The Need for and Effectiveness of an Individualised Therapeutic Programme for People living with Prolonged Disorders of Consciousness in Non-Specialist Care Settings in the Republic of Ireland

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Declaration

I hereby declare that this PhD thesis is my own work and effort and that it has not been submitted anywhere for any award. Where other sources of information have been used, they have been acknowledged.

Dedication

In loving memory of my sister Sarah Martha Morrissey

Acknowledgement

Completion of this thesis would not have been possible without the help of a number of people. First and foremost I wish to thank the participants and their families for their participation. I also wish to thank my supervisor Prof. Agnes Shiel for all her help and encouragement throughout the years. I also wish to thank Dr Saorse NicGabhainn for her kindness and help.

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Abstract

Title: The Need for and Effectiveness of an Individualised Therapeutic Programme for People living with Prolonged Disorders of Consciousness in Non-Specialist Care Settings in the Republic of Ireland

Introduction: Disorder of consciousness are an increasing phenomena and people are living longer with these conditions. The care needs begin with acute medicine and ICU care and frequently end up with life-long nursing care (Royal College of Physicians [RCP], 2013). Little is known about the care and treatment this clinical population receive long-term. This group of patients will require care for many years following injury (Fins, 2013). This can place strain on budget limited healthcare systems. Interventions should be aimed at minimising carer burden and developing individualised programmes (Wheatley-Smith et al., 2012). Local, individualised, timely and integrated services which are flexible and responsive to personal need are the goal for future neuro-rehabilitation services (Health Service Executive [HSE], 2011). This study developed and implemented such local individualised programmes for people with prolonged disorders of consciousness (PDoC).

Method: Firstly a nationwide cross sectional survey was conducted in order to evaluate current care services and determine if there was a need for the development of a specialised therapeutic programme. Following this, 5 in-depth case studies were conducted in 4 long-term residential care settings. An individualised therapeutic programme was developed and implemented for each participant. Each intervention was 3-6 months in duration. This study was evaluated from three perspectives: the participant with PDoC, their family and the professional staff caring for them. The behavioural changes for participants were measured using three standardised assessments, the Wessex Head Injury Matrix (WHIM), the Sensory Modality Assessment and Rehabilitation Technique (SMART) and the JFK Coma Recovery Scale Revised (CRS-R). Quantitative measures were also used to record changes in family members and professional care staff's knowledge, anxiety, caregiver strain and attitudes towards people with PDoC.

Results: Rehabilitation services for people with PDoC in this country for found to be very limited. There is a low level of follow up and re-assessment for this population also.

When evaluating a therapeutic programme for people with PDoC significant positive statistical and clinical changes were recorded for participants, family members and care staff. This study highlights the value and importance of such non-pharmacological interventions for PDoC and their practical implementation in nursing home settings. Staff attitudes towards care were shown to have significantly changed following the study. Family strain and anxiety were also reduced as a result of this study. A positive impact on reducing misdiagnosis and increasing behavioural repertoire was shown for participants.

Conclusion: People with PDoC are cared for in a multiple of residential care settings and there is considerable variation in the care and treatment services they receive long-term. In this study in-depth case study methodology contributed rich and valuable data to the study of treatment for PDoC. This study supports the provision of long-term rehabilitation for people with DoC and identifies how it can be implemented in non-specialist clinical environments.

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1: Introduction to the Thesis

1.1. Introduction

The contribution of this research thesis is twofold. This thesis describes a novel investigation of understanding the need for assessment and treatment interventions in a population of people with Disorders of Consciousness (DoC) in Ireland. It also documents the design, implementation and evaluation of an individualised therapeutic programme for people with Prolonged Disorders of Consciousness (PDoC) in long-term Irish care settings. This introductory chapter outlines why such a study was selected as the focus of this thesis. Section 1.2 provides an overview of the background to the study. Section1.3 summarises the need for this study while Section1.4 provides an overview of current care and treatment for people with DoC in the Irish context. Section 1.5 presents the research questions and research aims while Section 1.6 outlines the Research Impact Framework (Kurvilla, Mays, Pleasant & Walt, 2006) that will be used to assess the contribution of this study to health science research. Finally an outline of the thesis structure is provided in Section 1.7.

1.2. Background

Brain injury is a serious public health concern (Lefebvre & Levert, 2012) with considerable personal, familial, societal and economic consequences (Ma, Chan & Carruthers, 2014). Disorders of consciousness (DoC) are the result of a severe brain injury whereby the person is left living in a reduced state of consciousness, dependent for all their care needs. The number of people living with DoC in the form of vegetative state (VS) and minimally conscious state (MCS) has increased over the last few decades all over Europe (Giovannetti, Leonardi, Pagani, Sattin & Raggi, 2012; Symons 2008). This has led to an increased strain on already limited rehabilitation resources.

DoC can be the result of a number of aetiologies including traumatic brain injury, cerebrovascular injury, central nervous system infections, tumours, poisoning and neurodegenerative conditions (Seel et al., 2013). The most common causes of DoC are traumatic brain injuries and hypoxic-ischemic encephalopathy (Multi Society Task Force, 1994a). Falls are also becoming responsible for the increasing prevalence of traumatic DoC in older adults (Ní Lochlainn, Gubbins, Connolly & Reilly, 2012). The duration of these conditions can vary from brief periods (seconds, minutes or hours), to transient stages of recovery (days or weeks) or they can become chronic stable conditions (lasting months or years) (Bernat, 2009).

It is less than forty five years since these diagnoses entered medical nomenclature so they are relatively new medical phenomena when compared to other medical conditions. Many questions remain regarding their neurophysiological basis and effective rehabilitation strategies. While scientific advances are being made in the understanding of DoC, people with DoC may not benefit directly from these advances as they do not have the appropriate evidence base (Fins, 2013). The clinical assessment and treatment of DoC is one of the key recommendations for future brain injury rehabilitation programmes internationally (De Tandi, Zampolini & Pregno, 2014). Increased focus needs to be given to these conditions to support rehabilitation and help this clinical population and their families.

1.3. Need for this Research

Large amounts of health resources and research are focused on keeping people alive after life-altering brain injury. Advancements in critical and intensive care have meant that people can be kept alive with minimal brain function, with emergency medicine technology controlling and regulating basic organ functions (Tan et al., 2012). Recently the Irish healthcare system introduced a mandate that all patients who were intubated on an emergency basis had to be transferred immediately to large critical care units so as to promote as much recovery as possible for people with severe brain injuries (O'Connor, D'Alton & Carey, 2015). All severe brain injuries require specialist medical management. Intensive Care Units (ICU) are the most expensive departments in all hospitals worldwide as they provide high intensity of staffing and highly specialist interventions. The average daily cost of providing intensive care in the United States is $1,522 with mechanical ventilation associated with higher costs (Dasta, McLaughlin, Mody & Piech, 2005). In Europe the direct cost of daily ICU care ranges from €1168 to €2025 with healthcare staff being the most important cost driver (Tan et al., 2012).

People surviving with prolonged DoC are the focus of this research study. While every effort is made to stabilise their complex medical condition, little is known about the care and treatment they receive following acute care. This research study will explore the care and treatment received by people surviving with long-term DoC in this country.

DoC are an increasing phenomena and people are living longer with these conditions. The most at risk group for DoC are young people, particularly young males and this age group will require care for many years following injury (Fins, 2013). The care needs begin with acute services and frequently end up with life-long nursing care (RCP, 2013). In order to meet the acute and rehabilitative care for people with DoC in the Republic of Ireland there are two national neurosurgical units and one three bedded specialist rehabilitation unit. For people who do show early recovery and get a place in rehabilitation settings, the length of this placement can be severely limited and this can be seen too at an international level (Fins, 2013). The flow of people through intensive care units and rehabilitation settings is delayed by a lack of post discharge services for people with DoC (Zylberman, Carolei, Sacco, Mallia & Pistoria, 2016). A significant number of people with DoC are discharged home, into nursing homes, long-stay community hospitals or inappropriate care (Neurological Alliance of Ireland, 2010). This puts community hospitals and primary health care systems under increasing strain as a result of the rise in such chronic conditions (National Health and Hospitals Reform Commission, 2009). Nursing home settings are largely unsuitable for this population as young people with head trauma are treated alongside older adults with dementia and other conditions, despite the different care needs for these conditions (Fins, 2013). The average weekly cost of nursing home care in Ireland can vary between €715 and €1800 euro (HSE, 2016). Those who do not receive nursing home care and cannot be cared for at home can often only be accommodated in public hospitals. The average cost for an inpatient bed in a public hospital now stands at €331,000 a year based on costs submitted by hospitals throughout Ireland (HSE, 2016). The provision of specialist rehabilitation and therapeutic interventions add to this expense. Thus the ongoing care of people with DoC has both economic and ethical considerations. In the United States it is estimated that the care costs associated with a diagnosis of VS is $100,000 annually (Fleck, 2011).

There are no clear data relating to how much rehabilitation people with DoC would benefit from so it is difficult to advocate for an increase in the length and type of rehabilitation people with DoC receive. With long-term residential settings providing the majority of care for those with long-term DoC over their life-span, there is an increased demand for therapy services such as occupational therapy services in both public and private residential units. This supported by the Health Information and Quality Authority (HIQA) 2016 standards for residential care settings which state that therapeutic services must be provided in residential care settings as required. Thus, it is important to investigate the effectiveness of the provision of such therapeutic services with this client population.

1.4. Irish Context

The extent to which consensus based criteria have been adopted into clinical care may vary by discipline and geographic location (Giacino & Kalmar, 1997). Currently there is no single policy that informs neurorehabilitation in this country and there is an urgent need for policy and service frameworks (HSE, 2011). There is no population register of people with brain injury in this country and with no true epidemiological data the scope of this issue may be underestimated. The lack of current information and data is a barrier in quantifying the number of people needing neurorehabilitation services in Ireland. This paucity of information is compounded by even more limited information on conditions such as DoC. There is no evidence of the numbers of people needing neurorehabilitation at different stages or levels of care at any one point (HSE, 2011).

Early rehabilitation has positive benefits in promoting functional recovery (Elliott & Walker, 2005; Gelling, 2004; Mazaux, De Seze, Joseph & Barat, 2001). Services should be needs-led regardless of age or diagnosis (HSE, 2011). Interventions should be aimed at minimising carer burden and developing individualised programmes (Wheatley-Smith et al., 2012). Local, individualised, timely and integrated services which are flexible and responsive to personal need are the goal for future neurorehabilitation services (HSE, 2011). Currently there is no transparency on the care that a person with DoC receives in this country long-term.

In both specialist and non-specialist care locations there is no clear guidance or national policy surrounding treatment and care for people with DoC. The National Standards for Residential Care Settings for Older People in Ireland state that all residential care services must “support the physical and psychological wellbeing for people with cognitive impairment” (HIQA, 2016, p.13). It also states that each resident should be offered a choice of “appropriate recreational and stimulating activities” to meet their needs and preferences (HIQA, 2016, p.14). The extent to which these policies are being met for people living with DoC is unknown and has not been investigated previously.

1.5. Research Questions

The overarching research question asks what is both the need for and the clinical effectiveness of providing an individualised therapeutic programme for people with a Prolonged Disorder of Consciousness (PDoC) in long-term non-specialised care settings in Ireland?

This is a complex and multifaceted question and was broken down into two sub questions;

1. *What care and therapeutic services are currently available to people with PDoC in the Republic of Ireland?*
2. *What clinical benefits are there to providing an individualised therapeutic programme to people with PDoC in long-term non specialised care settings?*

Within these sub questions there were a number of aims of this study which are reported in the form of secondary research questions under each sub question.

1. *What care and therapeutic services are currently available to people with PDoC in the Republic of Ireland?*
    - I. What are the current health settings providing care to people with PDoC in Ireland?
    - II. What are the common aetiologies of DoC in this client group?
    - III. What care services (neurology, occupational therapy, physiotherapy, speech and language therapy, neuropsychology and other) are provided to people with PDoC in Ireland at present?
    - IV. Are this client population receiving regular re-assessment of awareness?
2. *What clinical benefits are there to providing an individualised therapeutic programme to people with PDoC in long-term non specialised care settings?*
    - I. Are there any benefits (cognitive or physical) to the person with PDoC in participating in an individualised therapeutic programme?
    - II. What is the benefit to the families of people with PDoC from their family member participating in an individualised therapeutic programme?
    - III. Are there any benefits to professional care staff from a person with PDoC receiving an individualised therapeutic programme within their long-term care setting?

1.6. Research Impact Framework

Health Services Research (HSR) is a broad field of research that seeks to improve the efficiency and effectiveness of healthcare systems and services on behalf of the service user (Hiney, Curran & Clarke, 2011). This study is under the remit of HSR and as such its ultimate aim is to better understand and support the health and well-bring of people with PDoC. Health research can have a broad impact across four domains; research, policy, service and societal (Kurvilla et al., 2006). The framework outlined in Table 1.1 will be used in Chapter 4 to guide the evaluation this research makes to the field of health service research for people with PDoC.

Research Impacts	Policy Impacts	Service Impacts	Societal Impacts
• Type of problem/knowledge • Research methods • Publications and papers • Products, patents and translatability potential • Research networks • Leadership and awards • Research management • Communication	• Level of policy making • Type of policy • Nature of policy impact • Political capital	• Type of services: health/intersectoral • Evidence based practice • Quality of care • Information systems • Services management • Cost-containment and cost-effectiveness	• Knowledge, attitudes and behaviour • Health literacy • Health status • Equity and human rights • Macroeconomic/ related to the economy • Social capital and empowerment • Culture and art • Sustainable development outcomes

Table 1: Research Impact Framework - Adapted from Kurvilla et al. (2006)

1.7. Overview of PhD Thesis

This thesis begins with a review of the literature surrounding DoC and the literature surrounding their assessment and treatment. Clear, detailed definitions of each of the states of consciousness will be provided. It will describe the persisting difficulties in accurate diagnosis, the implications of assessment limitations and poor re-assessment levels prior to synthesising current available evidence for rehabilitation interventions.

In the methodology chapter the methodological assumptions and background will be discussed. The research study will be subdivided into two phases. Phase one is an epidemiological cross sectional study exploring people living with DoC in Ireland. Phase two examines the clinical effectiveness of an individualised therapeutic programme for people with prolonged DoC from the perspective of the person, their family and the professional care staff working with them. The research design for each phase will be discussed in detail and a rationale provided for choice of methodological design. The results for each individual phase will then be presented in the third chapter.

In the discussion chapter the results for each phase will be discussed in relation to the current literature and their clinical or statistical significance. The methodologies will also be discussed. Additional considerations for neurobehavioural assessment discovered during the completed of this study will also be discussed. The thesis will finish with a discussion of the clinical, societal, policy and research implications of the research study.

2. Literature Review

2.1. Severe Brain Injury in Ireland

The incidence of brain injury is estimated at between 150-250 cases per 100,000 of the population (Tagliaferri, Compagnone, Korsie, Servadei & Kraus, 2006; Thurman & Guerrero, 1999). While there are no official statistics for Ireland it is estimated that between 9,000 and 11,000 people sustain a traumatic brain injury annually (Headway, 2015). Early rehabilitation, improved emergency department practices and enhanced medical technology have improved survival and outcome post brain injury. This has led to an increase in the prevalence of people surviving brain injuries.

A European study found that the ratio of all people hospitalised with a brain injury was approximately 22:1.5:1 for mild vs. moderate vs. severe cases, respectively (Tagliaferri et al., 2006). On average 10% of brain injuries are classified as severe. A severe brain injury is classified as a Glasgow Coma Scale (GCS) (Teasdale & Jennett, 1974) score of less than 8. In Ireland 20% of all patients admitted to the two national neurosurgical units were found to have a severe TBI (Phillips Report, 2008).

Little is known about the impact and extent of severe brain injuries in Ireland but they are recognised as one of the leading causes of death and disability (Acquired Brain Injury Ireland, 2013). In the absence of high quality epidemiological data it is suggested that the incidence and impact of brain injury in this country is underestimated. Many people with severe brain injuries are not treated in neurosurgical units; 59% of people with severe brain injuries are treated in the initial referring hospital (Phillips Report, 2008). Data on this population and on long-term survivors of severe brain injury are lacking.

Following severe brain insult a person may lose consciousness and enter a state of unconsciousness. While 80% of people with traumatic brain injuries recover consciousness (Dolce & Lucca, 2010), those who do not recover consciousness may remain in a state of reduced awareness. This is known as a disorder of consciousness. Disorders of consciousness can also result from non-traumatic aetiology such as cerebrovascular injury and hypoxic injury.

2.2. Consciousness

Consciousness is "an attempt to make as sense of as much data as possible at the most functionally useful level" (Marcel, 1983, p15). The idea the consciousness can be divided into 'levels' has been described previously. In the early 1900s Sigmund Freud explored the unconscious, preconscious and the conscious. Mead in 1934 was the first person to contrast levels of consciousness into two categories, outward attention and focus on the environment (consciousness) and inward attention focused on the self (self awareness). Baars (1988) then proposed a contrastive approach to exploring consciousness in terms of awareness and wakefulness. This concept is still widely used today and consciousness is typically said to comprise the two notions of wakefulness and awareness. Wakefulness refers to the level of consciousness present while awareness of environment and of self reflects the content of consciousness (Laureys, 2005). Self-awareness may be viewed as a superior form of consciousness (Morin, 2006).

The exact link between global brain functioning and awareness remains unknown (Boly et al., 2008). The neural correlates of consciousness are as yet undiscovered (Laureys, Owen & Schiff, 2004) but may be associated with the functional connections of the pontine tegmentum in the brainstem (Fischer et al., 2016). Understanding the psychological or neurobiological causes of consciousness also present a major scientific challenge (Kouider, 2009). Block (1995) proposed that consciousness be divided between 'phenomenal' and 'access' consciousness. Phenomenal consciousness is defined in terms of what it is like to 'experience' and have a conscious experience. Access consciousness is defined in functionalist terms. Functional explanations of consciousness are said to be restricted to cognitive mechanisms of the brain (memory, attention, etc) which allow access to conscious content (Kouider, de Gardelle, Sackur, & Depoux, 2010). While Block (1995, 1997) viewed these two concepts as distinct from each other, this is increasingly being called into question as it does not account for unconscious processing i.e., information that is processed but remains below a conscious level

(Kriegal, 2006). Perception of stimuli can take place in three different ways. The first being complete awareness in which all levels of processing are accessed. The second method is complete unawareness in which no levels of processing are accessed and the person has no awareness of any stimulus. Finally stimuli may be perceived with partial awareness combining awareness on some level and unawareness at other levels (Kouider et al., 2010).

2.3. Disorders of Consciousness

DoC are an umbrella term used to describe states of low awareness following severe brain injury. They can be categorised in terms of degree of awareness, on a continuum. This continuum comprises coma, the Vegetative State (VS) and the Minimally Conscious State (MCS). These disorders may present as transient states or as chronic conditions. When a person has 'emerged' from a minimally conscious state they are said to have thus emerged from a DoC. DoC are relatively new phenomena in the medical and research realms.

2.4. History of Disorders of Consciousness

Apoplexy, literally meaning "to be struck by violence" was a term used to describe a number of neurological conditions in ancient Greece. It is one of the terms defined by Hippocrates that refers closely to what is now known as the vegetative state,
"*the healthy subject is taken with sudden pain; he immediately loses his speech and rattles his throat. His mouth gapes and if one calls him or stirs him he only groans but understands nothing. He urinates copiously without being aware of it. If ever does not supervene, he succumbs in seven days, but if he does he usually recovers*" (Clarke, 1963, p.307).

The above definition of apoplexy remained largely intact up until the 17th century until Thomas Willis (1672) first recorded the term 'coma' (as cited in Walter, 1998). In 1898 Oppenheim developed an early taxonomy of consciousness in which he distinguished between somnolence, dazedness, stupor and coma. This was the beginning of the distinction between different states of consciousness.

In the Middle Ages the diagnosis of brain injury began to be considered based on the presence of observable features, consisting largely of “inspection, palpitation of the pulse and urinoscopy” (Walter, 1998, p.157). This was seen as a rudimentary neurological examination. Between the Middle Ages and the 20th century the field of apoplexy and consciousness remained largely unexplored and little progress was made. The contemporary history of DoC began with the invention of the artificial respirator in the 1950s by Bjorn Ibsen. Ibsen founded the first intensive care units, keeping people alive following severe brain insult. The term ‘vegetative state’ was not explicitly defined until 1972 when Brian Jennett, a British neurosurgeon and Fred Plum, an American neurologist wrote their landmark Lancet paper, ‘A Syndrome in Search of a Name’. The term ‘vegetative’ remains the most widely used term throughout medical literature and popular culture (Laureys, 2010). However VS has been known by many alternative names down through the years including coma vigil (French term used in the 1940s), akinetic mutism (Cairn, 1941), appalic syndrome (Kretschemer 1940), severe traumatic dementia (Strich, 1961) pie vegetative (Arnaud, 1963) and vegetative survival (Vaspalahti & Troupp 1971).

The term Minimally Conscious State was defined in 2002 by Giacino et al. Research and investigation into DoC has greatly increased in the 21st century. While conditions of reduced consciousness are not new, the terminology surrounding them has changed over time. They have been better defined and delineated from one another and research in this area has increased significantly in the past two decades. While much progress has been made in term of identifying these conditions the neurobehavioural basis for these conditions remains unknown. In addition the assessment of these conditions remains largely dependent on ‘observable factors’ as first highlighted in Oppenheim’s rudimentary examination.

2.5. Definitions of Disorders of Consciousness

Definitions of each disorder of consciousness are now well accepted throughout medical literature (Berube et al, 2011). A detailed description of the criteria of each diagnosis will be provided so as to provide a clear understanding of each of these medical conditions.

2.5.1. Coma

Following severe brain injury the person may first lose consciousness and enter into a coma. Coma is a state of eyes closed unresponsiveness from which a patient cannot be aroused to wakefulness and was thought to be caused by a disturbance to the reticular system and its thalamic projections (Plum & Posner, 1980). It has since been shown to be significantly associated with the pontine tegmentum area of the brain (Fischer et al., 2016). Recovery and emergence from coma is demonstrated by eye opening. Coma usually lasts no longer than 4-6 weeks in the absence of complicating toxic, metabolic or infectious factors (Bernat, 2006; Sinclair & Faleiro, 2006).

For the purposes of clarity coma is excluded from the definition of DoC from this point and DoC, when mentioned, will refer to a diagnosis of VS or MCS.

2.5.2. Vegetative State

For those people who do not regain full consciousness spontaneously, coma evolves to a state of eyes open wakefulness without awareness called VS (Plum & Posner, 1980). This condition, first defined over forty years ago (Jennett and Plum, 1972), indicates a complete absence of behavioural response to any stimulus. The person in VS has no awareness of their internal or external environments.

People in a VS display sleep-wake cycles and eye-opening. They are unable to produce any purposeful or voluntary behaviour in response to auditory, visual, tactile or noxious stimuli (Giacino, 2004). These patients do not exhibit any sign of language comprehension or expression and have generalised physiologic responses to pain (Giacino, 1996). People in VS also have preserved reflexive activity (Jennett & Plum, 1972).These reflexive behaviours and physiological responses can be misinterpreted as behavioural evidence of awareness without careful examination. For example roving eye movements may be misinterpreted as visual pursuit, a behaviour that indicates some level of responsiveness to visual stimuli. Individuals in VS may also grimace or smile, shed tears or make sounds/noises for no discernible reason (Multi Society Task Force, 1994a; RCP, 2013). These behaviours do not indicate awareness as they have also been demonstrated in anencephalic infants lacking a functional neocortex (Massimelli, 2007 as cited in Chatelle, Laureys, Majerus, & Schnakers, 2010). It is paramount that during assessment and diagnosis a clear distinction is made between reflexive and meaningful behaviours.

The VS is still described in terms of clinical presentation rather than according to any underlying pathophysiology (Bagnato et al., 2013). While the VS is thought to be the result of an anatomical/functional disconnection between the brainstem and cortex as a result of diffuse axonal injury (Dolce & Lucca, 2010) there is no definitive diagnostic test for this condition. Diagnosis requires serial bedside examination with support from any relevant neuroimaging or laboratory tests (Multi Society Task Force, 1994b).

The diagnosis of VS continues to pose ethical, legal, social, medical and therapeutic challenges. VS is sometimes considered a pejorative term (Machado et al., 2012) which may suggest that this person is no longer a human being and that there is no hope for recovery. Many terms have been proposed over the years for this diagnosis. The term ‘apallic syndrome’ was first used in 1940 by the neurologist Kretschmer to describe people who had eye opening, no communication and were unresponsive due to a variety of brain impairments. This term was not widely used with the exception of Viennese neurologists (Gerstenbrand, 1977; Avenarius & Gerstenbrand, 1977). Laureys et al. (2011) proposed the term ‘Unresponsive Wakefulness Syndrome’ to describe this condition. For the purposes of clarity and because it remains the most widely used term in academic, clinical and public environments the term VS will be used to describe this condition in this thesis.

2.5.3. Persistent Vegetative State (PVS)

The persistent vegetative state (PVS) is a chronic neurological disorder of consciousness characterised by wakefulness without awareness. It is diagnosed when a patient is unaware of himself or herself and his or her environment and there is no prospect of any change in this state by any means (Wade, 2001). The Multi Society Task Force (1994) recommended that the term persistent VS should be applied one month after onset. This recommendation was challenged by academics and practitioners who believed that persistent VS should only be diagnosed until twelve months post-injury (American Congress of Rehabilitative Medicine et al., 1995).

PVS has provoked intense debate among scientists, health practitioners, lawyers and moral philosophers (Jennett, 2002b), many of whom argue that there is not enough evidence to suggest that there is no hope for any form of change or recovery

2.5.4. Minimally Conscious State

The Minimally Conscious State was first defined in 2002 by Giacino and colleagues. They reported the minimally conscious state to be a condition of severely altered consciousness in which minimal but definite behavioural evidence of self or the environment is demonstrated. Therefore it is distinctly different from VS where no behavioural evidence is demonstrated.

In order to diagnose the MCS there must be clear evidence that the person has some form of awareness of their internal or external environment. This can be demonstrated on a consistent or inconsistent basis by the following behaviours; following simple commands, gestural or verbal yes/no response, intelligible verbalisation, any purposeful behaviour that occurs in relation to environmental stimuli that is not reflexive in nature (Giacino et al., 2002). This list has been accepted internationally as the criteria for meeting a diagnosis of minimally conscious state and has not been altered or contested since its introduction.

Bruno, Vanhaudenhuyse, Thibaut, Moonen and Laureys (2011) subdivided this state of low awareness further into MCS+ and MCS- based on the complexity of behaviours demonstrated. MCS+ was introduced to describe people functioning at the higher end of the MCS spectrum such as people who could follow commands and have some form of verbal/non-verbal non-functional communication. MCS- describes people at the lower end of the MCS spectrum including people who demonstrate some appropriate responses to environmental stimuli, who can localise to noxious stimulation or who demonstrate visual tracking/pursuit.

