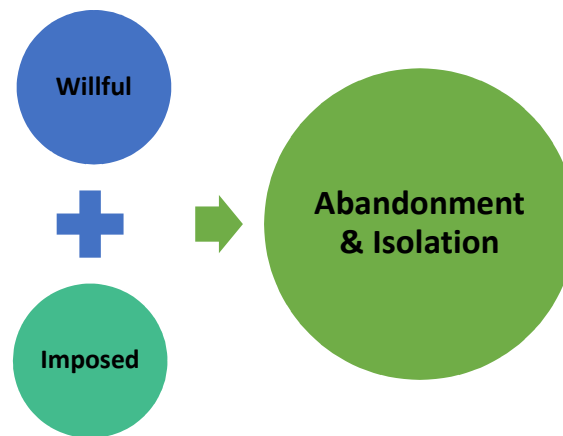


Figure 4.12 Abandonment and Isolation.

4.11.1. *Wilful abandonment and isolation*

“Ah, well if I tell you the things I don’t do anymore, that would be easier. Yeah, ok, that would be a good way of starting”- P2MR.

The abandonment of social and leisure activities was a prevailing theme emerging from the interviews. The precedence of caregiving in their everyday routine, financial

pressures and having less time, along with the loss of one's occupational and social companions were reasons described for abandoning social and leisure activities. Generally participants expressed an awareness that they had started to actively avoid and withdraw from social activities. The demands of caregiving along with feelings of grief and loss for their relative impacted upon their motivation and interest to engage in activity. Phrases were used such as "my grieving days" and "trying not to dwell in the sadness of it all" to illustrate how sometimes it was difficult to be motivated to interact and participate in meaningful activities. Participants described how they often did not have the mental reserve to engage in social activities with fatigue a compounding factor.

"Everyone was ringing, ringing, ringing and I never answered a call...Because I felt I couldn't leave (daughter) and I just wasn't in the mind-set. I just wasn't able and also I didn't want to talk...So I literally lost track of my friends for about two years"- P4MH.

Some described how they felt the demands of caregiving and the extent of their relatives' disability had made them feel less tolerant or 'snappy' with other people. The experience of dealing with well-meaning friends and acquaintances frequently enquiring about their relative was very stressful and upsetting to cope with. This was particularly the case as there were no changes or improvements to report and sometimes led to the caregiver feeling maybe they were not doing enough to enable improvement. On occasion, the comments of others had resulted in participants and other family members retreating from social contact and abandoning activities so as to avoid difficult conversations about the care recipient.

"I've noticed that people can be very moany about little things that are annoying them and in the back of my mind I'm saying 'Really? It's not worth moaning about because it's so tiny'. I think my tolerance level for those kinds of things wouldn't be at its best and it (social activity) wouldn't be that much fun

because I definitely think my tolerance levels are less than they would have been and it would kind of impact on me”- P2MR.

“For instance, one of the directors. Every time he meets me ‘How’s (husband)?’ He would ask me every time and every time I would say ‘there’s no change’. ‘Oh it’s a tragedy, I know a guy who had a stroke and this and the other’. And then one day I was trying to avoid him and I could see him heading for me and I said ‘shit, here he comes’. And it’s so painful to say it every single time and he came towards me and ‘How’s (husband)?’ ‘Ah, that’s terrible, does he recognise you?’ I said ‘Do you think I’d be standing here with a face like a slapped arse if he was?’ (Angry and upset)”- P5WR.

“You can feel that you are not doing enough if you are forever telling family members that the patient is ‘fine’, ‘no change.”-P10HR.

Social and leisure activities often failed to offer a break from caregiving. Participants described how conversations in social contexts usually reverted to talking about their relative. Opportunities to fully ‘escape’ from thinking about, talking about, or doing care-related tasks were rare.

“Like I say, going to the match, I wouldn’t ask my friend, I wouldn’t say it to him because I just didn’t want anyone. I didn’t want to-up and down in the car, the whole game and the whole thing talking about (son). I just wanted actually to be away. Its funny how you could be in a crowd of 80,000 people and just feel- this is great...That was a good day out but there’s very few days. God that was the first day I’d say I had off”-P1FR.

“Talk to me about the weather or football or hurling or something but the first thing out is: ‘How’s (wife)?’ I’ve insulted people to the point of – they’d hardly speak to me now. ‘Leave me alone. I’ve come in here to try to forget about it. If you’re that worried about her, she’s above in (residential care unit); go up to her. Don’t be annoying me here in the pub. I’ve come in here to try to forget it. Now I have to go again because you’ve just upset the whole bloody thing.’”- P8HR.

Constantly prioritising caregiving, work and other essential activities were reasons to abandon previously enjoyed leisure activities as participants described how they lacked the energy and time required to keep them up. Moreover, participants had often shared an interest in leisure and social activities with the care recipient (spousal caregivers) or with other family caregivers (parental caregivers) and as such, these activities were abandoned as participants had lost their social companions to either requiring care or providing care. Celebrating events was challenging for most of the participants and was often compounded by a feeling of guilt that they might be enjoying themselves whilst their relative remained confined to requiring care. More than half of the participants described seeing other people enjoying themselves as being emotionally difficult. This resulted in most of the participants “going off the radar”, losing touch with friends for long periods of time.

“I don’t feel like going. We went together to all of those things. I did go to one wedding without (wife) and I felt totally at a loss. So I got out of there as soon as I could get going...You’d be miserable looking at everybody enjoying themselves and my little partner up here. You have to experience it to know the feelings”- P8HR.

Financial restraints were a commonly cited reason for abandoning previously enjoyed leisure. Participants were conscious of the additional cost of care and reduced

incomes, therefore foregoing their social and leisure interests and prioritising money to support caregiving.

“And you’re going from two incomes to half an income but I don’t focus on it...I gave up on the dance classes. There’s just not the kind of time or money for those things”- P7WR.

A slow process of re-engagement in social and leisure activities were described by some of the participants, typically these participants were those who had been in the caregiver role for longer than five years. Home caregivers described being able to schedule social activity in the home environment that included the care recipient and this lessened their levels of social isolation and withdrawal.

“I started last year, just kind of walking and stuff like that and then I kind of hiked it up a gear this year...And it makes me happy because when I go out to exercise I think about all the things that are in my head but I feel I think about them more positively when I am doing that. It might be just a simple walk for an hour, getting away from it all”- P6SR.

“I must say we were all very nervous about bringing (daughter) away, but my two sons said ‘no you have to be able to do it. We all want to be able to go on family holiday, even if it’s within Ireland’...so it was no problem at all. Really it was fantastic...We’ve had a few parties here and (daughter) has been here as well or being entertained in other people’s houses”-P4MH.

A dearth of enjoyable activities in the lives of the participants was resounding in the interviews with the majority being unable to readily identify an activity that gave them enjoyment and satisfaction. Work or experiences of helping others outside of their

caregiving role, such as volunteering were noted by some. Others described enjoyment in simply being alone for an hour to 'escape'. The caregiving role was mentioned by a minority as facilitating a sense of satisfaction and self efficacy. The majority of participants found caregiving increasingly challenging as the years passed.

"Aah (sigh) I don't know. It's getting harder I think, yeah, what do you do? Go up and shave him, talk to him. There isn't a lot to talk about...Other than that I just sit quiet"- P1FR.

4.11.2. *Imposed abandonment and isolation*

"I find, I really find it's just so, so – you're isolated. Totally isolated"- P9MR.

Throughout the interviews participants described feeling 'let-down' and abandoned by the healthcare system, and isolated in their role as caregiver. Several interconnected subthemes contributing to this imposed abandonment were evident in the participant's descriptions (see Figure 4.13) resulting in feelings of anger and frustration.

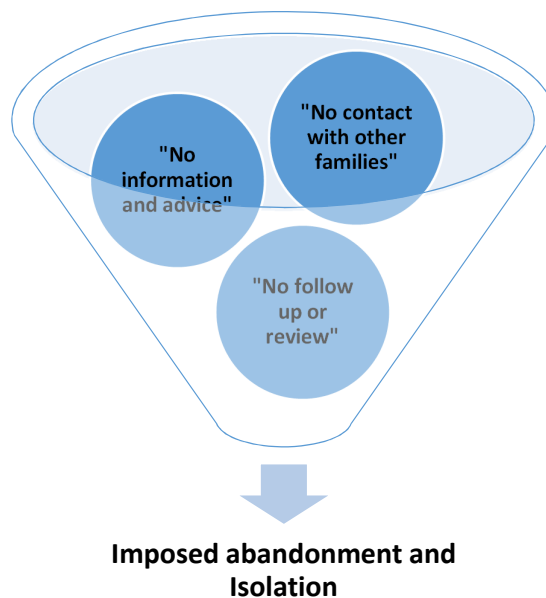


Figure 4.13 Imposed Abandonment and Isolation

4.11.2.1. *Always fighting*

Participants described how they felt the care recipient had been abandoned initially by both acute and rehabilitation services, and then later through a withdrawal of community services and supports. Participants described that accessing services involved a constant fight, and the burden of this ‘fight’ fell on the caregiver. Participants described a general lack of knowledge and a ‘fear’ among healthcare providers about managing the needs of people with PDOC. Caregivers themselves felt pressured to ‘fill the gaps’ such as supplementing therapy, a pressure described by both the home caregiver and the residential caregivers.

“So, you have to fight the whole system. The challenge is getting him the amount of therapy he needs. If we are going to save a life, we really need to think about what we do with that life. And the system is saving lives and the rehabilitation hospital - I found my time pretty useless there because it didn’t equip us to keep (husband) physically well and comfortable”- P7WR.

4.11.2.2. *No follow up*

“We need the professionals, we need the experts. We need to be kept linked in. We find that the (rehabilitation hospital)- its very hard to get linked back in”- P2MR.

Participants indicated how they felt the healthcare system had ‘washed its hands’ of their family member. The majority of participants described a lack of follow-up review at acute and rehabilitation hospitals, with more than half stating that their relative had never had a follow-up review since discharge from acute or rehabilitation services. A small number had a follow-up review at the outpatient clinic with a consultant or other member of the multi-disciplinary team. Participants described dissatisfaction with the

limited follow-up that was provided and described feeling 'in the dark' with regards to what to expect in the future.

"There is no follow-up...There is no follow-up for people that are put into places like this...None at all, except for the three months that (wife) spent up there (rehabilitation hospital). We did have to go back. There was one review after about six months and that was a joke. The Consultant spent more time talking to me than checking over poor (wife). I could have done it on a video link, no problem, instead of the stress of bringing her all the way up there (to hospital)."- P8HR.

Participants described how while they were doing as much as they practically could for their relative, they were often unsure if their input was beneficial or harmful. They lacked feedback about the effectiveness of their role in caregiving over the life-time of the person and this impacted upon their level of confidence in their role with the care recipient. Participants believed that it would be preferable for follow up therapy and clinical reviews to be provided by people with experience and expertise in the care of PDOC.

"Even to know that you're doing the right thing or the wrong thing. Or there's nothing more you could do. That would give you some peace of mind. You do hate to walk away feeling afterwards 'God if only I had known, if I had done this or that, that would have given them a little more something"- P10HR.

4.11.2.3. No contact with other families

Over half of the participants reported that they had no links with other family caregivers of people with PDOC. Some noted that it might not be helpful to make links with others in similar situations in the early stages as the prognosis was relatively uncertain. Some described how it might have been difficult to consider that their relative would be as profoundly injured and slow to recover as somebody else's

relative and this may have compounded their grief and despair with the situation. Others explained that they would have found it beneficial to be able to hear the experiences of others, and the techniques and therapies they tried. Overall the majority of participants felt that it would be helpful to have a forum to meet other families, with a general preference for this to occur in later years, following the acute and rehabilitation phases.

“I just think maybe that someone who has been there and can say ‘well listen we done this and this is how we dealt with it’ or ‘we found this works..I’d like to meet somebody who has somebody like (daughter) and how did they cope through it and somebody just to give you a little tip, because there’s support groups for everything in the country but there is nothing.”- P9MR.

4.11.2.4. No information

“What do I need to do? I need somebody to tell me what I need. I don’t know what I need to find out. Expertise- I need someone to say have you tried this? Have you done that?”- P10HR.

Participants described how the healthcare services were poor at providing information and advice and subsequently caregivers had to spend significant proportions of their time sourcing information themselves. The lack of ongoing guidance and support from specialists in the area was a major course of stress for the participants.

“There’s nothing out there. We have to do everything ourselves. We have to go physically and mentally and do the research ourselves. Instead of somebody coming who works in the community ‘I’ll be with you in two weeks’ time. I’ll have all of the details necessary you need. You can apply for this, this and this. I’ll help you with the forms or any details or information that you want’. They’re not there”- P8HR.

The view of all of the participants was that follow up, information and guidance at different intervals across the journey from experts who understand the needs of people with PDOC and their caregivers would assist in reducing the sense of 'abandonment'. Long-term contact with social work services or case management for their relatives was suggested by a number of participants to reduce the sense of isolation over the years. An advocate for families was also recommended.

In summary, participants illustrated how they had wilfully abandoned a range of social and leisure activities and isolated themselves from social contact so as to avoid thinking and talking about their relative and about caregiving. Similarly, juggling caregiving with other pressing tasks resulted in limited time, energy and finances for their own leisure and social occupations. Caregiving for a family member with PDOC resulted in the loss of social and leisure companionship. Further, participants described feeling abandoned and isolated by healthcare services and experts in the field of severe acquired brain injury. They described disappointment with access to follow up and review from specialists following inpatient rehabilitation. They described how they were required to fight for services and supports. This led to uncertainty and a lack of confidence in their role as caregivers and feelings guilt with regards to striving to ensure that they were providing the best care possible for their relative.

4.12. The Constant Caregiver: The enduring nature of caregiving

The final theme that emerged in the interviews, 'the constant caregiver' relates to the enduring nature of caregiving for a person with PDOC. Caregiving occupied a central place in participants' lives, defined by constantly thinking, doing or talking about their relative and their care. The participants illustrated a realisation that having a family member survive with a PDOC and the commitment to care for that person had profoundly changed their lives and would steer the courses of their lives into the future. They described how looking to the future was challenging due to the uncertainties that existed in relation to the care needs of their relatives, and a fear that their caregiving role could not be replaced should their relative outlive them. Two

subthemes emerged in relation to the 'constant' nature of caregiving for a person with PDOC (see Figure 4.14):

- a) A life changing experience
- b) Enduring and perpetual nature of caregiving.

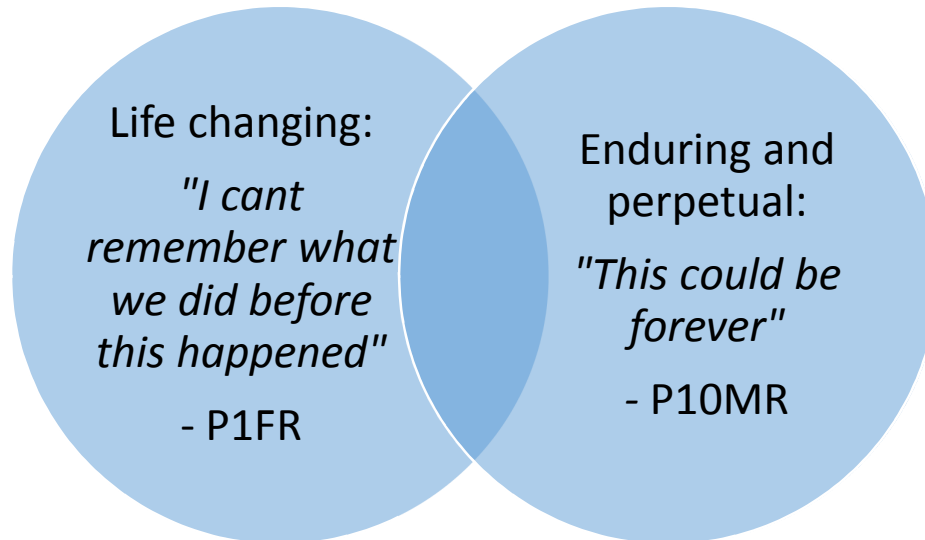


Figure 4.14 The Constant Caregiver.

4.12.1. Caregiving: A life changing experience

"I don't know what we did before it happened. I suppose we did what everyone else did...It's hard to think back three years as to what I was doing that summer. My life just stopped, came to a full stop." - P1FR.

The ability to recollect what life was like before their relative's accident or illness was a challenge for participants because the transformation in their lives had been so immediate and significant. As time-use changed suddenly participants described how they have had little opportunity since the event occurring to resume their 'normal' activities due to the chronic and enduring nature of PDOC and the caregiving role. A number of participants made reference to the experience of loss associated with

PDOC. Participants described grieving for their relative whilst also dealing with a sense of loss of meaningful occupations within their own lives, governance over one's own time and loss within personal relationships as a result of their commitment to provide care to their relative. Caregiving became a new identity for participants with the routine of caregiving subsuming previous routines. The home caregiver and those who were caregiving for longer periods of time were more likely to define it as being "*part of their lives*", whilst others described it as more encompassing and consuming- becoming "*my life*".

"But when something like this happens you mourn everything that you lose and you just lose so much"- P6SR.

"I suppose it's become a part of our lives really"- P4MH.

The constancy of caregiving, requiring thinking ahead, planning, doing, co-ordinating and advocating impacted upon experiences of quality of life. Having to constantly think about what would be best for their relative added to a sense of strain and burden with some describing feeling that they were 'living for' the care recipient. Phrases such as 'my only goal in life' and the care recipient being 'my priority' were frequently used. The majority of participants described how they perceived that 'life was on hold' as the future was defined by continued commitment to caregiving. Some described having little happiness in their lives and little sense of quality of life.

"Like I said, you exist. That's what you do. You do not live. You get up to exist...and that falls from one day to another. That's it. There is no happiness in life anymore." P1FR.

"As long as (daughter) is here, this is where we'll be, this will be our future"- P9MR.

Three participants described occasions when they had thought about their relative dying instead of surviving. The descriptions of such occasions illustrate reluctance

among the three to actively pursue withdrawal of life sustaining measures, despite constancy in caregiving.

“If you’d asked me that two or three years ago, I’d have said ‘yes, it’s extremely stressful’. It probably was at that point my every waking hour and when I’d wake up in the morning I’d think about it and when I’d go to bed I’d think about all the implications, about where he was at and what the future held and worry about him dying, even though this many years on we always say to ourselves ‘God maybe it would have been the best thing for him’ because of the way he is. You just worry that he’s uncomfortable and that he can’t vocalise, he can’t tell you, you worry about stuff like that all the time”- P6SR.

“And I do believe she is here for a reason. Someone, somewhere hasn’t learned the lesson, whatever this lesson is about. But I really hope that lesson will be learned because I don’t want to come back and do this all again in another life. And I did think about euthanasia. And I thought of all of that. If (daughter) could ask, but she can’t ask, so I won’t take that decision for her. It’s not an option in this country, I know. So, I said about the machine, the ventilator, in the hospital- ‘go ahead and take her off that’ and after that it’s ‘pass the book to God. It’s up to you God’- P9MR.

“Shortly after (daughter) came out of the acute hospital an aunt of mine who was a nurse said ‘would it not have been better if (daughter) had died?’. Now, I stormed out of the house and I never forgave her for that, and she is dead herself now. And no, I would not have wanted (daughter) to have died. I was very, very annoyed and upset, and I still get upset about it (tearful)”- P4MH.

4.12.2. *Enduring and perpetual nature of caregiving*

“I think this could be it, this might be as good as it gets. So there is no future- really there isn’t”- P9MR.

Some experienced a feeling that constancy in caregiving resulted in a sense of one's "freedom" being taken away to make plans and choices about their own lives. The descriptions echo a sentiment of feeling 'stuck' and confined, tied into a situation that they felt they would have to endure for many years; as they perceived that nobody else could fill their caregiving role even if that was an option to them. A sense feeling both obligated and sentenced to the role was portrayed, a role that was likely to be constant and prevailing for as long as their relative required care, which could be for many years to come. This compounded a sense of burden.

"We have to be here for her and we want to be here for her. We don't want to be anywhere else because if you're anywhere else you couldn't, you wouldn't be able to relax or anything."- P9MR.

"When (daughter) came out (from hospital) first you think, this is my life now and I'm never going to be able to do anything else. I'm never going to be able to leave the house, and that's exactly the attitude that I had. I thought I'm never going to be able to do anything again because I'm never going to be able to leave (daughter)"- P4MH.

Many participants described the experience of being 'in limbo' and stuck in a constant caregiving role that they had not been prepared for. There was a strong awareness of the enduring nature of the caregiving role with no end in sight, but the added expectation that the situation was most likely to get progressively worse and worries about being able to continue to provide the level of required care in to the future.

"Because (daughter) is so young and she's so healthy, so it could be long term. You have to look at it like it is forever, for 30 years or whatever."- P9MR.

"It just seems to be going on and on...and God forbid something would happen to one of us that the other would have the strength to keep going."- P1FR.

“It’s like you have a sense of foreboding. Although the bad thing has already happened, there’s probably something else to come. You just don’t know when or how”- P5WR.

Participants described a perpetual obligation to provide for their relatives’ continuing care needs. Particularly among parental caregivers, there was the awareness that this level of care input would still be required beyond their own death which was a source of constant worry for them. Some described how they hoped the care recipient would not outlive them as they were fearful that the required levels of care would not be provided after their own death.

“I feel that I am responsible for his happiness- but I just think, if something happened to me then (sigh)”- P2MR.

“Like I say, you just cope. You survive. You exist just to be with him. You’d say ‘God forbid anything would happen to any of us ‘cos there would be a huge void that couldn’t be filled’. And the reason for that is because the back-up isn’t there”- P1FR.

“I just hope God takes her even the day before I go so that I haven’t got to worry about her when I’m gone”- P9MR.

In summary, having a family member survive with PDOC and adopting the caregiver role for that person was a life changing experience for the participants. The role was enduring with participants spending considerable amounts of time thinking, doing or talking about the care recipient. Their ‘old’ lives had been largely forgotten, as the new routine of caregiving became embedded. All participants worried about the future and tried not to think about it with one’s own life being put ‘on hold’ to provide care to their relatives. Alternatives to long-term caregiving such as allowing the person to die were not considered an option for the participants that volunteered their thoughts about this. The role of caregiver had perpetual qualities, as participants described

feeling that their role was irreplaceable and that they would continue to worry about the care recipient after their own death should their relative outlive them.

4.13. Chapter summary

The routine of caregiving involved intensive time commitments regardless of care location, with the majority of the participants spending considerable time each day dedicated to providing care or co-ordinating care for their relative. The caregiver role was broad and encompassed practical care, supplementing therapy, advocacy and care co-ordination. Caregiving had a considerable impact on the lives of the caregivers with a theme of the participants placing themselves and their needs as secondary to the care recipient's needs. All of the participants described how they had abandoned activities, particularly social and leisure activities to facilitate caregiving or to escape from being asked about their relative. Despite the challenges of juggling work with caregiving, remaining in paid employment had a positive impact on feelings of self efficacy and opportunities for social support. A theme of feeling abandoned by healthcare services and feeling isolated in their caregiving role was also described by the participants.

Caregiving was central to the lives of the participants and the role was enduring. Some defined themselves as the 'constant'- the consistent provider of care to their relative. Participants also felt duty bound and obliged to provide care and this resulted lack of escape from caregiving. Participants described how their lives had changed with a sense of duty to provide care defining their futures. They perceived the role to be perpetual should their relative outlive them, a sense that they would worry about them even after their own death, and they viewed their contribution to caregiving as being irreplaceable.

5. CHAPTER 5.0 DISCUSSION

5.1. Overview

The focus of this study was to explore the lived experience of informal caregivers of people with PDOC and the impact of caregiving on occupational engagement and time use, and the roles and routines of the informal caregiver. It also explored perceptions of quality of life, caregiver strain and future care needs of their relatives. Mixed methods research using quantitative survey design embedded in an overall qualitative description design was the methodology employed to achieve the following objectives:

- To examine the prevalence of informal caregiving for people with PDOC, including the type and patterns of informal care provided
- To explore informal caregivers' perceptions of preparation they received from specialist healthcare professionals to enable them to adopt and manage caregiving roles.
- To explore the lived experience of informal caregivers of people with PDOC and the impact caregiving has on their occupational engagement, roles and routines
- To explore perceptions of quality of life and levels of caregiver strain among informal caregivers of people with PDOC.

In this chapter, the overall findings will be discussed and the strengths and limitations of the study will be acknowledged along with implications of the findings for clinical practice and future service development.

5.2. Study sample

Methods to increase response rates in survey research such as giving prior notice via a gatekeeper, sending a stamped addressed envelope, and following up with a reminder card (Edwards *et al.*, 2002; Oppenheim 1992) were used in the current study. While the possible sample to draw on was small to start with, given the incidence and survival rate for PDOC, a response rate of 54% was achieved for the postal

questionnaire which is well within the average expected response rate of between 40-60% for questionnaire type research (Drummond 1996; Oppenheim 1992). Subsequently 27% of the target population agreed to participate in the qualitative interview phase of the current study.

5.2.1. *Demographic profile of the participants*

The majority of respondents to the survey and participants in the interview are female caregivers (60% and 60% respectively), which is in keeping with international trends that females are more likely to adopt roles as informal caregivers (Care Alliance Ireland 2015; Juratovac and Zauszniewski 2014; Hollander *et al.*, 2009). More than half of the caregivers in the current study are of working age which also matches the national profile of informal caregivers with the majority in Ireland being of working age (Care Alliance Ireland 2015). The majority of caregivers in the current study are aged 46 years or older, with the largest number in the 56-65 year age bracket, but some are in their late 60's. The age and gender profile of the participants in this study correlates with the demographic profile of informal caregivers involved in international studies of informal caregiving for people with PDOC (Giovannetti *et al.*, 2015; Cruzado and Elvira de la Morena 2013; Giovannetti *et al.*, 2012; Guarnerio *et al.*, 2012; Leonardi *et al.*, 2012). The advancing age of the informal caregivers reflects the increasing survival rate of people with PDOC and is a factor that is likely to pose challenges to health and social care providers in to the future as caregivers themselves develop their own healthcare needs associated with older age (Covelli *et al.*, 2014; Navaie-Waliser *et al.*, 2002).

Parents represent the largest relationship group of questionnaire respondents, with spouses the largest of the relationship groups participating in interview. One sibling responded to the questionnaire and interview. There are no children caregivers in this study, most likely due to the overall age profile of the care recipients (mean= 40.7, range 23-72 years) and the sampling methodology which specified that participants be over 18 years old and the next of kin involved in caregiving, which was more likely to be a parent or a spouse/partner. Whilst not captured by the survey questionnaire,

qualitative data from the interviews expose how adult children play a substantial role in caregiving for adult siblings and parents with PDOC, even though they may not be the primary caregiver nor were they the participants in this study.

The findings in relation to the demographics of the care recipients reflects how men are more likely to be effected by acquired brain injury in Ireland (Philips 2008), with 70% of respondents to the questionnaire and 50% of interview participants providing care to male care recipients. Respondents to the questionnaire indicted that the majority of care recipients had minimal or no awareness, which highlights the pessimistic prognosis characterised by a slow course of recovery of awareness and functional ability among people with PDOC lasting longer than one year from onset of injury (RCP 2013; Luaute *et al.*, 2010). The care recipients in this study have profound disability resulting in significant care needs and the findings illustrate that this is an enduring, long-term situation as participants in the study had been providing care for a considerable period of time, ranging from 3-14 years. No other studies of informal caregiving for people with PDOC over such a prolonged period were found. This prolonged exposure to caregiving potentially adds credibility to the findings of the current study as the participants have extensive experience in the role of caregiver with the impact of caregiving on their daily roles and routines being well established.

5.3. Context of care provision- Caregiving locations and availability of formal care

The majority of the participants provide care for relatives who reside in residential care units which is similar to other studies of informal caregiving for patients with PDOC, whereby their care needs are usually met in residential nursing units (Covelli *et al.*, 2014; RCP 2013; Giovannetti *et al.*, 2012; Guarnerio *et al.*, 2012; Leonardi *et al.*, 2012; Chiambretto *et al.*, 2010; Chiambretto *et al.*, 2001). Whilst the numbers of home caregivers responding to both the questionnaire and interview are low, it is interesting that they are all parents of care recipients, a finding consistent with Giovannetti *et al.* (2012). This may reflect a sentiment that long-term residential care units in Ireland are generally not designed to cater for young people with ABI (Dwyer *et al.*, 2017), as

highlighted in media reports in recent years (Ryan 2013). It may also reflect values of personal responsibility that parents experience to provide for their children's wellbeing despite the child developing into adulthood (Huber and Kuehlmeier 2012) or having significant specialist care needs.

The home caregiver who participated in the interview acknowledged being able to provide care for their relative in the family home as the care recipient had received compensation following their injury. However, on receipt of compensation they reported that all HSE services and supports that had been available through the Medical Card Scheme were withdrawn with the exception of Public Health Nursing and some healthcare assistant hours which were supplemented with privately paid healthcare assistants. The burden to prudently manage large compensation awards is a recurring theme in the interviews with informal caregivers feeling obliged to ensure that the funds were budgeted in such a way as to provide for the care needs of the individuals over their life time, which was recognised, could be substantial time period. Access to formal respite such as day services or in-patient respite was limited. This perhaps indicates a dearth of this type of resource for young adults with a severe acquired disability.

Further, qualitative findings would suggest that there may have been reluctance to access respite care as being away from the care recipient for any length of time caused stress and worry. This may be indicative of an anxious-attachment style of coping which can result in caregiver burden among PDOC caregivers (Romaniello *et al.*, 2015). Moreover, respite is conceptualized among the participants as something of benefit for the caregiver themselves (e.g. to take a holiday or have a rest), rather than benefiting the care recipient, and as such, it is not prioritised by participants. This illustrates the centrality of the caregiving role in the lives of the participants and how they consistently placed their own needs secondary to those of the care recipient.

All of the residential care recipients in the current study were residing in long-term care homes designed primarily for older people, with some people living in these facilities up to 11 years. This inappropriate long-term placement of people with severe

brain injury in elderly nursing homes and community hospitals has been highlighted by ABI Ireland, as well as the lack of specialised units designed specifically to meet the needs of patients with PDOC (ABI Ireland 2015; An Saol 2017). The findings from the current study highlight the difficulty in sourcing what caregivers felt was an acceptable standard of long-term care placement, with some participants reporting their family member had been through up to six different facilities before their current residence. This finding suggests problems with implementing an integrated model of care for this patient group from acute care, to rehabilitation and through to a suitable long-term care facility. Further exploration of the entire care pathway would be useful in assisting with implementing greater integrated care in line with national goals towards simplifying the patient journey and facilitating smoother access to suitable long-term care placement or support in the community for those with chronic diseases (Department of Health and HSE 2011).

5.3.1. *Prevalence and patterns of caregiving*

Findings from the current study highlight that informal caregiving is intensive and time-consuming regardless of whether the person is being cared for at home or in a residential care unit. The daily average time spent caregiving is 2.6 hours for residential caregivers, spanning as long as seven hours per day for some. While this figure is similar to that reported in other studies of informal caregiving of people with PDOC residing in care facilities (Elliott and McVicar 2016; Giovannetti *et al.*, 2012; Chiambretto *et al.*, 2001), it is well in excess of the average of two hours of daily care reported in national surveys relating to informal caregiving (Central Statistics Office 2012). Reasons are cited in the literature for intensive levels of care provision by family caregivers including feeling guilty when not being with the person with PDOC (Huber and Kuehlmeier 2012) and gaps in care provision by formal services for people in residential care (Trepel 2011).

Whilst the interview participants report short-comings in the care provided at residential care units and a feeling of guilt at stepping back, it is clear that the level of disability that a person with PDOC presents with, being totally dependent upon others to meet their basic care needs is a reason for intensive levels of family caregiving. The

perceived vulnerability of the person with PDOC is a contributing factor to intensity of caregiving that may not exist among informal caregivers of more able-bodied patient populations. It is evident from interview findings that the perceived vulnerability results in maintaining a vigil, always having someone with the care recipient, which contributed to intensive caregiving durations among this population. Thus, as national statistics relating to informal caregiving are generally based on care in the family home (Department of Health 2012) it is possible, given the majority of people with PDOC are usually cared for in residential care settings in Ireland, that the extensive contribution of informal caregivers is hidden and under-acknowledged in national data.

Within the interviews, participants described how caregiving extended beyond providing actual hands-on care to include other activities such as advocacy, fundraising, and driving to and from the residential care facility. When these factors are considered, the time spent in providing this extended range of tasks which were perceived as caregiving would well exceed the Central Statistics Office figure of two hours per day (Central Statistics Office 2012B). It is perhaps important to consider and include these 'non-direct' caregiving tasks when estimating amounts of time spent caregiving as duration of time spent engaged in care-related tasks is a significant factor associated with overall levels of perceived burden among caregivers (Giovannetti *et al.*, 2012).

Findings from the interviews show that caregiving is the central priority in the lives of the participants, with all other routines and plans made around caregiving commitments. Some reported that their caregiving routine is similar to that of a full-time job, with time structured in a manner reflective of a 'working day' routine. These findings echo other studies of informal caregivers of people with PDOC whereby caregiving tasks dictated the caregiver's daily routine (Elliott and McVicar 2016; Gourdarzi *et al.*, 2015; Covelli *et al.*, 2014). Moreover, in the current study participants described how caregiving became a 24 hour task that did not stop at night-time. Interview participants, particularly the home caregiver, described how they had experienced broken sleep and all of the participants had needed to take sleep medication at some stage or another since having the caregiver role imposed upon

them. Anxiety was typically experienced by participants at night time, with negative thoughts directly stemming from the circumstances of their caregiving and its related duties. Similarly, other studies have described how informal caregivers experience significant levels of depression and prolonged grief related to having a relative survive in a vegetative or minimally conscious state (Chiambretto *et al.*, 2010). Additionally, the physical and mental effort of caregiving for a person with PDOC can contribute to high levels of fatigue (Gourdarzi *et al.*, 2015), and is further compounded by a lack of time to rest, to take a break or to be away from the care recipient.

5.3.2. *Caregiving and the family*

The existing literature highlights that having a relative with an ABI can affect the entire family unit (Peterson and Sanders 2015) and place unique demands upon each family member (Degeneffe 2001). The current study findings illustrate that surviving with PDOC affects not just the patient but a community around them, with family members and friends often involved in caregiving tasks. Medale (1997), in outlining the principles relating to care of patients with chronic disease and their families noted that there are three different types of 'family forms' which are important when it comes to the care of people with chronic disease and disability. These include firstly the biological family; secondly the household family and finally the functional-intimate family. It is this third family group, which may be made up of related family members, friends, neighbours and members of the healthcare or medical teams who become most closely involved with the care of the patient with chronic illness and disability.

This idea of the functional-intimate family assuming a prominent role in care provision assists with explaining the findings emerging in the qualitative phase of this current study. Interestingly, the findings illustrate that family caregivers are particularly careful about whom they permit to be involved in this functional-intimate group with not all who offered assistance being included. Medale (1997) pointed out that while other distant family members and friends may have roles to play such as financially and in other ways, it is those in the functional-intimate group who take responsibility for the ongoing day to day support and care. In the current study, the functional-intimate family was made up mostly of close immediate family members, usually parents,

spouses, children and siblings of the care recipient, and generally their roles seemed to be clearly defined and somewhat gender-related. 'Trusted' friends whom possessed certain characteristics such as a gentle demeanour were included in the functional-intimate family. Similar findings were reported in an Italian study with caregivers of relatives in PDOC describing that "only the right person" can take care of their relative (Giovannetti *et al.*, 2015; p.475). Although healthcare professionals and formal caregivers are a key part of the caregiving network for the care recipient, they are less likely to be identified by the participants in the current study as having become part of the close network of caregivers included in the functional-intimate family.

Qualitative data from the interviews highlights a wide family involvement in caregiving for people with PDOC, particularly with adult children playing a substantial role in caregiving for adult siblings and parents with PDOC even though they may not be the primary caregiver. Adult siblings often expect that they will have to adopt caregiving roles when their parents are no longer able to fulfil this role (Degeneffe and Olney 2010) and there can be mixed feelings about this ranging from reluctance, resentment and anger towards parents and the care recipient, to willingness and motivation to adopt the role (Degeneffe 2015). Qualitative findings from the interviews alluded to the considerable impact upon the lives of adult children and siblings as they put their careers on hold and made significant changes such as relocating from abroad, to be involved in supporting family caregiving for a sibling or a parent. This illustrates the wide impact that having a family member survive with PDOC has on a community of people particularly upon the lives of those in the functional-intimate caregiving group.

Of particular interest is the importance of the caregiving rota and the decisions that families make in relation to allowing others to assist with care. Rotas are an important strategy in facilitating a break for principal family caregivers, however organising rotas is time-consuming and involves considerable co-ordination. They may be seen however as a positive coping strategy and a resource to managing stressors and facilitating respite. This is evidenced in narratives of the participants in the current study and in existing literature with accepting and asking for help a common coping

strategy among informal caregivers (Greenwood *et al.* 2009; Calassanti and Bowen 2006).

5.3.3. *Caregiving tasks*

This study is unique in that it gathered rich data about the types of caregiving tasks undertaken by family members of people with PDOC adding to a small body of existing knowledge (Goudarzi *et al.*, 2015). A dominant subtheme of 'Caregiver as Expert' emerged in relation to the range of skills and tasks undertaken by informal caregivers of people with PDOC. Findings from the postal questionnaire show that the range of caregiving tasks completed varies depending on care location.

It was evident that home caregiving necessitates developing a greater level of applied clinical skills than is necessary for some of the residential caregivers. This makes sense, given that home caregivers have adopted responsibility for every aspect of the persons care. Complex tasks that involved a certain level of both clinical skill and clinical risk are completed with confidence by home caregivers, including suctioning, catheterisation, managing clinical artificial nutrition and hydration and administering medications. These findings are consistent with findings by Goudarzi *et al.*, (2015) who found that home caregivers of patients with PDOC adopt a range of specialist caregiving skills (Goudarzi *et al.*, 2012). Caregiving at home necessitated completion of all aspects of personal care including intimate care such managing bowel care, menstruation and oral hygiene for their adult relative, transfers using a hoist and other equipment, positioning including frequent repositioning during the night to protect pressure areas and physical exercise programs including use of tilt tables, passive ranging and application of splints.

Residential caregivers on the other hand, report feeling restricted in how much they can assist with the hands on care of their relative. This was a source of frustration and anger for the participants as they perceived that they were failing their relative by not being able to carry out therapy and care programs or arrange for private therapy to be provided in the residential care unit. Variances in how much caregivers are 'allowed' to do existed from one residential care unit to another. While home caregivers appeared

to have more control over their relative's care, the residential caregivers on the other hand felt restricted in the amount of 'hands-on' care they felt they were allowed to provide for their relative. Kitzinger and Kitzinger (2014 B) described how families of people with PDOC often have a mistrust of and dissatisfaction with formal care provision. Similar findings emerged in the current study as participants describe needing to supervise, monitor and in some cases teach the formal caregivers how to carry out essential care tasks.