Minimally responsive wakefulness state (MRWS) or Minimally Aware Wakefulness State (MAWS) have also been suggested to replace MCS (Machado et al., 2012) and to provide greater clarity on the meaning of this diagnosis.

2.5.5. Emergence from Minimally Conscious State

Emergence from MCS is synonymous with emergence from a disorder of consciousness. There are two criteria that characterise an emergence from the MCS - functional communication and functional object use. Functional interactive communication may occur through verbalisation, writing, yes/no signals or use of augmentative communication devices (American Congress of Rehabilitation Medicine, 1995). At a minimum the patient must be able to answer the six out of six basic yes/no questions on two separate occasions regarding personal or environmental orientations (e.g. are you sitting down?). If the person is unable to communicate by any means then emergence may also be demonstrated by consistent and reliable functional use of at least two different objects (American Congress of Rehabilitation Medicine, 1995). This functional use must be demonstrated on two consecutive evaluations e.g. bringing comb to head or pencil to paper.

2.5.6. Prolonged Disorders of Consciousness

PDoC is defined as any DoC persisting for four or more weeks (RCP, 2013). It is an increasing phenomenon in hospitals and rehabilitation units (Symmons, 2008).

2.5.7. Summary of Definitions

While these definitions represent an advance from the earlier nomenclature they are not without flaw. Following severe brain injury they can present with differing physical, cognitive, linguistic, psychological and social consequences of the injury. People with DoC are a heterogeneous group. Therefore people in VS or MCS may present along a spectrum of varying physical and mental disabilities which can all impact on a person's ability to demonstrate awareness. Similarly people can demonstrate awareness in different ways using different media. The defining of the different states of consciousness coincided with the development of standardised neurobehavioural tools (Laureys, 2005) which helped establish the level of behaviours being demonstrated by the person.

While the boundaries of VS and MCS have been defined clearly the variety of ways they can present clinically is not as clear cut. Behaviours observed can be open to interpretation, for example is a smile reflexive, spontaneous or purposeful? Two people in a MCS can share a diagnosis but be unalike in their aetiology and clinical presentation. It is also important to consider the person who presents with fluctuating levels of awareness – for example if somebody demonstrated functional use of an object on two consecutive occasions but then did not demonstrate this behaviour again, how should this condition be defined? All of these examples illustrate the heterogeneity of people with VS and MCS

While it is important to have a clearly distinguishable diagnosis, the quantity of names and terminology surrounding disorders of consciousness can be confusing. In clinical practice a number of accepted terms to describe these conditions can be found. This variation can make it confusing for the family of the person and lead to difficulties in collating epidemiological data. The definitions are at times vague and little has been done to clarify these definitions further.

2.6. Incidence and Prevalence of Disorders of Consciousness

Most authors agree that the prevalence of DoC will increase in the coming years owing to improved survival and patients of this nature living longer. One prevalence study carried out by Løvstad et al (2014) suggests that the incidence rate of DoC is still rare and, contrary to the above belief, is not increasing in incidence. The incidence this study found at twelve months post injury was .01 per 100,000 for VS and .04 per 100,000 for MCS. These figures were based on a prospective study of people from four neurosurgical departments. However this finding is inconclusive as not everyone surviving with a DoC is admitted to a neurosurgical unit. Therefore these data may be somewhat skewed towards those who had had neurosurgery or have been cared for by a neurosurgeon. In a Swedish-Icelandic study the approximate annual incidence of post-traumatic DoC persisting for at least 3 months was found to be 3 per million people of working age per year (based on 20 recruited patients from a population of 4.7 million) (Godbolt et al., 2013). This study also found that PDoC continuing for over 1 year after injury had an incidence of 1.4 per million working age people per year.

There is evidence of national variation when it comes to social and economic factors, emergency department practice and legal aspects surrounding these conditions. Due to these difficulties, novel approaches must be used in order to capture this rare population group. Methodologies employed to determine numbers of disorder of consciousness patients include retrospective analysis (Wilson, Harper, Watson & Morrow, 2002), hospital point prevalence (Stepan, Hardinger & Binder, 2004), telephone interviews (Lavrijsen, van den Bosch, Koopmans & van Weel, 2005) and cross sectional postal surveys (Saoût et al., 2010). All of these studies focused on regional centres. Only one study (Lavrijsen et al., 2005) focused on people with long-term DoC who were cared for in nursing homes. No study to date has explored the prevalence of both vegetative and minimally conscious states from acute to long-term care.

It can be difficult to quantify the incidence and prevalence of DoC. This is due to a number of factors. Beaumont and Kennealy (2005) found that obtaining epidemiological data for this population was difficult to collate owing to the complex nature of the conditions, the non-uniform care pathways and the varying terminology surrounding the conditions (Beaumont & Kennealy, 2005). Detailed data surrounding frequency are needed to devise effective preventative measures and to plan the most appropriate health care provision (Jennett, 2002a). Research into the long-term care of these severely brain injured patients will help in the diagnosis, prognosis and treatment of these conditions (Fins, Master, Gerber & Giacino, 2007).

2.7. Care Pathways

There is a lack of universal agreement about what the optimal care pathway would be for this patient population (Godbolt et al., 2013). Care pathways for people with DoC may involve several transfers between healthcare settings at various times following the initial injury. People with DoC are first cared for in acute hospitals or other specialist settings where the person is made medically stable. The person then moves to post-acute care, followed by medium and long-term care (RCP, 2013). This pathway is not universal and is dependent on physician, geographical and financial factors.

It is recommended that rehabilitative interventions begin early in the intensive care unit. The early initiation of an unbroken chain of rehabilitation can improve outcomes following severe brain injury significantly (Andelic, Sigurdardotti, Schanke, Sveen & Roe, 2012). Where this is not possible interventional strategies are often implemented in the post-acute phase, often taking place in rehabilitation settings. The provision of rehabilitation beds for people with DoC allows those people to demonstrate greater awareness, when compared to those in care settings with minimal rehabilitative input (Gelling et al., 2004b). However it can be difficult for people with DoC to access specialist rehabilitation beds for a number of reasons. Firstly neurosurgical intensive care units are often geographically distant from rehabilitation units and so medical complications may preclude transfer to specialised rehabilitation facilities in the post-acute phase (Godbolt et al., 2013). Secondly, with limited bed spaces**,** people with DoC compete for admission with people who have less severe injuries and for whom there is a greater evidence based for providing rehabilitation resources (Godbolt et al., 2013). Thirdly, in some countries, inclusion criteria for admission to neurorehabilitation units requires that the person is able to actively participate in rehabilitation interventions.

This automatically excludes people with UWS and the majority of MCS patients. Patients can remain in the acute/post-acute setting from 2-6 months (RCP, 2013); however it is not unusual to have longer waiting lists for specialist settings. Little is written about the care locations of people with DoC medium or long-term care although it is assumed that the majority are cared for in nursing home settings (Berube et al., 2011; Donis & Kaftner, 2011). In Ireland there is one three bed specialist rehabilitation unit for people with a DOC that serves the entire country. This rehabilitation unit is primarily used for diagnostic assessment and is situated in the capital city. It currently provides time limited admission for a twelve week period. Medically stable patients with a disorder of consciousness can often be cared for in local acute hospitals for months or years while they await specialist neurological assessment and rehabilitation in another location. It is not always possible that daily therapeutic intervention be provided for long periods in non-specialist acute care due to limited resources. It can also be difficult to advocate for such intensity of services.

People with DoC are one of the most vulnerable patient populations as they are unable to communicate, fully dependent for all activities of daily living and face a high chance of misdiagnosis (Schnakers et al., 2009). Despite this, little is known about people with DoC in Ireland. There is no set care pathway for this population and geographically specific guidelines are not available. There is no national register to provide epidemiological information and no study to date has explored the impact these conditions have on caregivers in this country. They appear to be a forgotten population in terms of neuro rehabilitation as no clear resources exist. There is no designated charitable or community organisation working specifically with DoC and there no formal support group is in existence.

2.8. Prognosis of Disorders of Consciousness

The rate of spontaneous recovery in the first year following injury can be up to 50% (Braakman, Jennett & Minderhoud, 1988; Kampfl et al., 1998; Kotchoubet et al., 2005). This makes it difficult to prove if interventions were effective or if spontaneous recovery had taken place. Long-term prognosis for people surviving with DoC ranges from moderate to severe disability and functional recovery can vary based on earlier recovery of consciousness and aetiology (Choi et al., 1994; Giacino, Kezmarsky & DeLuca 1991; Levin et al., 1991; Multi Society Task Force 1994; Whyte et al., 2005).

A meta analysis of recovery from VS in 434 patients from 6 studies found that of those considered to be in VS 1 month after TBI, 33% recovered consciousness by 3 months, 46% by 6 months and 52% by 1 year (Multi Society Task Force, 1994a). This meta analysis pre-dates the 2002 definition and diagnostic criteria for MCS. In a retrospective study of 36 patients with VS (8/36) and MCS (14/36) admitted to a slow-to-recover unit, 7 out of 8 patients diagnosed with VS improved to MCS while less than half of these later emerged from MCS (Katz, Polyak, Coughlan, Michols & Roche, 2009). Of a total of 103 patients with DoC there was a 76% survival rate after one year (Godbolt et al., 2013).

Prognostic timeframes have been proposed for DoC. The VS may be considered permanent twelve months after a traumatic brain injury or six months following an anoxic or other metabolic brain injury (RCP, 2003; RCP, 2013). Similarly US clinical guidelines see the twelve month marker for TBI and a 3 month marker for nTBI as points after which recovery is highly improbable but not impossible (American Academy of Neurology, 2011; Multi Society Task Force, 1994a). European guidelines view these prognostic timeframes as points in which treatment limitation and further active therapy must be discussed (Wild et al., 2007). However new single case reports on late recovery for both traumatic and non-traumatic aetiology may call these prognostic parameters into question (Kuehlmeyer, Klinger, Racine & Jox, 2013; Wilson, Dhamapurkar & Rose 2016). If these timeframes are to be re-assessed and evaluated further research needs to be conducted into the long-term assessment and management of this client population.

There are limited data on the long-term outcome of persons with impaired consciousness beyond the critical twelve month period for patients with VS. No cut off beyond which future recovery is improbable has been established for the MCS (Giacino & Kalmar, 1997) and follow up of this patient population is also lacking. While full neurological recovery is not expected, some patients may go on to regain some alertness and expand the nature and amount of behaviours they are able to demonstrate (Dewar, Pickard & Wilson, 2008). Patients who showed late recovery were more likely to be young and have experienced a TBI as opposed to an anoxic event or haemorrhage (Estraneo et al., 2010). It is suggested that a limited number of MCS patients may improve a year after coma onset (Luaute et al., 2010). Patients in MCS or anaesthetized 3 weeks after brain injury have a better prognosis than those in a coma or UWS after 3 weeks (Godbolt et al., 2013). The presence of early signs of attentional behaviours may also be predictive of a better functional outcome (Shiel & Wilson, 2005).

Evolution into a minimally conscious state is common and preliminary to recovery and is observable even after 1–5 years. The boundaries between the vegetative and minimally conscious states are somehow blurred and experience suggests sequential phases in a recovery process, rather than independent conditions. Systematic investigation on the pathophysiology of vegetative and minimal conscious states and a close revision of the nosographic and diagnostic criteria are warranted. It is suggested that there may be a 'slow to recover' population among patients with a PDoC (Dewar, Pickard & Wilson, 2010) and the behavioural recovery of this population was not explored in studies. Axonal regrowth may be responsible for late recovery (Voss et al., 2006). Pistoia, Sara, Sacco and Carolei (2013) suggest that the behavioural unresponsiveness may be a consequence of a number of combinations of five sub-syndromes: pyramidal syndrome, extrapyramidal syndrome, cortical syndrome, disconnection of associative areas and brainstem dysfunction. They suggest that any combination of such syndromes can generate an unresponsive phenotype even in the presence of a partially preserved cerebral genotype. In a similar way any treatment which improves one or more of the sub-syndromes may lead to increased ability to demonstrate behaviours, e.g. pharmacological interventions.

People with traumatic injury continue to have a better outcome than those with non-traumatic injury (Ledoux et al., 2008). One study has shown that outcome is also significantly better for patients who are MCS at one month post-acute injury when compared to patients who remain in VS after one month (Ledoux et al., 2008). This was shown following the establishment of a centralised database with longitudinal follow up. Evidence suggests that the length of time a person is in a MCS state does not predict recovery (Lammi, Smith, Tate & Taylor, 2005; Tierney, Darcy & Mackey, 2007; Watson & Morrow 2002). All of the prognostic studies mentioned took place in a neurorehabilitation unit. In addition different methodologies and tools to explore functional outcome were employed and so comparisons between studies is difficult.

2.9. Legal and Ethical Aspects

A detailed discussion surrounding all of the legal and ethical considerations is beyond the scope of this research study but two important aspects will be highlighted; these are consent to treatment and withdrawal of artificial hydration and nutrition. The diagnosis and prognosis of PVS have reached public attention through several landmark high court rulings involving termination of life-sustaining treatment.

2.9.1. Significant Legal Rulings – Persistent Vegetative State

The 1970 landmark ruling of patient Karen Quinlan set a precedent for a surrogate to refuse life-sustaining treatment on behalf of an incompetent patient which would result in that patients death (Andrews, 2004). This case clarified that should death result as a result of stopping life sustaining treatment than no charge of homicide could be enforced because the patient would be seen to have died due to the pre-existing condition. The life-sustaining treatment in this case was a ventilator. The Quinlan case therefore initiated ground breaking change in the legal rulings of such cases.

The case of Nancy Cruzan in the 1990s also provided an important legal precedent for a legally-authorised surrogate to withhold life-sustaining treatment. Like Quinlan, Cruzan developed PVS as a result of a diffuse hypoxic-ischemic injury. Following the Supreme Court judicial decision Cruzan's feeding tube was withdrawn (*Cruzan v Harmon* [1988]).

The case of Terry Schiavo in the USA created worldwide publicity as well as controversy. She had been in a PVS for fourteen years and there was little hope for her recovery. A dispute between her husband and parents unfolded as both argued over whether she would want to receive artificial life-sustaining treatment or not. The courts ruled that it was in fact her husband that could best represent her best interests. The Cruzan case provided precedent for this ruling. While the Schiavo case was not a ground breaking legal case, it generated much publicity (*Bush v Schiavo*). The recent case of Vincent Lambert in France (June 2015) is similar to Schiavo as there was family disagreement surrounding what was in his best interests but ultimately the courts decided it was in his best interest to withdraw artificial hydration and nutrition.

Applications to the court for withdrawal of artificial feeding methods are increasing in Ireland (Cox, 2015) and precedent for this type of case in relation to PVS is set in *re a Ward of Court* [1996]. The person in this case was considered to be in a PVS for the past 20 years and was fed by a gastric tube for the last four of them. It was decided by the Supreme Court of Ireland that such artificial nutrition constituted medical treatment, was not considered to be medical care, was intrusive with no curative effect and was merely prolonging her life artificially.

In the United Kingdom the legal precedent was provided by *Airedale NHS v Tony Bland*. In this case it was ruled that the removal of artificial hydration and nutrition ultimately leading to death was lawful. This ruling by the House of Lords was also surrounded by controversy with many questioning how such a ruling was in any way lawful (Keown, 1997).

2.9.2. Significant Legal Rulings – Minimally Conscious State

A diagnosis of prolonged VS or PVS allows that person's family to apply to the courts to have any artificial hydration and nutrition withdrawn, thus ending the person's life. Currently the court has only approved cases of people in a proven PVS. The same is not true of MCS. The M Case [W v M 2011] in the UK ruled that somebody in a MCS may have the potential to have positive experiences and so it was not lawful to withdraw artificial hydration and nutrition.

2.9.3. 'Best Interests'

Courts applying this standard may also take into account the best interests of the patient's family. In the case of *Frenchay Healthcare NHS Trust v S*, the Court of Appeal upheld a decision that the re-insertion of a feeding tube would not be in the patient's best interest. S was suffering severe brain damage as a result of a drug overdose and was in a PVS. Similarly in the cases of *Airedale NHS Trust v Bland* and *a Ward of Court* it was concluded that it was not in the patients' best interests to be continued to be fed artificially. In this case it was ruled that it was not part of the duty of care of a medical professional to keep a patient with no possibility of ever regaining awareness alive. There are however a number of limitations to employing a ‘best interests’ standard. When a healthy surrogate employs a quality-of-life assessment on somebody who is severely disabled there is also a risk of choosing under-treatment. Surrogates may undervalue the continuation of life in VS that, for religious or other personal reasons, some patients may believe to be beneficial (Dresser & Robertson, 1989).

Despite precedents, major controversy continues to surround the removal of life sustaining treatment for patients with VS in Catholic hospitals. Pope John Paul II (2004) stated that feeding tubes in PVS patients were ‘not a medical act’ constituting their use as normal care. Therefore there is still controversy surrounding the withdrawal of this treatment within religious communities. In addition, legal precedents were established in significant rulings (except the case of Vincent Lomardi) which took place prior to the definition of MCS in 2002 by Giacino et al. and with high rates of misdiagnosis, objective and evidence based approaches are needed. However some authors argue that these diagnostic definitions are arbitrary and do not provide consistent categorisation for the best interests framework (Wade, 2016).

2.10. Misdiagnosis

Despite the availability of differential definitions and behavioural distinctions between the states of consciousness, the presence of awareness remains difficult to identify clinically. In the 1990s the rate of misdiagnosis of VS was between 37 and 43% (Andrews, Murphy, Munday & Littlewood, 1997; Childs, Mercer & Childs, 1994). Over a decade later Schnakers et al. (2009) found that of 44 people diagnosed with a VS/UWS 41% were misdiagnosed. This study also explored the potential for misdiagnosis of a MCS state and found that 10% of those thought to be in a MCS had emerged from this state. Misdiagnosis remains a clinical challenge and brings with it serious consequences (Giacino, Kalmar & Whyte, 2004; Andrews et al, 1996; Childs, Mercer & Childs, 1993; Tresch, Sims, Duthie, Goldstein & Lane, 1991). Diagnostic accuracy is essential to ensure fitting medical management (Giacino & Kalmar, 2005). Misdiagnosis can impact the intensity and length of rehabilitative input a person receives. This is because people with MCS are more likely to benefit from rehabilitation (RCP, 2013) and so are more likely to be in receipt of these services (Fins, 2013).

2.11. Assessment of Disorders of Consciousness

The diagnostic assessment of DoC consists of evaluating the level and type of conscious awareness that the individual has. This determines whether or not the person meets the criteria for VS, MCS or EMCS. Reaching clinical consensus about a person's level of ability requires information from an experienced and skilled multidisciplinary team (Berube et al., 2011; Giacino, Fins, Laureys, & Schiff, 2014). Currently there are no internationally agreed guidelines surrounding assessment of DoC and no national guidelines are available in Ireland. British guidelines state that assessment should be multifaceted and lengthy, consisting of a person's clinical history, neurobehavioural assessment, structural neuro-imaging and functional neuro-imaging where possible (RCP, 2013). Consultants making the assessment must take into account information from the medical staff, other clinical staff, including neuropsychologists, occupational therapists and physiotherapists and particularly from nurses, carers and relatives who are likely to spend most time with the patient (Bates, 2005).

There is a future need for a multimodal approach incorporating neurobehavioural, electrophysiological and functional neuroimaging approaches so as to improve diagnostic accuracy; however, it is acknowledged that behavioural assessment remains the centre of diagnostic procedures (Jöhr, Pignat & Diserens 2015; Phan 2013). Neurobehavioural assessment is the chosen methodological instrumentation in this research study and so will be examined in depth in this literature review. Other methods of diagnostic assessment showing promise but requiring further research prior to clinical implementation are discussed under section 'Emerging Assessment Techniques'.

2.12. Neurobehavioural Assessment

Neurobehavioural assessment involves systematic observation of behavioural responses to both naturally occurring and presented stimuli across all five senses (RCP, 2013). This is done using one of a number of standardised neurobehavioural assessments. Behavioural assessment measures were once viewed as the 'gold standard' in establishing diagnosis and prognosis of DoC (Giacino & Smart, 2007). They are, however, reliant on the person being able to demonstrate behavioural awareness and increasingly other methods of non-behaviour based assessment are being explored (Coleman, Menon, Fryer & Pickard, 2009; Wade 2016). Despite their limitations, neurobehavioural tools remain the most robust and accessible choice in clinical practice (Giacino et al., 2009; Giacino et al., 2007).

Behavioural assessment has a key role to play throughout the care continuum. As the patient moves through the care continuum into non-specialist long-term care, behaviours may be under reported or misinterpreted when staff do not have specialist training. It can assist practitioners in identifying and monitoring the person with DoC on a regular basis and provide a template for care staff. (Majerus, Gill-Thwaites, Andrews & Laureys, 2005). The behavioural assessment should be conducted over a period of weeks and during different times of the day by a trained and diverse multidisciplinary team inclusive of the person's family (Wild et al., 2007).

There are a number of neurobehavioural assessment tools available to the clinician. Choice of neurobehavioural tool can be difficult and it is not a 'one size fits all' approach. Consideration must be given to the needs and environment of the person with DoC (Doig & Lane-Brown, 2013). In order to optimise their efficiency in capturing behaviours it is important that their use in reducing misdiagnosis be explored in detail. Structured assessment using validated tools to quantify the level of response can help to reduce diagnostic error, and also provides a basis for recording change over time (RCP, 2013).

The Glasgow Coma Scale (GCS) (Teasdale & Jennett, 1974) is an internationally accepted tool that provides a rapid, reproducible assessment of consciousness in coma (Sinclair & Faleiro, 2006). It is one of the most widely used measures of level of consciousness and is used during the initial stages of acute and post-acute recovery (Jennett, 2002a). The GCS is useful as it allows comparison between an initial post injury assessment and subsequent early recovery. It does not however have sufficient sensitivity to small changes during the recovery stage (Gelling et al., 2004). The GCS is an unsuitable measure of assessment for people with DoC following coma due to its limits in capturing behaviours associated with VS and MCS. Its focus is on verbal and motor responses, which can be significantly impaired in people with DoC. This can lead to a floor effect when used for reduced consciousness following coma.

A systematic review found that no neurobehavioural assessment is without reservation (American Congress of Rehabilitation Medicine et al., 2010) and recommended six scales for use with only minor or moderate reservation. These assessments include The JFK Coma Recovery Scale-Revised (CRS-R) (Giacino, Kalmar & Whyte, 2004), the Wessex Head Injury Matrix (WHIM) (Shiel et al., 2000), the Sensory Modality Assessment and Rehabilitation Technique (SMART) (Gill-Thwaites & Munday, 1999), The Western Neuro Sensory Stimulation Profile (WNSSP) (Ansell & Keenan, 1989),the Disorders of Consciousness Scale (DOCS) (Pape, Heinemann,.Kelly, Hurder, & Lundgren, 2005) and the Sensory Stimulation Assessment Measure (SSAM) (Rader & Ellis, 1994).

The WHIM and the SMART are the most commonly used assessments in the UK and Ireland (Delargy et al., 2013). The WHIM has been shown to be a useful tool for assessing patients with PDoC (Turner-Stokes, Bassett, Rose, Ashford & Thu, 2015) and consistent use of the WHIM may help to detect changes over short periods of time (Symons, 2008). The SMART is designed as a diagnostic tool (Gill-Thwaites & Munday, 2004) and is less used in rehabilitation studies. The JFK CRS-R is also widely used and is recommended as the only neurobehavioural tool which can be used with only minor reservation (Seel et al., 2010). It is also widely used in research. While the psychometric properties of these assessments have been explored (American Congress of Rehabilitation Medicine et al., 2010), no study to date has explored these assessments in terms of clinical usability.

The M case, in which a person living with MCS was found to have positive experiences, highlighted the crucial role neurobehavioural assessment plays in determining levels of awareness. In this legal ruling joint use of both the WHIM and the SMART was recommended so as to avoid ‘missed clinical opportunities’ [W v M, 2011] associated with misdiagnosis in DoC.

2.13. Limitations of Neurobehavioral Assessment

While the definitional parameters between the three states appear clear cut, assessment of DoC in practice can be very difficult. In diagnosing these disorders there exists a ‘diagnostic illusory’ of ambiguities and nuanced complexities that make it difficult to distinguish the VS from the MCS (Nettleton, Kitzinger & Kitzinger, 2014, p.134). The assessment of awareness remains complex and the difficulties surrounding accurate diagnosis have been documented (Gill-Thwaites, 2006; Majerus et al., 2005; Shiel, Gelling, Wilson, Coleman & Pickard, 2004). While the aim of behavioural assessment is to elicit behaviours this can be made difficult in many circumstances due to several medical, personal and environmental factors. This may include the presence of motor impairment, tracheostomy, rapidly habituating responses and fluctuating arousal level (Gill Thwaites, 2006). In addition, it is affected by the presence of sensory deficits, motor dysfunction, language impairments (Andrews et al., 1996; Giacino et al., 2014; Majerus et al., 2005), co-morbid medical conditions, lack of involvement of family and carers (Formisano et al., 2011; Gill-Thwaites, 2006), assessor experience/inexperience (Gill-Thwaites, 2006) and length and timing of assessment (Shiel et al., 2004). Diminished drive can also lead to clinicians underestimating a person’s level of awareness and cognitive capacity (Giacino et al., 2002).

There is also disagreement in research regarding what is and what is not a behavioural sign of conscious awareness. One example of this is visual fixation whereby the individual visually focuses on an object for a short period of time. Orientated eye movements have been considered to be associated with conscious processing at a neurobehavioural level (Giacino et al., 2002). Mental imagery tasks also contribute to the idea that visual fixation may be a sign of consciousness (Owen 2008; Schnakers et al., 2008). However, no differences in brain activity or connectivity (as measured by PET scans) in individuals with VS/UWS presenting with and without visual fixation have been found (Bruno et al., 2011). Further discrepancy surrounding this behaviour is demonstrated in international guideline documents where the American Aspen Working Group considers visual fixation as a sign of consciousness whereas the RCP (2003, 2013) in Britain consider fixation to be a reflexive activity. Thus, it remains unclear whether or not visual fixation reflects conscious interaction between the individual and his/her environment (Chatelle et al., 2010). Similarly blinking to visual threat, previously indicated as a behavioural sign of consciousness in neurobehavioural assessments may not indicate consciousness or recovery of consciousness in people with severe brain injuries (Vanhaudenhuyse et al., 2008).

There is no set range of behaviours to indicate possibly meaningful behaviours so, even with behavioural assessment, awareness can still be missed. The detection of behaviours as the person moves through the continuum of consciousness from VS from MCS is challenging as these behaviours may also fluctuate and present erratically (Pistoia et al., 2013). The most important issue for this patient group remains the detection of any signs of awareness.

2.14. Re-Assessment

As with the initial diagnostic assessment there are no internationally agreed standards surrounding the frequency or nature of re-assessment and follow up. Re-assessment can be more difficult as people with PDoC may have moved from specialist centres and from specialised multidisciplinary teams when they need to be re-assessed. Families and care staff observing behavioural change may not have the resources or training to document these appropriately and bring them to the attention of specialist rehabilitation teams. This makes follow up and re-assessment difficult to monitor.