Whilst questionnaire respondents rate the care provided by formal care staff in residential care units as 'good' or 'excellent', interviews yielded some differing findings. The majority of residential caregivers interviewed are dissatisfied with levels of supervision, the skill-set of formal caregivers, a lack of empathy for the profound vulnerability of the care recipient; and an inability to respond in a timely way to the needs of the care recipient, which highlights a level of mistrust and general dissatisfaction. Challenges for family caregivers in dealing with shortfalls in the provision of consistent basic care, a lack of follow up and not being included in decision making about the care of their relatives has been reported as a source of distress for family members, sometimes resulting in families feeling regret that the person was kept alive to endure what they believed was substandard care (Kitzinger and Kitzinger 2014 B). Informal caregivers in the current study describe themselves as 'constant' in care provision, highlighting inconsistencies and lack of continuity by formal services. Despite the constancy in caregiving and the sense of isolation, none of the participants expressed regret that the person had lived.

In the current study, heightened vigilance can be borne out of a desire for greater control over the type and quality of care provided (Elliott and McVicar 2016; Fox 2000). Anger, frustration and disappointment are expressed among participants in the current study particularly among the residential caregivers. Family caregivers of people with PDOC in post-acute facilities found to experience higher levels of anxiety and negative mental health outcomes compared with home caregivers (Giovannetti *et al.*, 2012). Although there was only one home caregivers involved in this current study, a greater sense of control over the care of their relative was described compared with

the residential caregivers and a surprising finding is a lower level of caregiver strain (scored using the Modified Caregiver Strain Index) reported compared with the residential caregivers, perhaps due to having greater autonomy and control in relation to care provision for their relative.

Despite recommendations made in recognised clinical guidelines that staff be suitably trained in the care of people with PDOC (RCP 2013), in many cases residential nursing care is provided by staff and teams who have no specialist training in the assessment and management of PDOC and their co-morbidities (Whyte and Nakase-Richardson 2013). Further, Martone (2006) argued that the first line of responsibility in meeting the needs of a person with PDOC should rest with the family. The findings from this current study would support a view that this responsibility is much desired by family caregivers, despite the enormity of the care needs of the individual with PDOC. The high levels of monitoring of formal care staff in the current study is also driven by a sense of obligation or a fear of abandonment of their relative. The qualitative descriptions provided by interview participants illustrate how this desire for more control over the care was, in many instances, in direct conflict with restrictions imposed by the 'system' such as policies and procedures that corral the amount of involvement they can have in hands-on care. This added to a sense of frustration and strain for the participants, and exacerbated the intensity of monitoring and checking to ensure that their relative was receiving what they viewed was the best care possible.

Providing ongoing therapy for the care recipient to prevent further physical deterioration and to promote recovery is a caregiving task that is prioritised by the study participants. They describe gaps in service provision with few of the care recipients having regular contact with allied health services provided by the State, such as primary care physiotherapy or occupational therapy. The Public Health Nurse was the only state-funded resource routinely available to home caregivers. Low frequency of contact with allied healthcare professionals is consistent with findings of other studies of informal caregiving for people with PDOC (Goudarzi *et al.*, 2015; Kitzinger and Kitzinger 2014B). In the current study, the frustration and anger among participants in feeling obliged to 'fill the gaps' in relation to providing or sourcing on-

going therapy for their relatives adds to a sense of burden in the role. The qualitative findings illustrate a perceived need to do everything possible to supplement and substitute this aspect of care so as to ensure the best possible opportunity for improvement and quality of life for the care recipients. Ambiguous loss can result in a hope that both the care recipient and life will return to how it used to be (Boss 1999) resulting in every effort being invested to trying to reverse the situation, perhaps in the absence of clarity from experts that this may or may not be possible. Living continuously with levels of uncertainty, fear and sense of the persons' vulnerability results in a perceived need to protect them (Nalder *et al.*, 2012; Boss 1999) and to preserve what remains of the person. Whilst informal caregivers in the current study describe feeling abandoned by formal services, it is unlikely that the lack of provision by the State to this area of care for people with PDOC reflects the sense of "fatalism" among healthcare providers as suggested by Whyte and Nakase-Richardson (2013) and as perceived by the participants; but rather most likely reflects the lack of empirical evidence to support the benefits of intensive therapy input in influencing the functional recovery for people with PDOC in the longer term (Giacino 2005; Klingshirn *et al.* 2015; Wheatley-Smith *et al.*, 2013; Wilson *et al.*, 2013). However there is a reasonable argument for the prescription of therapeutic interventions to prevent unnecessary suffering, reduce caregiver burden and promote conditions that might support any delayed recovery of consciousness (RCP 2013; Andrews 1996).

The participants of this study argue that at a minimum, this level of therapy, frequently referred to as 'maintenance therapy' is not being provided. Such measures include those to prevent secondary complications (Wheatley-Smith *et al.*, 2013; Fabbri *et al.*, 2010) and to promote increased arousal and responsiveness (Wilson *et al.*, 2013). Participants describe feeling that their relatives are disenfranchised in this regard which results in informal caregivers feeling a sense of duty to supplement and fill gaps with some reporting how their efforts are stymied by local policy preventing them from carrying out programs that many have been trained up to do and are willing to do. The findings suggest that if people with PDOC were at a minimum receiving the recommended maintenance therapy programs consistently either from therapy teams or with support for family members to carry out programs themselves, informal

caregivers may experience less strain, improved satisfaction in their caregiver roles and may have moved towards improved occupational balance in their own lives.

5.4. Preparation to adopt and manage caregiving roles

Clinical care guidelines state that healthcare professionals with specialist skills in the care and management of patients with ABI and PDOC should take responsibility for ensuring that the needs of family caregivers are met including education and training with practical care tasks (RCP 2013; BSRM and RCP 2003). Three quarters of those who responded to the postal questionnaire report some or a lot of preparation by healthcare professionals to assist them to learn skills required for the caregiving role. Interestingly two of the home caregivers indicated in the questionnaire that they had received no training from the specialists in the rehabilitation hospital. Within the subsequent interviews it became clear that local and regional care facilities and community healthcare professionals particularly PHN's, played a more significant role in preparing the home caregiver than the rehabilitation hospital staff.

While there is a dearth of empirical information on the training, educational and support needs of caregivers of people with PDOC and how best to provide this training it is acknowledged that family members value training and education to prepare them for the their caregiving role (Covelli *et al.*, 2014; RCP 2013; Leonardi *et al.*, 2012). Within the current study the type of caregiving training that was provided revolved around the physical care needs of the care recipient including techniques to assist with personal care, positioning and stretching exercises, use of specialist equipment and clinical procedures such as suctioning and managing feeds and medication. Findings indicate that many of these skills were learnt by observation as family members spent much time at the person's bedside in the rehabilitation hospital.

Given that the findings of the current study highlight the broadness of the role and the variety of tasks undertaken by family caregivers that extend beyond 'hands-on' care tasks to include financial planning and management, care rota management, fundraising and advocacy the need for a more comprehensive approach to caregiving

training is indicated. Similarly, Seel *et al.*, (2013) highlighted the need for education and training for PDOC family caregivers regarding medical information, case management skills for life-long care planning, information about accessing local medical and support services, financial support options and strategies for disability advocacy as well as hands on skills training. Additionally, Giovannetti *et al.*, (2012) suggested that caregiver training should include strategies to deal with the emotional impact of caregiving, redefining the caregiver relationship with the patient, and strategies to strengthen social cohesion among family members. Findings from the current study would support this proposal as participants described the impact of caregiving on their daily lives and that of their extended families.

Whilst the resounding preference of the questionnaire respondents and interview participants is to have direct contact with healthcare professionals, online resources were noted as the third most useful initiative identified from a list of eight suggestions to support informal caregivers. Telephone and internet contact with a professional support network has been found to be a relevant venue to providing emotional support and information for family caregivers of people with ABI in Canada (Gan *et al.*, 2010). Additionally, empirically evidenced resources such as Healthtalk.org (healthtalk.org.uk, 2017; Kitzinger and Kitzinger 2016) may be useful tools for all family members especially those most directly involved in caregiving and decision making for the patient, and experts should be signposting them towards such resources.

Interestingly, of the list of eight suggested resources to support caregivers included in the questionnaire in the current study, initiatives designed to directly assist the caregiver with reducing burden in caregiving are ranked least useful among the respondents. A lifestyle design program aimed at achieving greater occupational balance for example is viewed as the least useful initiative by the caregivers in the current study. Instead, interventions that directly involve providing a service to the care recipient are viewed to be of more use. This strongly reflects the dominance of the themes 'Self as Secondary' whereby the needs of the caregiver were subordinate to the needs of the patient, and the theme 'Imposed Abandonment and Isolation' which was experienced in the years following rehabilitation as caregivers perceived a

withdrawal of services and supports. It may also indicate a difficulty in the caregivers recognising or acknowledging that they themselves have needs.

Despite inconsistencies in caregiver training, a high level of confidence is reported among participants with regards to carrying out caregiving tasks. Home caregivers are the most confident of both groups despite being least satisfied with preparation for caregiving from the specialist rehabilitation hospital. Descriptive narratives from the interviews with the residential caregivers reflect challenges with identifying with the caregiver role due to being restricted in how much they could assist the care recipient. Roles that emerge suddenly, without prior build up to their development and with no clear expectations or meanings can be ambiguous and role identity is nurtured when others acknowledge the person in the particular role and interact and respond to them as the person who holds the role (Kielhofner 2008).

A lack of validation for the role is experienced by some of the caregivers in the current study, particularly the residential caregivers, and measuring effectiveness and efficacy in caregiving is a reported challenge. This is compounded by lack of feedback from experts in the area, resulting from challenges with accessing clinical reviews by rehabilitation specialists. Validation for the role is also impacted by lack of change in the care recipients' condition, which leads to participants questioning whether they are doing enough to assist in the care of their relative. These findings are similar to other studies of informal caregiving experiences (Kitzinger and Kitzinger 2014 B) whereby family members have reported feeling helpless in their caregiving efforts and excluded from important decision making processes relating to the care of relatives with PDOC. The findings of the current study suggest a need for ongoing contact with experts in the area of PDOC to support families in their caregiving roles and with moving gradually towards adjustment and acceptance of the prognosis for PDOC patients.

5.5. The impact of caregiving on occupational engagement, roles and routines

The findings from this current study illustrate how the imposed caregiver role impacts upon the everyday lives of the participants. Participants describe how caregiving results in considerable restrictions to engagement in other occupations across the domains of self-care, work and leisure. This finding is consistent with other studies of the experiences of informal caregivers of people with PDOC (Goudarzi *et al.*, 2015; Covelli *et al.*, 2014; Giovannetti *et al.*, 2012; Leonardi *et al.*, 2012). The availability of time, financial resources, physical and mental capacity (energy) and volition were all impacted as a result of substantial commitments to caregiving, regardless of care location. The constant juggling of tasks and demands upon one's time from other sources resulted in participants experiencing what Elliott and McVicar (2016, p. 14) described as "occupational squeeze" whereby caregivers feel constant demands on their time with little or no time available to relax or to do something for themselves. Contrary to the findings of Elliott and McVicar (2016) who reported that the experience of 'occupational squeeze' slowly subsided from six months post injury in their sample of six informal caregivers for people with PDOC, the longitudinal nature of the caregiving role amongst the participants in the current study suggests that "occupational squeeze" prevails for many years, particularly impacting upon areas of self-care, social activity and leisure.

5.5.1. Self care

The manner in which one does things, the timing of doing (when) and what exactly one does in everyday life is related to habits (Kielhofner 2008). Findings from the qualitative interview data illustrate how caregiving requires a reorganisation and development of new habits over time in response to the changed demands from the environment and the life situation of the participants (Kielhofner 2008). Participants describe the centrality of caregiving in their lives resulting in what Kielhofner (2008) has described as 'negative habits', where caregivers reprioritise and find ways to fit their own self-care around the caregiving tasks. Changes reported by the participants include reduced exercise, less time for activities with other family members, unhealthy sleep patterns, and little rest. These findings are consistent with those of Goudarzi *et*

al., (2015) who studied the experience of 13 home caregivers of people in a vegetative state and identified similar negative impacts of caregiving such as disorder to the daily activities of caregivers whereby they struggled with meeting their own nutritional, exercise, sexual intercourse, hygiene and sleep needs.

Negative habits can impact on wellbeing and performance capacity (Kielhofner 2008) as evidenced in the interviews, with participants describing difficulty sleeping and being unable to relax, corresponding with scores obtained on the Modified Self Rating Questionnaire which illustrate moderate to high levels of strain in more than half of the sample. Previous research has highlighted that informal caregivers of people with PDOC experience a dominance of caregiving over other occupations most notably in the first six months after injury (Elliott and McVicar 2016). However the current study highlights the prolonged prioritisation of the care recipients needs over the caregivers' own needs resulting in long-standing experiences of occupational loss and negative habit formation.

5.5.2. *Social and leisure activity*

Participants describe occupational loss and deprivation in areas of leisure and social participation as a result of caregiving. The reasons for this are similar to those found in a number of other studies relating to the response to caregiving for people with PDOC (Elliott and McVicar 2016; Giovannetti *et al.*, 2015; Covelli *et al.*, 2014; Leonardi *et al.*, 2012; Chiambretto *et al.*, 2001) including financial pressures, lack of time, reduced energy, fatigue and difficulty with being away from the care recipient. As highlighted in studies of informal caregiving for people with PDOC by Elliott and McVicar (2016) and Giovannetti *et al.*, (2015) a lack of enjoyment from social activities and events, and being unable to relax when attempting to partake in leisure seemed to negatively compound attempts to re-engage in previously enjoyed social activities and leisure. Further, participants in the current study describe how the loss of one's social companion negatively influences their volition for participating in, and the experience of satisfaction from leisure and social activity as it reinforces a sense of bereavement for their relative and a feeling of guilt at engaging in a pleasurable activity. The sense of guilt in enjoying previously shared activities has also been reported in other

research (Elliott and McVicar 2016) who suggested that encouraging caregivers to engage in novel activities rather than previously shared activity may be one strategy to reduce this associated level of guilt.

Social engagement and support is recognised as being an important factor in promoting and maintaining psychological wellbeing when people are experiencing periods of prolonged emotional distress (Huber and Kuehlmeier 2012). Descriptive data from the interviews highlights a problem encountered by the participants whereby attempts to take a break from caregiving are frequently sabotaged by others enquiring for the care recipient. For well-meaning acquaintances, this probably was intended to be a thoughtful gesture, and an offer of social support. However, the findings illustrate that constantly having to answer well-intended questions, usually to reiterate that the situation remained unchanged, has a negative rather than positive, impact upon the caregivers, adding to an internal sense of burden and failure in the caregivers' efforts to rectifying the situation. Participants described how they sought wilful social isolation, whereby engaging in activities alone seemed to offer the greatest opportunity for a break from caregiving by minimising the likelihood of thinking, doing or talking about caregiving. A sense of personal responsibility assumed by family members for the welfare of the care recipient and the emotional pain and disappointment in the lack of change in the situation over time is evident in the findings.

An unexpected finding is that residential caregivers seem to experience great difficulty with engaging in social and leisure activity compared with the home caregiver. Whilst acknowledging that the numbers of home caregivers in this study are very small, the finding reflects a paradoxical situation, as one might assume that home caregivers are less likely to have opportunities to engage in other activities due to the demands of providing twenty four hour care. Covelli *et al.*, (2014) proposed that home caregivers have greater opportunities for engagement in social and leisure activity as they develop relationships with formal caregivers who visit the home to assist with caregiving (Covelli *et al.*, 2014). In the current study, the reasons related more so to having a large group of trusted family and close friends involved in the care of the

person; the tendency to arrange social and leisure activities in the home; and the home caregiver was more likely to involve the care recipient in social events such as weddings.

5.5.3. *Work*

Interference to work (paid employment) due to caregiving significantly increases caregiver strain and the perceived likelihood of job termination. Those with flexible jobs tend to have lower levels of work interference, and interruptions are typically influenced by the level of impairment of the care recipient and the adequacy of other available caregiver supports (Scharlach 1991). Studies of caregiving and employment have shown that females are more likely to experience interruption to their working lives on assuming caregiving roles (Lee and Tang 2015). Similarly, females in the current study are more likely to experience interruption or changes to paid employment, perhaps because the caregiving role is traditionally and predominantly a female role (Chiambretto *et al.*, 2001; Care Alliance Ireland 2015). In the case of the male parental caregivers interviewed, their wives had given up their work to provide care on a full-time basis to their child. Nevertheless, in the current study, almost half of the respondents to the questionnaire are in fulltime paid employment and fit their caregiving duties around their work schedules.

Typically, caregivers of other diagnostic groups such as dementia reduce their work hours or cease working so as to manage caregiving (Trepel 2010). In the current study participants describe a range of changes such as reducing work responsibilities and altering work roles so as to manage the additional stress and cognitive demands associated with caregiving. In some cases, participants needed to keep working, and even increased the hours spent in paid employment to supplement loss of the care recipient's earnings to the family income. The younger age profile of the care recipients and caregivers in this study is likely to have contributed to this, with just under half (45%) of the survey questionnaire respondents reporting having to support other dependents also. Further, many of the caregivers are required to supplement the cost of care, which is an additional burden adding to experiences of caregiver strain. A number of parental caregivers in the current study describe how adult siblings

of the care recipient put their careers on hold to assist with caregiving, reflecting how the lives of other close family members are profoundly impacted by caregiving for a relative with PDOC, characterised often by a range of occupations and roles coming to a 'stop' (Kitzinger and Kitzinger 2014A). This trend has been reported in other studies relating to informal caregiving and PDOC (Goudarzi *et al.*, 2015; Kitzinger and Kitzinger 2014A). Whilst some have referred simply to the time-consuming nature of caregiving being the main reason for informal caregivers giving up work (Goudarzi *et al.*, 2015), findings from this study contribute further by highlighting that psychological reasons (including anxiety and fear of leaving the patient) and challenges with trusting that care would be provided safely, effectively and in a timely way as being additional reasons as to why caregivers perceive a need to reduce their work hours or to give up work.

Findings from the current study highlight that continuing to engage in paid employment and volunteering activities may positively impact on the lives of the caregivers. The participants describe how work played a role in maintaining well-established occupational and role identities and can be a source of distraction, providing a sense of 'escape' or respite, thus facilitating greater occupational balance. Whilst many studies have alluded to the negative impacts that juggling caregiving and paid employment can have such as increasing caregiver burden (Leonardi *et al.*, 2012) and depression (Juratovac and Zauszniewski 2013), this finding adds to existing research illustrating the positive benefit that continuing to work may have for informal caregivers of people with PDOC (Chiambretto *et al.*, 2001). The work role had fundamental attributes that were not readily experienced through the occupation of caregiving for a person with PDOC. Such attributes included feeling appreciated and valued for the role, seeing measurable results from one's efforts and offering a social supportive component. Isolation in caregiving, the lack of observed improvement in the care recipient's functional ability, and the care recipients' inability to express gratitude for the care received (Las Hayas *et al.*, 2014) are possible reasons for experiencing lower levels of satisfaction and efficacy in the caregiver role compared with other roles such as vocational roles.

5.5.4. *Impact on roles*

All of the participants describe role changes in their lives as a result of caregiving. The 'forced' nature of this unplanned and imposed role upon the participants emerged as a dominant theme from the qualitative data, involving significant reorganisation of identity, relationships, lifestyles and occupations. In addition to loss of roles, having a family member survive with PDOC results in new roles emerging, the predominant new role- 'caregiver'. Rich and detailed quantitative and qualitative findings from the current study add to the limited existing literature (Goudarzi *et al.*, 2015) relating to what this role encompasses. Findings from the current study illustrate it to be a multi-faceted role, encompassing clinical, practical, advocacy and financial tasks. The findings from the current study echo those of Elliott and McVicar (2016) who emphasised 'change' as a significant feature in relation to life roles when a family member is affected by PDOC. In the current study, family members experience altered roles with the care recipient and broader changes to occupational and family roles. Caregiving impacted upon opportunities to engage in preferred or chosen occupations resulting in role loss such as those associated with paid employment and social activities.