The RCP guidelines (2013) currently recommend that re-assessment should take place at six months and then annually. In addition it recommends that people diagnosed as VS be followed up formally for one year while people with suspected MCS be followed up formally for up to five years. This again highlights the importance of correct initial diagnosis and the limitations placed on rehabilitation opportunities once diagnosed as VS.

Neurobehavioural assessment tools have been suggested as suitable instruments for re-assessment (RCP, 2013). These assessment tools have predominantly been validated with an acute population and for the purposes of differentiating VS from MCS. Thus, the clinical validity of using these tools with a PDoC population, years after injury, remains unclear. Further research needs to be done to explore what assessments can explore small increments in behaviours long term when the diagnosis has been established.

2.15. Emerging Assessment Techniques

Due to the limitations of neurobehavioral assessment in uncovering awareness, studies exploring alternative methods of assessment are increasing (Monti, Coleman & Owen, 2009). Increasingly a multi modal approach to assessment is recommended inclusive electrophysiology and functional brain imaging alongside behavioural assessment (Bekinschtein et al., 2009; Coleman et al., 2009).

Electrophysiological and neuroimaging techniques are showing promise in capturing behaviours that may never be able to be demonstrated physically (Barker, 2005; Beckinstein et al., 2005; Gawryluk et al., 2010; Kobylarz & Schiff, 2005; Noirhomme, Brecheisen, Lesenfants, Antonopoulos & Laureys, 2015). While their use has been demonstrated in small scale studies, further research is required as to their application in clinical practice (Fins, 2013; Phan, 2013). Technological assessment is an area gaining much attention in the literature surrounding DoC. It is not reviewed here in detail as this type of assessment is accessible to a small minority of people with DoC, its use tends to be research rather than clinical based and in many cases neuroimaging techniques do not provide any more information than neurobehavioural assessment.

Other types of assessment which may assist in differential diagnosis but remain unavailable clinically due to limited evidence include quantitative assessment of visual tracking (Trojano et al., 2012), EEG (Fellinger et al., 2011; Wu et al., 2011), position emission tomography recordings to auditory stimuli (Boly et al., 2004), use of technology e.g. micro-switches (Lancioni et al., 2009) and skin conductance responses to auditory stimuli (Scott, Minati, Dienes, Critchey & Seth, 2011). An auditory based music therapy assessment, MATADOC (Magee, 2007) is showing increasing evidence for clinical practice (Magee, Siegert, Daveson, Lenton-Smith & Taylor, 2014) but requires increased research identifying its psychometric properties.

2.16. Rehabilitation for Disorders of Consciousness

In the older literature there was an argument against rehabilitation being provided in cases where there was no known evidence for recovery (e.g. Andrews, 1993), particularly with limited resources. However, there is increasing evidence for rehabilitation for people with DoC and PDoC. Early rehabilitation has been associated with better outcomes (Gelling 2004; Oh & Seo 2003) and can reduce long-term disability (Browne et al., 2013). People with severe brain injuries were also found to benefit from an increased intensity of rehabilitation (Shiel et al., 2001; Slade, Camberlain & Tennant, 2002).

People with VS and MCS can often encounter barriers when attempting to access early intervention services. Many services require a baseline level of responsiveness that people in VS or MCS may not demonstrate (Elliott & Walker, 2005). Specialist services also often have long waiting lists (Shiel et al., 2001). Therapy can often be provided, according to a healthcare policy and structure rather than being needs led (Martone, 2001). In this section the current evidence for rehabilitation for people with DoC will be documented.

2.17. Daily Management

The treatment and management of people with DoC raises medical, ethical and psychological issues and remain clinically challenging (Chiambretto, Rossi Ferrario & Zotti, 2001). A multidisciplinary interventional model has been shown to have benefits following traumatic brain injury (Browne et al., 2013). One of the most fundamental aspects of rehabilitation is teamwork between professionals

(Norrefalk, 2003). Many professionals are involved with the patient in acute care. Realistic goals with realistic measurements need to be established in order to promote best care. There is little documentation regarding the role of therapists specifically for this population group (Munday, 2005). There is no standard treatment approach and emphasis is on the prevention of further disability. In an environment where often the focus is on discharge planning, longer-term patients can slip down the priority list. Therapeutic input can then focus on the biomechanical level and discharge planning (Griffin 2002; Munday 2005). The provision of treatment programmes may be according to a structured environment and programme in certain units but otherwise all provision of treatment is largely up to the interest and experience of the clinician involved (Godbolt et al., 2013).

People with DoC are complex in terms of their presentation. Daily care can involve a number of care interventions. The person with DoC is dependent for all physical, emotional, cognitive and psychosocial needs and so the carer must accommodate for each potential need. This includes seating, positioning, splinting and casting to prevent physical deformity. Daily care for both acute and chronic cases of DoC involves pain assessment, management of skin hygiene, pressure care, nutrition, management of muscle spasticity, hydration, deglutition issues, respiratory, sensory activity, positioning, management of cardiovascular function and intracranial pressure, the provision of a structured environment and all activities of daily living (Eilander, Wijnen, Schiers, deKort & Prevo, 2005; Puggina, Paes de Silva, Schnakers & Laureys, 2012; Sorbo et al, 2005; Tierny et al., 2007). Pain responses should be routinely monitored (Puggina et al., 2012) by an appropriate scale for people with DoC who present with atypical pain behaviours (Gélinas et al., 2014).

Neuromuscular disorders are a common cause of acquired weakness in critically ill patients and have a profound effect on recovery (Bolton, 2005; Latronico, Shehu & Seghelini, 2005). Recognising and treating myopathy and or neuropathy should be an essential part of neurorehabilitative programmes for people with PDOC (Bagnato et al., 2011). The high incidence of spasticity in long term neurological conditions occupies a large part of any neuro-rehabilitation intervention (Andrews, 2005; Elliott & Walker, 2005) and physiotherapists are involved in managing tone, passive range of motion and tolerance to standing (Pilon, Sullivan & Coulombe, 1995). Neuromuscular disorders may be underestimated in people with DoC (Bagnato et al., 2011) and this may hinder their ability to demonstrate behavioural signs of consciousness. These signs include spasticity, paresis and increased deep tendon reflexes. Bagnato and colleagues (2011) call for strategies to prevent and treat neuromuscular complications in both VS and MCS as no significant differences were found for neuromuscular limitations between VS and MCS patients. Soft splinting may be used with people with PDoC to increase hand opening ability (Thibaut et al., 2015). As this does not require supervision it may be a useful alternative of manual stretching (Thiabaut et al., 2015).

2.18. Pharmacological Treatments

A number of medications have been trialled as interventional programmes for people with PDoC. These drugs include dopaminergic drugs, gaba-ergic drugs and medications that inhibit the reuptake of serotonin (DeMarchi et al., 2005; Lombardi et al., 2004; Matsuda et al., 2003; Meyer et al., 2010; Oliveira & Fregni, 2011). Two drugs intended to facilitate arousal and attention have demonstrated clinical effectiveness with this population in two randomised control trials. These are zolpidem and amantadine.

Following the initial brain insult the inside of the brain surges with amino acids such as the inhibitory GABA and the excitatory glutamate. The inhibitory response dominates and brain function is supressed. This leads to a loss of consciousness and reduced demand for oxygen (Giacino et al., 2014). In PDoC GABA levels maintain their suppressive effect. Gaba-ergic drugs such as zolpidem have demonstrated promise in increasing arousal levels in people with PDoC (Clauss, 2010; Whyte & Meyers, 2009). In addition to this depletion of dopamine or the suppression of the brain regions in which dopamine functions also contributes to DoC by reducing cognition and motor function (Clauss, 2010). Zolpidem has been shown to promote consistency and complexity of behaviours in some people with DoC (Clauss & Nel 2006; Cohen & Duong, 2008; Shames & Ring, 2008; Singh, 2008). Whyte and Myers (2009) conducted a placebo-controlled double blind crossover trial with 15 people with PDoC of at least one month in duration. People with traumatic and non-traumatic aetiologies were included and responses were measured using the CRS-

R. One of the 15 participants, reportedly in a VS for the past four year, demonstrated behaviours associated with the MCS following administration of zolpidem but not the placebo. These results were obtained quickly following administration of the drug but were not sustained over longer periods of time without further zolpidem. The other 14 participants did not demonstrate any clinically significant differences. The rehabilitation impact of zolpidem treatments remains undetermined.

Giacino et al. (2012) conducted a randomised clinical trial exploring the effectiveness of amantadine in promoting brain arousal and attention for people with PDoC. The drug was administered over a four week period followed by a two week washout period. The participant included people in VS and MCS 4-16 weeks post injury. During the four weeks rates of recovery were found to be significantly faster in the amantadine group when compared to the control group. Change was measured using the Disability Rating Scale (Rappaport et al., 1982) and thus it is difficult to compare the changes observed to other studies. The Disability Rating Scale is also not as detailed as other, more established assessments of awareness and changes are more difficult to analyse in terms of behavioural gains.

There is insufficient evidence to support pharmacological interventions as a routine part of care at present and intervention for people with DoC and their use is physician and context dependent.

2.19. Assistive Technology

Assistive technology consists of any piece of equipment that can be used to increase, maintain or improve the function or independence of an individual (Naudé & Hughes, 2007). The role of assistive technology in diagnosis and rehabilitation of DoC is increasingly important (Lancioni et al., 2009). The most common assistive technology used with this client group is switches (Naudé & Hughes, 2007) which require a consistent behavioural response to instruction, e.g. opening and closing hand (Lancioni et al., 2014). People in PDoC may demonstrate a minimal level of behaviour which is hard to define and measure. Assistive technology such as micro switches can help amplify these minimal levels of behaviour so that they can be observed and used to manipulate elements of that person's surroundings (Arthanat, Bauer, Lenker, Nochajski & Wu, 2007; Lancioni et al., 2007; Lancioni et al., 2009; Naude & Hughes, 2007). It can move the focus of intervention from passive interaction with sensory stimulation to an active role in communication (Daveson, 2010).

2.20. Tilt Table Therapies

Standing patients upright creates the best position for environmental exploration and sensory stimulation in addition to minimising the risks associated with prolonged immobilisation (Quintieri & Serra, 2002). Standing assists with distributing compression forces through bones and helps prevent contractures by applying a prolonged stretch to soft tissue (Carr and Shepherd, 1998). In standing, people with PDoC demonstrated improvements in arousal, cognition and motor response (Gelling, 2004b). Some people with DoC may perform better in sitting than standing as standing may place higher demands on cognitive resources (Berget, Brunner, Ader, Lovstad & Wehling, 2014). Standing and seating programmes can also assist in reducing carer burden (Wheatley-Smith et al., 2012).

The benefits of using tilt tables as part of a standing programme in increasing arousal and level of awareness in early rehabilitation has been shown in one prospective single blind randomised control trial (Krewer et al., 2015). People with both VS and MCS demonstrated higher level behaviours in standing (Berget et al., 2014; Elliott & Walker, 2005; Symons, 2008). Elliott et al. (2005) found that postural changes, i.e. moving the person from a lying to a standing position (tilt-table at 80°), could increase behavioural response. In these standing studies different assessment tools such as the WHIM (Elliott et al., 2005; Wilson, Dhamapurkar, Tunnard, Warson & Florschutz, 2013) and the CRS-R (Berget et al., 2014; Krewer, Luther, Koenig, & Muller, 2015) have been used to measure outcome. Across these studies different techniques for eliciting behaviours have also used such as the SMART (Wilson et al., 2013), WHIM (Elliott et al., 2005) and the JFK CRS-R protocol (Krewer et al., 2015). All three protocols allow different response times, use different stimuli and differ in their intensity of exploring responses to visual stimuli. Additionally two of the studies investigated behavioural responsiveness in standing within acute hospital care (Elliott et al., 2005; Krewer et al., 2015) while only one has examined its use for chronic DoC in long-term care settings (Wilson et al., 2013).

Standing has been shown to increase behavioural responsiveness as measured by the WHIM and sitting has been shown to be more beneficial than lying (Wilson et al., 2013). Tilt table therapies are particularly beneficial for people in MCS (Wilson et al., 2013) although in all studies benefits have also been shown for people in VS but not enough improvement to challenge diagnostic boundaries. All studies to date have chosen diverse participants in terms of their gender, nature of injury, diagnosis and time since injury. Participant numbers have also been low, ranging from 12 to 25 participants per study. It is difficult to draw a conclusion from these findings in terms of how a standing programme may benefit people with MCS and particularly VS in nursing home care as no study to date has explicitly explored this. However the results suggest that a standing programme assists in creating an optimum environment for behavioural response.

2.21. Sensory Stimulation

Behavioural experiences modify the structure and function of the brain throughout a person's life and may help shape neural reorganisation and functional outcome following brain injury (Kerr, Cheng & Jones, 2011). Sensory stimulation aims to promote brain arousal and behavioural responsiveness through environmental stimuli (Giacino, 1996). It can also promote neuronal plasticity (Di & Schnakers, 2012). It is a low invasive, inexpensive, easy to apply intervention which carries little risk (Abbate et al., 2014).

Neuroimaging studies support the idea that people with PDoC may respond to emotionally salient stimuli as previous studies have shown stimuli such as a child's cry (Laureys et al., 2004), the person's own name (Boly et al., 2004; Staffen, Kronbichler, Aichorn, Mair & Ladurner, 2006), familiar faces (Menon et al., 1998), family photos (Zhu et al., 2009) and familiar voices (Bekinschtein et al., 2004; Eickhoff et al., 2008) can evoke brain responses. Visual pursuit is more often observed in response to personal and emotional stimulation (e.g. the person's face in a mirror) than non-emotional stimulation (e.g. a person moving)

(Vanhaudenhuyse et al., 2008). Sensory stimulation has been shown to increase behavioural demonstrations of behaviour when compared to no treatment for people with PDoC (Cheng et al., 2014). When utilising behavioural experiences in increasing neural plasticity animal studies suggest that age, intensity and timing play important roles (Kerr et al., 2011). There may be benefit to increasing the personal relevance and complexity of sensory stimuli (Di Stefano, Cortesi, Masotti, Simoncini & Pierno, 2012). This includes provides autobiographical and emotional salient stimuli (Abbate et al., 2014).

There is no clear guidance on what subgroup of people with DoC may benefit from sensory stimulation, at what stage of their recovery it should be provided or how the stimuli should be provided (Wood, 1991). Following a Cochrane review it was concluded that there is a lack of evidence base to support or refute sensory stimulation as an intervention for people with DoC (Lombardi, Tarricco, DeTandi, Telero & Liberati, 2002). This review was limited to three studies, one RCT and two clinical controlled trials (CCT). In all three studies (Johnson, Roething-Johnston & Richards, 1993; Kater 1989; Mitchell, Bradley, Welch & Britton, 1990) the participants had acute traumatic brain injuries and their diagnosis was unclear. These studies also took place prior to the definition of the MCS and the development of many standardised neurobehavioral tools and thus the Glasgow Comas Scale was the principal outcome measure. Since this review two studies have explored the impact of sensory stimulation programmes specifically for people with PDoC in long-term care settings (Di Stefano et al., 2012; Lotze, Schertel, Birbaumer & Kotchoubey, 2011). These studies employed an ABABAB (Lotze et al., 2011) and ABCBA (Di Stefano et al., 2012) design and explored sensory stimulation programme over 6 months and 5 weeks respectively. Both studies found improved behavioural responsiveness using WHIM (Di Stefano et al., 2012) and video analysis (Lotze et al., 2012). In these two studies the type and nature of stimuli did not change and stimuli was administered at the same time every day. This may have further limited their findings as people with PDoC typically present with fluctuations in their brain arousal and responsiveness throughout the day. These studies also have low participant numbers ranging from 5-12 people with diverse aetiologies and time since injury. More studies are needed to provide a stronger evidence base for the use of sensory stimulation programme for people with PDoC, but the results to date indicate that enriched sensory environments contribute to rehabilitation. As such sensory stimulation is recommended as part of treatment programmes for PDoC (RCP, 2013).

2.1. Family and Informal Caregivers

Brain injury has negative implications for family, friends and the wider community (Andelic et al., 2010; Hawthorne et al., 2009). DoC arise from the severest of brain injuries, the onset of which is a traumatic and life changing event for family members and loved ones. Once the person is medically stable a long process of rehabilitation, assessment and treatment commences. Post-acute rehabilitation for people with complex and severe brain injuries is lacking with some authors suggesting that people of this nature are neglected once discharged from acute services (Fins, 2003; Fins, 2006; Fins et al., 2007). Fins (2013) also highlights that this neglect has an impact not only for the person but for their family who work to ensure appropriate care is provided. Needs of the family change with each stage of treatment and care (Keenan & Joseph, 2010; Lefebvre & Levert, 2012).

Caring for a person with a DoC is a difficult task. People living with DoC require twenty four hour care and are dependent for all activities. Disability and severe injury has a significant impact on family dynamics and family equilibrium (Bamm & Rosenthal, 2008). For families of people with PDoC there is an emotional paradox because while there is a significant mourning for the loss of their loved one as they knew him/her, they are not dead (Stern, Sazbon, Becker & Costeff, 1988). There is limited appropriate long-term care with rehabilitation input available. Relatives often report family members being cared for in inappropriate care settings such as orthopaedic units and clinical units that care for the elderly (Gelling et al., 2004) and this can have a psychological impact also. The different stages of care can also mean that families have to move or commute to different cities to visit their loved ones in specialised centres (Chiambretto et al., 2010). This contributes to the financial pressures facing caregivers (Leonardi, Giovannetti, Pagani, Raggi & Sattin, 2012). It is recommended that financial and psychosocial supports be given to caregivers of people living with PDoC (Leonardi et al., 2012).

A neuro palliative framework has been proposed (Fins, 2005) as a system of providing long term care for people with PDoC and their families however other authors believe that frameworks need to engage family members as active participants in rehabilitation (Foster et al., 2012; Gill, Wall & Simpson, 2012; Kuipers, Doig, Kendall, Mitchell & Fleming, 2014; RCP 2013; Turner, Onsworth, Cornwall & Fleming, 2009). This is not only applicable in the acute phase of care but in the medium and long term (Lanoix 2008). Interventions targeting families should be incorporated into rehabilitation programmes (RCP 2013; Lefebvre & Levert 2012).

Caregiver distress is a significant issue and should be included in studies examining the effectiveness of interventions in post-acute care settings (Sander, Maestas, Sherer & Nakase-Richardson, 2012). As time progresses caregivers of people in both VS and MCS can experience prolonged grief and depression, often presenting with significant clinical features of both clinical diagnoses (Chiambretto, Moroni, Guernerio, Bertolotti & Prigerson, 2010; Elvira de la Morena & Cruzado, 2013; Leonardi et al., 2012). Family members caring for loved ones with PDoC report reduced socialisation, limited personal interests, increased strain on family relationships, in addition to practical and economic problems (Chiambretto et al., 2001). Studies have shown high levels of anxiety, depression and psychological distress in caregivers of people in VS and MCS with a high need for communication and information (Leonardi et al., 2012; Machamer, Temkin & Dikmen, 2002; Moretta et al., 2014; Rivera et al., 2007). These can improve during sub-acute rehabilitation and improved scores are associated with improved functional recovery for the person with the brain injury (Norup, Siert & Mortensen, 2013). Levels of anxiety, depression and emotional burnout show little to no change over a one and five year period (Chiambretto & Vanoli, 2006; Moretta et al., 2014). Burden and distress are also high in caregivers of people with either VS or MCS regardless of time since injury and is significantly associated with daily hours of caregiving (Giovannetti et al., 2012). Even when in full time care families of people with PDoC can provide care for more than three hours per day (Chiambretto et al., 2010; Leonardi et al., 2012). Families often misinterpret reflexive movements as signs of improvements and this prolonged uncertainty can lead to insomnia, loss of appetite and psychosomatic disturbances (Tzidkiahu, Sazbon & Solzi, 1994).

There are power differentials between family and health care professionals (Fins et al., 2008; Levy, 2008). Coco, Tossavainen, Jaaskelainen and Turunen (2011) in their systematic review found that family members valued respect, empathy and listening from healthcare professionals. Families need accurate information throughout the care continuum (Fins et al., 2008). Despite expressing a desire for accurate and detailed information, family members also report that when healthcare professionals foster hope it leads to more positive outcomes in brain injury rehabilitation (Kuipers et al., 2014). In addition, despite knowing that the person with PVS was not expected to improve the majority of family members wanted them to receive therapeutic interventions, including surgery and transfer to acute hospitals (Tresch et al., 1991). Family caregivers of people in VS believe most medical acts were necessary and did not feel they received over treatment (Chiambretto & Guarnerio, 2007).

Family and close friends play an important role in the assessment and management of people with PDoC as they spend large amounts of time with the individual in a number of contexts and their familiarity is more likely to promote a response (RCP, 2013). Family members of people with brain injuries benefit from peer support (Hibbard et al., 2002). Families who receive comprehensive hands-on training with follow up support are twice as likely to care for their family member with PDoC at home than in a residential nursing unit (Seel et al., 2013).

2.2. Professional Caregivers

This clinical population receive care in a number of settings and encounter a variety of health care professionals. These professionals include everyone working in acute to rehabilitative to community healthcare. Staff need specific skills, knowledge and competence in order to effectively provide care for this non-communicative patient group (Puggina et al., 2012). Due to the relative rarity of this conditions when compared to other medical conditions the development of specialist skills and experience of working with people with DoC can be limited.

There is a burden on professional care staff when working with chronic conditions and burnout has been reported for healthcare working managing PDoC. This was found to be higher for staff in nursing homes as opposed to neurorehabilitation settings with 51% of carers presenting with burnout or emotional exhaustion (Gosseries et al., 2012). A further 36% of healthcare workers experienced depersonalization. The strongest variables associated with burnout include profession (nurse/nurse assistants), time spent with patients and place of work (nursing home). As discussed earlier, people with DoC are regularly transferred to nursing home facilities for long-term care and this, therefore, represents a high risk of burnout for staff. These settings have difficulty caring for this medically complex population due to inadequate staff training or resources (Fins, 2013). Prevention of burnout symptoms among caregivers is crucial and should be promoted in order to encourage best care for this patient group.

Professional caregivers and families can often have differing opinions regarding the care and treatment of people with DoC. Ninety percent of people with PVS were considered by family members to have some awareness of pain, light or darkness, environment, taste, verbal conversation, or the family member's presence (Tresch et al., 1991). This is in contrast to under thirty percent of physicians who believe people in PVS experience hunger, thirst or pain (Payne, Taylor, Stocking & Sachs, 1996). Differing beliefs and opinions can also exist between healthcare professionals. In the UK, U.S. and Belgium the majority of physicians believe it appropriate to not treat acute infections or life threatening conditions when managing a person with PVS (Dierickx, Schotsmans, Grubbs, Walsh & Lambe, 1998; Grubb, Walsh, Lambe, Murrells & Robinson, 1996; Payne et al., 1996). Japanese physicians report much lower agreement with less than 40% in agreement to withdrawing antibiotics (Asai et al., 1999). These discrepancies of beliefs and attitudes may be the result of a lack of research evidence into these states or a lack of consensus guidelines. The impact of these different beliefs and attitudes on the care of the person with DoC is not known.

3. Methodology

3.1. Introduction

In this chapter the chosen methodological design is defined and described. This study examines the need for and effectiveness of an individualised therapeutic programme for people with PDoC in long-term care settings. This is a multifaceted question and the study was subdivided into two phases, each with its own methodology. This chapter begins by stating the research question and framing the methodological approaches chosen in terms of philosophical paradigms. The chapter will then describe the chosen methodological design for phase one followed by phase two. For each phase the sampling, recruitment, instrumentation, proposed data analysis and reduction of bias will be detailed. The ethical considerations of this research project will be discussed as a whole at the end of this chapter.

3.2. Research Questions

The overarching research question of this study asks, "*What is the need for and the effectiveness of providing an individualised therapeutic programme to people with a PDoC in long-term care settings?"* This question aimed to address two main issues – what is the need for an individualised therapeutic programme for people with PDoC and also what would the effectiveness of implementation of such a therapy programme be?

Firstly, in order to determine the need for such intervention it was decided to explore "*what medical and therapeutic services were currently available to people with a PDoC in long-term care settings in the Republic of Ireland?"* This investigation was phase one of the study. In order to comprehensively answer this question a number of sub questions were posed. These were as follows;

I. *In what healthcare institutions are people with PDoC cared for?* – this is an important first area of investigation as people with PDoC do not have a uniform care pathway and it remains unclear and unpublished where people with PDoC reside long-term in Ireland. In order to establish the need for an intervention the nature and type of current care environments must be known.

II. *What medical and therapeutic services (broken down further into neurology, occupational therapy, physiotherapy, speech and language therapy, neuropsychology and other) are provided to people with PDoC within identified long-term care settings?* – this question forms the crux of phase one. Alongside this and other sub questions it was important to obtain demographic details regarding people identified as living with PDoC. This allowed for a more detailed analysis following data collection.

III. *What are the most common aetiologies of PDoC in Ireland?* – this question provides valuable information on the nature and patterns of severe brain injuries in this country. Through establishment of such patterns the type of interventions required within certain types of healthcare institutions can be explored. An example of this is the number of PDoC cases due to TBI versus the number of cases of PDoC due to neurodegenerative conditions within a particular healthcare settings.

IV. *Are this client population receiving regular re-assessment of awareness?* – as highlighted in the literature review misdiagnosis is a clinical concern when working with people with PDoC. Through exploration of the levels of re-assessment the level of need for interventional programmes is further examined as it determines the need for interventions around re-assessment also. It was decided also to ask about the type of tool used for re-assessment

Secondly this study asks *"What clinical benefits (if any) are there to providing an individualised therapeutic programme to people with PDoC in long-term care settings?"* While previous studies have explored aspects of interventions this study aimed to investigate the clinical effectiveness of a tailored therapeutic programme in a real world clinical context. The effectiveness of this programme was evaluated from the perspectives of the three main stakeholders involved in long-term care, the person with PDoC, the person's family and the professional caregiver (staff at the healthcare institution). This was phase two of the study and was broken down further into sub questions as follows;

I. *Are there any benefits (cognitive or physical) to the person with a PDoC in participating in an individualised therapeutic programme?* – this sub question explores the clinical benefit for the person with PDoC in long-term care from receiving a therapeutic programme.

II. *What is the benefit to the families of people with PDoC from their family member participating in an individualised therapeutic programme?* – due to the broad scope of this question it was decided to explore this question in relation to the programme's impact on family strain and levels of anxiety.

III. *Are there any benefits to professional care staff from a person with PDoC receiving an individualised therapeutic programme within their long-term care setting?* – this question could explore a vast number of variables and it was decided to focus this question on the impact the programme had on staff attitudes and knowledge surrounding PDoC.

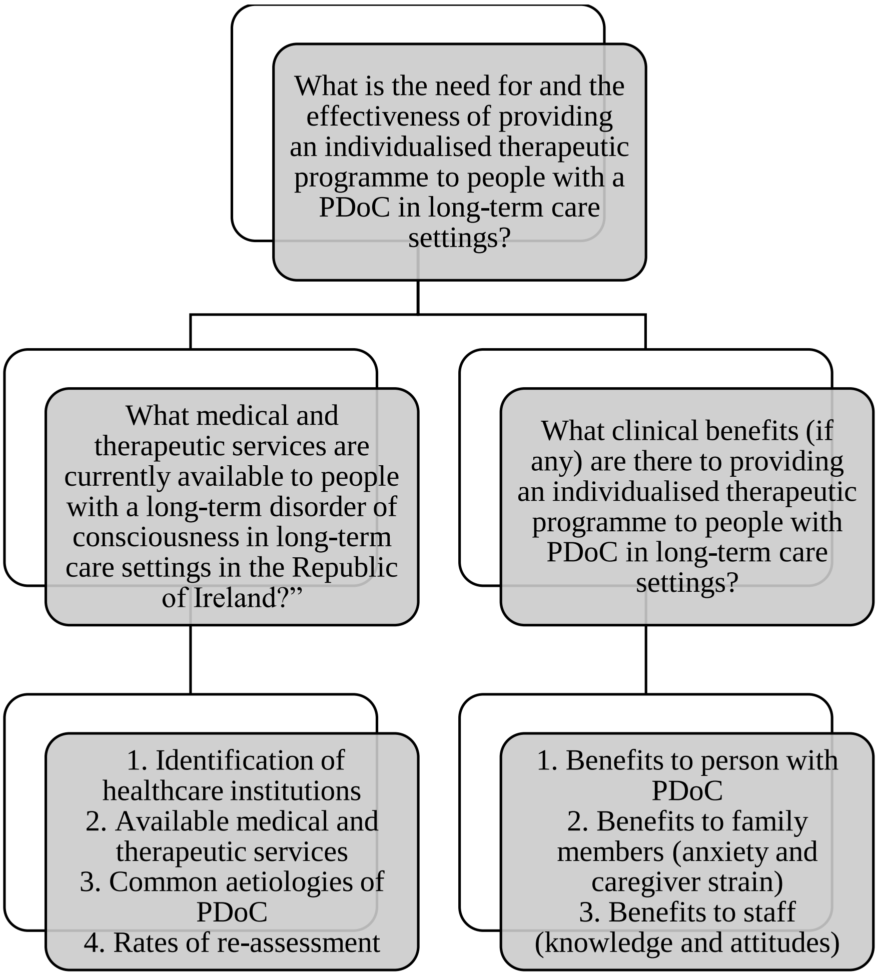

Figure 1: Breakdown of Research Questions into Two Phases of Investigation

3.3. Research Paradigm

In his book *The Structure of Scientific Revolutions* (1962) Thomas Kuhn first introduced the term 'paradigm' into academia. He characterised it as a worldview that embodied scientific belief. Since then there have been many schools of thought regarding this notion with its importance gaining recognition. Paradigms are defined as philosophical frameworks that delineate assumptions about ethics, reality, knowledge and systematic inquiry (Mertens, 2012). It has been stated that the researcher's assumptions around ethics, ontology and epistemology ground the nature of any investigation (Mertens & Wilson, 2012). There are four dominant paradigms: post-positivism, constructivism, transformative and pragmatism (Creswell, 2014).

Post-positivism paradigms pursue objectivity through the testing of hypothesis and experimental designs. Constructivism seeks to understand socially constructed experiences and unique realities using a predominantly qualitative approach. This was considered an inappropriate paradigm to guide this research study as the client population under investigation are unable to communicate. Similarly transformative paradigms support a qualitative approach in exploring an individual's reality through the lens of power structure. A pragmatic paradigm focuses on real world practice and employs a problem centred approach (Creswell, 2003). This study employed a pragmatic paradigm as it supported exploration of an intervention within a number of contexts. A pragmatic paradigm provides a suitable philosophical framework for this study as it allows for a variety of research methods to be employed (Tashakkori & Teddlie, 2003).

Pragmatic paradigms move away from the post-positivism biomedical paradigm previously seen in brain injury research. A post-positivism approach would limit the evaluation of the provision of any therapeutic intervention as it focuses on experimental design which is not always possible in the clinical setting and with participants who have fluctuating medical needs. The pragmatic approach is not committed to any one belief or paradigm. This type of research focuses on the 'what' and 'how' of the research question (Cresswell, 2003, p.11). It aims to identify the truth about clinical practice through the use of more than one scientific method of inquiry. It provides the underlying philosophical framework for a mixed methods approach (Somekh & Lewin, 2005; Tashakkori & Teddlie, 2003). It allows for flexibility and changing methods as the study progresses which is important when the expected results are unclear. This is important in addressing the number and variety of research questions being explored.

3.4. Methodology of Phase One

3.4.1. Background to Methodology

This phase explores the current medical and care services received by people with PDoC in long-term care settings. Without a national register to identify the target population a novel approach was required in order to capture details of all people with DoC in Ireland. In order to decide upon a research methodology it was important to understand the target population. People with DoC are a heterogeneous population, each presenting with different aetiologies, symptoms, medical issues, abilities and levels of awareness. Without a set care pathway they can be cared for in variety of care locations and receive any possible combination of medical and/or therapeutic services. They may be under the care of a variety of healthcare practitioners. Due to high misdiagnosis rates it must also be considered that a percentage of this population may be living with the wrong diagnosis and also acute cases could be living without an initial assessment or diagnosis. The care and management of the DoC patient is also a specialist area of clinical practice and so the sampling method needed to be considered carefully.

An in-depth exploration of incidence and prevalence was outside the scope of this research project. Rather, the main aim of this phase was to provide a snapshot of the current situation in an Irish context.

3.4.2. Chosen Methodological Design

A cross sectional descriptive epidemiological approach was chosen. Descriptive epidemiology is seen as the first stage of any epidemiologic investigation and focuses on describing disease distribution by characteristics relating to the person, time and care location (Hulley et al., 2001). Cross sectional methodologies are typical designs of descriptive epidemiological study and can aid healthcare planning (Grimes & Schulz, 2002). Good descriptive research should be able to answer the five ‘w’ questions – when, where, who, what and why in addition to an important sixth question – so what? (Grimes & Schulz, 2002). This choice of methodological design was suitable to address all research questions in this phase. The aim of this nationwide survey was to address all questions based on a distinct client group; who are those living with PDoC; what condition of disordered consciousness are they living with and what care services are they receiving; where are they being cared for; when did they sustain their injury and how did they sustain their injury (aetiology)? The overarching question of ‘so what’ is an important one. Phase one of the research study is an important first step in understanding the issue of DoC in Ireland. It provided nationwide data surrounding the demographics and care locations/services for those considered to have a DoC. Epidemiological data such as these are essential for planning and development of health care services (Giacino, 2002). Using this methodology a postal survey of health care professionals was used to capture relevant data.

A novel ‘venue approach’ was selected. The venue approach divided all care settings into acute, rehabilitation, community hospitals, residential care and home settings. People being cared for in acute, rehabilitation settings and community hospitals are under the care of a consultant. People being cared for in residential care settings are under the care of a Director of Nursing or Clinical Manager. People with PDoC living at home would be under the care of a local general practitioner (GP). Thus, by focusing on the providers of care within these institutions people with DoC were identified.

3.4.3. Participants

People in acute hospitals, rehabilitation hospitals and community hospitals are under the care of a medical consultant. Therefore if this population of consultants were surveyed this subgroup of patients could be identified. One previous study in Northern Ireland (Wilson et al., 2002) surveyed consultant neurosurgeons, consultant neurologists and rehabilitation medicine consultants in a regional neuroscience unit. It was originally proposed to survey these three groups of consultants but following consultation with the principal investigator of this study, Dr. Colin Wilson, it was recommended that other specialities of consultant namely cardiac and respiratory physicians be added to the survey. This was because many people with hypoxic brain injuries do not present through neuroscience units. In addition it was considered that people presenting to accident and emergency departments are under the care of the consultant on call. Widening the net of consultant specialities added value and depth to data collection. In total seven specialities of medical consultants were surveyed in phase one. These included neurologists, neurosurgeons, rehabilitative consultants, geriatricians, cardiologists, respiratory physicians and orthopaedic surgeons.

All suitable residential care settings in Ireland were surveyed. Settings excluded were designated mental health, learning disability and children and adolescent services. Each residential care service selected, both public and private is run by a Director of Nursing or a Clinical Manger. These people were contacted to answer on behalf of each setting.

Initially it was planned to also identify patients with PDoC living at home via their general practitioner. Approval to access the general practitioner database was applied for twice via the Irish College of General Practitioners (ICGP) and was denied on both occasions. This was due to the limited number of research studies chosen each year by the ICGP and the high volume of requests for access to this database. Therefore it was not possible to survey for people with DoC in the home setting.

Both groups of participants were healthcare professionals and able to understand medical information and clinical definitions. Thus it was ensured that all participants would be able to understand and report correct medical information as much as possible.

3.4.4. Recruitment

The Irish Medical Directory is an up-to-date and comprehensive list of all registered and practising medical consultants in Ireland, along with their contact telephone numbers and addresses. Participant information for all consultants was obtained in the 2011-2012 directory. Addresses of consultants' clinical practices were used in order to forward the postal questionnaire. While all addresses were available, a high number of consultants do not provide email addresses in this directory. This contributed to the choice of a postal survey.

Each residential care setting in Ireland, whether public or private, must be registered with the Health Information and Quality Authority (HIQA) and must agree to be inspected by this governing body. HIQA publish a list of all registered cares settings in Ireland on their website with up to date postal addresses. This list was used to identify and recruit all residential care settings in Ireland. The postal survey was then addressed to the Director of Nursing or the Clinical Manager of each setting.

3.4.5. Instrumentation

No suitable questionnaire was available and a new questionnaire was developed. This questionnaire explored the demographic and medical details of each person with DoC in addition to understanding the type of care they were receiving. As consultants, clinical nurse managers and clinical directors were surveyed, slight amendments were made to the questionnaire to make it relevant for each population. This included adding a section to the consultants' questionnaire asking their medical speciality which was not present in the residential care setting survey. Other changes were grammatical. The questionnaire for consultants is found in Appendix B while the questionnaire for residential care settings is found in Appendix C.

Each setting was initially asked if they had a person under their care who matched the definitions of DoC provided. If they did they were asked to tick yes and proceed to the next page of the questionnaire. If they ticked no then they were asked to return the questionnaire with the name of their setting on it. For those that identified a person with either VS or MCS they were asked to complete a short patient profile for each individual. They were asked to record that person's sex, age, nature of brain injury, time since onset, current services they were receiving, time since last cognitive assessment and diagnosis. Where possible multiple choice answers were provided in order to make completing the form as easy and as quick as possible.

One fundamental aspect of conducting any type of descriptive epidemiological survey is to have clear, measureable definitions of the condition under investigation. Clear definitions exist for the two diagnoses under the umbrella term of DoC, however it can be difficult for clinicians to distinguish VS from MCS. Detailed definitions of what was meant by each condition was provided at the beginning of the questionnaire. Correct differentiation between the two states requires a comprehensive multi-disciplinary assessment. It was only possible to ask the clinicians what the current diagnosis for each patient was as documented in their medical charts or as established by the team. By asking healthcare professionals directly about the diagnosis or what they believe the diagnosis to be a realistic picture of the care and therapy services people with DoC receive based on their believed diagnosis was obtained.

3.4.6. Pilot Study

A pilot study of the questionnaire was conducted on a small sample size of health care professionals. This consisted of three general practitioners and five clinical nursing staff. This population mirrored the target participants of medical practitioners and clinical nursing staff. Each person was asked to complete the questionnaire for their care setting. These care settings were outside the remit of the investigation and were not included in the main study. These included community general practices, mental health institutions and learning disability services. Feedback related to the design and format of the questionnaire as opposed to the content. Following feedback formatting changes were made to the questionnaire to make it clearer to read and easier to follow. This included increased use of headings where appropriate, font changes and an increased number of multiple choice answers.

3.4.7. Details of data collection

A postal questionnaire was chosen as the method of distribution. It was decided that for the variety and large number of health care professionals involved this would be the most appropriate method of contact. The questionnaire was distributed by post to all consultant practitioners and nursing/residential units. A request to return the questionnaire regardless of whether or not they had a person matching the criteria was stated clearly on the form. Each questionnaire numbered so that should the form be returned without any name it could still be identified. Each participant was informed that by completing and sending back the questionnaire this was taken as consent to participate. All postal questionnaires were posted on the same day in June 2011. It was not possible to send out reminders for this nationwide survey due to the cost and resources involved in doing so. There was no deadline for return of questionnaires so as to encourage the respondent to return the completed questionnaire at any time. All returned questionnaires were included for analysis no matter the time taken to be returned.

3.4.8. Data Analysis

The Statistical Package for the Social Sciences (SPSS) was used to conduct statistical analysis. Descriptive statistics were used in order to learn more about the demographics of the reported population. Univariate and bivariate analyses were conducted. These methods described the distribution of single variables and explore any relationships between pairs of variables respectively. Inferential statistics and correlation tests were conducted where possible. This included chi squared tests and Pearson tests of correlation. No qualitative data were collected within this survey.

3.5. Methodology of Phase Two

3.5.1. Chosen Methodological Design

This phase explored the real world benefits of an individualised therapeutic programme from three perspectives; person with PDoC, family and staff. A multiple case study methodological design was selected to best answer the research questions within this phase.

3.5.2. Case Study Methodology

Case studies can help explain, describe or explore phenomena in the contexts in which they occur (Yin, 2009). Multiple case studies allow a common phenomenon to be examined with a number of people in a variety of settings. It can therefore provide much more information than the single case approach. In this study, five case studies in total were examined. Selection of multiple cases can be exploratory, descriptive or explanatory. In this study a descriptive approach was selected as the research questions were set prior to the study and no causal relationships were examined. Multiple case study design allows for individual analysis and across cases analysis (Salminen, Harra & Lautamo, 2006).

Unlike previous research into the care and treatment of people with PDoC this study aimed to explore in-depth and over time the impact of daily interventions as well as the relationship of environmental and personal factors in demonstration of behaviours. The large focus on neuroimaging studies has meant that a person’s ability to demonstrate awareness is dependent on them performing in the short amount of time they are in the scanner. Similarly the few clinical studies available tend to measure responsiveness in specific environments over short periods of time. Case study methodology allowed the researcher to document and capture natural interactions and contextual variables over a longer period of time. The depth and breadth of this data collection is valuable for this client population, particularly when little is known about long term recovery. Similarly, the unknown prognostic signposts for this client population demand a more exploratory focus. Experimental case studies were also considered as a methodological design, however they do not allow the researcher to respond to naturally occurring changes while also setting the parameters of the type of responses being sought. Case study methodology also allows family members and caregivers to be actively involved in the research study and people with PDoC may be more likely to demonstrate behavioural responses to familiar voices and people (RCP, 2013).

Case study methodology (CSM) was first introduced in the early 1900s and was largely seen within the field of anthropology (Johansson, 2003). These studies were largely based on examining different cultures and societies. Later, this methodology was used within medicine, social work and psychology to highlight interesting cases practitioners worked with. CSM was less used when positivism and quantitative methods increased in popularity owing to their scientific methods and the statistics they could produce. Post 1950s, in the re-emerging of the case studies, grounded theory was the first type of methodology to emerge. Robert Yin in 1984 combined quantitative methods of inquiry with qualitative methods and advocated for this style of CSM. Since Yin (1984) much has been written on this type of design and its relevance to real world research is increasingly recognised. The situation whereby people living with PDoC are receiving care in residential care is real and increasing. As highlighted in the literature review, while new methods of assessment are investigated, the empirical support behind clinical interventions are lacking. Without research set in the real world context this will not change. Clinic based research has real world relevance and allows the researcher to experience the challenges and opportunities available to the clinician day to day. CSM does not necessarily fall under a single paradigm but rather advocates for a paradigm of choices (Patton, 1990). It allows for flexibility around choice of approach and also accommodates for what may only be possible within certain contexts.

3.5.3. Application of Case Study Methodology to this Study

A case study approach allows an in-depth exploration of an issue, event or phenomenon of interest in a real life setting (Crowe et al., 2011). There are many distinct features of case study methodology (Yin, 2014; Stake, 1995) that suit the aims of this research study. Each of these features will now be discussed in relation to how it applies in this study. The factors under discussion are the case itself, case study protocol, context and time frame, use of multiple sources and triangulation.

3.5.3.1. The 'Case'

A case study is expected to capture the complexity of a case (Johansson, 2003) but however complex it should be easy to visualise (Stouffer, 1941). A case is a complex functioning unit which can be investigated in its natural context with a multitude of methods and it should be contemporary (Johansson, 2003). A case can be a person, or a number of people, a service, a programme or an event (Salminen et al., 2006). The 'case' in this study is the person with PDoC. This case is defined as a person who meets the diagnostic criteria and chronicity to be considered to have PDoC. The case is further identified as a person who is cared for in a non-specialist health care settings. PDoC are complex conditions with the idiosyncratic symptomatology and are found in their healthcare contexts.

3.5.3.2. Case Study Protocol

With CSM the starting point is the research question and the methodology is developed around that (Yin, 1994). CSM address the 'how' and 'why' questions in relation to a phenomenon (Yin, 2014). In experimental case studies the researcher must be able to manipulate the variables (Tate et al., 2014) and this was not possible when working with this client group. It is not possible to withhold certain treatments or intervention from a person with PDoC. Similarly it is not possible to control their care environments including their levels of interaction with family members and staff in the setting. CSM is suitable in this case as it is a previously unexplored research question and it is appropriate that the research questions be the focus and starting point in developing this research design.

3.5.3.3. Context and Time Frame

CSM is suited to situations where there are no clear boundaries between the case and the context in which it is set (Yin, 1994). It had a significant role to play in this research study as it was a clinical environment and the home for the person with PDoC. It was important that contextually relevant information was collected in order to evaluate if the intervention was effective in real world environments. The time frame for CSM is often longer than other research methodologies. This research study provided therapeutic programmes with a minimum of three months duration. This provided an extensive and in-depth exploration and was supported by this choice of methodological design.

3.5.3.4. Multiple Methods

CSM advocates the use of multiple methods in order to evaluate a phenomenon (Creswell 2009; Fisch 1998; Merriam 1998; Golby 1993). This methodology was used in this research study. Relevant case study data are likely to come from multiple and not singular sources of evidence and in this study multiple points of data collection were chosen. It was not possible to collect qualitative data from this client population and so quantitative measures were employed in order to explore clinical effectiveness of the intervention. To evaluate this therapeutic intervention from the perspective of the person’s family quantitative measures were used. Staff were assessed using a non-standardised questionnaire exploring their beliefs surrounding care of the PDoC patient before and after the programme. This questionnaire is found in Appendix I.

3.5.3.5. Triangulation

Triangulation was achieved in this research study by examining an intervention from three perspectives. People with PDoC are unable to communicate and so it is not possible to capture any qualitative information regarding their participation in the study. By evaluating people also involved in their care and were impacted by participation in the programme. In addition observation, review of medical records and video recording was used to enrich data collection.

3.5.4. The Therapeutic Programme

Complex interventions are usually described as interventions that contain several interacting components (Medical Research Council UK, 2006). An individualised therapeutic programme, if implemented appropriately, is specific to the client and their needs. In order for a programme to provide the best possible intervention it must be tailored accordingly and cannot be a blanket intervention for each research participant. This type of intervention may be described as a complex intervention, due to the varying and demanding health care needs of persons with PDoC and also because of the difficulties that arise when trying to evaluate such a programme. The main objective for each research participant was to elicit and assess their highest levels of awareness during the study. With such an intervention based programme there were a number of variables and so casual relationships were not explored. Rather, a tailored holistic programme was evaluated.

The therapeutic programme provided consisted of numerous components, each administered as clinically needed. These included seating assessment and wheelchair review, positioning, splinting and range of movement interventions, sensory stimulation, sensory desensitisation programmes, establishment and development of a therapeutic relationship with the client, building of rapport with the patient's family, referral to other specialities where appropriate, staff training, functional assessment and introduction of meaningful and engaging activity. The therapeutic programme is within the scope of occupational therapy practice (CORU 2014; Association of Occupational Therapists of Ireland 2008). These elements of the therapeutic programme were assessed before, during and after using three standardised assessments of awareness.

There is a large ethical responsibility on the clinical researcher to address the care needs of a vulnerable patient as they arise appropriately and thus each programme was tailor made to the participant. This was true also during the implementation of assessments; not all assessments are suitable for the 'case' depending on their awareness levels and medical status and once this had been established it was unethical to administer full assessments with the participant.

3.6. Introduction to Phase Two Data Collection

Different instrumentation was chosen for the participant, the family of the participant and the professional care staff caring for the participant. Each aspect of the clinical evaluation will be discussed separately in the following section.

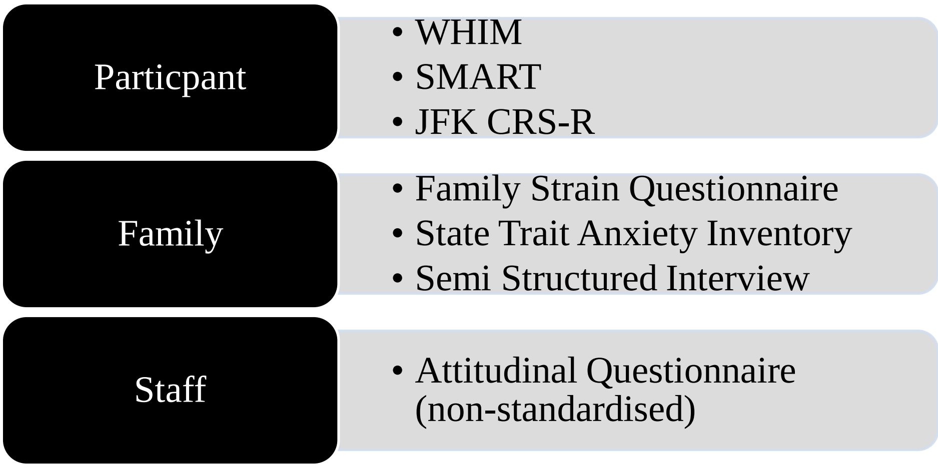

Figure 2: Summary of Instrumentation used in Phase Two of Study

3.7. The Participants

3.7.1. Sampling

Multiple case studies allow a common phenomenon to be examined with a number of people in a variety of settings. It can therefore provide much more information than the single case approach. This approach was chosen in order to explore the effectiveness of the intervention with contrasting aetiologies, care settings, ages and nature of brain injury. While it is believed that younger people with traumatic brain injuries demonstrate the best potential for rehabilitation, this needs to be explored further in long-term care. Therefore a variety of participants were chosen in order to explore the potential impact of provision of the therapy programme for a variety of people with PDoC. It was decided to obtain a diverse population sample. This is in keeping with a multiple case study design methodology where different cases can be chosen because they contrast each other. Purposive sampling with maximum variation was employed in order to survey people with a long-term DoC in a variety of settings. Variables included for examination were age, nature of brain injury, time since onset and gender. Each of these variables can play a part in rehabilitation and are important to understand when exploring the need for therapeutic intervention. Little is known about the effect of gender on brain injury rehabilitation and it was included so as to add to the literature on this topic. Five participants in total were selected reflecting three different care locations, males and females with both traumatic and non-traumatic injuries, prolonged DoC ranging from 6 to 108 months in duration and a wide age range. When using multiple case studies it is difficult to decide on the number of case studies as each case will cover a phenomenon within a particular context. Five cases were selected based on the time and resources available for this study. Their demographic information is summarised in Table 2.

Inclusion criteria were that the person had a PDoC (presenting with symptoms of DoC for more than four weeks), was receiving care in a non-specialist care environment (non-neurological rehabilitation setting), was receiving care or in the past received care under the Galway University Hospital Group and would not be transferring to a different care setting for a minimum of three months. All participants with neurodegenerative aetiologies were excluded.

Participant Number	Gender	Type of Brain Injury	Care Location	Time Since Onset	Age
1	Female	nTBI	Community Hospital	108 months	55
2	Female	TBI	Community Nursing Home	19 months	68
3	Male	TBI	Acute Hospital	6 months	23
4	Male	nTBI	Residential Care Setting	72 months	31
5	Female	nTBI	Residential Care Setting	41 months	59

Table 2: Summary of Demographics of Participants

It was hypothesised that the maximum variation within the sample would lead to contrasting results for predictable reasons, i.e. older people with longer onset since injury would have less positive results than younger people with more recent injuries. In this sense theoretical replication was applied over literal replication.

3.7.2. *Recruitment*

Participants were identified through the Galway University Hospitals Group as either currently in their care or having been discharged form their care. Participants were identified via the OT department within the hospital. The senior OT in Neurology acted as the gatekeeper, identifying suitable cases. Once identified, participants' families were approached by the researcher and provided with an information sheet (see appendix E) outlining the study and what participation would involve. If the family member that was the designated next-of-kin was agreeable they contacted the researcher and signed the consent form on their relative's behalf.

3.7.3. *Consent*

The normal process for consent in research is to provide potential participants with information regarding the research advising of the aims, purpose, benefits and risks of participation. The participant then has an opportunity to ask questions weighing up the information provided and decide whether to participate in the research without coercion or inducement. Individuals with a DoC by the very nature of their injury are unable to provide informed consent which is the cornerstone for research participation. As a result they are considered a vulnerable population who must be afforded special protections as they are unable to protect their own interests. It could be argued that they should be excluded from participating in research however to do so is to discriminate against this population as it is only by conducting research that potential advancements can be made in accurate assessment, diagnosis and ongoing treatment. It is considered ethically acceptable to conduct research on such vulnerable populations provided the research cannot be conducted on a population where consent can be obtained, that the research is likely to benefit the individual or a wider homogenous population and that risks, if any, are minimal. Such assertions are enshrined in national and international laws and guidelines such as the Declaration of Helsinki (World Medical Association, 2007) and the HSE National Consent Policy (2014). It is also asserted within the guidelines that consent should be sought from legal representatives for the individual. Until recently this has been a problematic concept within the Irish context. Until December 17th 2015 the Lunacy Regulations Act (Ireland) 1871 was the guiding legislation for decision making with respect to healthcare provision for individuals with a DoC. Where individuals were deemed to lack capacity an application could be made by interested parties to the High Court in order that the individual could be made a ward of court. A wardship committee would duly be appointed which would make day to day decisions on the wards behalf.

Consent for this study was sought from the treating healthcare providers and relevant family members. All materially relevant information was provided to interested parties in order that a decision could be made consistent with the individuals' best interests such as undertaking assessment to determine the level of awareness, if any, thereby ensuring appropriate intervention was provided without exposure to risk. It was considered that there was no risk involved in participating in the research. None of the participants had completed an advanced care statement outlining their wishes should they lack the cognitive capacity to do so in the future. Although they had not been tested before the courts and their legal position was not established it was considered that regard should be given should such a statement exist and it should be incorporated in the decision making process (Irish Medical Council 2009). Ethical approval was obtained from the research ethics committee in NUI Galway prior to the commencement of the research.