Role regression and 'extended parenthood' has been described as a feature when parents have to take on the role of caregivers for an adult child (Degeneffe 2015; Degeneffe 2001) and is experienced by parental caregivers in the current study, who otherwise should have been preparing for retirement and observing their adult children create independent lives of their own. This regression to caring for an adult 'infant-like' child with the same needs as a "new-born", and involving the same activities as feeding, cleaning, soothing, monitoring and decision-making for this once again helpless and dependent person was a deeply traumatic forced role change for the parental participants.

Previous studies have found that women tend to become engulfed by the caregiving role (Boeije and van Doorne-Huiskes 2003). Findings from both phases of this study show that women are more likely to give up their work to dedicate time to caregiving

which may illustrate a sense of being less able to divide their time between caregiving and other roles. However, descriptive narratives illustrate that both genders experience a significant struggle to find opportunities to have time away from doing, thinking or talking about caregiving, supporting the findings of Covelli *et al.*, (2014) whereby life roles were reduced to a single 'caregiver' role (Giovannetti *et al.*, 2015; Dempsey and Baago 1998).

Some of the findings in the current study suggest subtle gender-specific trends in the caregiver role with males more likely to be engaged in tasks such as moving the care recipient, carrying out physiotherapy and positioning programs- the 'heavy' tasks. Females were more likely but not exclusively to be involved in attending to intimate care needs and sensory stimulation programs. Typically research has shown that women tend to adopt a greater range of caregiving tasks (Calassanti and Bowen 2006), however the current study illustrates how male caregivers for example were prepared to undertake aspects of caregiving that may have been perceived to be traditionally 'female' roles such as intimate care. Participants in this study alluded how it was not a role that was wilfully chosen. It was instead, a forced role, carried out due to necessity, with significant levels of discomfort experienced by the male caregivers as they attended to the needs of their adult daughters. Managing bowel care and intimate grooming are tasks that are, under usual circumstance, unfamiliar to males and in this study, presented a significant challenge to the normal parental role when faced with having to care for a dependent adult daughter.

The findings highlight how caregiving impacted upon roles within the wider family unit, but moreover the role of the caregiver with the care recipient. The findings from the current study support those of Hamama-Raz *et al.*, (2013) who found that value systems strongly influenced the volition to prioritise caregiving among wives of men in VS. The influence of a sense of duty and obligation to the individual that forms part of a relationship status, and the values associated with loving somebody were motivations for not being seen to 'abandon' the care recipient (Hamama-Raz *et al* 2013; Huber and Kuehlmeier 2012). Ambivalence was described by some spousal caregivers with regards to their relationship status and spousal role with their relatives

(e.g. married but feeling 'single' again), a sense of being neither wife nor widow; husband nor widower. This ambivalence was in conflict with their value systems which was a driving force behind feelings of obligation, duty, commitment, and guilt at any thought of 'stepping back' or 'moving on' to new relationships.

Huber and Kuehlmeier (2012) noted that some partners can find ways of having new relationships whilst also maintaining their caregiving role. Despite the extended duration of time since onset of PDOC in this current study, this 'moving on' had not been experienced by the spousal caregiver participants, instead, a burden of guilt at the thought of 'moving on' is resounding in the descriptions of this ambivalent situation. Similar to the findings of Hamama-Raz *et al.*, (2013), marital commitments prevailed and were a source of strength for partners in coping with the situation, however findings from this study would indicate that caregiving for a partner who has survived in VS and MCS also posed considerable emotional challenges and conflicts regarding one's role and relationship status with their partners. A lack of response from the person resulted in having to 'learn to love unconditionally' an unresponsive partner and to spend time with one's spouse in a new way untypical of a partnership. The outcome for the participants was a feeling of loneliness, a finding consistent with that of Hamama-Raz *et al.*, 2013 who identified experiences of isolation, grief, reduction in hope and mourning among the wives caregiving for husbands with VS. An important finding also in the current study was that parental caregivers experienced loneliness due to separation from their partners as a result of one of them spending excessive amounts of time caregiving for their relative with PDOC. Participants describe a loss of their occupational companion to caregiving- the person they shared similar interests with and did activities together. This resulted in forced loss of role, occupational abandonment and loneliness.

5.5.5. *Routine: Slowly moving towards 'balance'*

A challenge to balance the tasks and activities that one needs to do with those that he or she desires to do may result in occupational imbalance or 'life imbalance' which in turn can trigger stress reactions (Christiansen *et al.*, 2009). Occupational imbalance

manifests for many of the participants through the 'Centrality of Caregiving' to their daily routines, the selfless approach to caregiving ('Self as Secondary') and the 'Constant' nature of caregiving duties and obligations. As reported in other studies of the impact of caregiving on the occupational lives of family members (Elliott and McVicar 2016), participants describe experiencing guilt when engaging in non-caregiving occupations. A strong sense of duty to provide care regardless of whether the caregiver resided in the family home or in residential care, and regardless of whether the participant feels physically or mentally capable of carrying out caregiving on a given day was evident, a sense of caregiving against all odds.

Caregiving and its related tasks had become habitual for the participants. From an occupational therapy perspective, MOHO describes how daily life is defined by routines (Kielhofner 2008), and the lives of the participants had become defined by their caregiving routines. Efforts to engage in other non-caregiving activities had become interruptive to the new 'caregiving routine'. Elliott and McVicar (2016) identified that informal caregivers of people with PDOC tend to give careful consideration prior to engaging in activities that are not directly related to their relatives care to ensure that they will not interrupt the routine of the care recipient. This was also evident in the findings of the current study whereby occupations that were once satisfying have become effortful, for example, taking a holiday, as much coordination and planning is required to ensure that other family members are available to carryout caregiving in the absence of the principal informal caregiver. Additionally Elliott and McVicar (2016) reported a reduction in the consuming nature of caregiving for people with PDOC at 12 months post-injury; however findings from the current study indicate that the consuming nature of caregiving for a person with PDOC can persist for many years. This is in keeping with the views of Tzidkiahu *et al.*, (1994) who found that adaptation is recognised when some previous activities are resumed, a process that can take many years. In fact, participants in the current study who have been caregiving for longer than five years describe 'only beginning' to step back from caregiving to resume previous enjoyed activities which resulted in feeling 'normal again'.

The majority of participants describe how they value the opportunity to have a break from caregiving, and appreciated that this was important, yet difficult, particularly emotionally, to do. Participants expressed a preference for a break of a couple of hours instead of longer holidays which were more likely to induce stress and anxiety. This substantiates an earlier study which found that caregivers who spent less time per day with the care recipient experienced a greater sense of burden (Giovannetti *et al.* 2012). Studies have also shown however, that lack of time to oneself results in caregiver distress (Giovannetti *et al.*, 2015); fatigue and physical injury (Goudarzi *et al.*, 2015) and emotional burden (Chiambretto *et al.*, 2001). A desire for time for oneself is recognised as an important catalyst to moving towards occupational adaptation (Elliott and McVicar 2016). The findings of the current study support this ascertain whilst also contributing to a unique longitudinal perspective of the impact of caregiving on occupational engagement, with the majority of participants continuing to struggle for many years to achieve meeting one's own needs and desires through occupation, whilst dealing with expectations from the environment, a process Kielhofner (2008) termed 'occupational adaptation' (Kielhofner 2008). Restructuring habits is one method through which people who are faced with adversity begin to find ways to re-engage in meaningful daily activities, work and leisure (Kielhofner 2008). The findings from the current study illustrate that whilst participants most part had choice and autonomy in relation of how they spent their time, they seemed to resist reducing their commitment to caregiving to move towards occupational balance.

A dominant theme that emerged is a lack of confidence among participants in the consistency and skills of formal caregivers to carry out caregiving tasks. This supports findings of previous studies that 'trust in care' provision and confidence in formal caregivers is an important catalyst in moving towards occupational adaptation for informal caregivers of people with PDOC (Elliott and McVicar 2016). The starting point to assisting caregivers to move towards occupational balance may thus lie with service providers, formal care agencies and caregivers for patients with PDOC. By helping to ensure that patients are cared for in safe and stimulating environments, informal caregivers are instilled with a sense of 'trust in care' which encourages them to step back and take some time for themselves (Elliott and McVicar 2016). Further, the 'seven

catalysts to support occupational adaptation' as noted by Elliott and McVicar (2016) are a useful guide in identifying factors that can improve occupational balance. Some similar prerequisites are noted by participants in this study including encouragement and support from others and having a rota of caregivers to support periods of respite and time away from caregiving.

5.6. Perceptions of quality of life (QoL) and experiences of caregiver strain

Findings from the WHOQOL-BREF and interview data illustrate some conflicting findings relating to QoL. Some participants describe their QoL as being 'very good' on WHOQOL-BREF, yet describe in the interview how life had changed considerably, the future was unthinkable and they are consumed by caregiving with little time to themselves. Other studies have highlighted generally negative life changing impact that having a family member survive with PDOC has on aspects of quality of life of family caregivers. These negative aspects include difficulty thinking about the future (Giovannetti *et al.*, 2015; Covelli *et al.*, 2014); feeling isolated and experiencing physical pain, fatigue and emotional distress (Goudarzi *et al.*, 2015). Participants in the current study described similar impacts such as "*just existing*", "*no happiness*", and a sense of resignation, with life being "*as good as it can be, under the circumstances*" in relation to describing QoL experiences.

5.6.1. Caregiving and quality of life: A life changing experience

Participants describe how caregiving was a life changing experience which became a predominant feature of their lives, resulting in them feeling constrained with making plans for their own lives. Kitzinger and Kitzinger (2014B) have similarly shown that feelings of being 'stuck with' or tied to the caregiving role are not uncommon among caregivers of people with PDOC, particularly home caregivers who used terms such as feeling "imprisoned" to describe the caregiving experience. Qualitative findings from the current study highlight that a sense of loss of autonomy over time use, and loss of

occupational companionship impact upon caregiver experiences of QoL, and this impact spanned the entire family unit. Dempsey and Baago (1998) described latent grief as grief that encapsulates the losses that caregivers endure on a daily basis resulting in a hidden grief for one's relative as they were before their injury or illness, dramatic changes in one's relationship with this person and being forced to relinquish occupations and roles to adopt the expansive role of caregiver.

The experience of many losses is important to recognise in caregivers of people with PDOC as it has been found to be associated with prolonged grief reactions among PDOC caregivers, more so than duration of caregiving or the severity of the care recipients condition, and it can lead to negative mental health outcomes for caregivers (Guarnerio *et al.*, 2012). Participants in the current study identified how there were many losses associated with adopting the caregiver role including the loss of one's occupational companion, loss of previously valued roles and loss of autonomy over one's time. Additionally, the participants describe a number of other impacts on QoL that have also been recognized in related literature including loneliness (Goudarzi *et al.*, 2015; Hamama-Raz *et al.*, 2013), reduced experiences of happiness (Goudarzi *et al.*, 2015) and difficulty looking to the future (Giovannetti *et al.*, 2015).

Participants described the enduring nature of caregiving and a resignation that this life changing experience would endure into the longer term. The increasing life expectancy of people with PDOC means that caregiving and lifestyle changes that ensue for caregivers are likely to persist for many years (Covelli *et al.*, 2014). Participants in the current study describe how thinking about the future was difficult as many of the plans they had made for their own lives had to be abandoned with the realisation that caregiving would persist in to the long-term. A striking theme of this study was the 'perpetual' nature of the caregiving role, a sense that caregiving would prevail for participants even beyond their own death, leaving behind a void in caregiving that participants perceived nobody else could adequately fill.

Giovannetti *et al.*, (2015) in their study exploring ambiguous loss among caregivers of people with PDOC highlighted how the absence of a ritual for dealing with the loss

associated with having a relative survive in PDOC triggered a reaction among family members to be present as much as possible with the person to the detriment of their other roles and occupations, a type of compensation or coping strategy. Thus, the thought of not being able to be physically close to the care recipient because of their own death may be a trigger for feelings of anxiety, anguish and fear among participants. Moreover, the majority of participants in the current study describe feeling that they are largely responsible for the well-being of the care recipient and believe their input to the care program is essential to ensuring that their relatives receive what they perceive is the best care. Thus, fearing a 'void left unfilled' signifies perhaps both the strong sense of duty that family members feel towards the care recipient on one hand, but also a perceived lack of confidence in formal services to provide the level of care that they feel their relatives require. This fear is expressed as a source of substantial strain among the participants in the current study.

The literature regarding caregiving for people with PDOC is biased towards the negative impacts of caregiving on the caregivers' life with no studies found reporting how adopting the caregiving role had enhanced the quality of life of family caregivers. This may reflect a reality that the role is demanding, time-consuming and presents few rewards. Giovannetti *et al.*, (2015), Covelli *et al.*, (2014) and Hamama-Raz *et al.*, (2013) noted how caregivers discovered that they had an inner strength that they were unaware of until faced with the task of caregiving for a relative with PDOC which in turn enhanced their self-esteem. Despite the centrality of caregiving in the lives of the participants in the current study, few examples are noted by the participants to illustrate the positive impact that this role has on their lives. A minority note a sense of reward from their efforts to prevent deterioration in the care recipient's condition. The majority however describe the enduring and relentless nature of the role and allude to a sense that caregiving becomes more difficult over time.

Caregiving required considerable changes to their routine, to the types of occupations they had to carry out, how they spent their time and who time was spent with, and these changes mostly negatively impacted upon QOL. Some participants describe how opportunities to have a break from caregiving (having 'something else' to do); social

support from the 'functional-intimate family' (Medale 1997), particularly using a rota to ensure that there is always somebody with the care recipient; continuing to engage in paid employment; proximity to the residential care unit and having a level of control over aspects of care enhanced their quality of life experiences. The findings suggest that facilitating families to participate in caregiving from an early stage rather than restricting them from participating may have a greater positive impact on the caregivers' sense of identity with and self-efficacy in the caregiver role. Further, opportunities to receive feedback regarding the efficacy of their role may promote stronger levels of satisfaction with the role, thus enhancing the meaning and quality of their lives.

5.6.2. *Strain*

The results of the MCSI indicate a modest trend towards lower levels of caregiver strain as time passes from onset. However, given the longevity of the caregiving role for all of the participants the results of the MCSI illustrate that strain is a persisting feature of the caregiving experience with those caregiving in excess of six years showing lower scores on the MCSI. A number of factors contribute to this including occupational imbalance and few opportunities to take a break from thinking, doing or talking about caregiving. A sense of abandonment and isolation appeared to be additional contributors to strain among the participants. Participants describe perceived abandonment by healthcare professionals and experts from the specialist rehabilitation hospital and a need to fight for information and support with their caregiving role.

Participants report limited access to clinical review and updates for the care recipient by the specialist services, with six of 10 participants in phase two reporting that had never been reviewed or followed-up by specialists following discharge from the rehabilitation hospital. A sense of having to fight the system, deal with bureaucracy and advocate for improved services has been reported in other studies of caregivers of people with PDOC and has contributed to strain and distress (Goudarzi *et al.*, 2015; Kitzinger and Kitzinger 2014B). Some authors have alluded to the symbolism associated with withholding or withdrawing services. This 'act' may be interpreted by

informal caregivers as there being no hope for further gains, or their relative is no longer recognised as having needs resulting in experiences of disillusionment, anger, frustration and isolation (Latchem *et al.*, 2015) as reflected in the current findings. Participants in the current study described the caregiver response to this, which was often to take it upon themselves to source alternative 'expertise' such as private therapy or therapy abroad in order to provide a service to their relatives that they believed they should have been receiving. It is not surprising therefore, that of a choice of initiatives to support their caregiving role, the majority of phase one participants indicated that an annual review of the patient and an update on diagnosis and prognosis would be the most helpful initiatives in supporting them to manage their roles in long-term care provision.

For some participants in this study it has taken many years to reach a realisation that the prognosis for their relative's recovery was poor or at best, guarded. Some continue to actively search and hope for a cure, a pursuit that induced strain and contributed to a sense of burden due to the perceived need to 'fight' for services and 'dig' for information. A study by Giovannetti *et al.*, (2012) highlighted that anxiety and depressive symptoms among caregivers of people with PDOC, along with a need for information about the persons' health condition were common years after onset of the injury. It may be argued that with consistent, albeit not necessarily intensive contact and feedback from experts at intervals over the years following rehabilitation, adjustment to their relatives' long-term prognosis might have been accelerated. This may have resulted in an earlier return to previously enjoyed and meaningful occupations and reduced levels of strain associated with 'finding a cure'. Some participants describe the relief that they may have experienced in knowing that there was nothing else that they could do, or that the caregiving they were providing constituted 'doing enough'.

The current study highlights that caregivers experience challenges with sourcing information, advice and support. The constant 'fight' for information is a significant contributor to strain and participants describe having no sense of universality in the role because of limited contact with other PDOC caregivers. Studies have shown that

when caregivers are well supported, role strain is reduced and they experience greater positive effects from caregiving (Bastawrous 2013). Home caregivers in a study by Chang *et al.*, (2009) who received emotional support, advice and information were more likely to be highly satisfied with their caregiving role. The current study illustrated that the experience of caregiver strain was not exclusive to home caregivers, with residential caregivers also perceiving strain, perhaps more so than the home caregivers.

The findings illustrate that the lived experience of caregiving for a relative with PDOC is punctuated with strain associated with being the 'constant' source of support for the care recipient. The experience of dealing with the trauma of the situation and the upheaval that ensues is not necessarily experienced by the care recipient as they are or were unconscious or minimally conscious; rather it is the family members who live the experience (Martone 2006).

Day-to-day hands-on caregiving occurs within a milieu of changed relationships and forced roles with the care recipient, ambiguous loss and latent grief, the challenge of juggling other tasks and demands on one's time and dealing with a healthcare system that participants believe to be bureaucratic and unsupportive. Moreover, managing the profound life-limiting and life-changing disabilities rendering the person with PDOC helpless and vulnerable and limited in their abilities to engage with the world around them further compound the caregiver experience and contribute to strain. The strain and burden associated with caregiving for a relative in PDOC is encapsulated by Margaret Chamberlain, mother of Lucy, who's right to die campaign was fuelled by the *"lived experience of observing Lucy in such a diminished state over such a prolonged period of time"* (Irish Times, 2017, p.14).

The current study provides initial insights to facilitate a greater understanding of the lived experience of caregiving on the lives of family members of people with PDOC including the impact upon occupational engagement, roles, routines and quality of life. By identifying the factors that aid and enhance the caregiving experience or contribute

to burdening the experience will assist with planning future services and supports for families of people in vegetative and minimally conscious states.

5.7. Strengths of the study

This is the first Irish study to capture the experiences of family members providing care to a relative with PDOC. All of the participants have been providing care for a number of years after onset of PDOC with the findings reflecting the longitudinal 'lived' experience, therefore roles, routines and caregiving occupations had become well established. This longitudinal aspect of caregiving may well be influenced by the social, moral and legal context of care provision. As noted, in Ireland there are no alternatives to providing long-term care, such as the withdrawal of CANH for instance, in cases whereby it might be deemed that ongoing administration is futile, as occurs in other jurisdictions including England and Wales (RCP 2013).

The postal questionnaires and the interviews yielded a modest response rate resulting in large volumes of qualitative data. The complexity of the mixed methods design allowed for comprehensiveness and breadth of findings offering important initial insights (Neergaard *et al.*, 2009) into the lived experience of the caregivers. Utilisation of methodological triangulation facilitated meeting individual study objectives and rich and detailed data collection. Using mixed methods also assisted with obtaining information about service delivery and the experiences of services users (Creswell *et al.*, 2015) so as to inform future service developments. The use of member checking may have offered a sense of universality for the participants in the experience of caregiving (Harper and Cole 2012).

5.8. Limitations of the study

A number of limitations to the study are acknowledged.

5.8.1. Sampling

Studies using purposive convenience sampling are not generalizable by their nature (Archarya *et al.*, 2013) however, they are a useful method of sampling when time is limited (Drummond 1996, Creswell 2013) as the case with this study. A relatively homogenous group was sampled using inclusion and exclusion criteria (Hultsch *et al.*, 2002) which may further restrict generalisability to wider populations and other caregiver groups. Whilst all of the participants had caregiving roles, they were not necessarily the principle caregiver. This was an inherent flaw with the inclusion criteria as it specified that 'next of kin' be included. Thus the extent of informal caregiving for people with PDOC is likely to exceed the levels reported in this study. Future studies should specify the 'principal' or 'primary caregiver' similar to other studies of PDOC caregiver experiences (Giovannetti *et al.*, 2015; Covelli *et al.*, 2014; Cruzado and Elvira de la Morena 2013; Chiambretto *et al.*,2001).

The decision to rely upon the participant/respondent diagnoses of the condition rather than a clinical expert diagnosis may have resulted in unreliable reporting of level of consciousness of the care recipients among the group of caregivers sampled. This is acknowledged as a limitation of the study as there was no way of verifying the accuracy of the diagnosis reported in the returned questionnaires. Therefore it is possible that those described as VS may be MCS or emerged MCS and those described as MCS may in fact be VS. As such, data relating specifically to the percentages of care recipients in each category are reported with caution.

The majority of participants sampled were residential caregivers with a lower representation of home caregivers. This possibly reflects the typical care pathway for patients with PDOC in Ireland with the majority receiving long-term care in a residential facility. However, the results may be more reflective overall of the experiences of those providing care for relatives in residential care.

The risk of sampling bias existed as the researcher had previously been involved in the provision of rehabilitation to relatives of some of the sampled population. The use of the gatekeeper (Sanders and Wilkins 2010) may have helped to prevent coercion in sampling.

5.8.2. *Data collection procedures*

The omission of a tool to measure mood which may have added richness to the findings is a potential limitation. Strain may have manifested from low mood and a challenge in the interviews was to identify the trigger for strain. However, as low mood may also have been triggered by caregiving, a measure of mood alone would have provided ambiguous data.

The Occupational Questionnaire yielded a low return rate. It may have been too time-consuming for participants given the already enormous time constraints resulting from caregiving and other commitments.

A risk of interviewer bias was minimised by the use of field notes to document reflections and opportunities to debrief with the research supervisor so as to explore and minimise the influence of the researchers own biases throughout the data collection phase.

5.9. Recommendations for future research

The findings from the current study indicate some areas for future research:

- Mood was not accounted for in this study. It is a variable that may have compounded feelings of strain. Future studies are warranted to explore the impact of mood and coping on occupational engagement among caregivers of people with PDOC.
- The majority of participants in this study were residential caregivers. Future studies focusing on the experience of providing care in the home for people

with PDOC would be useful to identify the unique challenges and supports they may require to manage long-term caregiving in the family home.

- A longitudinal perspective of the informal caregiver experience of caregiving for a person with PDOC and the stages of adjustment and occupational adaptation is indicated.
- This study did not include the service providers (formal caregivers) perspective their own experiences of caregiving for a person with PDOC; and their experiences of informal caregivers' contribution to caregiving. This type of research may provide useful insights into how family caregivers may be further supported in adopting and managing caregiver roles.
- The findings highlight significant hidden costs associated with long-term management of severe ABI. With growing incidence and survival rates, this will likely become an expensive area of health spending, with many personal costs for individual families. Such 'hidden' costs include those associated with changes to employment, lack of opportunity to engage in social and leisure activities, and the impact of caregiving on the well-being of the caregiver. Further research would be valuable to establish the cost of surviving with PDOC in Ireland, taking into account the hidden costs and the different models and contexts of care provision.
- The Irish legal system lags behind other jurisdictions such as England and Wales (RCP 2013) on such matters as best interests decision making. The question, 'is it in the persons' best interests to keep him or her alive, indefinitely, using artificial means with abating chance of recovery?' is rarely asked by healthcare and legal experts and family members in Ireland. This emotive issue was not addressed in this study. However, the findings from this study highlight the occupational, social and emotional costs associated with providing long-term care indefinitely to people with PDOC. Further research to establish the views of family caregivers regarding neuro-palliative care as alternatives to long-term care will be useful in informing the development of a holistic care pathway that encompasses a range of options for the clinical management of PDOC based on best interests, the views of the patient (if known) and the family caregivers.

5.10. Implications for healthcare services and professional practice

The findings reflect the overall negative impact of caregiving on the occupations of informal caregivers for people with PDOC. Findings from this study indicate potential areas for future development at service level. These include:

- A more formal approach to training and preparation of family members to adopt and manage their caregiving roles, with the focus not just on physical and medical based caregiving tasks but an approach that is caregiver-centred and designed to assist the family members to transition into the role of caregiver whilst maintaining occupational balance and self-care.
- This study supports the view of other researchers who assert that family caregivers require support in all phases of the condition and for the lifetime of the patient (Giovannetti *et al.*, 2012). Ongoing interventions to support the caregiver and to assist them in managing the caregiver role are indicated. The need for access to ongoing psychological support was highlighted in this study. Follow-up by a specialist team, access to information, support, validation and feedback may reduce role strain; expedite adjustment to the chronic nature of the condition and promote earlier occupational adaptation for caregivers. Examples of methods to provide follow-up services include the use of telemedicine, the establishment of regional satellite clinics, and the development of an outreach team from the specialist hospital, also recommended in national strategy (Department of Health and HSE 2011).
- Education and training for private providers of long-term residential care, community care teams, general practitioners and public and private care agencies in the management of this complex group may be warranted. In turn, this may instil confidence in family members to be able to resume some of their previously enjoyed roles facilitating a greater sense of occupational balance.
- Occupational therapists are well placed to assist family members to develop effective strategies to deal with new demands on their time brought about by having a family member survive with PDOC. Facilitating family decision making about foregoing paid employment, finding ways of re-engaging in previous or

new social and leisure activities and exploring occupational choices are areas in which occupational therapists can effectively assist families to manage caregiving roles. Useful strategies identified by caregivers in the current study include rotas, delegation of caregiving tasks to others and accepting support can be promoted by occupational therapists to both prepare and support families with the caregiving role.

5.11. Conclusion

This is the first study to provide empirical evidence regarding the lived experience of caregiving for a family member with PDOC in Ireland. It offers valuable, in-depth information on the immense contribution made by family members' to long-term care provision for people with PDOC. This caregiving role is a multi-faceted, enduring and extended experience. Caregiving is often juggled with other commitments including paid employment and the majority of participants' experienced occupational imbalance with few opportunities to 'escape' from caregiving. Social and leisure activities are often abandoned and the struggle to achieving occupational adaptation is a slow, time-consuming process. The experience of caring for somebody so profoundly disabled for prolonged periods of time has a detrimental impact on the quality of life of informal caregivers who may even come to feel as though they 'just exist', no longer able to feel happiness or satisfaction from other activities. Caregivers in this study described many shortfalls in formal care provision resulting in a perceived duty to provide care. Caregiver strain was a consequence of the constancy and endlessness nature of the role and caregivers described numerous unmet needs as their own lives were put on hold.

The findings indicate that the current care pathway for people with PDOC in Ireland finishes with the transition to long-term care. This study illustrates an urgent need for an expansion of the current care pathway to address the longer-term needs of families who continue to provide ongoing care for relatives long after formal services have been withdrawn. Opportunities to facilitate clinical review, updates on prognosis and

information and advice regarding benefits, social and emotional supports and advances in rehabilitative techniques should be included in future developments to the care pathway for PDOC. An expanded and more comprehensive role for occupational therapists and other healthcare professionals in preparing caregivers to adopt and manage caregiver roles and moving towards occupational balance and improved quality of life is strongly indicated and supported by the outcomes of this study.

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7. APPENDIX 1

Participant Information Letter

Study Title:

An Exploration into the Lived Experiences of Informal Caregivers to people with Prolonged Disorders of Consciousness- Occupational engagement patterns, role change and perceptions of their loved one's care needs.

Researcher: Ms Alison McCann

Dear Sir or Madam,

You are receiving this invitation to participate in the above research study as you have a family member who was treated in the High Dependency Unit/Prolonged Disorders of Consciousness Service at the National Rehabilitation Hospital (NRH) between 2000 and 2013. The aim of this study is to explore how caring for a person with a disorder of consciousness following brain injury impacts on the everyday life of the caregiver. Even if the person is not being cared for at home, he/she may be resident in a nursing home for example; there may still be a requirement for family members to provide some level of on-going care or to be actively involved in coordinating necessary care.

The study will be conducted in two phases. Phase one requests that you complete an anonymous questionnaire (attached to this letter), and phase two involves an individual interview with the researcher where the issues around care provision and how it impacts on your daily life will be explored. You are invited to participate in one or both phases of the study if you so wish.

The enclosed questionnaire is designed to find out the extent of caregiving that you feel you need to provide for your family member. There are separate sections if your family member is being cared for at home or if he/she is being cared for in a residential care setting. The questionnaire should take approximately 30 minutes to complete. The questionnaire is completely anonymous and you are not required to give any personal identifying information about yourself or your family member. There will be no way of linking the questionnaire back to you or your family member so you can be

assured that your responses are completely confidential and will not have any impact on your family member's future care at the NRH (if such care is ever required).

The second phase of the study will involve you participating in an individual interview with the researcher where these issues of providing care will be discussed further. The aim of this phase of the study is to find out how much of your day to day time is taken up with providing care or coordinating care for your family member, and how providing this level of on-going care has impacted on your general day to day life. The interview will be audio-recorded but all of the information you provide will be treated in strictest confidence and the tape recordings will be wiped once they have been transcribed. The information you provide in the interview will not have any impact on your family member's future care at the NRH (if such care is ever required).

There will not be any direct benefit to you or your family member from participating in this study. However, the information will potentially assist in creating awareness of the impact of caring and the needs of the caregiver, and will inform future development of the rehabilitation programme to place more focus on the family caregivers of people with disorders of consciousness.

The study has been approved by the ethics committees at National Rehabilitation Hospital and the Faculty of Health Sciences at Trinity College Dublin. You may participate in both phases of the study, or you may complete the questionnaire component only. If you do not wish to participate in either phase of the study this is fine also and please know that the decision will not impact on your family member's future care at NRH. If you wish to complete the questionnaire you can return it, once completed, in the large envelope provided. If you are interested in participating in the interview please fill in your details on the enclosed Expression of Interest Form and return it in the small envelope provided. The researcher will follow up with a telephone call to explain the study further and answer any questions you may have with regard to the study. If you have any questions regarding any part of this study please feel free to contact Alison McCann at 01 2355000.

Dr. Mark Delargy.
Principal Investigator.

Ms. Alison McCann
Lead Investigator.

8. APPENDIX 2

Anonymous Postal Questionnaire

This is an anonymous questionnaire. Please do not put your name on it or the name of your relative who has had severe brain injury/PDOC.

Thank you for taking the time to complete this questionnaire. It is divided into four parts. You only have to complete three of the four parts. The information below will help to clarify some of the terminology used in the form.

Prolonged Disorder of Consciousness (PDOC): This is an ‘umbrella’ term for states of impaired consciousness that present after severe brain injury. Often, after trauma or illness of the brain people will spend time in a deep sleep called coma. Generally, coma is temporary however a small number of people can stay asleep for a long time. When in coma, they are unresponsive. With time, some will begin to open their eyes but may be unaware of what is happening around them. This is often described as the ‘Vegetative State’.

Vegetative State (VS): People in VS will open their eyes for periods of time and will appear to be ‘awake’, however they will be unaware of what is going on around them. They may be able to move their limbs. This movement will not be voluntarily. It happens without the persons’ conscious control. For example the person may ‘startle’ to a loud sound, flex their limbs or grind their teeth. They will have no ability to communicate. They may have facial expressions that resemble smiling, grimacing, etc. They may also cry, laugh, moan or say random words for no obvious reason.

Minimally Conscious State (MCS): People in a minimally conscious state show inconsistent signs of awareness of themselves and what is happening around them. For example, they may follow people moving around them with their eyes; they may be able to communicate using their voice or simple gestures and may be able to use familiar objects. Typically, these signs of awareness will be inconsistent. For example, he or she might be able to track with their eyes as you enter the room, but may not be able to repeat this again within the same day or even for a number of days. Consciousness may vary from moment to moment.

Emerging MCS: People with this level of awareness have the ability to use some familiar objects, to communicate using gestures and words or writing, but continue to have physical and sensory disability and will need help with most activities.

Locked in Syndrome (LIS): People who have LIS are sometimes treated in our PDOC service. Typically, they have severe physical disability but are fully conscious. They will have lost the

ability to move their limbs, although may have a very small amount of movement in certain joints. The person can interact with others using eye movements to spell words, or indicate yes/no. Some will use computer software to help them to communicate.

The person with PDOC/severe brain injury: The person who has or had a prolonged disorder of consciousness/severe brain injury may be your relative, friend or neighbour. To account for all of these situations, the individual will be referred to as 'the person with PDOC/severe brain injury'. Time may have passed since the person's injury or illness occurred and their ability, awareness and communication may have improved since their inpatient care at the National Rehabilitation Hospital. Regardless of this, we would still like you to complete the form.

Informal Caregiver: This term is used to describe a person who provides care to somebody but who is not paid for this.

Please return in the large envelope to:

Alison McCann,
Occupational Therapy Department,
National Rehabilitation Hospital,
Rochestown Ave,
Dun Laoghaire,
Co. Dublin.

Thank you for taking the time to complete this questionnaire.

Section 1.

1.1 Are you involved in providing care to, or organising care and support for the person with PDOC/Severe brain injury? Yes No

1.2 Are you the Next of Kin for the person with PDOC/Severe Brain Injury? Yes
No

1.3 About you:

<p>Your gender</p>	<p>Male <input type="checkbox"/> Female <input type="checkbox"/></p>
<p>Your Age What age are you?</p>	<p>25 years or younger <input type="checkbox"/> 26-35 years <input type="checkbox"/> 36-45 years <input type="checkbox"/> 46-55 years <input type="checkbox"/> 56-65 years <input type="checkbox"/> 65 + years <input type="checkbox"/></p>
<p>What is your relationship to the person with PDOC/severe brain injury?</p> <p>I am his/her....</p> <p>Husband <input type="checkbox"/> Wife <input type="checkbox"/> Partner <input type="checkbox"/></p> <p>Brother <input type="checkbox"/> Sister <input type="checkbox"/> Brother in law <input type="checkbox"/> Sister in law <input type="checkbox"/></p> <p>Father <input type="checkbox"/> Mother <input type="checkbox"/> Stepfather <input type="checkbox"/> Stepmother <input type="checkbox"/></p> <p>Son <input type="checkbox"/> Daughter <input type="checkbox"/> Step son <input type="checkbox"/> Stepdaughter <input type="checkbox"/></p> <p>Grandchild <input type="checkbox"/> Other- related <input type="checkbox"/> Other- unrelated (e.g. neighbour/friend) <input type="checkbox"/></p>	
<p>Your Employment status.</p> <p>How would you describe your <i>current</i> employment status? (You may choose more than one option to describe your employment status).</p> <p>Working for payment or profit <input type="checkbox"/>: I work: Full-time <input type="checkbox"/> Part- time <input type="checkbox"/> How many hours per week? <input type="text"/></p> <p>Unemployed <input type="checkbox"/></p> <p>Retired from employment <input type="checkbox"/></p> <p>Student <input type="checkbox"/> : Full-time <input type="checkbox"/> Part- time <input type="checkbox"/></p>	

Looking after the home/young children

Unable to work due to own sickness or disability

Paid care-giver Full-time Part- time (including Carer's benefit)

Unpaid care-giver Full-time Part- time

Did your employment status change when the person became ill with PDOC/severe brain injury?

Yes No

If Yes, what was your employment status **before** the person became ill? (if **no**, please progress to 'Income' section)

Working for payment or profit: Yes No

If '**yes**' please choose from the following:

Full-time Part- time How many hours per week?

If '**no**' please choose from the following:

Unemployed

Retired from employment

Student : Full-time Part- time

Looking after the home/young children

Unable to work due to own sickness or disability

Paid care-giver Full-time Part- time (including Carer's benefit)

Unpaid care-giver Full-time Part- time

Your Income.

How would you describe your **main** source of income currently?

Please tick one box only.

Employment

Social welfare/Benefits

Family support

Compensation/Insurance

Pension

Other_____.

Your home.

Who do you live with? Please tick the relevant boxes below.

Alone

With relatives/partner

With friends/'house-mates'

Other

Does the person with PDOC/severe brain injury live with you?

Yes No *Sometimes

*(For example, has an overnight stay from a care facility but lives in that facility on a permanent basis).

Are there other adults living with you who require care? Yes No If 'yes', how many other people require care?

Do you have other dependants (children/young adults/elderly parent etc) who live with you?

Yes No If 'yes', how many other dependants live with you?

1.4 About the person with PDOC/Severe Brain Injury.

The person with PDOC/Severe brain injury is	Male <input type="checkbox"/> Female <input type="checkbox"/>
How long has it been since the person became ill/had accident?	Years: <input type="text"/>
What age is the person?	She/ he will be ____years on their next birthday.
What age was the person when she/he had their brain injury?	Years: <input type="text"/>
What type of brain injury listed best describes his/her injury?	Traumatic (e.g fall, road traffic accident) <input type="checkbox"/> Stroke (e.g. clot or brain haemorrhage) <input type="checkbox"/> Hypoxic (e.g with a cardiac arrest) <input type="checkbox"/> Infection (e.g caused by bacteria or a virus, such as with encephalitis) <input type="checkbox"/> Tumour <input type="checkbox"/> Other _____
What level of awareness do you feel the person has now?	No awareness <input type="checkbox"/> Minimal/intermittent <input type="checkbox"/>
The definitions at the beginning of the questionnaire	

may assist with answering this question.	Full awareness <input type="checkbox"/>
Where does the person live?	At home <input type="checkbox"/>
	Nursing home <input type="checkbox"/>
	District care unit <input type="checkbox"/>
	Acute hospital <input type="checkbox"/>
	Rehabilitation Unit <input type="checkbox"/>
	Other (specify) _____.
Which of these statements best describes the type of care that the person receives?	
a) 24 hour nursing care in a <u>residential setting</u> (nursing home/hospital) <input type="checkbox"/>	
b) 24 hour nursing care provided by a mix of family care-givers and paid formal care in <u>residential setting</u> <input type="checkbox"/>	
c) A mix of therapy and nursing care in a <u>residential setting</u> _____ <input type="checkbox"/>	
d) 24 hour nursing care in the person's <u>own home/ or relatives home</u> provided by paid carers. <input type="checkbox"/>	
e) 24 hour care provided by a mix of family care-givers and paid formal care in <u>own home/relatives home</u> <input type="checkbox"/>	
f) A mix of therapy and nursing care in his/her own home or a relative's home <input type="checkbox"/>	
g) Other _____.	

If the person with PDOC/severe brain injury lives in a residential care setting such as a nursing home or district hospital, please progress to [Section 2](#).

If the person with PDOC/severe brain injury lives in the family home, please skip Section 2 and move to [Section 3](#).

Section 2- Residential Care.

2.1 How long has the person lived at the current facility?

2.2 How many different facilities has the person received care from?

(For example, if the person received acute care in Beaumont Hospital, then went to a county hospital before rehabilitation at NRH, and then was transferred to a nursing home, this is a total of 4 different facilities).