Since December 17th 2015 the Advance Decision Making (Capacity) Act 2015 was enacted, this affords legal status to advance healthcare directives ensuring that they are binding regarding future healthcare provision and decision making should the individual lose the capacity and autonomy to make such decisions at a future date. The Act also permits assisted decision making whereby a named person can assist the individual in the decision making process in instances where cognitive capacity may be compromised but not absent. A proxy decision maker may also be appointed (who has previously been identified by the individual) to make decisions on the individuals behalf having regard for the previously held wishes and beliefs of the individual. This may help to ensure that consent in the research process is consistent with international laws and guidelines.

3.7.4. Instrumentation

Three standardised neurobehavioural assessments were selected to measure behavioural responses of the participant with PDoC before, during and after the study. These were the Sensory Modality Assessment and Rehabilitation Technique (Gill-Thwaites & Munday, 2004), the Wessex Head Injury Matrix (Shiel et al., 2000) and the JFK Coma Recovery Scale Revised (Giacino et al., 2004).

3.7.4.1. Sensory Modality Assessment and Rehabilitation Technique

The SMART was developed as both an assessment and treatment tool. It is a diagnostic neurobehavioural tool to determine VS from MCS. It has demonstrated good reliability and content validity (Gill-Thwaites & Munday, 2004; Gill-Thwaites, 1997). The SMART identifies the consistency and quality of behavioural response to all sensory modalities. Using these results, the tool guides treatment plans to optimise the patient's potential. The SMART consists of a structured and regulated sensory instigation programme.

It has two separate components: formal and informal. The formal assessment takes place over three weeks and comprises a detailed sensory assessment in addition to structured behavioural observations. The informal component involves obtaining information from family, friends and carers regarding their observations of behavioural responses as well as the person's pre-morbid interests, likes and dislikes. When the assessment phase is complete these components are synthesized to create a detailed patient profile to report the level of awareness. Findings from the assessment phase guide the subsequent treatment blocks.

The SMART scoring levels range from 1 (no response) to 5 (differentiating response). For example, the lowest response seen on the SMART profile is SMART Level 1, up to the highest level, SMART Level 5 Consistent (5C). A responses in any modality between 1-3 is indicative of VS, SMART level 4 is MCS- and 5 is MCS/MCS+ dependent on the type and frequency of responses observed.

The SMART outlines optimal conditions needed for assessment clearly including nutritional status, medications, presence of infection and importance of proper positioning and rest periods. It uses standardised stimuli to elicit a behavioural response across all of the five modalities (vision, hearing, touch, taste and smell) and also explores wakefulness, functional motor movement and functional communication. The SMART provides a hierarchical categorization of behavioural responses in patients believed to be in VS or MCS. The systematic, repeated assessments over time aid in reaching a diagnostic conclusion.

SMART includes a re-assessment phase so that the outcome of treatment can be evaluated and any changes identified. The programme itself is designed not only to optimise arousal but also to provide structured opportunity for a meaningful and positive response.

3.7.4.2. Wessex Head Injury Matrix

The WHIM was designed to monitor behavioural responses of patients emerging from coma through to emergence from post-traumatic amnesia. Developed in 2000, it consists of a list of sixty two behaviours typically observed as the patient moves along the continuum of consciousness and awareness. It guides rehabilitation for patients following a brain injury. It provides a framework of responsiveness from which clinicians can set goals and manage expectations in both acute and longer-term care. The WHIM has shown good reliability and strong face validity (Majerus, van der Linden, & Shiel 2000; Shiel et al., 2000). This however is preliminary and requires further more robust examination.

The WHIM allows for systematic observations to be recorded in a regular and quick manner by all members of the multidisciplinary team and family members. It allows behaviours seen at any time and in any context to be monitored on an on-going basis. It is designed to capture and monitor a wide range of behaviours. One study has demonstrated its sensitivity in detecting subtle changes between VS and MCS (Wilson, Elder, McCrudden, & Caldwell, 2009). The behaviours are varied and include some fine grain hierarchical behaviours with more widespread behaviours so the list is not strictly hierarchical. Its strength lies in its usability by all members of the patient’s care team as it does not require additional training. It can also be used by family and friends to record their own observations. Therefore it encourages interdisciplinary working and collaboration from the initial eye opening period.

3.7.4.3. JFK Coma Recovery Scale Revised

The CRS-R is a 32 item scale designed to distinguish the VS from the MCS using different sensory modalities. It differs from the previous two assessments in the nature and administration of the sensory stimulation and so it adds another element to assessment. It also includes an assessment of neurological reflexes prior to administration. It is used widely in North America and has established good interrater and test-retest reliability (Giacino et al., 2004). It was the only neurobehavioural tool recommended for use with only minor reservations due to its strong psychometric properties (American Congress of Rehabilitation Medicine et al., 2010). It has demonstrated excellent validity (Schnakers et al., 2008; Giacino, 2004) and good reliability (Giacino, 2004). It takes approximately 30 minutes to administer the scale with a strong focus on functional physical movement. It was originally designed for use in acute and rehabilitations settings, much like the previous two scales and its applicability to the long term non-specialist setting is unknown.

3.7.5. Alternate Assessment Measures

The three assessments chosen are recommended for use by the American Congress of Rehabilitation Medicine et al. (2010) systematic review but also by the Prolonged DoC Guidelines from the RCP (2013). They are all deemed suitable and appropriate for use in long-term care and as an accurate assessment of levels of awareness. There was one further assessment recommended for use by these reviews which was considered but not included. This was the Disorder of Consciousness Scale (DOCS) (Pape et al., 2005). It was not included for three reasons; its use in previous research studies is limited, the impact and burden of use of more than three assessment scales on the participant and also due to the fact that the previous three are most commonly used in clinical practice in Western Europe (Delargy et al., 2013; RCP, 2013). Through selection of the three most commonly used assessments, this allows any results yielded form this research study to be more generalizable and comparable to previous studies.

3.7.6. Details of Data Collection

When trying to evaluate a therapeutic programme the priority must be to determine whether or not the intervention works in everyday practice. In this research project the benefits of the provision of a therapy programme are evaluated from the patient, family and staff perspectives.

In order to evaluate the effectiveness of each therapeutic programme the participants with PDOC were assessed using three commonly used standardised neurobehavioural measures. The tools selected were the SMART, the WHIM and the JFK CRS-R. Each participant was assessed using all three measures before and following the intervention programme. Additionally each participant was assessed using the WHIM each week of the intervention programme. This repeated assessment was important to capture the level of behavioural responsiveness over short periods of time. Due to the nature of PDoC, particularly MCS (where one of the diagnostic criteria is fluctuating behaviours) it is possible for this population to demonstrate a single high level behaviour which does not get repeated often or indeed ever again. Therefore limiting the testing to pre and post scores limits the research design as important behaviours demonstrated during the intervention phase may go unreported. This is a unique consideration when conducting research with people with PDoC. Pre and post scores are effective at exploring overall results of a programme, however, in this study repeated testing allowed patterns of behavours to be explored. These patterns could then be examined in terms of what stimuli, personal or environmental factors may have contributed towards expression of this behaviour. By its nature the repeated testing consisted of sensory stimulation provided in an informal and naturalistic environment which reduced any concerns surrounding habituation or over-testing of the participant.

While these standardised neurobehavioural assessments were the main methods of assessment, there were other aspects of the programme outside of standardised testing. These included staff and family involvement, observation and video.

Interventions need to be developed using the best available evidence and appropriate theory and practice.

All three neurobehavioural tools were administered with the participant in a variety of seated, standing and lying postures where appropriate. This was to allow for scoring across all three postural positions. Preference was given to sitting and standing postures as these have been demonstrated to support a higher level of behavioural responsiveness in previous studies (Wilson et al., 2013; Elliott et al., 2005).

3.7.7. Data Analysis

Descriptive statistics were conducted to summarise the data and to describe the demographic information of the participants. In addition Wilcoxon signed rank tests were used to compare pre and post test scores across the three neurobehavioural tools. Weekly evaluations of awareness levels using the WHIM were also conducted and these results were analysed using visual inspection and Wilcoxon Signed Ranks Test.

Visual inspection and analysis of graphed behavioural data is the primary method of analysis in case study methodology (Mercer & Sterling, 2012). It explores patterns of trends and variability across intervention phases (Parker, Cryer & Byrns, 2008). Simple visualisation can also help decide whether to exclude outliers (Fisch, 1998). However in this instance it must be used with caution as visual inspection is more prone to error when significant baseline trend is present (Cooper, Heron & Heward, 2007). Mathematical techniques can be implemented to reduce baseline trend, however these were not employed in this study. They were not considered appropriate due to the complexity of statistics required to address characteristics features of this single case data (Shadish, Rindskopf & Hedges, 2008).

In order to analyse the video data, time interval analysis (National Centre for Research Methods, 2012) was conducted by an independent clinician and also the principal researcher. For recorded assessments and re-assessments the video was stopped every five minutes and watched for one minute. For intervention sessions the video was stopped every twelve minutes and observed for one minute.

3.7.8. Reduction of Bias

The principal researcher in this study carried out each in-depth case study and was responsible for all data collection. This technique can potentially lead to bias. While alternative methods of data collection were considered it was not possible for another person to provide the time and skills to conduct case studies to this depth.

A number of measures were taken to reduce bias in this study. All sessions were video recorded for later analysis and to collect detailed data surrounding the individualised therapeutic programme. In addition an independent clinician with a background in neurological rehabilitation was recruited. This independent clinician conducted video analysis of all recorded sessions. This analysis was conducted blind as the independent clinician was not shown any results or completed assessment forms. Supervision with detailed feedback sessions were conducted on a regular basis with the research study supervisor. The research supervisor also carried out site visits on two occasions and conducted independent, brief assessments. The use of standardised measures also assisted in reducing bias.

3.8. Family Members

3.8.1. Method

The case study methodology allowed for both quantitative and qualitative measures to be used in evaluating the programme from the family members' perspectives. Initially it was proposed that family members would partake in semi structured interviews exploring their experience of care services to date and of the individualised therapeutic programme alongside the standardised questionnaires. Owing to resources and time the interviews were not included in the final study design.

3.8.2. Sampling

Opportunity or convenience sampling (Farrokhi & Mahmoudi-Hamidabad, 2012) was employed as all family members involved in any way in the care of the participant were asked to complete both standardised measures. Both assessments were completed without the researcher present and were returned within a two week period.

3.8.3. Recruitment

When the person with PDoC was recruited to the study all family members were asked to participate in both standardised measures. This was completed at a formal meeting prior to commencement of the research study. As many family members as possible were recruited as only those who completed the pre study measures were invited to participate in post study measures.

3.8.4. Instrumentation Measures

Attention to the health of caregivers is both an ethical duty and a strategy to reduce health and social costs (Vidotto, Rossi Ferrario, Bond, & Zotti, 2010). Two standardised assessment tools were used to evaluate both family strain and anxiety. As discussed previously levels of strain and distress are high in caregivers of people with either VS or MCS regardless of time since injury and are significantly associated with daily hours of caregiving (Giovannetti et al., 2012). Caregivers of post-acute patients report higher rates of anxiety when compared to caregivers in other care institutions (Giovannetti et al., 2012). Not every aspect of psychological well-being could be explored. Due to the high levels of strain and anxiety reported in the literature it was decided to focus on those two aspects of mental health and evaluate if the programme would have any effect in lowering their incidence. The State Trait Anxiety Inventory and the Family Strain Questionnaire were chosen as the evaluation tools for family members. Both tools have been employed in previous studies relating to caregivers of people with PDoC (Moretta et al., 2014; Giovannetti et al., 2012; Leonardi et al., 2012; Chiambretto et al., 2001).

3.8.4.1. Family Strain Questionnaire

The FSQ short form (Vidotto et al., 2010) was used in order to obtain a measure of the levels of strain each family member was currently experiencing. It is designed for families of people with chronic conditions. It is a self-report measure consisting of 44 yes/no questions. A total score, ranging from 0 to 30 is obtained with higher scores indicating a higher level of burden. The questionnaire is composed of five main areas; emotional burden, problems in social involvement, need for knowledge about the disease, satisfaction with family relationships and thoughts about death. The short form was used as the long form involves a semi-structured interview about family strain in addition to the questionnaire. It was decided not to use the long form in this study as a qualitative exploration of family burden was not a main area of investigation. It has good construct validity, internal consistency and test re-test reliability (Rossi Ferrario, Baiardi & Zotti, 2004; Rossi Ferrario, Zotti, Zaccaria, & Donner, 2001; Rossi Ferrario, Zotti, Baroni, Cavagnino, & Fornara, 2002; Rossi Ferrario, Zotti, Massara, & Nuvolone, 2003). It can be used to assess care giving-related problems across diagnoses and has been used for caregivers of people with PDoC (Chiambretto et al., 2001). It takes caregivers 10 minutes to complete the questionnaire (Vidotto et al., 2010). This measure examines the severity of stress and allows categorisation of caregivers based on psychological risk. Higher scores correlate with greater problems with the exception of Satisfaction with Family Relationships (where a higher score indicates a more positive relationship).

3.8.4.2. State-Trait Anxiety Inventory

The STAI (Spielberger, 1983) measures the tendency to a person to react to events or stimuli with high level of anxiety (trait) and their current level of tension and apprehension (state). It is a 40 item Likert scale, with responses ranging from 1 to 4. Higher scores are indicative of higher levels of anxiety. The STAI was employed as a quick measure of the anxiety levels of the families. It takes 10 minutes to administer and explores the experiences of anxiety for that person as self-reported over the last week.

3.8.5. Details of Data Collection

The pre-test questionnaires were completed prior to commencement of the study and the post-test measures were completed following the study. Copies of the questionnaires were provided to family members in person. Two weeks were allowed for their completion either side of the programme.

3.8.6. Method of Analysis

Descriptive statistics were used to summarise the data. Visual inspection of the data obtained from both questionnaires was also completed. In terms of inferential statistics, Wilcoxon Signed Ranks Tests were employed to test for differences in pre and post test scores.

3.8.7. Reduction of Bias

The questionnaire were provided to the family for completion in the absence of the researcher. This was so as to reduce any social bias and allowed each member of the family to submit their responses anonymously. The selection of two standardised measures with strong validity also helped to reduced bias.

3.9. Staff Members

3.9.1. Method

In order to explore the individualised therapeutic programme from the perspective of staff members a cross sectional methodological design was selected. This involved staff members completing a pre and post intervention questionnaire. No such questionnaire was available through the literature and so one was developed. This is detailed in Section 3.9.4. It was decided to explore what attitudes and knowledge care staff had about people with PDoC prior to and following the programme. Staff members in this research study were responsible for the provision of daily and long-term care and acted as the person's source of referral to other agencies. Therefore this perspective would identify clinically relevant information.

3.9.2. Sampling

All professional care staff involved in any way in the care of the participant were asked to complete the questionnaire pre and post study. The questionnaires were completed without the researcher present and were returned to the researcher anonymously. Staff were asked to disclose their discipline of work, e.g. physiotherapist, nurse, health care attendant, etc. The questionnaires prior to the study were all returned before the study commenced. Following the study staff members were allowed two weeks to return the questionnaire. Inclusion criteria were that the staff member had to work at the care location in which the study was taking place and have worked with the participant at least once. No exclusion criteria were set and all staff were included.

3.9.3. Recruitment

In order to recruit staff to the study the researcher sought permission from the clinical manager of each study location and asked for permission to recruit staff members to the study. The researcher then met with as many staff as possible and provided them with copies of the questionnaire. In order to survey as many staff members as possible multiple meetings were set up with groups of staff within the care setting. This was to accommodate a large number of staff, shift work and staff rotation.

In addition to the above a poster was put up in each staff room informing all staff about the upcoming study. This was accompanied by the questionnaire. A locked box was also put into the staff room into which staff members could return completed questions safely and confidentially. This was to accommodate night shift workers. It was important to recruit as many suitable staff members as possible in the pre-test as only staff members who have participated in this round of questionnaires were invited to complete post-test questionnaires.

3.9.4. Instrumentation

A staff questionnaire was developed as part of the research study. No appropriate scale could be found following a literature search and thus one was developed. The staff questionnaire consisted of open and some closed questions exploring staff beliefs and experiences surrounding disorders of consciousness.

The first section of the questionnaire explored demographic data of the participants including age, gender, care location, job description, clinical experience of working with people with PDoC and frequency of contact with the person with PDoC during working hours. The second part of the questionnaire explored knowledge, attitudes and beliefs surrounding PDoC. These questions explored the staff members' familiarity with PDoC, beliefs about level of awareness and attitudes towards rehabilitation services for people with PDoC. The second section of the questionnaire consisted of yes/no responses and tick boxes were provided for ease of completion. Common misunderstandings and myths surrounding PDoC in the public (Laureys & Boly, 2007) were used as the foundation of the questions.

Qualitative interviews were also sought with staff and this formed part of the original methodological design. However when in the field of data collection it was observed that staff did not consent to be interviewed or be recorded around the topic of caring for somebody with a PDoC.

3.9.5. *Pilot*

It was piloted during the first case study and one amendment made to it following a staff feedback session. The change made to the form was the objection by nursing staff to the question "would you consider yourself a religious and/or spiritual person?" Some staff declined to answer this question and the feedback was that it was inappropriate to ask this question as one could be making assumptions about how nurses provide care. This question was removed and is not reported on.

3.9.6. *Data Analysis*

The questionnaire provided a mixed of nominal and ordinal data. All results were inputted into SPSS. Descriptive statistics were conducted to identify the basic features of the data and allow for simple summaries to be formulated. Inferential statistics were also employed. McNemar tests were used to investigate if differences between pre and post-test measures were significant.

3.10. Ethics

There are numerous ethical factors to be considered in both the assessment and intervention stage when working with people with PDoC. In this section those issues will be highlighted and discussed. The choice of research methods in this study were selected to maintain the highest ethical standards when working with people with PDoC.

3.10.1. *Ethical Approval*

Ethical approval for both phases was granted by the NUI Galway Ethics Committee (see Appendix A and Appendix D). In phase two, ethical approval was also obtained from each individual care setting that had an ethics committee in situ. This was relevant for the care location of P1 and P3 only. Other settings did not have a formal research ethics committee in place and were agreeable to proceed with University ethical approval.

The ethical principles for medical research involving human subjects as described in the Declaration of Helsinki were adhered to at all times. This included the principal investigator being a qualified occupational therapist, risk assessments being conducted where necessary, the use of evidence based interventions (in this case the intervention was also non-invasive) and the privacy, dignity and health of the research participant was protected at all times.

3.10.2. Ethical Considerations in Methodological Approach

It is important to remember that people living with DoC are typically a non-communicative and physically disabled population. The ethical issues of a person of this nature participating in a research study such as this must be carefully considered. For this research a principalism approach which was described by Beauchamp and Childress (2009) will be used. Principalism is concerned with four ethical principles namely: autonomy, beneficence, non-maleficence and justice. Autonomy encompasses respect for the person, the right to consent to or refuse treatment and it underpins the legal principles of informed consent, confidentiality and capacity for decision making.

3.10.2.1. Beneficence

Beneficence is concerned with the duty to 'do good' and to uphold the individuals best interests at all times. It places an obligation upon the healthcare provider to balance the benefits and burdens of proposed treatments or interventions in favour of benefits for the individual at all times.

In phase one the response burden on practitioners participating in the survey must be considered. Certain consultant practitioners (particularly neurologists and neurosurgeons) may have several patients who match the criteria for either VS or MCS. Completing the survey may also involve a review of the medical file. In order to respond to this potential burden it is important to make clear the benefits of participating in the survey. This is documented in the participant information sheet at the beginning of the questionnaire. Every effort was also made to keep the questionnaire as short as possible. Short clear questions were asked with multiple choice answers in many incidences.

Should awareness be discovered during this study then there are additional ethical considerations. All must be done to ensure that this potential awareness is highlighted, that it was documented appropriately and that the person was then connected with appropriate services that can further this discovery. The family needed to be supported throughout this process also. This was done mainly through referral to psychological and support services.

3.10.2.2. Autonomy

The confidentiality of all research participants must be ensured in both phases of the study. In phase one it was made clear to participants not to include any names of patients on the questionnaire. The data, once returned, were made anonymous and stored confidentially. All paper questionnaires were stored in a locked filing cabinet on university grounds. When these raw data were computerised it was ensured to password protect this data on a computer with strong security protection. In the second phase all videos, photographs and audio recordings were backed up on an external hard drive and password protected. The hard drive, along with completed assessments and questionnaires were stored in a locked filing cabinet within the university. In keeping with NUI Galway data protection measure all data are to be stored on-site for a minimum of five years before being destroyed.

One of the main ethical considerations which must guide practice when working with PDoC is the assumption of awareness at all times. When working with this client population it is important to approach them and work with them as though they are aware of everything that is happening. This involves speaking to them in an appropriate manner, introducing the task before performing it, repeating instructions regularly to allow for possible memory impairment and also allowing time for the person to process information. This ethical consideration often excludes a more experimental approach with this population as researchers must respond to needs as they arise, e.g. allow suction and rest periods as required. It also means that the employment of standardised measures may not be always possible at set times, depending on how they can be introduced and conducted.

3.10.2.3. Non-maleficence

Non-maleficence cautions the healthcare provider explicitly to avoid undertaking actions which would deliberately cause harm to the client or to subject them to a treatment that is unduly burdensome and outweighs the benefits if indeed any exist. Its corresponding points of law are: breaches of confidentiality, medical negligence, acts and omissions and standard of care provision.

Interviews with families may evoke a multitude of emotions. While it is the person with the DoC who experienced the brain injury, the family of that person has also had a traumatic change in their lives and, as discussed in the literature review can experience a number of psychological issues. If the study or the conduction of interviews caused upset the researcher was available to talk. In addition information regarding local and national psychological services was provided.

3.10.2.4. Beneficence and non-maleficence

Assessment and intervention with the research participant should add to the quality of their care. The researcher has a responsibility not to disrupt or disturb established healthy routines for the person. For example if the client engages in an activity such as going to his/her physiotherapy appointment in the morning then the researcher should arrange not to see the person in the morning. This is the same for other therapies or services that person is receiving. As the project develops this schedule can be re-negotiated should it be deemed to be in the best interest of the participant.

3.10.2.5. Distributive Justice

Justice or distributive justice is concerned with fair distribution of scares resources or the greatest good for the greatest number. It serves to ensure fair and equitable provision of services and prevents preferential treatment and discrimination. In some settings, no therapeutic services may be available. The provision of such therapy may be limited to participation in this research project. Therefore, when the project concludes, that person may receive no further therapeutic input. Should the project have demonstrated that therapeutic intervention is beneficial then there are ethical considerations to then leaving this person with no rehabilitation service. In order to counteract this, the researcher put in place a continued therapy programme to be implemented by allied healthcare staff. Training was provided to these staff where possible. Similarly close relationships with families and participants will be developed during the research study. The conclusion of these relationships must also be dealt with carefully. This was done through good communication where the conclusion of the study was discussed regularly. Where appropriate information was provided regarding other available services in their communities.

4. Results

4.1. Results – Phase One

Phase one examined the care locations and care services for people with PDoC using a venue model approach. The main research question for this phase asks what care and therapeutic services are currently available to people with a long-term DoC in the Republic of Ireland?

4.1.1. Response rate

There was an overall response rate of 24.3%. Of a total of 417 consultants surveyed 24.7% (n=103) responded. Of a total of 568 care facilities surveyed a 24% (n=136) response rate was obtained. Positive responses accounted for 5.46% (n=31) of responses.

4.1.2. Diagnosis of Disorder of Consciousness

In total one hundred and three patients matching the criteria for either VS or MCS were identified by the respondents. Of these 48.5% (n=50) had dementia and 11.7% (n=12) had other neurodegenerative aetiologies. These diagnoses are not reported in this study as determination of states of consciousness in these populations is subjective and unclear (Volicers et al., 1997). Excluding dementia and other neurodegenerative causes, information was available for 41 people with a disorder of consciousness, 34.1% (n=14) in a vegetative state, 61% (n=25) in a minimally conscious and 4.9% (n=2) unknown. The majority of people identified (58.5%, n=24) were male. The following results are based on the 41 people and exclude those with dementia and other neurodegenerative conditions.

4.1.3. Aetiology

53.7% (n=22) of cases were of traumatic aetiology including road traffic accidents (n=4), falls (n=4), assault (n=3), suicide/parasuicide (n=2). All cases for ‘other’ aetiology were also of traumatic origin including near drowning and gunshot injury.

Non-traumatic aetiology consisted primarily of various cardiovascular injuries (46.3%, n=19). Time since onset ranged from one month to twenty-four years.

4.1.4. Care Setting

The most common care settings were full-time residential care and rehabilitation facilities each with 24.4% (n=10) of respondents. Community hospitals cared for 21.9% (n=9) of patients. Less common care settings found were acute hospitals with 17.1% (n=7) patients cared for on specialist wards and 12.2% (n=5) on non-specialist acute hospital wards. Both VS and MCS patients were found in all of the settings. Thirteen people in VS/MCS were identified by consultants in neurology (n=2), neurosurgery (n=3), geriatric medicine (n=1), orthopaedics (n=2), cardiology (n=1) and rehabilitation medicine (n=4). No person was reported by a consultant in respiratory medicine.

4.1.5. Time since Assessment

46.34% (n=19) of surveys returned contained information on re-assessment of consciousness for people with VS or MCS. This was the least frequently answered question. While 90% (n=9) of the MCS group were re-assessed within six months, 43% (n=3) of the VS group had received re-assessment within the same time period. Some respondents named the reassessment tool which was being used in the setting. These assessments included the Mini Mental State Examination, the Wessex Head Injury Matrix and the Sensory Modality Assessment and Rehabilitation Technique. Regardless of tools used, half of patients reported to be in a VS (n=3) had not been assessed in over five years.

Time Since Onset (in months)	No. of People in VS	No. of People in MCS	No. of People with undefined DoC
0-6	3	9	2
13-24	1	0	0
37-48	0	1	0
61+	3	0	0

Table 3: Time since Last Assessment of Awareness

4.1.6. Service Provision

People reported to be in a MCS were more frequently in receipt of medical and allied health services than those in VS. The most common service provided to both groups was physiotherapy with 53.7% (n=22) of the MCS and 26.8% (n=11) of the VS group receiving this intervention. 19.5% of people believed to have a disorder of consciousness were in receipt of neurology services. Neuropsychology was the least frequent intervention with only one patient in a MCS receiving it. Additional services identified included medical social work, dietetics and music therapy. The percentages of patients identified currently receiving various medical services are summarised in Table 4.2. There were no missing data in this domain.

Service	VS	MCS	Undefined DoC
Neurology	7.3% (n=3)	9.8% (n=4)	2.4% (n=1)
Occupational Therapy	17% (n=7)	39% (n=16)	0%
Physiotherapy	26.8% (n=11)	53.7% (n=22)	4.9% (n=2)
Speech and Language Therapy	7.3% (n=3)	39% (n=16)	0%
Neuropsychology	0%	2.4% (n=1)	0%
Additional Services	4.9% (n=2)	12.2% (n=5)	2.4% (n=1)

Table 4: Percentage of People with PDOC Receiving Medical and Therapeutic Services

4.2. Overview of Results from Phase Two

This section will begin by reporting demographic information on participants. Grouped results for all five participants are then reported, followed by analysis of each individual case study. The results of quantitative questionnaire measures with both family member and staff are then described. Finally the results pertaining to each of the proposed research questions will be outlined.

4.3. The Participants – Group Results

4.3.1. Demographics

Participant demographics are outlined in Table 1. Participants were three females and two males. Four had a formal diagnosis of either VS or MCS. Medical consensus agreed that P3 had a disorder of consciousness; however he was awaiting formal assessment by a specialist rehabilitation team. The participants ranged in age from 23-68 years with a mean age of 47 years. The duration of their disorder of consciousness ranged from 6 months to 9 years. Three of the participants had a non-traumatic aetiology and they were cared for in a variety of care settings all within the West of Ireland.

All participants were recruited through Galway University Hospitals Group either as a current inpatient or having been discharged with a diagnosis of DoC.

Participant Number	Gender	Type of Brain Injury	Care Location	Time Since Onset	Age
1	Female	nTBI	Community Hospital	108 months	55
2	Female	TBI	Community Nursing Home	19 months	68
3	Male	TBI	Acute Hospital	6 months	23
4	Male	nTBI	Residential Care Setting	72 months	31
5	Female	nTBI	Residential Care Setting	41 months	59

Table 5: Demographics of Research Participants

4.3.2. Standardised Behavioural Assessment – Group Results

This section presents a brief overview of the five participants' scores on standardised neuro behavioural tools pre and post intervention. A detailed account of scoring and individual assessment performance is provided under each case study profile.

4.3.2.1. *Coma Recovery Scale-Revised (CRS-R) - Group Results*

All five participants completed the CRS-R during the assessment period and again during the re-assessment period of the research study. All participants' scores improved on this scale following the individualised therapeutic programme except for P4 whose scores remained the same.

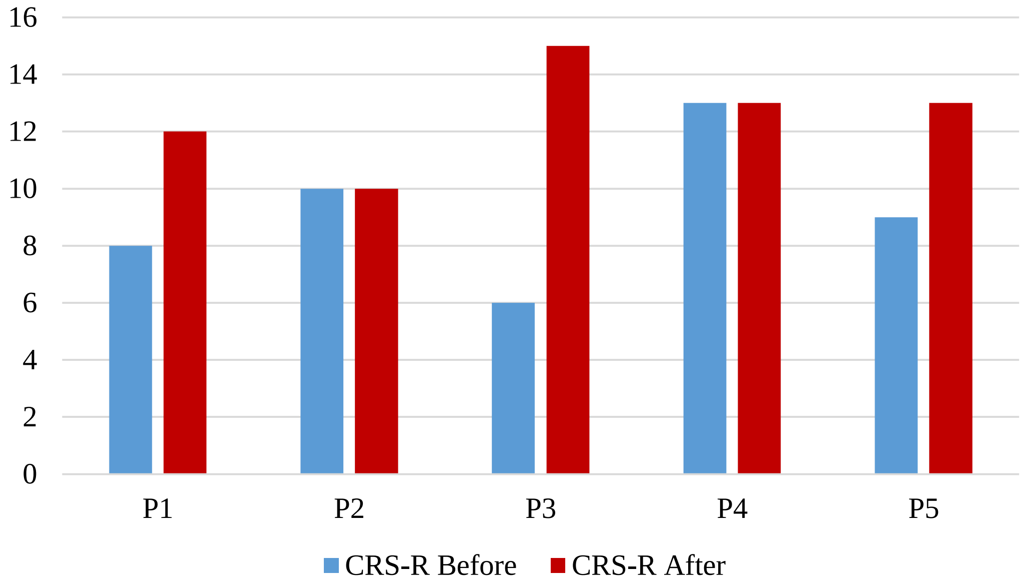

Figure 3: Summary of Total Scores on CRS-R Before and After Intervention

4.3.2.2. *Wessex Head Injury Matrix (WHIM) – Group Results*

Four of the five participants had a higher score on both the highest ranked behaviour and the total number of behaviours as measured by the WHIM following intervention. P4 scores remained the same on both of these scales.

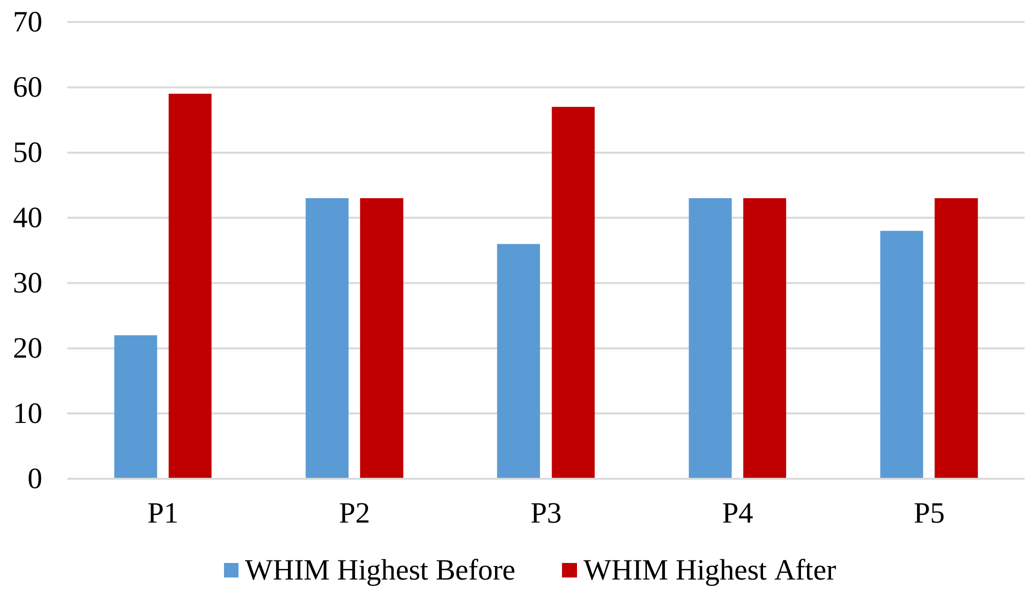

Figure 4: Highest Ranked Score on the WHIM Before and After Intervention

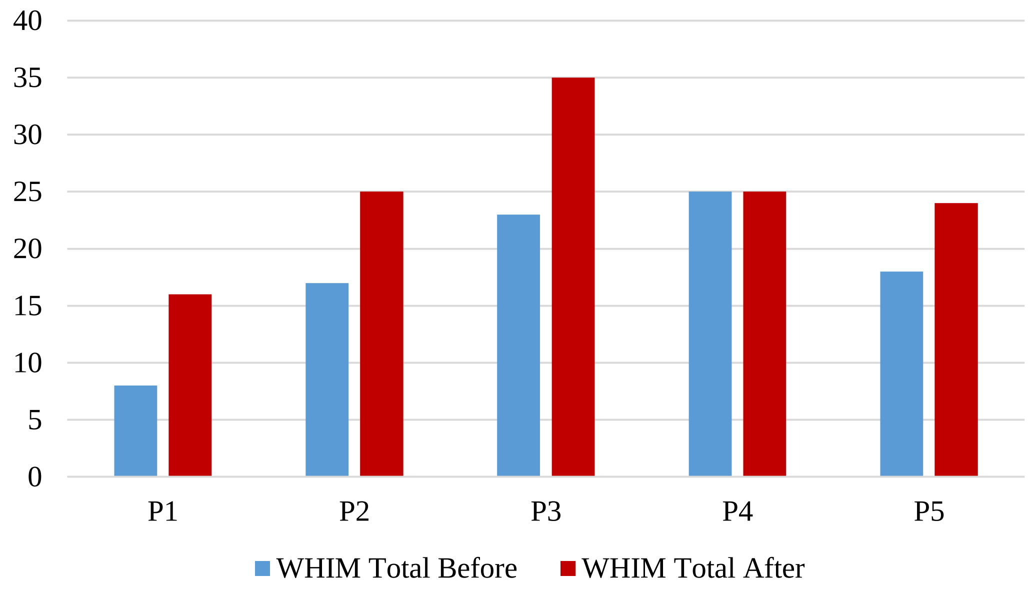

Figure 5: Total Number of Behaviours on WHIM Before and After Intervention

The WHIM was also used to monitor progress throughout the intervention phase. The initial intervention phase was 12 weeks duration. Both P1 and P3 had a longer intervention period owing to the exploration of functional communication and the implementation of a standing study respectively. This will be discussed further during the individual case results.

4.3.2.3. Sensory Modality Assessment and Rehabilitation Technique – Group Results

The SMART does not provide total scores. During the assessment phase it was not possible to complete the SMART assessment with P3 and P5. The remaining 3 participants demonstrated behavioural signs of MCS on this assessment measure during this assessment phase. During re-assessment it was not possible to complete this assessment with P1, P3 or P5. P2 and P5 continued to demonstrate behaviours indicative of the MCS during re-assessment.

	SMART Level (before)	SMART Level (after)
P1	Behavioural signs of MCS	Could not re-assess Consistent functional yes/no
P2	Behavioural Signs of MCS	Behavioural signs of MCS
P3	Could Not Complete	Could Not Complete
P4	Behavioural Signs of MCS	Behavioural Signs of MCS
P5	Could Not Complete	Could Not Complete

Table 6: Level of Behaviours Observed on SMART Before and After Intervention

4.3.3. Diagnostic Criteria Recorded – Group Results

Four of the five participants had received a formal diagnosis. Where no formal diagnosis had been made medical consensus agreed if behaviours were indicative of a certain state. During assessment, intervention and follow up new behaviours were observed and recorded. While the assessment provided as part of this research study does not constitute a formal MDT specialist assessment as recommended it did highlight behaviours which indicated misdiagnosis. This was the case for four participants.

	Diagnosis	State of awareness as indicated by behaviours observed and recorded
Participant 1	PVS	Emerged MCS
Participant 2	MCS-	Emerged MCS
Participant 3	?MCS	MCS+/Emerged MCS
Participant 4	MCS	?Emerged MCS
Participant 5	MCS+	MCS+

Table 7: States of Consciousness Demonstrated Before and After Study

4.3.4. Changes to Clinical Care – Group Results

A number of changes to the participants' clinical care and care environment following the research study were also recorded. While these were difficult to quantify these adaptations were recorded and noted by both family and staff. It is suggested that these changes will have a positive therapeutic impact for the participants and will contribute to providing an optimum environment for recovery. These included changes to medication regimes, seating and positioning systems, range of movement interventions, increased access and referrals to other disciplines, changes to sensory environment and an enhanced daily routine. An enhanced daily routine is defined as that which has an increased number of activities or occupations in it suitable to the person's needs.

	P1	P2	P3	P4	P5
Medication	X				
Seating and Pressure Care Issues	X	X			
Range of Movement/Splinting		X	X	X	X
Increased Access to other Therapies	X	X	X		
Sensory Environment	X	X	X	X	X
Enhanced Daily Routine	X	X	X	X	X

Table 8: Summary of Changes to Clinical Care for Participants

4.4. Case Studies – An Overview

In this section each of the participants will be discussed individually. Each description will begin with a participant profile detailing demographic information and baseline functional status. A detailed description of their assessment, intervention and re-assessment during the study is then provided. P1 and P2 have additional information surrounding additional interventions they received as part of the study. These were a detailed exploration of functional communication and an intensive standing study respectively.

4.5. Participant 1

4.5.1. Participant Profile

Background Information	• 55 year old woman • 9 years post ictus • Hypoxic, non-traumatic brain injury
Diagnosis	• PVS
Family	• Informed of diagnosis • One family member involved
Care Location	• Acute Hospital (9 years) • ICU followed by General Medical Ward • Community Hospital (6 months)
Specialist Assessment and Rehabilitation	• None
Nutritional Status	• 1,000kcal per day (Jevity Plus) • PEG Fed
Respiratory Status	• Tracheostomy in situ • Required frequent suctioning
Sensory Status	• Sensitive (grimacing) to loud or sudden auditory stimuli
Cognitive Status	• PVS
Physical Status – Passive Range of Movement (in degrees)	**Right** **Left** **SHOULDER** Flexion 20 20 Abduction. 10 0-10 Internal Rotation 30 20 External Rotation. 5 Extension. 5-10 5-10 **ELBOW** **Right** **Left** Elbow flexion Held in tight flexion bilaterally Extension. 80. -95

	WRIST		
	Wrist Flexion	Fixed Bilaterally	
	KNEE		
	Flexion		
	Extension	90	90
	ANKLE		
	Plantar Flexion	25	30
	FOOT		
	Inversion	30	30-35

Table 9: Summary of P1's Clinical Profile

4.5.2. Daily Routine

Prior to the commencement of the study P1 spent the majority of the day in bed. This information was obtained from care staff and also her medical records. She was not seated out of bed every day. On days where she was seated out into her wheelchair this was for a maximum of 3 hours. She spent every day in her room where she was provided with auditory stimulation, mainly music and the radio. She did not leave her room due to health and safety concerns -her respiratory status required her to have frequent suctioning and this machine had to be accessible for the staff at all times, however P1's suctioning machine was fixed to the wall in her bedroom. Her interests were reported by her husband to be country music and getting her hair done. These reported preferences were found in her medical chart and were documented on after her initial injury. She was reported by staff to dislike loud noises.

4.5.3. Therapeutic Services

From a review of her medical records it was found that while in acute care P1 was seen by dietetic, occupational, speech and language and physiotherapy services for seating, pressure care and her feeding needs. This was on a needs basis only and for short duration.

In the community hospital she received physiotherapy three times a week for passive stretching exercises. This programme was delivered by the physiotherapy assistant who had a good relationship with participant one. No other therapeutic services were involved in her care at this time.

4.5.4. Assessment

The assessment period for P1 took place over 5 weeks. She was initially assessed with the WHIM and CRS-R followed by the 3 week SMART assessment.

4.5.4.1. Pre-Assessment Intervention

The SMART protocol of putting in place optimum conditions for assessment, reducing all physical, medical and environmental factors which may impact participation in the assessments was adhered to. Before commencing the formal evaluation of care needs P1 was referred to physiotherapy for a review of her total range of movement and current status. A referral was also sent to the dietician to review her daily calorific intake. Following these assessments it was decided that no further dietetic or physiotherapy intervention was required. As part of the research study P1 was provided with a palm protector so as to maintain current limited extension in her hands and to increase comfort. This is shown in photograph 1. She was also provided with a T roll for her knees to gently encourage flexion, to support her current range of movement and allow her to lie more comfortably. Her wheelchair was also adjusted to improve seating posture.

Photograph 1*: P1's Palm Protectors Maintaining Range of Movement*

4.5.4.2. Standardised Assessment

The assessment period was broken down as follows;

Week 1: WHIM completed on 5 occasions – highest scoring assessment reported

- Highest Score 22/62 (tracks a source of sound)
- Total number of behaviours 8/62

Week 2: The CRS-R was completed on 3 occasions in this week. The highest score obtained by P1 was 8/23 broken down as follows;

  - Auditory function scale – 2 (localisation to sound)
  - Visual function scale – 1 (visual startle)
  - Motor function scale – 2 (flexion withdrawal)
  - Oromotor/verbal function – 1 (oral reflexive movement)
  - Communication Scale – 0 (None)
  - Arousal Scale – 2 (eye opening w/o stimulation)

Weeks 3-5: 10 SMART assessments completed

- Behavioural signs of MCS
- Highest Response - Level 4 localising response (in both auditory and olfactory subscales)

Modality	Type of Response	P1's Highest Level of Response
VISUAL	No Response	No response to light or threat
	Reflex Response	
	Withdrawal Response	
	Localising Response	
	Differentiating Response	
AUDTORY	No Response	
	Reflex Response	
	Withdrawal Response	
	Localising Response	Turned head towards voice
	Differentiating Response	No response seen with AF buzzer switch at head
TACTILE	No Response	
	Reflex Response	
	Withdrawal Response	Withdrawal of head from feather stimulus

	Localising Response	
	Differentiating Response	
OLFACTORY	No Response	
	Reflex Response	
	Withdrawal Response	
	Localising Response	Movement of head towards coffee smell
	Differentiating Response	
GUSTATORY	No Response	Unable to complete this modality
	Reflex Response	
	Withdrawal Response	
	Localising Response	
	Differentiating Response	
MOTOR FUNCTION	No Response	
	Primitive Reflexive Response	
	Non-Purposeful Spontaneous Movement or Withdrawal Response	Withdrawal response, spontaneous movement at head seen during observation
	Inconsistent Purposeful movement	
	Consistent Purposeful Response	
FUNCTIONAL COMMUNICATION	No Response	
	Non-specific Response	No specific or regular response
	Specific Response	
	Inconsistent Communication	
	Consistent Communication	
WAKEFULNESS/ AROUSAL	Unarousable	
	Minimal Arousal Level	
	Medium Arousal Level	
	Minimal Prompts Required	
	Optimum Arousal Level	Maintained wakefulness for the majority of assessment sessions

Table 10: P1's Response on SMART during Assessment and Re-assessment

4.5.5. Intervention

Each intervention was individually designed and was grounded by the available evidence base. The different aspects of intervention were implemented simultaneously and thus it was not possible to individually evaluate each aspect. As the study progressed suitable alternative and novel interventions were also trialled. These will be described in this section.

Type of Intervention	
Sensory	
Establishment of a Controlled Sensory Stimulation Environment	YES
Desensitisation Programme	
Physical	
Biomechanical Interventions (seating, splinting, prevention of further contractures, maintaining range of movement)	YES
Standing Position	UNABLE
Communication	
Additional Exploration of Functional Communication	YES
Novel Stimuli	
Video Analysis	YES
Building Therapeutic Rapport	YES
Standardised Behavioural Assessment	YES
FORMAL PSYCHO-EDUCATION	
Family Education	
Staff Education	INFORMAL

Table 11: Types of Intervention Trialled with P1

4.5.5.1. Controlled Sensory Environment

The first aspect of the intervention phase was the establishment of a controlled stimulation environment for P1. This involved establishing a balanced daily routine involving increased interaction and sensory input. This daily schedule was placed in the room on a small whiteboard and all staff were educated on its use. A multi modal stimulation timetable was developed to meet P1 own interests and needs. The daily timetable involved outlining the different types of stimulation to be introduced at different times throughout the day. Rest periods were also incorporated into the timetable. Tactile, olfactory and auditory sensory stimulation were the main modalities used. Sensory stimulation was provided for 15 minutes at a time followed by a 20 minute rest period. The timing was selected following observing P1's endurance and fatigue during the assessment phase. The sensory environment was monitored throughout the research project and amended according to P1's need. There were also at least three breaks between sensory stimulation periods each lasting at least two hours. Sensory stimulation was varied so as to avoid habituation. An extract from the daily timetable is provided below;

Time	Sensory Modality	Possible Activities (choose one)
10-10.15am	Tactile	Massage, feathers, tactile balls, box of rice, water bath, box of sand, 'slime'
10.15- 10.35am	Rest Period	None
10.35- 10.50am	Olfactory	Scented Candle, scented oils, toiletries, flowers
10.50-11.10am	Rest Period	None
11.10-11.25	Visual	Lava lamps, magazines, picture book, projector, fibre optics, positioning her to look out of the window, family photographs, newspapers

Table 12: Extract from P1's Controlled Stimulation Daily Timetable

4.5.5.2. Seating

A number of care staff reported a lack of confidence around seating. Service providers of her current wheelchair were invited to come to the care setting and provide a brief in-service training for all staff regarding all the mechanisms of the chair. While there they also demonstrated how to sit P1 out into the chair appropriately and assessed her for a new lap-tray. While the provision of the in-service training was not formally evaluated, informal feedback from staff revealed that they found it useful and more staff reported increased confidence around seating out P1.

4.5.5.3. Audio Feedback (AF) Buzzer Switch

During the assessment phase P1 demonstrated inconsistency pressing an AF buzzer switch in the SMART. It was decided to explore this ability further in the intervention phase. The switch was trialled with the voluntary movement she had with her head, whereby she would use the small amount of movement she had at her head to press the switch which was held in an appropriate position by the researcher. As she appeared to be very sensitive to certain auditory stimulation, particularly loud noises and when trialling this with her head she would often grimace and groan to the noise. On a few occasions she did press the buzzer to command 2/5 or 3/5 times. This was not enough to fulfil the scoring requirements to meet consistency but did highlight potential ability that needed further exploration.

During the intervention phase P1 was also referred to a neuropsychologist. The neuropsychologist found increased consistency with the same AF buzzer switch when using the limited movement at P1's right hand. This had not been seen using her head, her shoulders or her lower limbs. It was later established that P1 could press the switch using her right hand to command on 5/5 occasions. This was the required level of consistency needed in order to explore her functional communication further according to the SMART.

4.5.5.4. Standardised Behavioural Measurement

During the intervention phase P1 was assessed using the WHIM on a weekly basis. The assessment itself also provided a source of sensory stimulation to P1. It was found that during the initial weeks of intervention P1's scores were increasing slightly on the WHIM. Once a consistent yes/no response was found her scores increased to the higher end of the scale as she was demonstrating functional communication. P1's WHIM scores during intervention are reported in Figures 6 and 7.

4.5.6. Re-assessment

The re-assessment phase took place over 3 weeks. The WHIM was conducted on three occasions over the first two weeks and the CRS-R was completed once in the third and final week. The highest re-assessment scores obtained are reported. Using the AF buzzer switch to communicate yes/no P1 demonstrated improved scoring in both the WHIM and the CRS-R. Scoring during the re-assessment period were as follows;

4.5.6.1. WHIM Re-Assessment

During re-assessment scores on the WHIM were as follows;

- 59/62 (3-5 orientation items correct)
- Total number of behaviours 16/62

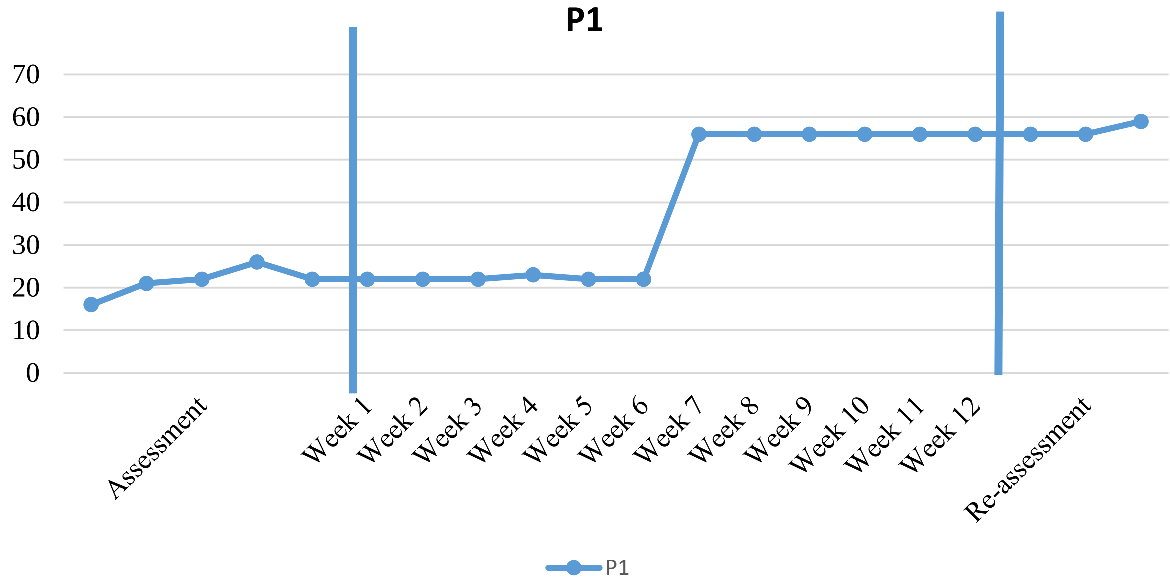

Figure 6: P1's Highest Scores on WHIM during Assessment, Intervention and Re-assessment

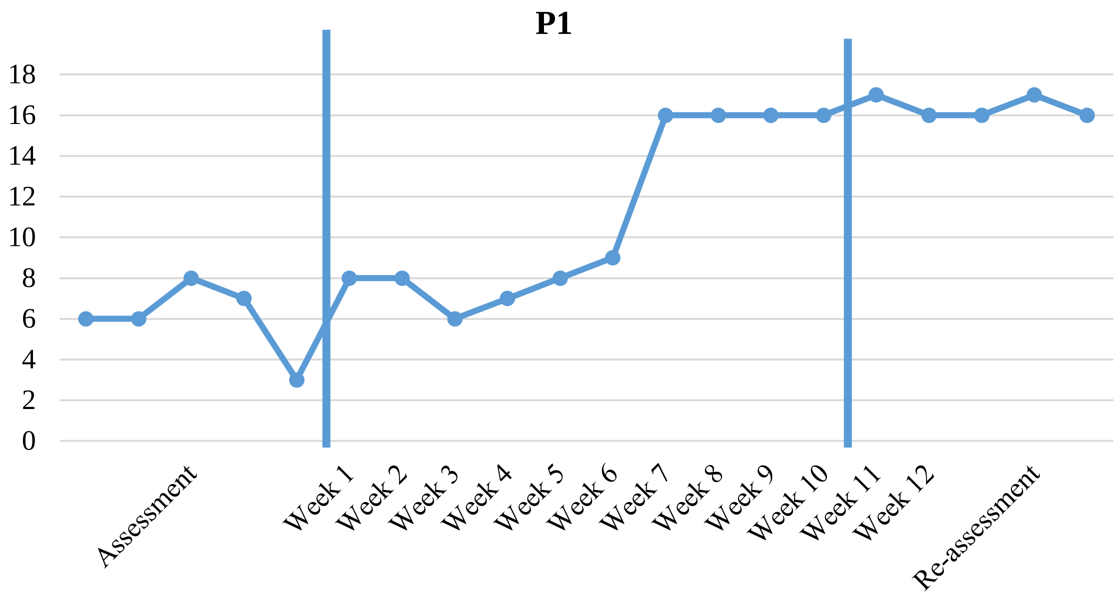

Figure 7: P1's Total Number of Behaviours on WHIM during Assessment, Intervention and Re-assessment

4.5.6.2. SMART Re-Assessment

The SMART assessment was not re-administered as functional communication had been established. As stated in the methodology chapter the SMART assessment is a diagnostic tool and thus it would be unethical for a person who is demonstrating higher levels of awareness to undergo this assessment again for the sole purpose of data collection.

4.5.6.3. CRS-R Re-Assessment

The CRS-R was completed once in the final week of the study. P1 obtained a total score of 12/23 during re-assessment.