2.3 On average, how often do you visit the person?

- Daily
- Several times per week
- Once per week
- Several times per month

- Once per month
- Less frequently than once per month

2.4 How much time do you spend with the person during an average visit?

Hr(s)

2.5 How would you rate the overall care being provided to the person? (***Please circle a number***).

1 2 3 4 5 6 7 8 9 10

Inadequate	Adequate	Good	Excellent
-------------------	-----------------	-------------	------------------

2.6 Tick which tasks you assist the person with and note how frequently?

Activity	Every visit	Occasionally	Rarely or never	Just started
Personal care such as assisting with bathing, dressing, grooming hair, oral care				
Managing food (oral feeding or PEG)				
Transfers and positioning				
Stretching exercise				
Doing their laundry				
Replenishing care necessities such as toiletries				
Sensory stimulation				
Talking to the person, telling stories, reading to him/her, telling him/her news, playing music, singing to them				
Watching TV/ listening to music/radio with the person				
Massage, aromatherapy, other complimentary care				
Taking him/her on outings around the facility, its grounds or on				

trips				
Taking the person to the family home for day leave/over night				
Other (please explain)				

2.7 How much of the everyday care do you feel you and other informal caregivers provide even though the person is in residential care?

75-100% 50-75% 25-50% less than 25%

2.8 a) Did you ever consider taking the person home to care for him/her? Yes No

b) If yes, but you decided against it, what made you decide not to pursue it?

_____.

c) What do you feel are the barriers to caring for him/her at home?

_____.

d) If taking the person home was to be a goal for the future, what are the three resources or supports you feel would **be most influential** in helping towards achieving this?

- 1)
- 2)
- 3)

2.9 Does the person have access to therapy services? *Please tick in the relevant boxes below.*

Service	Routinely	Review basis only	When organised privately by family	Never
Occupational Therapy				
Physiotherapy				
Speech & Language Therapy				
Music Therapy				
Dietician				
Psychology				

Please move to Section 4.

Section 3. Caring for the person at home.

3.1 What are the three **most important resources/ supports** that you feel have helped you to be able to care for the person at home?

- a)
- b)
- c)

3.2 Did the person go straight home from the National Rehabilitation Hospital when discharged? Yes No

If **'no'**, how many other facilities did they receive care from before eventually going home?

(For example, if the person received acute care in Beaumont Hospital, then went to a county hospital before rehabilitation at NRH, and then was transferred to a nursing home before eventually moving home).

3.3 Do you receive help from **formal** caregivers (i.e. care that is provided by someone who is paid to care for the person – either paid privately by yourself or provided by the State)?

Yes No ***(If no, please move to question 3.6).***

3.4 How many days per week does the person receive **formal** care?

7 Days 6 Days 5 Days 4 Days 3 Days 2 Days 1 Day

3.5 How many hours of formal care does the person receive daily or weekly?

Daily: 12-24 hours 10-12hours 8-10 hours 6-8 hours 4-6 hours 2-4 hours 1-2 hours

Or:

Weekly: A number of hours per week, totalling hrs

3.6 Tick which tasks **you** assist the person with and note how frequently?

Activity	Every Day	Occasionally	Rarely or never	Just started
Personal care such as assisting with bathing, dressing, grooming hair, oral care				
Managing food (oral feeding or PEG)				
Transfers and positioning				
Stretching exercise				
Doing their laundry				

Replenishing care necessities such as toiletries				
Sensory stimulation				
Talking to the person, telling stories, reading to him/her, telling him/her news, playing music, singing to them				
Watching TV/ listening to music/radio with the person				
Massage, aromatherapy, other complimentary care				
Taking him/her on outings around the facility, its grounds or on trips				
Other (please explain)				

3.7 Apart from the assistance you provide to the person, what other supports does he/she receive?

Supports	Daily	Weekly- once or more	Monthly - Once or more	Once per year
Formal care-givers assisting with personal care				
Home help to support you with domestic tasks				
Help from other family members/friends				
GP Service				
Visits from Public Health Nurse				
Private therapy (paid for by the family) such as Occupational Therapy, Physiotherapy, Speech & Language Therapy, Music Therapy etc.				
Community Rehabilitation/Primary Care Teams.				

Day centre attendance				
Inpatient respite				
Other _____.				

3.9 Even if you are in receipt of formal care, how much of the care do you feel you and other informal caregivers have to provide?

75-100% 50-75% 25-50% less than 25%

3.10 Who provides the formal care? HSE Privately funded Combination

Please move on to Section 4.

Section 4. Preparation for Caregiving.

4.1 Are you involved in making decisions regarding the persons' care?

Yes Please choose from the following:

Frequently

Sometimes

Rarely

No Please choose from the following (*You can answer more than one*):

I trust the care team to make the right decisions

I have never been invited to be involved in making decisions about the person's care

I don't wish to appear like I am interfering

Other _____

4.2 When the person was discharged from the NRH, do you know if a care plan/care management programme was handed over to the new care team?

No advice was provided from NRH (*If no, please skip question 4.3*)

Some advice was provided from NRH

A clear care plan was provided from NRH

4.3 Do you feel that the care plans were implemented in their subsequent care environment (e.g. nursing home)?

Always and consistently

About half of the time

Occasionally followed

Rarely followed

4.4 In your view, what is the most ideal care environment for the person with PDOC/severe brain injury?

- Specialist residential care facility for younger people with severe physical disability
- A long term rehabilitation unit
- A long term care/nursing home environment
- The person's own home
- A combination of the above at various times

Other _____.

4.5 Did the National Rehabilitation Hospital prepare you for engaging in caregiving roles? **Please circle the relevant number.**

1 2 3 4 5 6 7 8 9 10

No preparation **Some preparation** **A lot of preparation**

Details:

_____.

4.6 How confident do you feel when carrying out caregiving tasks with the person? **Please circle the relevant number.**

1 2 3 4 5 6 7 8 9 10

Not confident **Somewhat confident** **Very confident**

4.7 Which caregiving tasks do you feel are particularly challenging for you to undertake?

_____.

4.8 Is there anything that the National Rehabilitation Hospital could have done to help you to be more prepared for the role you have in caring for the person with PDOC/severe brain injury?

_____.

4.9 Please outline below, any recommendations that you would like to make to the healthcare system to support you and the person with severe brain injury/PDOC.

4.10 Please use the following marking system to rate how useful you feel the following initiatives might be in supporting your role in caring for a person with PDOC/severe brain injury.

- 1- Not useful
- 2- Somewhat useful
- 3- Useful

1	A support group for people caring for relatives/friends with Prolonged Disorders of Consciousness. The emphasis is on group members sharing experiences and supporting each other emotionally.	
2	A lifestyle design programme- The emphasis is on helping you to achieve a balance in your own routine between work and leisure tasks, helping you to cope with life's demands and providing you with strategies to look after yourself.	
3	Training related to the practical hands-on care related tasks- This training would be provided by clinicians from the NRH.	
4	A yearly review for your relative by a specialist from the National Rehabilitation Hospital.	
5	Update on diagnosis and prognosis	
6	An online package of tips, advice and strategies to support care-givers of people with Prolonged Disorders of Consciousness.	
7	An annual care-givers day- An opportunity to meet with other care-givers and to receive support and information.	
8	An educational/training booklet with a combination of text and pictures to help guide you through the completion of a range of care-giving tasks with your relative.	
*	The initiative I would find most attractive is number: (please write number in the box opposite)	

9. APPENDIX 3

Expression of Interest to Participate in Interview

Study Title:

An Exploration into the Lived Experiences of Informal Caregivers to people with Prolonged Disorders of Consciousness- Occupational engagement patterns, role change and perceptions of their loved one's care needs.

Researcher: Ms Alison McCann

I have read the information letter for the above study and I am interested in possibly participating in the interview phase of the study. I am happy for the researcher to contact me to explain the study and the focus of the interview in more detail. My contact details are provided below.

Signed _____.

Print Name _____ Tel: _____.

Please return to:

ALISON MCCANN, OCCUPATIONAL THERAPY DEPT., NATIONAL REHABILITATION HOSPITAL, ROCHESTOWN AVE, DUN LAOGHAIRE, CO. DUBLIN.

10. APPENDIX 4

Reminder Letter

Dear

RE: Reminder regarding invitation to participate in research.

Study Title: An Exploration into the Lived Experiences of Informal Caregivers to people with Prolonged Disorders of Consciousness- Occupational engagement patterns, role change and perceptions of their loved one's care needs.

Researcher: Alison McCann

Please find enclosed information relating to the study titled above. If you have already completed and returned the questionnaire and considered participating in the phase 2 of the study, please ignore this reminder.

Your participation in the study will make a valuable contribution to enriching an understanding of the impact that care-giving for a person with severe brain injury has on family members. It will assist with the development of future services at the hospital to support family care-givers and enhance services for patients.

The closing date for return of the questionnaire is September 25th 2015.

Sincerely,

_____.

Lisa Held.

Research Gate-keeper.

11. APPENDIX 5

Confirmation of Interview Letter

Mrs. XXXX

00/00/2015

RE: Letter of Confirmation of Interview.

Study Title: An Exploration into the Lived Experiences of Informal Caregivers to people with Prolonged Disorders of Consciousness- Occupational engagement patterns, role change and perceptions of the care needs of their loved one.

Dear

Thank you for agreeing to participate in an interview for the above study.

The interview will be held on **21/11/2015 at 11am.**

As discussed on the telephone, we will meet at your home.

The interview will be recorded. Once completed, the recordings will be transcribed and any information that identifies you will be made anonymous. The recordings will be wiped once the transcripts have been checked for accuracy.

Please find enclosed an interview schedule to help you to prepare for the interview, and a consent form. I will collect the signed consent form on the day of the interview.

If you have any queries, please do not hesitate to contact me.

Kind regards,

Alison McCann.

Lead Investigator.

12. APPENDIX 6

Consent Form

INFORMED CONSENT FORM.

Study Title: An Exploration into the Lived Experiences of Informal Caregivers to people with Prolonged Disorders of Consciousness- Occupational engagement patterns, role change and perceptions of the care needs of their loved one.

Researcher: Ms. Alison McCann

I _____ confirm that I have read and understood the Participation Information Leaflet relating to this study and I have had ample time to ask questions, all of which have been satisfactorily answered. I have been given sufficient time to consider my participation in the study. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that my participation in this study is entirely voluntary and that I may withdraw at any time, without giving a reason, and withdrawal from the study will not affect my relative’s future treatment or medical care at National Rehabilitation Hospital. I understand that my identity and the identity of my relative will remain confidential at all times.

I understand that the interview will be recorded. I understand that recordings will be confidential and any identifying information will be removed to ensure my anonymity and the anonymity of my relative. I understand that the tape recordings will be wiped as soon as the content has been transcribed and I will have an opportunity to review my transcriptions if I so wish. I understand that information I provide during the study may be used for publication in journal, a thesis submission to Trinity College, or as part of presentations to the public and healthcare professionals. I understand that my identity will not be disclosed in any such publication.

Participant Signature and dated.

Participant Name in Block Capitals.

For the Investigator: I have explained the nature and purpose of this study and have obtained written consent prior to the subjects' participation in the study. I have answered any questions to the best of my ability and believe that the participant understands the nature of the study and has freely consented to participate in the study.

Investigators name (Capitals)

Investigators Signature.

Date.

13. APPENDIX 7

Interview Schedule

The following topics and themes will be discussed during the interview.

- **Daily routine:**

Describe your daily routine or a typical day.

Describe how you spent yesterday.

- **Roles and relationships**

Tell me about the roles you play in your family.

How has your relative's illness influenced the roles you play?

Describe the role you have with your relative who has a brain injury.

- **Activity balance**

How balanced do you feel your lifestyle is...self-care, work (including care-giving & employment), rest and play?

What influences being able to achieve a balance?

Activities that you'd like to be doing that you are not doing....

- **Activity Satisfaction**

Tell me about the activities that you find satisfying in life...; how often do you participate in them?

What influences how frequently you do these activities?

- **Care-giving activities**

Tell me about how you spend time with your relative? How has this changed over the course of their illness?

Describe the care-giving tasks that you do.

What are the challenges you face in caring for your relative?

- **Care-giver tasks-priorities**

What are the things that you do with/for your relative that you feel are the most important for you (or other family members) to do with them?

What would it mean if for some reason you were unable to do these things-impact for you/for your relative?

Are there tasks that you do that you would prefer not to have to do?

- **Activity engagement, wellbeing and quality of life**

What does "quality of life" mean to you? Tell me about your quality of life...what influences it positively/ negatively?

What do you think contributes positively/negatively to your well-being?

How has your quality of life changed since your relatives' brain injury (if you feel it has)?

- **Preparation for role of caregiver**

What would be (or would have been) beneficial in helping to support your role in providing care to your relative?

How do you see that NRH could support other family caregivers of people with PDOC in their care giving role?

- **Future care needs:**

Thoughts on the most important factors that constitute good care for a person with severe brain injury.

Do you have any thoughts regarding the future care needs of your relative?

How do you think the HSE and other services can support your relative in the future- and your role in caregiving?

14. APPENDIX 8

Modified Caregiver Strain Index

Directions: Here is a list of things that other caregivers have found to be difficult. Please put a checkmark in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes, on a regular basis =2	Yes, sometimes =1	No =0
My sleep is disturbed (for e.g. I wake to check on the person).			
Caregiving is inconvenient (for e.g. helping takes so much time or it's a long drive over to help)			
Caregiving is a physical strain (for example, effort or concentration is required, pushing the wheelchair is effortful)			
Caregiving is confining (for e.g. helping restricts free time or I cannot go visiting)			
There have been family adjustments (for e.g. helping has disrupted my routine; there is no privacy)			
There have been changes in personal plans (for e.g. I had to turn down a job; I could not go on holiday)			
There have been other demands on my time (for e.g. other family members need me)			
There have been emotional adjustments (for e.g. severe arguments about caregiving)			
Some behaviour is upsetting (for e.g. incontinence, drooling, spasms or the person is unable to communicate with me)			
It is upsetting to find the person I care for has changed so much from his/her former self (for e.g. he/she is a different person than he/she used to be)			
There have been work adjustments (for e.g. I have to take time off for caregiving duties)			
Caregiving is a financial strain			
I feel completely overwhelmed (for e.g. I worry about the person I care for; I have concerns about how I will manage)			
<i>Sum responses for "yes, on a regular basis" (2 points each) and "yes, sometimes" (1 point each)</i>			
TOTAL SCORE:			

Thornton, M., & Travis, S.S. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. The Journal of Gerontology, Series B, Psychological Sciences and Social Sciences, 58(2), p. S129. Copyright © The Gerontological Society of America. Reproduced by permission of the publisher.

Email to request modification of the tool:

To: Hartford.ign@nyu.edu
Subject: The Modified Caregiver Strain Index.

Dear Sir or Madam,

I would like to use the Modified Caregiver Strain Index to gather data in a piece of research relating to the experiences of informal caregivers of people with profound brain injury. I would like to request permission to make two modifications to the tool to make the examples provided more applicable to the experiences that this particular subject group are likely to experience.

The two modifications related to:

- **My sleep is disturbed:** whereby I would like to substitute the current example with “I wake to check on the person”
- **Some behaviour is upsetting:** whereby I would like to substitute the current example with “incontinence, drooling, grimacing”.

Perhaps you might advise as to whether these modifications are permissible.

Sincerely,

Alison McCann.

15. APPENDIX 9

WHOQOL-BREF

The World Health Organization Quality of Life (WHOQOL)-BREF © World Health Organization 2004

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

		Very poor	Poor	Neither poor nor good	Good	Very good
1	How would you rate your quality of life?					
		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?					

The following questions ask about how much you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	Extremely
3	To what extent do you feel physical pain prevents you from doing what you need to do?					
4	How much do you need medical treatment to function in your daily life?					
5	How much do you enjoy life?					
6	To what extent do you feel your life to be meaningful?					
7	How well are you able to concentrate?					
8	How safe do you feel in your daily life?					

9	How healthy is your physical environment?					
---	---	--	--	--	--	--

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy to enjoy life?					
11	Are you able to accept your bodily appearance?					
12	Have you enough money to meet your needs?					
13	How available to you is the information that you need in your day-to-day life?					
14	To what extent do you have the opportunity for leisure activity?					
		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?					

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very Satisfied
16	How satisfied are you with your sleep?					
17	How satisfied are you with your ability to perform daily life activities?					
18	How satisfied are you with your capacity for work?					
19	How satisfied are you with yourself?					
20	How satisfied are you with your personal relationships?					
21	How satisfied are you with your sex life?					

22	How satisfied are you with the support you get from your friends?					
23	How satisfied are you with conditions of your living place?					
24	How satisfied are you with access to health services?					
25	How satisfied are you with your transport?					

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite Often	Very often	Always
26	How often do you have feelings such as blue mood, despair, anxiety, depression?					

Do you have any comments about the assessment?

16. APPENDIX 10

Occupational Questionnaire

(Smith N.R, Kielhofner G. & Watts J.H. 1986).

Instructions:

In this questionnaire you will be asked to record your usual daily activities and to answer some questions about these activities.

Part One:

Please think about how you have been spending your time over the past few weeks. Try to decide what you do on a usual weekday (Monday-Friday). Using the worksheet that begins below, record your activities from the time you wake up. Each row represents a half hour. For each half hour record the main activity that you would be doing during that half hour. An activity can be anything from talking to a friend, to cooking to bathing. If you do an activity for longer than a half hour, write it down again for as long as you continue to do that activity.

Part Two:

After you have listed your activities, answer all four of the questions for each activity by circling the number of the most appropriate answer. Notice that the questions ask you to decide whether your activities are work, daily living tasks, recreation, rest or caregiving, and to consider how well you do these activities, how important they are to you and how much you enjoy them. In the first question, work does not necessarily mean that you are paid for the activity. Work can include productive activities that are useful to other people like volunteering at a hospital. Daily living tasks are activities related to your own self-care such as housekeeping and shopping. Rest includes taking a nap and not doing anything in particular. Caregiving relates to activities associated with the care of another person. Even if a question does not seem appropriate for some of your activities, please try to respond to each one as accurately as possible. Your answers to every question are important.

Occupational Questionnaire.

Occupational Questionnaire.				
Today's date:		Name:		Age:
Typical activities	I consider this activity to be:	I think that I do this:	For me this activity is:	How much do you enjoy the activity:
	1) Work 2) Daily living work 3) Recreation 4) Rest 5) Caregiving	1) Very well 2) Well 3) About average 4) Poorly 5) Very poorly	1) Extremely important 2) Important 3) Take it or leave it 4) Rather not do it 5) Total waste of time	1) Like it very much 2) Like it 3) Neither like nor dislike it 4) Dislike it 5) Strongly dislike it
For the half hour:				
5.00am	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
5.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
6.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
6.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
7.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
7.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
8.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
8.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
9.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
9.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
10.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
10.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
11.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
11.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
12.00pm	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
12.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
1.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
1.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
2.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
2.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
3.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
3.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
4.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
4.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
5.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
5.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
6.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
6.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
7.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
7.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
8.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
8.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
9.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
9.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
10.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
10.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
11.00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
11.30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5

Permission to modify Occupational Questionnaire

From: Taylor, Renee R [<mailto:rtaylor@uic.edu>]

Sent: Tuesday, 23 December, 2014. 16:05

To: Alison McCann

Subject: RE: Modification of Occupational Questionnaire for Research Purposes

Alison,

Thanks for conducting research based on MOHO.

You may modify the form as you wish. As you probably know, the validity can no longer be supported with these modifications and you will need to be transparent about how you modified the scale within the methods section of your publication.

Best Wishes,

Renée R. Taylor, Ph.D.

Vice Provost for Faculty Affairs

Professor of Occupational Therapy

University of Illinois at Chicago

312-413-3472

From Alison McCann [<mailto:Alison.McCann@NRH.IE>]

Sent: Tuesday, December 23, 2014 8:55 AM

To: Taylor, Renee R

Subject: Modification of Occupational Questionnaire for Research Purposes

Dear Sir or Madam,

I am would like to use the Occupational Questionnaire (Smith N.R, Kielhofner G., Watts J.H 1986) as part of my data collections tools in a study addressing the impact of informal caregiving on the occupational lives of relatives of people with profound brain injury. I would like to seek permission to modify the Occupational Questionnaire slightly from its original design to add in a 5th activity (under question 1) which would relate to care-giving. Thus Question 1 would read: 1= work, 2= daily living work; 3= recreation; 4= rest; 5= care-giving. Perhaps you might be able to advise me as to might be the best person to direct this query to?

Many thanks in advance for your assistance,

Sincerely,

Alison.

17. APPENDIX 11

Member-checking Summary

xx/xx/2016.

RE: Study :

An Exploration into the Lived Experiences of Informal Caregivers to people with Prolonged Disorders of Consciousness- Occupational engagement patterns, role change and perceptions of their loved one's care needs.

Dear

Many thanks for meeting earlier in the year to take part in an interview for this research project. There was a tremendous response to research and I visited 10 people from various parts of the country for interview. An analysis of the data is underway. I have enclosed a document called "Member checking Summary". This is an amalgamation of the main findings from the 10 research interviews.

I would appreciate if you took some time to read it and consider whether points raised reflect aspects of your experience. Some of the themes may not apply to you as there were unique features of everyone's experience of caregiving for a relative with PDOC, however there were also many similar themes. If you feel there is something you would like to add, please do so, and indeed write any additional comments or thoughts on the notes page attached.

It is important to note that this document is confidential and not for general distribution public discussion beyond those involved in the interview. Following completion of the study, the results of the study will be presented for publication in relevant clinical journals and made available to other interested parties and stakeholders. Once again, I would like to thank you for your generosity of time and the rich information that you have contributed to this study. Please return this document in the stamped addressed envelope before Oct 21st 2016.

Sincerely,

Alison McCann
Lead Investigator.

Dr. Mark Delargy
Principal Investigator.

Member Check Summary of Findings

While everybody's experience and circumstance is unique and individual, there were many shared experiences and common reactions among the people interviewed. I am presently analysing the findings from the study and as part of that process I am providing you with a summary of the experiences and issues reported. Because this summary is an amalgamation of the findings from all of the interviews, some of the issues reported may not relate specifically to your own experience.

Please read through this summary of the findings and if you think there is anything important that has been missed out please let me know. The summary is a little long as so many issues were raised and I am keen to capture all of them. I have summarised the main findings under four broad categories:

- The role of the informal caregiver in providing care for people with prolonged disorders of consciousness
- The impact of informal caregiving on the roles, routines and time use of caregivers
- The impact of caregiving on the caregivers quality of life
- The caregivers views on the future care needs of people with disorders of consciousness

Some general information will be provided about those who took part and about the type of caregiving they were providing.

Context of Caregiving

Ten people were interviewed for the study. One participant was providing care for the patient/ care recipient in their own home (home caregiver), and nine were providing care for their relatives in a residential care setting (residential caregiver). The people interviewed (participants) had been providing care for between three and nine years, with the majority providing care for longer than four years. The participants were related in a variety of ways to the care recipient- some were spouses, parents and siblings. One of the most striking findings of the study is the immense amount of time that family members give to caring for their relatives with PDOC. This huge time commitment was remarked on by all participants and the amount of time did not seem to differ regardless of whether the patient lived at home or in residential care. Some

participants described spending full days providing care, a similar amount of time that a person would give to full time employment. Even when the patient was living in a residential care setting, participants described how family members would spend a number of hours every day helping with care for the patient. Others described their need to make sure that there was always somebody (family member) present with the care recipient. Some described the need to visit multiple times a day, every day of the week. None of the participants were alone in providing care to their relative. It was clear from the interviews that the commitment to care for a person with PDOC tends to be adopted by the entire family and as such, the impact of having a family member survive with significant disability effects not just the patient but a community of people around them.

Rotas and schedules were frequently referred to as a strategy to assist with co-ordinating care. Some family members have specific caregiving roles, for example some assist with physical exercise; others are involved in sensory stimulation or help with managing trust funds. Some participants noted that they were not the main person involved in the patients care. However, they participated in the interview because they were the patient's next of kin, and although playing a big role in caregiving, they also acknowledged that the other family members were more 'hands-on' with the care recipient than they were.

The role of informal caregivers

Participants described how their role in providing care varied depending on individual circumstances. For some, their relationship to the patient, their gender, and the environment in which the patient lived influenced the roles undertaken. Consistency in the care provided by services (private caregivers or residential care unit staff) and the level of trust in the formal caregivers influenced the caregiving roles. For most of the participants, the care-giving role involved a number of tasks including:

- Providing practical care
- Supplementing therapy
- Advocacy and care co-ordination

- Supervising and teaching formal care-givers

Providing Practical Care

Practical caregiving involved tasks such as helping with personal care, medical and nursing care, and contributing financially to the cost of care. Regardless of whether the person was being cared for at home or in residential care, most participants described how they or another family member were involved in helping with personal care such as help with washing and dressing, feeding, toileting or grooming (hair and mouth care). Home caregivers were very involved in providing practical “hands-on” care but so too were a number of residential caregivers with some seeing to all of the person’s needs on a daily basis. Some participants had developed skills in providing medical care for the person, including such tasks as changing catheters, care of the PEG and administration of medications. There was a trend among the participants that female caregivers tend to complete intimate care and male caregivers are more likely to undertake physical aspects of caregiving such as stretching and passive ranging exercises.

All participants reported a role in the financing of care. Tasks such as arranging fundraising events, managing trust funds, paying for private therapy, dealing with the cost of transport (either to appointments or for visits home) and arranging and paying for private therapy were mentioned. This ‘financial role’ was a strong theme regardless of whether the care recipient is being cared for at home or in a residential care unit. Participants explained that helping finance the cost of care can be difficult particularly for those who have lost the second income of the patient in supporting the family and for those who are retired.

Supplementing Therapy

The majority of participants were very frustrated and angry with the lack of ongoing therapy that was provided for patients following discharge from rehabilitation hospitals. Therapy was viewed by participants as playing an important role in preventing complications such as infections and in promoting recovery. There was a

strong sense that families felt let down by the healthcare system and by healthcare providers in meeting the therapy needs of the patient. The feeling of abandonment by health services was described. To this end, the majority of participants invested a considerable amount of time to this aspect of care. Family caregivers either do the therapy themselves or co-ordinate private therapy generally at considerable expense. Participants felt obliged to do this to ensure the best care possible for their relative.

The types of tasks being carried out range from physical therapy including passive stretching, massage and use of therapy equipment such as the 'Motomed', to sensory stimulation including using music, tastes and smells and varying the persons' environment. Some participants made reference to the use of therapy guidelines that were issued from the rehabilitation hospital on discharge. Some explained how they are consistently used by both formal and informal (family) caregivers. Others noted that they have never been used by formal care staff. A few described how they had used them initially but over time they gave up using them as they seemed to have little effect on the care recipient.

Arranging private therapy seemed to be easier to organise if the patient was living at home or spent periods of time in the family home, e.g. some hours at home at the weekend. It seemed more difficult to co-ordinate if the care recipient lived in residential care. Some participants felt confined and restrained by HSE regulations or other policies. Not being allowed to buy in therapy or to do therapy themselves with their relative, despite receiving training from therapy staff at other facilities was a source of anger and stress for participants. A feeling of failing their relative by not being able to provide therapy for them was a worry for some with concerns about the care recipient seeming to have deteriorated as a result of not having therapy, or concerns they had been denied this element to their care. Obeying the 'rules' of the care facility was difficult to cope with as they felt a duty to do as much as they could to enhance the persons wellbeing. This sometimes resulted in feelings of guilt and confinement in one's caregiving role.

Advocacy and Care co-ordination

Participants described how as part of the caregiver role they felt that they had a responsibility to be a strong advocate for their relative. Participants described how they felt they had to constantly fight for services and supports, and that they had the responsibility of being the 'voice' of the care recipient in making decisions regarding care and advocating for their relative's needs. Some residential caregivers described how their role had changed over the years from being very practical and "hands on" with "physical care" in the initial years to having greater focus on advocacy, fundraising, and co-ordinating care in recent years.

Participants described how they had taken on the responsibility of coordinating care rotas for the patient and the efforts they had to make to try and ensure that there was always somebody available to be with the care recipient. This was a responsibility particularly for those who were providing care at home, but it was also reported by those whose family member was living in residential care. A sense of concern that the care needs might not be adequately met if a family member was not there to oversee the care, or that some aspect of the care might go wrong or not be completed correctly was a worry to some participants and resulted in high levels of vigilance. Co-ordinating rotas involved considerable commitment from other dedicated family members and friends and this was greatly valued and acknowledged by the participants. Participants were aware of the impact that caregiving might be having on other family members such as putting their careers on hold.

Overall, however there was a sense within the interviews that participants felt duty-bound to ensure that care from family members was coordinated and provided for their relatives. Rotas were essential to ensuring that needs could be met in so far as possible, with the needs of the care recipient generally coming first, over and above other commitments and priorities. It was apparent that schedules and rotas offered a way of ensuring some consistency and control over the care, and for many of the participants, these rotas had become well established over the years.

Supervising and teaching formal caregivers

Participants described how they felt responsible for the supervision of their relatives overall care, and they described the obligation they felt to be ‘constantly checking’ and monitoring to ensure that the care recipient received the level of care required. They described how this need for constant vigilance was partly due to the vulnerability of their relative, and that it contributed to the intensity and demands of the caregiving role.

Participants described how the care recipients had complex needs and many observed that formal caregivers often did not seem to have the required level of expertise, skill or experience to carry out some of the care tasks effectively. This led to the family caregiver having to take on the task of training the formal caregiver. Participants described how family caregivers had developed a level of expertise in caring for the person, mostly as a result of having spent so much time with the patient at each step of their journey. A knowledge of the patient before their injury and opportunities to observe specialists, along with considerable researching about severe brain injury contributed to this level of expertise. This expertise was helpful as formal caregivers often looked to family caregivers for guidance in how to provide the required care.

Participants described how they needed some assurance that they can ‘trust’ the formal caregivers to be able to provide care correctly and compassionately, taking time to ensure that they were safe and comfortable. Taking steps to maximise their trust in the care being provided by formal caregivers, such as supervising the care resulted in fewer concerns regarding the quality of care provided. Observing formal caregivers consistently checking and attending to or interacting in empathetic ways with the patient helped to promote trust in care. Participants described how their concerns were lessened somewhat when they had observed and felt assured that staff demonstrated empathy and respected the dignity of the patient. Despite the need for continuous monitoring of the care being provided by others, the majority of participants expressed overall satisfaction with the level of nursing care provided to the patient by formal caregivers but there was prevailing sense that this was fragile and never guaranteed as staff turnover, shortages in staffing and any change to the

care location (i.e. being moved from the current care environment to another) would have significant impacts on the family caregivers satisfaction with and trust in care. It would be, as described, like having to start all over again.

A hidden and confined role

Participants described feeling isolated in their caregiving role. Beyond the assistance and support from other family members, they felt that they were very much on their own. In many circumstances, there was apprehension about their role due to lack of feedback from healthcare professionals who, they sometimes felt, had abandoned them and their relative. Some described feeling uncertain and anxious that they may not be providing adequate care, or were sometimes unsure if they were carrying out care tasks correctly. This sense of isolation and being alone in the caregiving role was added to by the fact that there was a lack of interaction or feedback from the care recipient, and this constant 'one way conversation' was challenging and also very wearing. Along with this, some participants found that as time progressed finding meaningful ways to spend time with their relative was a challenge. Participants described how while they were doing as much as they possibly and practically could, however, they felt guilty that they should be doing more or that there may be other things that they could be doing but they were just not aware of those things. A sense of worry, strain and anxiety existed among several of the participants in providing a demanding level of care but also feeling that perhaps they should or could be doing more.

The impact of caregiving on roles, routines and time use

Caregiving was described as being central to the participant's daily routines, with the care recipient and his or her needs being prioritised over other commitments and activities.

Role regression and forced role change

A number of the participants who were providing care for an adult child described how they perceived their child having changed from being an independent young person to someone who is once again vulnerable and in need of their care. Some of

the parents described feeling like they had regressed back to carrying out similar tasks that were required when their child was an infant. This role regression along with the level of dependence of the children was extremely unsettling and upsetting for the participants. Some of the participants who provided care to partners described how their role with them had also changed. This change was accompanied by a sense of loss and grief. The role had changed from the 'usual' husband-wife role with a 'two-way' nature to the relationship to a situation whereby the caregiver was required to second-guess what their partner would want; to doing everything for them and for the family; and to give them love without it being reciprocated. Some described a feeling of ambiguity and explained how they sometimes felt like 'single' people again, particularly at social functions. Phrases like the loss of "my wingman" were used to describe the experience of going to an event without one's partner. Some people described how sometimes they feel others may be expecting or thinking that they should 'move on' and find other relationships, but that this was very challenging and upsetting as they continued to feel committed to their partner.

Some participants described how their roles within a range of contexts had been forced to change as a result of having a relative with PDOC. Role changes reported included becoming a single mother as a result of the injury sustained by a partner or having to adopt roles that were formally held by the patient such as the cook or the person who completed the housework. Participants who were in paid employment described how they have had to change an aspect of their work role such as increasing their hours to supplement the loss of a second income, or reducing the level of responsibility held to facilitate care-giving. Simply having to "to do everything now" added to a sense of burden with little time to oneself commonly reported among the participants. The opportunity to share duties no longer existed.

Some parents were conscious not to let caregiving impact on parental roles with other children. Efforts were made to keep things as 'normal as possible' and guilt was felt if participants perceived that their commitment to caregiving for the patient impacted too much on usual family life. It seemed that a constant 'balancing act' was being

played out to juggle all of the demands on one's time with caregiving to ensure minimal impact on others.

Impact of Caregiving on Routines

Participants gave rich detail about their individual caregiving routines. Caregiving naturally resulted in changes to their routines with time being spent differently since their relative's illness. Two main themes emerged relating to the impact of caregiving on routines- the 'centrality of the patient to one's routine' and living in the 'here and now'.

Caregiving routines

Most of the participants noted how central caregiving was to their routine and how it takes time to settle into caregiving routines, with some saying that it took two years or more to establish a pattern. Caregiving was a feature of their daily lives from early in the morning until late into the night, and also throughout the night as the care recipient slept. The home caregiver described how they may be up during the night to check on the their relative, and residential caregivers also spoke of the night time awareness of the patient and sleeping with the telephone close by in case there was a problem during night.

Even if not providing direct hands-on care there was the responsibility of ensuring care was provided through coordinating care-giving rotas or ensuring that they could be available to the patient immediately if they were required. Some participants described the daily struggle of trying to juggle other responsibilities such as work, caring for children etc. around the commitment to provide care.

The individual routines of each of the participants were influenced by a range of factors including other family and work commitments, proximity to the care recipient, use of caregiving rota's and teamwork. Generally, every minute of time seemed to be accounted for from early in the morning until late at night. Some participants explained how they went straight from work to caregiving either at home or to a residential care unit, often not getting home or having time for themselves until later

at night. Some spent a number of hours each and every day with the care recipient, a similar time commitment that one might give to paid employment. A sense of pressured time was evident in the participant's accounts of how they spend their time, with there not being 'enough hours in the day'. This resulted in juggling activities, sometimes cancelling plans or for some feeling like they themselves had no routine at all.

Weekend routines were described as being less structured for the home caregiver with time feeling a little more 'relaxed'. They were not juggling work commitments along with caregiving or confined to the schedule of formal caregivers who came to help with the morning routine on weekdays. The amount of time spent with the care recipient increased for most of the participants during weekends with activities such as taking them for visits to the family home more likely to occur over the weekend.

Caregiving as central to routine

This centrality of caregiving to one's routine was described by most of the participants. Much of the participant's time was spent either physically doing caregiving related tasks or thinking about their relative. Some participants described how they have "no usual routine" and how "every day is different". Being unable to plan activities was an emerging theme and it was frustrating for some. A few described having to stick to rigid schedules and emphasised the importance of planning to ensure minimal disruption to the care recipients' routine. Sometimes however, the best made plans failed as participants described how they often had to change their daily schedule to meet the needs of the patient. Overtime activities that some had enjoyed were given up to free up time for caregiving and other more pressing daily tasks.

Some participants conceded to feeling tied or feeling confined themselves, by caregiving. Others explained that even though they did not experience a sense of burden in their role and the routine of caregiving, they were aware of how a commitment to care might result in a feeling that 'your wings had been clipped' and one's time might become restricted. Participants generally emphasised that they did not blame the patient or feel resentful towards their relative as they realised they

themselves had a choice in terms of how much time they spent with them, yet a feeling of being duty bound and wishing to do as much as they could for the care recipient resulted in high levels of commitment. The fear of abandoning the care recipient was also expressed along with the guilt that may be associated with it. Furthermore, caregiving was central to the participant's routine if trust in the abilities of other caregivers was not present.

'Living in the here and now'

The majority of participants described how it was very difficult to make plans and to think of the future. Many described how they really just go from day to day, and even thinking beyond today or tomorrow can be a challenge. Participants described a constant underlying worry associated with the uncertainty of what the future may hold and concerns about how changing demands or life circumstances might affect their ability to provide care in the future was expressed. This worry and anxiety was not just related to the ability to provide physical hands-on care but also there was a worry associated with being able to ensure an adequate level of care was provided by others including continued advocacy on behalf of their relative. To this end many tended to focus more on the here and now and to a certain extent avoided becoming overwhelmed if they were to start thinking in the longer term.

Impact on Occupations

Participants described how dedicating time to caregiving had an impact on a wide range of daily activities. Self-care, domestic, social activities, holidays and work were mainly referred to. The majority of participants described changes in levels of enjoyment and satisfaction from activity. Some had abandoned activities that they had previously enjoyed due to the need to provide care.

Self Care Activities

Self-care activities such as sleep, exercising and preparing a meal were activities that caregiving had an impact on. The majority of participants said that their sleep was affected at some point over the course of their relative's illness. Some described needing to take medication to help. Waking in the night to check on the person (home

caregiver) or waking and worrying about the care recipient was frequently reported and this added to the burden of the situation and had an impact on the participant's wellbeing. Participants who spent a number of hours per day caregiving tended to cook 'quick' meals, have takeaways or try to limit what they ate, and it was a challenge to fit exercise in to their daily routine. There was a sense that participants were disappointed with this and aware that it was a struggle to fit in healthy options and have enough time for cooking.

Some described how they had less time to do day-to-day household tasks. Those who juggled their time between caregiving and paid employment were more likely to report challenges with fitting in domestic and home-making activities in their routine. Housework was 'fitted' in throughout the day early in the morning or late at night generally. A common theme among parents was an effort to minimise the impact of caregiving on other family activities. They described trying to make sure they scheduled time to see other children and to 'keep things as normal as possible' when their other children were around. Some participants were also caregivers for other family members and this placed additional demands on their time.

Social disengagement

The majority of participants described how they spend less time engaged in social activities. A number of reasons were noted for this. Generally there was an awareness expressed by the participants that they had started to avoid and withdraw from engagement in social activities. Sometimes they were grieving and they were just not in the mood. Sometimes they did not have the 'mental reserve' to participate in social activities with others. Some described how they felt the demands of caregiving and the extent of their relatives' disability had made them feel less tolerant or 'snappy' with other people.