CRS-R Total Scores Before	CRS-R Total Scores After
Total score 8/23 • Auditory function scale – 2 (localisation to sound) • Visual function scale – 1 (visual startle) • Motor function scale – 2 (flexion withdrawal) • Oromotor/verbal function – 1 (oral reflexive movement) • Communication Scale – 0 (None) • Arousal Scale – 2 (eye opening w/o stimulation)	Total score 12/23 • Auditory function scale – 4 (consistent movement to command) • Visual function scale – 1 (visual startle) • Motor function scale – 2 (flexion withdrawal) • Oromotor/verbal function – 1 (oral reflexive movement) • Communication Scale – 2 (functional: accurate) • Arousal Scale – 2 (eye opening w/o stimulation)

Table 13: P1's Scores on CRS-R Before and After Study

4.5.6.4. *Summary of Standardised Re-Assessment Scales*

Differences in scoring between the assessment and re-assessment periods are highlighted in Figure 8 below.

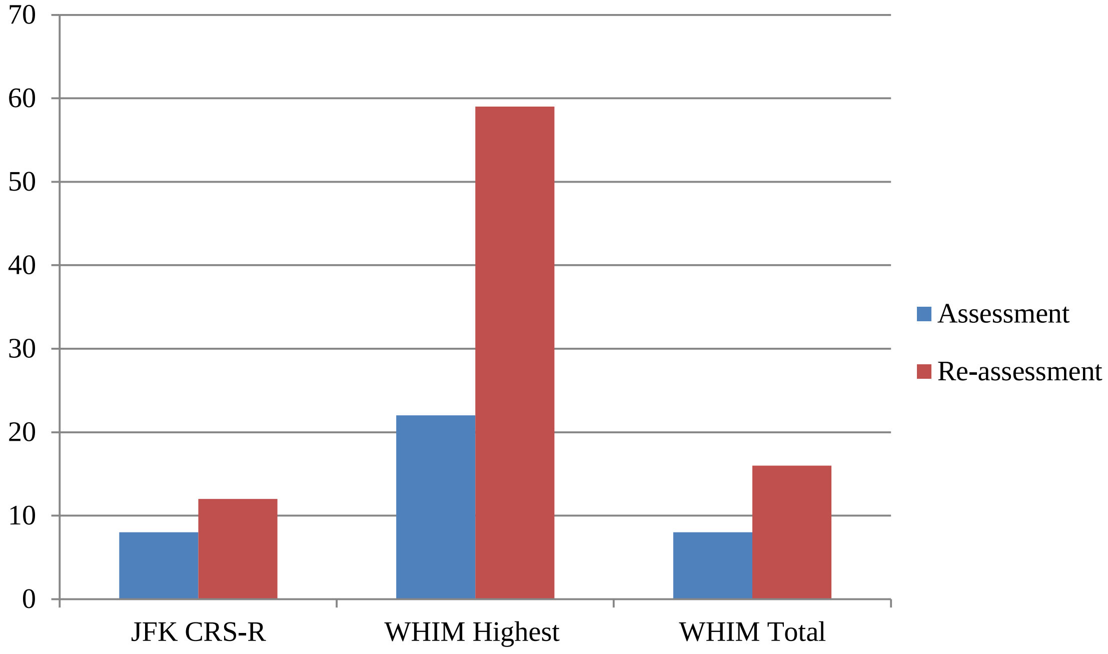

Figure 8: P1's Summary of Assessment Scores Before and After Study

4.5.6.5. *Non Standardised Results*

One of the main results for P1 was her increased autonomy and involvement in her daily care. This will be highlighted further in the following section.
Following the study a number of changes to P1's daily routine were observed. It was found that P1 had increased amounts of sensory stimulation but in a controlled manner. P1 was also seated out every day following the study. With the purchase of a portable suctioning machine P1 was also able to attend the day room and the sensory garden.

Increased family involvement was observed also. Prior to the study one family member visited P1. Following the study the number of family members involved had increased to 4. P1 was able to report that this was important to her. Following a re-referral to the dietician P1 dietary intake was also increased by 250kcal daily.

4.5.7. Additional Intervention: Exploration of Functional Communication

Consistent yes/no responses via an AF buzzer switch were obtained using the knuckles of P1's right hand. The following are the findings in terms her functional communication.

4.5.7.1. Reliability/Switch consistency

At the beginning of each functional communication session consistency with the switch was established by P1 correctly answering seven reliability questions correctly;

1. Press the switch with your right hand
2. Press the switch once
3. Press the switch twice
4. Press the switch once for yes
5. Press the switch twice for no
6. Is your name ______? Yes
7. Is your name Mary? No

- Sessions with the switch were kept to no more than twenty minutes at a time due to P1 falling asleep or ceasing to press the switch.
- There were three sessions in which consistency could not be established. This coincided with the introduction of the drug Buscopan to help alleviate her increased salivations; however this may be coincidental. Interestingly however, as the Buscopan was reduced her responses became more consistent but this is in no way conclusive.
- Once consistency was established it was important that P1's autonomy and choices were respected. On occasion she reported that she did not want to partake in therapy and this was respected.

4.5.7.2. Comprehension

- Non-biographical questions from the Putney Auditory Comprehension Screening Tool (PACST) (Beaumont e al., 2002) were administered. Participant one scored 32/42 on this assessment over multiple sessions. Questions on this scale require yes/no answers and examples include: “are baby cats called kittens?”, “is Paris the capital of Spain?”, “is art creative?”, “is cheese made from flour?”, etc.

- Biographical questions: Participant one correctly answered basic biographical questions including her name, husband’s name and brother’s name.

- Blind Questions: Five blind questions with three multiple choice answers were asked of P1. These questions were compiled from information from P1’s medical notes. On this occasion participant one correctly answered four out of five questions. She answered one incorrectly but it transpired that this question was incorrectly phrased. Building on this P1’s brother sent five more blind questions to administer. These questions had three multiple choice answers and asked her questions about her address growing up, her mother and father’s name, her childhood friend’s name and an amenity that they grew up beside. Her brother reported that she only scored 2/5 on these questions. When these questions were repeated her scores did not improve significantly.

4.5.7.3. Insight

- Using the switch P1’s understanding and insight was explored. She answered the following questions consistently over three sessions with these responses: “Can you fly?” No / “Can you walk?” No / “Can you hear me?” Yes / “Can you run?” No / “Do the nurses do your hair?” Yes / “Are you able to do your hair yourself?” No / “Can you see?” No

- When asked does she know what has happened to her she also responded yes.

- P1 also reported on three occasions that she cannot see. She was put on the waiting list for further eye examinations with an ophthalmologist.

4.5.7.4. Orientation & Environmental Awareness

- P1 can correctly identify when she is sitting in a chair and when she is in bed. She has also correctly indicated the location of the hospital. She also correctly answered six questions relating to situational orientation from the JFK Coma Recovery Scale Revised, e.g. am I clapping?

- P1 can answer questions relating to orientation when provided with a choice of three answers. Initially she reported that it had been five years since her accident and she was unsure of the year. When told that the year was 2013 P1 demonstrated some signs of agitation and cried. On the last two occasions participant one correctly identified the year from a choice of three.

- On one occasion she identified a pain in her left arm and upon further inspection her left arm was over the side of the chair and pushed against a rough surface. This was not immediately visible as her arm was under a blanket.

4.5.7.5. Memory and Learning

- She has also demonstrated ability to remember things told to her for up to one hour. When asked to remember something overnight she was unable to do so on two occasions.

- She showed ability to answer simple mathematical questions on one occasion (4-1, 2+2, 3+1, etc.). To answer these questions she pressed the switch the correct number of times.

4.5.7.6. Affect

- During one session P1's affect was further explored. She reported she feels sad some of the time but not all the time. She also reported she was happy sometimes. When asked did she feel angry or afraid she responded no. Her affect could only be explored in one session.

4.5.7.7. Alphabet Scanning

- To encourage participant one to express feelings and words the alphabet was recited slowly and she was instructed to stop at a letter that she wanted by pressing the switch when that letter was said. This was unsuccessful on six trials over three sessions. She was unable to spell out basic words (cat, dog, egg) when provided with the spelling using this method.

4.5.8. Follow Up

Following the discovery of functional communication the researcher participated in a lengthy follow up and handover to ensure that P1 received appropriate therapeutic services and further exploration of her ability to communicate.

In-service training surrounding use of the switch was provided to key care workers so that they could take responsibility for asking her questions using the switch. It was important to regulate the use of the switch so as to avoid overstimulation and also incorrect usage by non-trained staff. This is currently still in use in the setting.

Before the programme ended a multi-disciplinary team meeting was called to guide handover of care following the study. P1's consultant and the clinical nurse manager on site agreed to take responsibility for managing her new care needs and need for further rehabilitation. It was decided that participant one would be referred to a specialist rehabilitation setting in order to explore assistive communication technology. It was also agreed that with a portable suctioning machine, P1 would be brought outside into the garden more and also go to the dayroom more for art classes, music, etc., if she was agreeable. It was also agreed that her established controlled sensory environment would remain and be implemented daily.

4.6. Participant Two

4.6.1. Participant Profile

Background Information	• 23 year old male • 6 months post ictus • TBI following an assault
Diagnosis	• No formal diagnosis
Family	• Supportive family • Daily involvement in his care
Care Location	• Initially presented in the local ICU department (regional hospital) • Transferred to neurosurgical unit in different hospital where he underwent a craniotomy • Transferred back to HDU department in local regional hospital • Currently cared for in a general medical ward under the care of a Consultant general surgeon. • Awaiting a bed at a specialist rehabilitation centre
Specialist Assessment and Rehabilitation	• None
Nutritional Status	• 3250kcals per day (Jevity Plus) • Fed vis PEG tube
Respiratory Status	• Tracheostomy in situ • Required frequent suctioning
Sensory Status	• No known issues
Cognitive Status	• Unknown
Physical Status	• No contractures • High tone in upper limbs bilaterally – daily passive stretching administered • Received botulinum toxin injections and serial casting to maintain full range of movement in left elbow joint

Table 14: Summary of P2's Clinical Profile

4.6.2. Daily Routine

As reported by staff and documented in the medical chart P2 was seated out once every day. He only left his room to attend physiotherapy downstairs in the physiotherapy department. His main source of stimulation was auditory stimulation. He slept a lot during the day and the TV and radio were his main sources of stimulation.

4.6.3. Therapeutic Services

P2 received OT and physiotherapy to meet his biomechanical and positioning needs including seating, range of movement exercises and serial casting. Due to resources and time constraints therapeutic input was limited to once a week, apart from chest physiotherapy which was daily. A designated nurse cared for him 24 hours a day. These nurses were present to manage his craniotomy and tracheostomy needs as he was on a standard medical ward.

4.6.4. Assessment

4.6.4.1. Pre-Assessment Intervention

No pre-assessment intervention was provided to P2. His seating, physical and nutritional needs were provided.

4.6.4.2. Standardised Assessment

The assessment period was broken down as follows;

Week 1: JFK completed on 3 occasions. His highest score during the assessment phase was 10/23 broken down as follows;

- Auditory function scale – 2 (localisation to sound)
- Visual function scale – 2 (visual startle)
- Motor function scale – 2 (flexion withdrawal)
- Oromotor/verbal function – 1 (oral reflexive movement)
- Communication Scale – 0 (None)
- Arousal Scale – 3 (eye opening w/o stimulation)

Week 2: WHIM completed on 5 occasions – highest scoring assessment as follows;

- Total Score – 43/62
- Total Number of Behaviours – 17/62

Weeks 3-5: 10 SMART assessments completed (more detailed information provided in re-assessment section)

- Behavioural signs of MCS
- Level 4 localising response – auditory and olfactory
- During assessment P2 demonstrated behaviours indicative of a minimally conscious state during this time such as a delayed response to verbal and written instruction, demonstrating preference for particular staff, and localising to auditory stimulation (both liked and disliked music).

4.6.5. Intervention

A nine week intervention period was provided to P2. Interventions were based on the SMART protocol whereby exploration of functional communication and auditory differentiation were focused on. This was because P2 had demonstrated potential with these sensory instigation techniques during assessment.

Type of Intervention	
SENSORY	
Establishment of a Controlled Sensory Stimulation Environment	YES
Desensitisation Programme	
PHYSICAL	
Biomechanical Interventions(seating, splinting, prevention of further contractures, maintaining range of movement)	
Standing Position	YES
COMMUNICATION	
Additional Exploration of Functional Communication	YES
Novel Stimuli	
Video Analysis	YES
Building Therapeutic Rapport	YES
Standardised Behavioural Assessment	YES
FORMAL PSYCHO-EDUCATION	
Family Education	Informal/limited
Staff Education	None

Table 15: Types of Intervention Trialled with P2

4.6.5.1. Controlled Sensory Environment

A controlled sensory environment was established for P2. This was similar to P1's daily timetable. P2 had greater endurance and so sensory input was provided for 30 minutes at a time followed by a rest period of 20 minutes. The layout of his bedroom was changed so as to avoid overstimulation and the number of items hanging on his wall and around his bed (e.g. cards, photos) was also reduced, to control the amount of visual stimulation. Prolonged use of the radio or people talking for prolonged periods in his room was also reduced.

4.6.5.2. AF Buzzer Switch

Exploration of P2's ability to press the AF buzzer switch to command was completed during the intervention phase. P2 was observed to answer 4/5 blind autobiographical questions correctly using this switch. He demonstrated this by selected the correct response from a choice of three. He correctly identified his name, place of birth, mother's name, his age and his football club from a choice of three each time. He continued to use the switch during sessions for a period of about 3 weeks. Then, towards the end of the intervention phase, he no longer demonstrated any consistency with the switch. There was no change to his medication, diet, bowels, pain management, positioning, medical status or daily routine during this time.

4.6.5.3. Standardised Behavioural Measurement

The WHIM assessment was completed weekly during the intervention phase. A summary of the highest scoring behaviours and highest number of behaviours are summarised in Figures 9 and 10.

4.6.6. Re-Assessment

P2 was re-assessed using the WHIM, JFR-CRS-R and the SMART. Due to his plateau in rehabilitation it was decided, following re-assessment, to complete an additional standing programme with P2 in collaboration with two physiotherapists. This will be discussed in the next section.

4.6.6.1. WHIM Re-Assessment

The WHIM was completed on three occasions during the re-assessment phase. The highest total score and highest number of recorded behaviours were as follows;

- Total Score – 43/62
- Total Number of Behaviours – 25/62

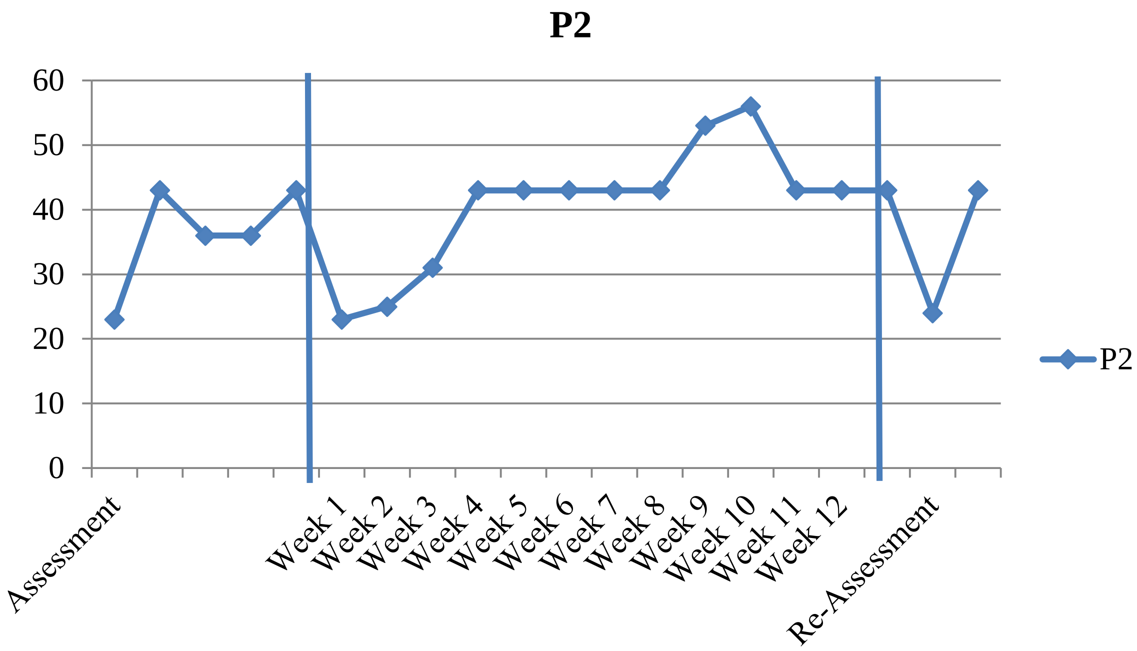

Figure 9: P2's Highest WHIM Scores during Assessment, Intervention and Re-Assessment

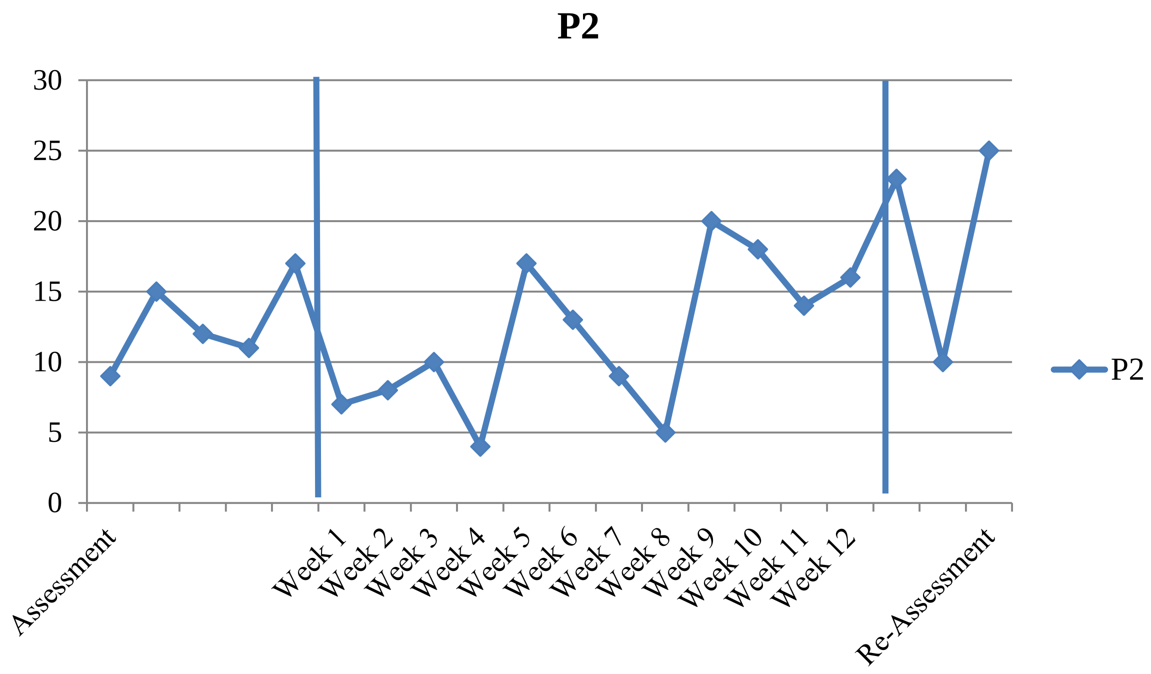

Figure 10: P2's Total Number of Behaviours on WHIM during Assessment, Intervention and Re-Assessment

4.6.6.2. SMART Re-Assessment

The SMART was also re-administered over a three week period in the re-assessment phase. Results obtained included;

- Behavioural signs of MCS
- Level 4 localising response – auditory and olfactory
- During re-assessment P2 demonstrated behaviours indicative of a minimally conscious state during this time such as localising to auditory stimulation (music he disliked).

The SMART results from the assessment and re-assessment phases are summarised in the following table;

Modality	Type of Response	P2 Highest Level of Response Before	P2 Highest Level of Response After
VISUAL	No Response		
	Reflex Response		
	Withdrawal Response		
	Localising Response		Visual tracking for more than 90 degrees to photo of a baby
	Differentiating Response	Inconsistent response to written instruction to 'smile', 'move your leg' and 'move your arm'	
AUDITORY	No Response		
	Reflex Response		
	Withdrawal Response		Movement of head away from sound of blocks hitting together
	Localising Response		
	Differentiating Response	Inconsistent response to pressing AF buzzer switch	
TACTILE	No Response		
	Reflex Response		
	Withdrawal Response	Movement of stimulated arm away from cold stimulus	Movement of stimulated arm away from cold stimulus
	Localising Response		
	Differentiating Response		
OLFACTORY	No Response		
	Reflex Response		
	Withdrawal Response		
	Localising Response	Localising response to smell of coffee	Localising response to smell of coffee
	Differentiating Response		
GUSTATORY	No Response		
	Reflex Response		
	Withdrawal Response		
	Localising Response	Localising response to sugar stimulus	Localising response o sugar stimulus
	Differentiating Response		
MOTOR FUNCTION	No Response		

	Primitive Reflexive Response		
	Non-Purposeful Spontaneous Movement or Withdrawal Response		Withdrawal response to cold pack, spontaneous movement also observed
	Inconsistent Purposeful movement	Inconsistent movement to written instruction and verbal instruction (AF buzzer switch)	
	Consistent Purposeful Response		
FUNCTIONAL COMMUNICATION	No Response		
	Non-specific Response		No specific response observed
	Specific Response		
	Inconsistent Communication	Inconsistent with switch and response to written instruction	
	Consistent Communication		
WAKEFULNESS/ AROUSAL	Unarousable		
	Minimal Arousal Level		
	Medium Arousal Level		At times required 2-4 prompts to maintain wakefulness
	Minimal Prompts Required	Required minimal prompts to complete assessment	
	Optimum Arousal Level		

Table 16: P2's on Response on SMART during Assessment and Re-Assessment

4.6.6.3. CRS-R Re-Assessment

The CRS-R was completed twice in a period of one week with P2. He obtained a total score of 10/23 during re-assessment. CRS-R scores before and after the study are summarised in Table 4.11.

CRS-R Total Score Before	CRS-R Total Score After
Total Score 10/23 • Auditory function scale – 2 (localisation to sound) • Visual function scale – 2 (visual startle) • Motor function scale – 2 (flexion withdrawal) • Oromotor/verbal function – 1 (oral reflexive movement) • Communication Scale – 0 (None) • Arousal Scale – 3 (eye opening w/o stimulation)	Total Score 10/23 • Auditory function scale – 2 (localisation to sound) • Visual function scale – 2 (visual startle) • Motor function scale – 2 (flexion withdrawal) • Oromotor/verbal function – 1 (oral reflexive movement) • Communication Scale – 0 (None) • Arousal Scale – 3 (eye opening w/o stimulation)

Table 17: P2's Scores on CRS-R Before and After Study

4.6.6.4. Summary of Standardised Re-Assessment Scales

Differences in scoring between the assessment and re-assessment periods are highlighted in the figure below.

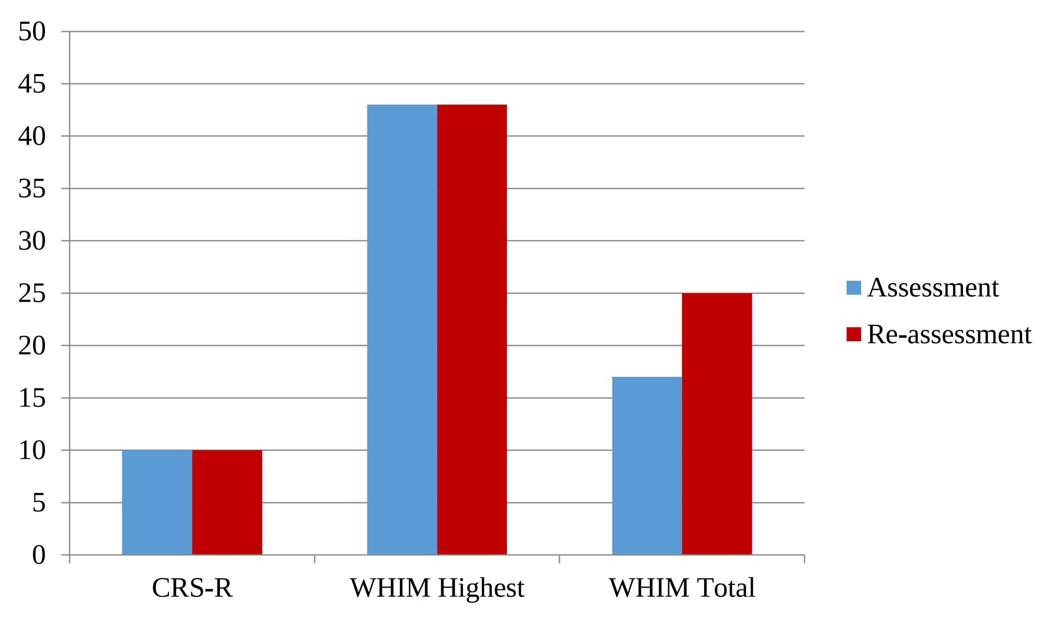

Figure 11: P2's Pre and Post Measures

4.6.6.5. Non Standardised Results

P2’s daily routine changed as a result of participation in the research study. He was provided with daily sensory stimulation in a controlled manner. All observed behaviours were documented in a diary and he continued to be assessed regularly using the WHIM by OT staff in the hospital. The amount of therapeutic involvement was also increase by one session a week for both OT and physiotherapy. Following the study P2 was transferred to a specialist rehabilitation unit where his scores on all completed standardised tests meant that his assessment could be built upon instead of having to complete all baseline measures from the beginning.

4.6.7. Additional Intervention: Standing Programme

Due to the unexplained plateau in rehabilitation and a decrease in demonstrated awareness it was decided by the researcher and supervisor to complete a novel standing programme. With assistance from the physiotherapy department P2 participated in a two week standing sensory stimulation intervention in which he was stood using a tilt table on 10 occasions over two weeks. Sensory stimulation was provided while P2 was in standing and the WHIM assessment was selected as the evaluation tool. This standing programme allowed the OT and physiotherapist to work collaboratively, meant that both interventions could be conducted in one session and also had implications for infection control. Due to the presence of infection all of P2’s therapeutic sessions in the clinic rooms had to be at the end of the day. This was so as not to spread infection to other patients. The clinic rooms were disinfected at the end of each day. The standing programme, because carried out in his bedroom, could be conducted at different times of the day.

4.6.7.1. Assessment of Awareness

While in standing, P2 demonstrated behaviours not previously seen in other sessions. This included right side visual tracking (through 90º) with a mirror. He also was observed to demonstrate other previously seen behaviours such as a delayed response to a limited number of verbal commands. While this did not indicate change to the diagnostic category, it did highlight other behaviours that P2 could use in further neuro-rehabilitation. In standing P2 demonstrated 7 more behaviours than in sitting and 13 more behaviours than in the lying position. This represents an 11.3% increase in behavioural repertoire in standing as opposed to sitting. While he was observed to press the switch 3-4/5 times again he did not achieve consistency with it over the standing sessions.

4.6.7.2. Neurofatigue

P2 tolerated up to 30-40 minutes of stimulation at a time. This was much improved from previous sessions where he could tolerate up to 15 minutes before a rest period was required.