One particular issue that was reported to be extremely difficult to deal with was how to manage well-meaning friends and acquaintances asking after the welfare of the patient. Participants described how they experienced this to be extremely stressful and upsetting to cope with especially when they were aware that often there really were

no changes or improvements to report. Comments from others intending to be well meaning were often perceived as hurtful- a further reason to avoid social contact.

Participants described how engaging in social activities often failed to offer a break from caring, as they were very often having to talk about the patient – so there was no ‘escape’ from ‘caring’ even when being away from caring. For others who were caring for a spouse or partner, they described how they had lost their ‘social companion’, the person they would normally have attended social engagements with. This loss of their social partner often led to the participant withdrawing from or avoiding social engagements. Celebrating events was challenging for some of the participants and was often compounded by a sense of grief for the patient and guilt that they might be enjoying themselves whilst their relative remained confined to requiring care.

Re-engagement in social activities was a slow process. Some people who had been in the caregiver role for a longer period of time did report that they had slowly started to re-engage in some previously enjoyed social activity, but acknowledged that this had taken some time as well as encouragement and support from others. The home caregiver had been able to include the care recipient in wider family based social activities and this had lessened their level of social withdrawal and isolation. For some, particularly residential caregivers, disengagement from social activity was simply a matter of time constraints as they seemed to feel obliged or required to spend time with their relative and this often took precedence over re-engagement in social activity outside the home.

Holidays and Rest

The majority of participants described difficulties in taking holidays, particularly in the early years of caregiving. Holidays were generally not enjoyable due to constant worrying about the patient. Those that did take holidays explained how having a trusted team to care for the person, often made up of family and friends, was a factor that helped them worry less when they were away. Some have never taken a break with a couple of days being the longest time away from the patient. The idea of taking a break from caregiving merely added to feelings of strain rather than reducing it. A

small number of participants had taken the care recipient on holidays with them. A frustration and disappointment with the lack of suitable wheelchair access in public places, restaurants and hotels around the country was reported and some felt that this confined their options when planning to include their relative in holidays.

Caregiving and the experience of paid employment

Two findings emerged in relation to the experience of paid employment and caregiving: (a) changed working roles and routines, and (b) the positive influence of work on one's life.

a) Changes to working roles and routines

A sense of duty to be with the care recipient when they were critically ill resulted in a number of participants foregoing work as it was just not possible to do both. Some however, had planned to retire in the year leading up to or shortly after their relative becoming unwell. Some retired participants found fulfilment in their new caregiving role and were grateful for the opportunity to be able to have dedicated time to caregiving. A number of the retired participants spent many hours per day with the care recipient. A need to have a role outside of caregiving was identified by some of the retired participants, and as such with time they had adopted other mostly voluntary activities in addition to caregiving for their relative, such as helping neighbours with odd jobs or caring for children.

Just under half of the interview participants worked in paid employment and had taken on caregiving in addition to their work role. Taking on caregiving alongside work involved making changes to work roles and routines. Some had increased their hours to supplement the loss of a second wage to the household; others had reduced their work hours and level of responsibility. There was an added pressure on participants to get home promptly to free up other family members who had been with the care recipient all day.

A sense of duty to provide the best care resulted in family members making difficult choices in relation to their work and their careers in the context of ensuring a commitment to care for one's relative. Some described how family members had put their careers on hold or relocated from abroad in order to become involved in caregiving on a full-time basis rather than pursuing their original career path. Whilst this was a choice wilfully made by family members, the interview participants gave a sense of initial guilt and a fear that resentment towards the care recipient might be experienced by those who made career choices, but generally overtime, participants have been assured by family members that they have a desire to be a caregiver rather than feeling under duress to care.

b) Positive influence of work

Despite the demands of working alongside caregiving, participants reported that continuing to work has had a positive influence on their lives. Benefits such as a sense of respite, structure to routine, and distraction were reported. Paid employment also assisted with the financial pressures of caregiving. All of the retiree's described the value of engaging in some kind of 'work' (paid or unpaid) on their wellbeing and ability to cope. The retired participants described how doing other things offered structure to one's time and helped to distract from the worries of care-giving. Some of those who had retired to take on caregiving described how they missed the structure and support that they had previously found in their paid employment. Using skills to help others in a way that was different to their caregiving role seemed to contribute to feelings of being effective and valued.

Despite the immense demands of continuing to work alongside caregiving all who were in paid employment acknowledged benefits including finding 'escape', respite and distraction through work. Participants were fearful that not being in work would leave too much time for thinking and worrying about their relative, or more time for car-giving which some participants noted would not have a positive impact on their own wellbeing. The value of having something else to do was recognised by the

majority of participants as having a positive influence on their well-being and ability to cope with the demands of caregiving.

Another theme that came up was the support network that people experienced through their work colleagues. Those who continued to work described how it may not have been possible to both work and help with caregiving without the flexibility and understanding of their employers and the support from their colleagues. The financial pressure associated with caregiving was a strong theme that emerged in the interviews. Many who had continued to work alongside caregiving did so mostly to supplement the cost of care or to substitute family income due to the loss of a second income to the household.

Changed experience of Occupational Engagement

Participants described their experiences of engaging in meaningful activity. Two core themes emerged- a) 'abandoning of occupations' and b) 'changed experiences of enjoyment and satisfaction in occupation'.

a) Abandoning Occupations:

As noted earlier, the loss of a social companion was a reason why activity was often abandoned. Another theme that came up was the loss of their relative as an 'occupational' companion- someone who the participant enjoyed doing activities with, such as leisure, gardening, and trips away etc. Both spouses and parental caregivers experienced this. For parental caregivers it occurred as a result of both parents taking turns to provide care to the child, thus impacting on time to spend with each other. Leisure activities were abandoned by many of the participants. The precedence of caregiving in their everyday routine, financial pressures and having less time, along with loss of one's occupational companion were reasons outlined for abandoning leisure. Participants described feeling disappointed by this sense that they "should be doing more" in terms of leisure and particularly exercise. For some, allowing one to enjoy oneself or to step away from care-giving was difficult and triggered feelings of guilt.

Along with describing how certain occupations had been abandoned, some participants described how they have abandoned future plans such as plans they may have had for retirement, progressing in one's career, travel and family plans. Some referred to the sense of one's "freedom" being taken away to make plans and choices about their own lives and to fulfil dreams because of the sense of duty to provide care, support and ongoing advocacy for the care recipient. Many acknowledged that the situation could be prevailing for many years to come and expressed worry and a sense of burden about this.

b) Changed satisfaction levels

Participants described changed experiences of enjoyment and satisfaction from engaging in activity. Some found it difficult to identify sources of enjoyment and satisfaction in their lives. Activities were not as enjoyable without one's occupational companion. However some participants described how the companionship of the care recipient in their lives continues to be important despite the patient's difficulty in communicating with them. For some, the most satisfying activities are related to caregiving, being with their relative or seeing them make progress, or not deteriorating as a result of the intensity and quality of the care they provide. However, for others, caregiving was not a satisfying activity with some describing how they felt it was something they never thought they would have to do, or should have to do. A trend towards re-engaging in social and leisure activity was identified in some of the interviews, particularly those who had been caregiving for longer than five years. These activities were noted as sources of satisfaction and enjoyment, along with time to oneself being cited as giving satisfaction.

Experiences of work-rest balance

A theme of work-rest '*imbalance*' emerged throughout the interviews, with a minority describing feeling that their lifestyle was balanced, i.e. that they had opportunities for rest and relaxation as-well as work, care-giving and other commitments. Mostly, participants described a struggle to 'find time for oneself', with limited 'downtime' a recurring theme. Not being able to switch off from care-giving was difficult and added

to a sense of strain. Others described their sense of balance as “as good as it’s going to be” and didn’t seem to expect any change or improvement in that area. Some were very clear that there is no balance in their lifestyle with little rest, interrupted sleep, no leisure time and relentless feelings of strain. The early days of caregiving were often described a stressful time with little balance to one’s lifestyle as prolonged periods of bedside vigil were kept. Some, particularly those who had been caregiving over longer periods of time, experienced a greater sense of balance. A ‘good day’ was often characterised by having an opportunity to do something for oneself, such as exercise, meeting friends, or simply a day that is less “chaotic”.

“Escape” through occupation

Several participants discussed the importance of having “something else to do”. There was an acknowledgement that periods of time doing other things, apart from caregiving was important to one’s well-being and that this time away added to the quality of care that one can provide when they are with the care recipient. Having some time to oneself was valued by the majority of the participants. Re-engaging in previously enjoyed activities was seen as a symbol of “normality”. A few participants described how re-engaging in social activity helps with facilitating a sense of balance. Participants were able to identify how other family caregivers also needed to take a break and have time to do something for them-selves such as take a holiday, get some time in the gym or meet with friends.

Facilitators of balance

A sense of balance was supported by a number of factors. These include proximity to the care environment (distance to residential care unit); ‘teamwork’ and having a rota; trust in the care provided by others and having some control over the care being provided; and learning to give oneself permission to “step back”. Some explained how others have helped and encouraged them to find ways to balance their care commitment with other activities in order to take a break. For several of the participants, feedback and encouragement from other family members was an important trigger for taking action to achieve greater balance in their lives. Time and

acceptance has had an influence on achieving some sense of balance for some of the longer term caregivers.

Perceptions of quality of life and experiences of caregiver strain.

In relation to quality of life, four themes emerged- a) 'self as secondary'; b) 'care-giving and self –efficacy'; c) 'mirrored wellbeing'; and d) the 'influence of emotional drivers for caregiving'.

Quality of Life and Caregiving

Four themes emerged relating to care-giving and quality of life.

a) Self as secondary

All participants described how the patient was their “number one” priority and the needs of the patient always came first. This was reflected through many other themes emerging with participants describing some of the sacrifices they have made in their lives so to be able to commit to caring for their relative. Sometimes the commitment to care has placed their own health at risk and for some, their relationships with others. All of the participants acknowledged that the commitment to providing care was borne out of love for the person but that they had a choice regarding the amount of time they committed to it. For some, the commitment to provide care, along with other factors such as the trauma of initial injury and a grief for the person impacted negatively on their quality of life. Some frankly explained how there was little ‘quality’ in their lives and how they lived merely to see to the needs of the patient. Some participants felt that their own lives were ‘on hold’ as a result of their commitment to care.

b) Care-giving and self-efficacy

Self-efficacy means how effective and satisfied we feel we are with the things that we do. High levels of satisfaction and efficacy in caregiving were reported by a small number of participants. Satisfaction in caregiving was compounded by receiving little or no feedback about how effective their role was with the patient as a result of having little, if any contact with experts who would tell them whether they were “doing the right thing” or “doing a good job”. In the absence of feedback from healthcare

specialists, their relative remaining well was used as a yardstick to measure how successful the care they provided was. This lack of support from services was a source of significant dissatisfaction and concern for the participants. However, seeing that the care recipient got fewer infections or maintained gains made in therapy was naturally a source of satisfaction and pride for the participants. A small number described how observing their relative making progress was a source of satisfaction and self efficacy. Functional changes such as being able to swallow safely or communicate, even if infrequently were sources of satisfaction for the participants.

c) Mirrored wellbeing

This theme describes how the wellbeing of the participants was directly affected by the wellbeing of the care recipient. The majority of participants described how their own feeling of wellness tended to deteriorate if the patient was unwell or if they perceived their relative to be having a bad day. This impacted on their mood, sleep, energy and appetite. This theme demonstrates the strong interconnections between the caregivers and the person being cared for.

d) The influence of emotional drivers for care-giving

A number of residential caregivers described feeling a sense of duty to provide care. This manifested simply out of “love” and “care” for the person. This sense of duty at times seemed to create a struggle for some of the participants who acknowledged that they did not have to visit every day yet felt that they should. Deciding not to visit- to take a ‘day off’ from going to the residential care unit was a big decision for many of the participants and as such it tended to be rare, particularly for those caregiving for less than five years. Not visiting created a feeling of guilt. For some, doing activities that signified that they might be ‘getting on with’ their lives or activities that might be enjoyable were avoided as they often triggered feelings of guilt. Indeed observing others appearing to ‘get on with their lives’ was also a very difficult. Some could not ‘not’ visit, as they described feeling that they needed to be there to check that their relative was well before they had the peace of mind to get on with other tasks in their day.

Experiences of caregiver strain

Two themes emerged in relation to caregiver strain- a) 'the enduring nature of caregiving' and b) 'the system and resources as a source of strain'.

a) The enduring nature of caregiving- "This could be forever"

Most of the participants reflected that caregiving for someone with a disorder of consciousness could go on for years. All acknowledged how healthy the care recipients tended to be and how caregiving most likely would require long term commitment. Not only was it an enduring situation but it also impacted upon the lives of other members of the family with more than one person usually involved in the care. There was a sense of fear of what the future might hold. The desire to provide care for their relatives was a feeling that participants described as having perpetual qualities- in that they were aware that the care recipients need for ongoing care would exist after their own death. A number of participants described for this reason, praying that their relative would not outlive them, because they feared a "void" in the persons' care would be left unfilled if they were not there to provide that care.

b) The system and resources as a source of strain

Hands-on care was not the main source of strain for participants. The main sources of caregiver strain apparent in these interviews were:

- feeling abandoned by services
- constantly having to "fight the system"
- a need for constant vigilance
- financial pressures of caregiving.

Care recipients had little if any follow- up from the rehabilitation hospital following discharge to other care services. Follow up generally consisted of a once off appointment with a Rehabilitation Physician at an outpatient clinic. Some reported no contact at all. The participants reported that often community teams, if involved, do not know "what to do with the patient" due to their level of complexity. All of the participants described how therapy services had gradually reduced over time and this resulted in the participants feeling that the patient had been abandoned. This sense of

abandonment resulted in a relentless searching for solutions to “fill the gaps” or supplementing reduced services such as buying in private therapy and skilling themselves and other family members up to carry out the therapy. Participants were frustrated and felt stymied by the lack of follow up or the approach to follow up by specialist services in general.

A lack of information relating to disorders of consciousness, benefits and entitlements and ideas about therapies that may be potentially useful were noted by most of the participants. Searching for information was described as ‘digging’ and this was a source of stress and frustration for the majority of participants. The lack of “one source” for information was problematic and stressful and many relied on the internet as replacement for contact with specialists. The view of all of the participants was that follow up, information and guidance at different intervals across the journey from the experts would assist in reducing the sense of ‘abandonment’. The “wish that someone would tell you” whether the care one was providing was helping or harming was a common theme.

The need to “fight the system” to source information and services was reported by all participants as a source of stress. Experiences of unsupportive staff, staff not understanding the needs of patients with complex brain injury, a “passing the buck” approach to dealing with issues and a lack of “thinking outside the box” were described and caused untold distress for the participants. A few participants noted how the “fight” reduced over time and this was mainly linked to improved consistency in care. The “constant checking, checking, checking” was a source of strain for many. Although participants described care staff as being mostly caring and kind, there was much concern and dissatisfaction with the lack of experience of community staff and healthcare professionals generally in dealing with the needs of people with prolonged disorders of consciousness.

Finally, financial pressures were reported by the majority of participants as a source of “sleepless nights” and worry. Some who were retired described how their savings were “running out fast” as they attempt to supplement care. Compensation settlements

whilst helpful in providing for the care needs were attributed to placing a heavy burden on the shoulders of family caregivers who have to ensure that the finances are managed effectively to provide for the care recipient for the rest of their lives, which was acknowledged could potentially be some time.

Future care needs

A number of suggestions were made by the participants in relation to providing care for people with PDOC into the future. These included:

- Long term skilled follow-up by experts in the area of complex brain injury:
A team of experts to travel to review their relative rather than them go to the experts. The majority of participants reported how taking the care recipient to a specialist centre for a once off follow up was ineffective due to the impact of travel on the person. Some suggested solutions included the use of teleconference, satellite clinics around the country, or over the phone contact to ask questions or seek advice. The majority of participants were frustrated and disappointed with a 'once off' appointment to see a specialist for a review. There was a sense that repeated opportunity for contact with experts at intervals over the life time of the person would be beneficial.
- Opportunity for timely access to a range of medical and therapy services over the lifetime of the patient: Suggestions included opportunities to avail of schemes such as the Treatment Abroad Scheme, and provision of therapies at residential care units to reduce the need for families to supplement gaps.
- Training for both formal and informal caregivers, relating to topics such as safe moving and handling techniques, physical exercises and stretching, sensory stimulation or other potentially beneficial therapies.
- Advice, information and support for families available throughout the lifetime of their relative: Long-term case management or social work contact was identified as a potential source of support. Information relating to benefits and entitlements, where to source services, "what to expect" in the long term and feedback about the caregiving role were also considered important.

- Suitable placement options with care units close to where the family live were recommended to support families in the role as caregivers.
- Links with other families. Some had no links with other people who were going through similar experiences. A forum to connect families was identified as being potentially beneficial in reducing the sense of isolation.

18. APPENDIX 12

Trinity College Dublin: Ethical Approval



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Dun Laoghaire,
Co. Dublin.

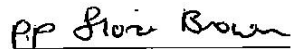
Ref: 150502

Title of Study: An exploration into the lived experiences of informal care-givers of people with prolonged disorders of consciousness-occupational engagement patterns, role change and perceptions of the care needs of their loved one.

Dear Applicant,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in July 2015, we are pleased to inform you that the above project has been approved without further audit.

Yours sincerely,



Dr. Ruth Pilkington
Chairperson
Faculty Research Ethics Committee

Appendix 13

National Rehabilitation Hospital: Ethical Approval

National Rehabilitation Hospital
An Ospidéal Náisiúnta Athshlánúcháil

Rochestown Avenue, Dún Laoghaire, Co. Dublin, Ireland
Tel: +353 1 235 5000 | Fax: +353 1 285 1053 | www.nrhu.ie



5th November 2014

Dr. Mark Delargy
Consultant in Rehabilitation Medicine
National Rehabilitation Hospital

Re: Research Proposal: ““An Exploration into the Lived Experiences of Informal Care-givers of people with Prolonged Disorders of Consciousness – A perspective on occupational participation and role change of informal care givers and their perceptions of the care needs of their loved ones”

Dear Dr. Delargy,

I would like to thank yourself, as Principle Investigator and Alison McCann for your presentation to the Ethics Committee in relation to the above-mentioned Research Proposal, on 3rd November 2014. The Ethics Committee formally consents to the above Research Project subject to the following:-

1. That the research adhere to the National Stroke Program guidelines and adhere to the HIQA recommendations with regard to the national guidelines with regard to data control.
2. Appropriate and best recommended practice data protection measures being taken. The Ethics Committee require that laptops that are used within during the study are data encrypted, in relation to appropriate security and safety procedures and requirements.
2. The appropriate measures of informed consent being taken.
3. To inform the NRH Data Controller Mr. John Maher that the above named research will be commencing and to notify Mr. Maher of any issues that may arise during the study that concern him.
4. The submission of an interim report 6 months from commencement of the study to the Ethics Committee.
5. Appropriate Indemnity is provided and maintained and the hospital is alerted to any issues, which arise pertaining to same.
6. Should any issues arise in relation to the study, in the first instance the Principal Investigator will be first notified. If there are any significant changes arise during the research, this information should be communicated to the Ethics Committee by the Principal Investigator.

7. Presentation of a Final Report when the study has been completed.

8. Abstract published on the NRH Website in accordance with guidance template.

The Ethics Committee would like to remind you that it is the responsibility and obligation of Co. Principle Investigator to ensure that the above requirements are adhered to for the above research proposed.

In addition, I would like to confirm that Alison McCann gave her consent to publication of the research, and also to the above study being included in a 'Register of Research' to be placed on the hospital website.

May I take this opportunity to wish yourself and Alison McCann every success with this study.

Yours sincerely


Kieran Fleck SC
Chairman, Ethics Committee

Cc: Alison McCann