4.6.7.3. Family Feedback

Family members were very positive about the standing programme. They reported that they loved to see him in the standing position as opposed to other postures, particularly lying. They also stated that they, for the first time, understood what P2 was capable of and they were surprised that he could tolerate sessions so well. It was observed that more family members attended the standing sessions than any other session.

4.6.7.4. Cost Effectiveness

The multi-professional standing programme was over twice as cost effective when compared to two therapy disciplines seeing the patient separately. With limited resources in the acute hospital setting this study shows that such a programme could provide patients with much longer rehabilitation in a more cost effective manner.

Costing based on 35 hour working week	Independent Physiotherapy session	Independent Occupational Therapy Session	Multi Professional Sensory Session
Staff Grade Physiotherapist (x2)	1 hour 15 mins (23.325 x 2 = 46.65)		1 hour (18.66 x 2 = 37.32)
Physiotherapy Assistant	1 hour 15 (17.56)		
Hospital Porter	30 mins (6.80)	30 mins (6.80)	
Cleaning Staff	30 mins (6.80)	30 mins (6.80)	
Nurse	1 hour 30 (24.92)	1 hour 30 (24.92)	1 hour (18.66)
Occupational Therapist		1 hour 15 (23.325)	1 hour (18.66)
TOTAL	€102.73	€61.85	€74.64
Combined Total		**€164.58**	**€74.64**

Table 18: Cost of Standing Programme versus Individual Therapeutic Intervention

As the full time nurse had to attend all therapy sessions due to health and safety protocol there was no difference in the cost of nursing staff. However nursing staff reported that the standing sessions assisted them with bowel management and care.

4.7. Participant Three

4.7.1. Participant Profile

Background Information	• 68 year old female • 18 months post ictus • TBI following a road traffic accident
Diagnosis	• MCS -
Family	• Husband visited three times daily - involved in daily care and support
Care Location	• ICU department • general medical ward of the same hospital • Transferred to a specialist rehabilitation centre for 12 weeks where she received a formal diagnosis • Currently cared for in a community nursing unit
Specialist Assessment and Rehabilitation	• 12 weeks specialist assessment (SMART and WHIM)
Nutritional Status	• In the specialist rehabilitation setting P3 was allowed semi solid food, spoon fed by her husband or care staff. • In her current setting she was on a liquid diet. Her husband was not involved in her feeding regime • She is also PEG fed at different times of the day
Respiratory Status	• Independent
Sensory Status	• Extremely sensitive to touch on upper limbs bilaterally • Observed to grimace and groan upon touch.
Cognitive Status	• MCS -
Physical Status	• No voluntary movement in all four limbs • Elbows and Knees held in full flexion • Arm and leg splints donned while P3 in sitting

Table 19: Summary of P3's Clinical Profile

4.7.2. Daily Routine

P3 had her own room in the community nursing unit. Her husband visited twice each day. As she had a grade 2 pressure ulcer at the time of the study and her pressure care guidelines stated that she was to be seated out of bed for a few hours on alternate days. Therefore every second day she spent the day in bed. Once weekly, she attended the day room and also attended a music session or art session occasionally. She enjoyed watching TV, listening to the radio and looking at pictures, particularly pictures of flowers or dogs.

4.7.3. Therapeutic Services

OT services were provided on a needs led basis in order to meet her seating and positioning needs. The nursing staff sent a referral to OT for this intervention each time. The speech and language therapist (SLT) saw P3 every 3 weeks. The SLT completed the WHIM with her regularly and also treated her swallow issues. Physiotherapy input was limited to maintaining range of movement.

4.7.4. Assessment

4.7.4.1. Pre-Assessment Intervention

No pre-assessment intervention was provided to P3.

4.7.4.2. Standardised Assessment

The assessment period was broken down as follows;

Week 1: The WHIM was completed on 5 occasions – highest scoring assessment reported

- 36/62 (switches gaze from one person to another spontaneously)
- Total number of behaviours – 23/62

Week 2: JFK completed on 3 occasions – the highest score obtained during the assessment phase was 6/23 broken down as follows;

- Auditory function scale – 0 (none)
- Visual function scale – 0 (none)
- Motor function scale – 3 (localising to noxious stimuli)
- Oromotor/verbal function – 1 (oral reflexive movement)
- Communication Scale – 0 (none)
- Arousal Scale – 2 (eye opening w/o stimulation)

Weeks 3-5: The SMART assessment was trialled on 10 occasions. Due to P3 closing her eyes or falling asleep no SMART sessions could be completed.

4.7.5. Intervention

Type of Intervention	
SENSORY	
Establishment of a Controlled Sensory Stimulation Environment	YES
Desensitisation Programme	
PHYSICAL	
Biomechanical Interventions(seating, splinting, prevention of further contractures, maintaining range of movement)	
Standing Position	Unable to stand
COMMUNICATION	
Additional Exploration of Functional Communication	YES
Novel Stimuli	YES
Video Analysis	YES
Building Therapeutic Rapport	YES
Standardised Behavioural Assessment	YES
FORMAL PSYCHO-EDUCATION	
Family Education	Informal/limited
Staff Education	None

Table 20: Types of Interventions Trialled with P3

4.7.5.1. Video Analysis

All therapeutic sessions were video recorded. On many occasions throughout intervention the video was left running so as to document spontaneous behaviours while P3 was in her room alone. On two occasions P3 was observed to open her eyes upon the researcher leaving the room and look towards the door. Upon hearing the footsteps of the researcher returning P3 was recorded closing her eyes again and appearing to be asleep. On other occasions she was captured spontaneously exploring pictures and photographs, looking towards the television for long periods and quickly glancing with her eyes before closing them again.

4.7.5.2. Building Therapeutic Rapport

A number of sessions were conducted with their aim to develop a stronger therapeutic rapport with P3. During assessment it was discovered using the WHIM that she demonstrated a preferred response to different people. Based on this information it was decided to encourage responses by building on therapeutic rapport. This involved discussing topics she was interested in, bringing her outside the nursing unit to the garden, sharing some personal information, reading her the newspaper and exposing her to novel stimuli. Time was also spent with P3 and her husband where he would discuss her past experiences and interests in an informal manner. Regular sessions were provided to P3 at specific times and it was ensured that no sessions were cancelled so as to establish trust and security.

4.7.5.3. Informal Presentation of Sensory Stimuli

Following the limited assessment for P3 it was decided to provide sensory stimuli in a more informal manner. Having informal conversations about the news that day or sitting watching programmes that she enjoyed appeared to provide a better opportunity to explore functional communication. Through personalised, informal approaches (utilising personal stimuli) she was observed to eye point correctly 10/10 times to coins and also was heard to utter sentences (in a whisper) which were totally appropriate to the conversation. A calendar was provided to P3 for her room and while putting it on the wall the researcher asked ‘isn’t your birthday in March?’ to which P3 was heard to whisper ‘no, in April’. Islets of functional communication such as this were difficult to capture and could not be measured using standardised assessments.

4.7.5.4. Additional Exploration of Functional Communication

Multiple attempts were made to establish functional communication and build on existing observed abilities. The AF buzzer switch was trialled over several sessions using her head to press the switch. Other body parts could not be trialled as she did not have voluntary movement at these areas. P3 did not engage with the switch in any way. Eye pointing to yes/no cards or visual representations of yes/no (smiley/sad face, green tick/red cross, etc.) was unsuccessful. P3’s husband also trialled use of a non-invasive microphone which sat on P3’s voice-box so as to amplify her whispers so that they were audible. This was also shown to be unsuccessful and functional communication could not be established on a consistent basis.

4.7.5.5. Standardised Behavioural Measurement

The WHIM was completed weekly with P3 throughout the intervention phase.

4.7.6. Re-assessment

4.7.6.1. Standardised Assessment Results

The SMART assessment was not used for re-assessment purposes as it did not form part of the assessment. The WHIM and CRS-R were completed during the two week re-assessment phase.

4.7.6.2. WHIM Re-Assessment

The WHIM was completed on three occasions on the first week of re-assessment The highest behaviour recorded during re-assessment was 57/62 (indicates left and right on self). The total number of behaviours observed during the re-assessment phase was 35/62.

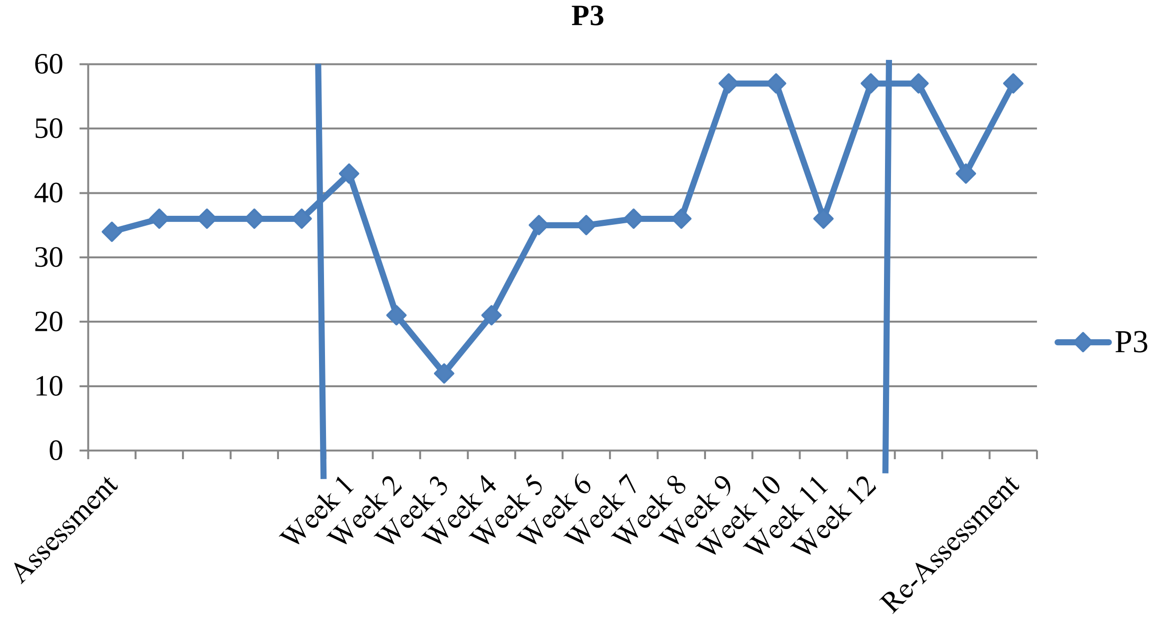

Figure 12: P3's Highest WHIM Scores during Assessment, Intervention and Re-assessment

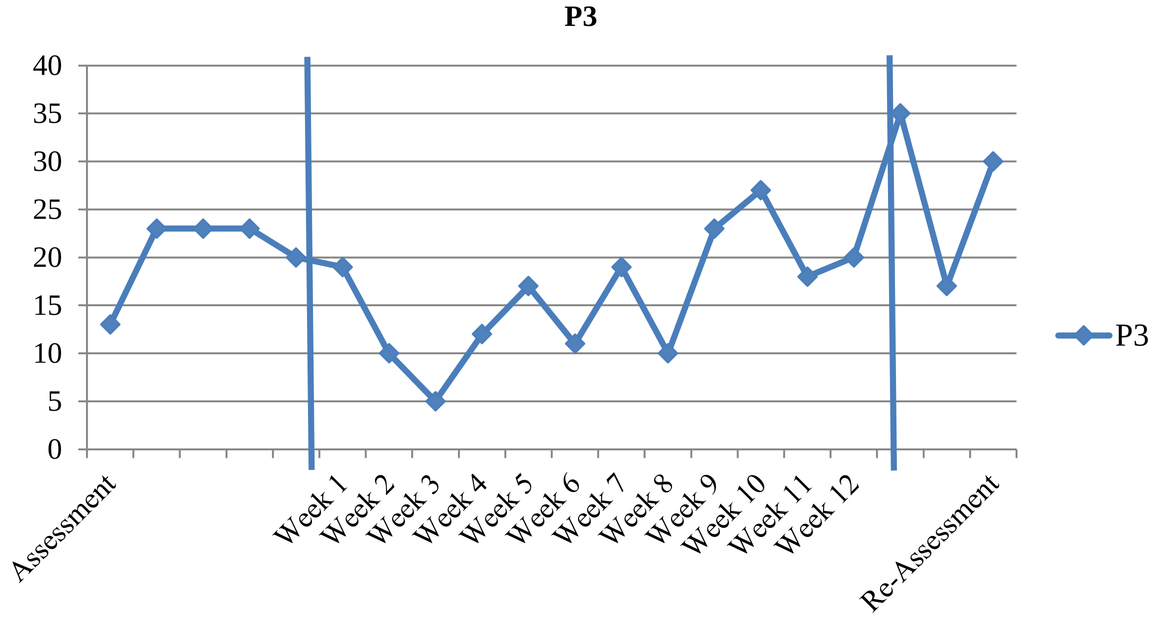

Figure 13: P3's Total Number of Behaviours on WHIM during Assessment, Intervention and Re-assessment

4.7.6.3. CRS-R Re-Assessment

The CRS-R was completed twice in the final week of re-assessment. The highest score obtained was 15/23.

CRS-R Total Score Before	CRs-R Total Score After
Total Score - 6/23 • Auditory function scale – 0 (none) • Visual function scale – 0 (none) • Motor function scale – 3 (localising to noxious stimuli) • Oromotor/verbal function – 1 (oral reflexive movement) • Communication Scale – 0 (none) • Arousal Scale – 2 (eye opening w/o stimulation)	Total Score - 15/23 • Auditory function scale – 4 (consistent movement to command) • Visual function scale – 5 (object recognition) • Motor function scale – 3 (localisation to noxious stimuli) • Oromotor/verbal function – 1 (oral reflexive movement) • Communication Scale – 0 (none) • Arousal Scale – 2 (eye opening w/o stimulation)

Table 21: P3's Scores on CRS-R Before and After Study

4.7.6.4. Summary of Standardised Re-Assessment Scales

Differences in scoring between the assessment and re-assessment periods are highlighted in Figure 14 below.

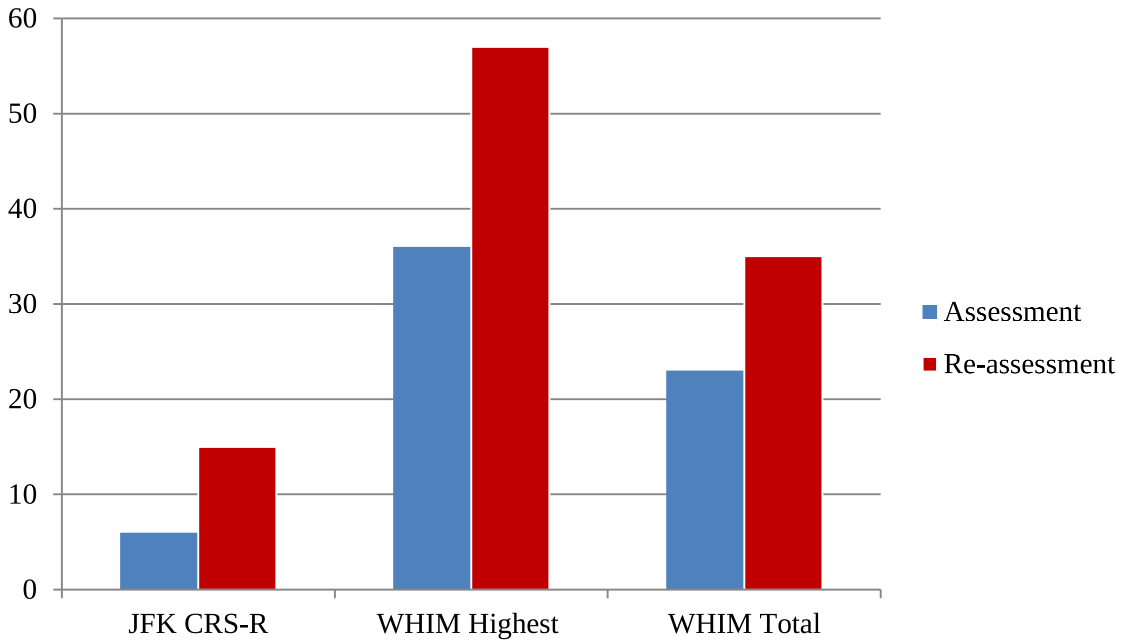

Figure 14: P3's Pre and Post Measures

4.7.6.5. Non Standardised Results

While P3 demonstrated behaviours indicated of EMCS, she did not demonstrate them consistently. These fluctuating behaviours were documented so as to encourage further exploration of level of awareness. There were no significant changes to her daily routine following the research study. Staff declined an invitation to participate in formal in-service training. A diary was set up in her room so as to document observed behaviours on a daily basis, however only her husband participated in this documentation. Her care plan continued as it was before the research study.

4.8. Participant Four

4.8.1. Participant Profile

Background Information	• 31 year old male • 6 years post injury • nTBI as a result of hypoglycaemia • Co-morbid diagnoses of diabetes and epilepsy
Diagnosis	• MCS-
Family	• Daily involvement from parents and three siblings
Care Location	• His brain injury happened outside of Ireland and so his acute medical needs were taken care of in another country • Once medically stable he was flown home and taken care of in the local regional hospital on a general medical ward • He was then transferred to a specialist rehabilitation unit for 12 weeks • He was then cared for in a local residential nursing unit prior to being transferred to a local brain and spinal cord injury rehabilitation unit
Specialist Assessment and Rehabilitation	• 12 week specialist assessment
Nutritional Status	• All nutritional requirements were taken orally • His family took care of his diet which was organic, consisting mainly of vegetables and fruit, with very limited dairy and fat intake. • It was difficult to establish his daily calorific intake but it was estimated at 1300kcal per day.
Respiratory Status	• Independent
Sensory Status	• Hypersensitivity in his upper limbs bilaterally • Observed to groan and withdraw limb upon touch.
Cognitive Status	• MCS-
Physical Status	• Full range of movement in all four limbs • Tolerated standing for up to 30 minutes

Table 22: Summary of P4's Clinical Profile

4.8.2. *Daily Routine*

P4 spent all day in his room with limited stimulation, mostly picture books placed in his eye line. He went swimming one day a week with his family. His mother or father visited every day. P4 woke at 7am and slept from 2-4pm. At night time he had the television on for one hour and slept around 11pm. He did not go to the day room with the other residents upon his parent's request. He was reported to enjoy music and so his music CDs were played regularly for him.

4.8.3. *Therapeutic Services*

P4 received physiotherapy five times a week. During these sessions engaged in standing on a manual standing frame for approx. 30 minutes. He used the supported hand bicycle for up to 20 minutes. His occupational therapy input was around seating and pressure care and was provided on a needs led basis. He received daily nursing care and was seen by the local GP for medical issues.

4.8.4. *Assessment*

4.8.4.1. *Pre Assessment Intervention*

No intervention was provided prior to standardised behavioural assessments.

4.8.4.2. *Standardised Assessment*

The assessment period was broken down as follows;

Week 1: JFK completed on 3 occasions – highest scoring assessment reported

- Total score 13/23
    - Auditory function scale – 2 (localisation to sound)
    - Visual function scale – 3 (visual pursuit)
    - Motor function scale – 4 (object manipulation)
    - Oromotor/verbal function – 2 (vocalisation/oral movement)
    - Communication Scale – 0 (none)
    - Arousal Scale – 2 (eye opening w/o stimulation)

Week 2: WHIM completed on 5 occasions – highest scoring assessment reported

- 43/62 (smiles)

- Total number of behaviours – 25/62

Weeks 3-5: The SMART assessment was completed over 10 sessions in three weeks (detailed results will be provided in the re-assessment section).

- Behavioural signs of MCS

- Level 4 localising response – auditory (name calling) and visual (photograph)

4.8.5. Intervention

A number of intervention strategies were employed with P4. These are summarised in Table 23.

Type of Intervention	
SENSORY	
Establishment of a Controlled Sensory Stimulation Environment	YES
Desensitisation Programme	YES
PHYSICAL	
Biomechanical Interventions(seating, splinting, prevention of further contractures, maintaining range of movement)	YES
Standing Position	YES
COMMUNICATION	
Additional Exploration of Functional Communication	YES
NOVEL	
Novel Stimuli	YES
Video Analysis	YES
Building Therapeutic Rapport	
Standardised Behavioural Assessment	YES
FORMAL PSYCHO-EDUCATION	
Family Education	
Staff Education	YES

Table 23: Types of Intervention Trialled with P4

4.8.5.1. Maintenance of Range of Movement

P4 was provided with a T roll to maintain full extension at his knee joints. This was used for 5 hours during the night. As he had full range of movement at all joints family and staff were educated on the importance of maintaining this and how to identify muscular tightness.

4.8.5.2. Postural Changes

P4 was assessed in lying, sitting and standing positions. Aspects of the WHIM and the CRS-R were conducted while P4 was in standing so as to encourage responses. Tracking with a mirror and tactile stimulation was also trialled while in standing.

4.8.5.3. Establishment of a Controlled Sensory Environment

A controlled sensory environment was set up for P4. This was designed specifically for P4's needs. Multi modal sensory stimulation was provided for 30 minutes at a time, followed by 30 minute rest periods for certain periods throughout the day. Staff were advised not to have the radio playing for long periods of time. Changing P4's seating position regularly was also encouraged as P4 was often positioned towards the door instead of the garden or other visual stimuli. P4 was observed to demonstrate a high level of alertness and so he was also provided with sessions in a multi modal sensory room.

4.8.5.4. Desensitisation Programme

P4 was observed to have hyper sensitivity in both upper limbs and would withdraw from all tactile stimuli. This made it difficult to explore alternative communication devices with his hands, due to him avoiding touch. It was decided to establish a hand de-sensitisation programme that was carried out by nursing staff and healthcare assistants with P4. A training workshop was provided to the staff on this programme and how it would be monitored. Documentation was set up in P4's room so as to monitor the frequency of stimulation and the amount of time P4 would tolerate same. A tactile stimulation box with various types of tactile stimulation (feathers, rice, sand, water) was kept in P4's room. Towards the end of this intervention programme P4 tolerated tactile stimulation by approximately 10 seconds longer that at his baseline. This was observed by the researcher, care staff and family. This desensitisation programme was continued following the research study.

4.8.5.5. Exploration of Functional Communication

An AF buzzer switch was trialled using P4's knee and his head. Both were unsuccessful over the trial periods. Long handled bells which would 'ping' upon touch were also trialled as an alternative. Due to the hyper-sensitivity of his hands it was difficult to explore his ability to press switches and other alternative communication devices. Eye pointing using visual and written yes/no cards were also unsuccessful. Exploration of gestural responses (thumbs up/down, head shake) failed to demonstrate potential for functional communication. P4 did not exhibit any form of verbal communication.

4.8.5.6. Novel Stimuli

A number of novel stimuli, outside of those detailed in standardised neurobehaviorual assessments were trialled. These included functional assessments using different textured items so as to encourage their use, e.g. soft handled paintbrush, hard and thick handled fork. P4 was also provided with an iPad so as to encourage him to press items on the screen in order to obtain a meaningful response. Visual fixation and visual tracking was also explored using the iPad (youtube clips, music videos, images, family photographs).

4.8.5.7. Video Analysis

In order to document spontaneous behaviours the video tape was left running during periods where P4 was by himself or while he was in different environments. During one session in the sensory room P4 was observed to pick up a small piece of fibre optic equipment from his lap-tray after approximately 12 minutes. Later on that day he repeated this behaviour while in his bedroom. It was later discovered that by using this behaviour he was able to pick up his flask spontaneously and take a drink. This had not been seen previously by his family or care staff. Over the intervention period he was able to carry out this behaviour in under 2 minutes. He was also observed to pick up some tactile stimuli from his lap tray independently after 3-12 minutes. He was also able to pick up an adapted toothbrush but never used it functionally. He did however pick up an adapted hairbrush (thickened handle) and was observed to use it functionally on one occasion.

4.8.5.8. Standardised Behavioural Measurement

The WHIM was completed weekly with P3 throughout the intervention phase. His scores are highlighted in Figures 15 and 16.

4.8.6. Re-assessment

4.8.6.1. Standardised Assessment Results

During the re-assessment phase the WHIM, SMART and CRS-R were repeated over a 5 week period.

4.8.6.2. WHIM Re-Assessment

The WHIM was completed on three occasions over a one week period. The highest recorded behaviour was 43/62 (smiles). During re-assessment the total numbers of behaviours seen on WHIM was 25/62.

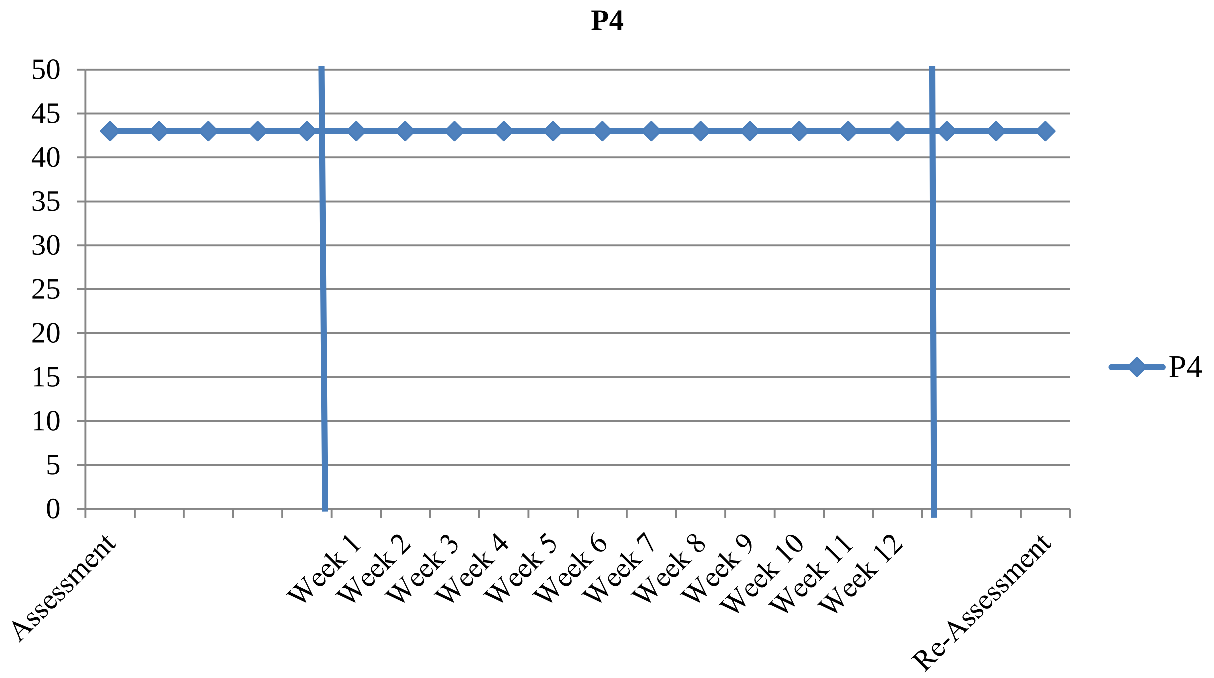

Figure 15: P4's Highest WHIM Scores during Assessment, Intervention and Re-assessment

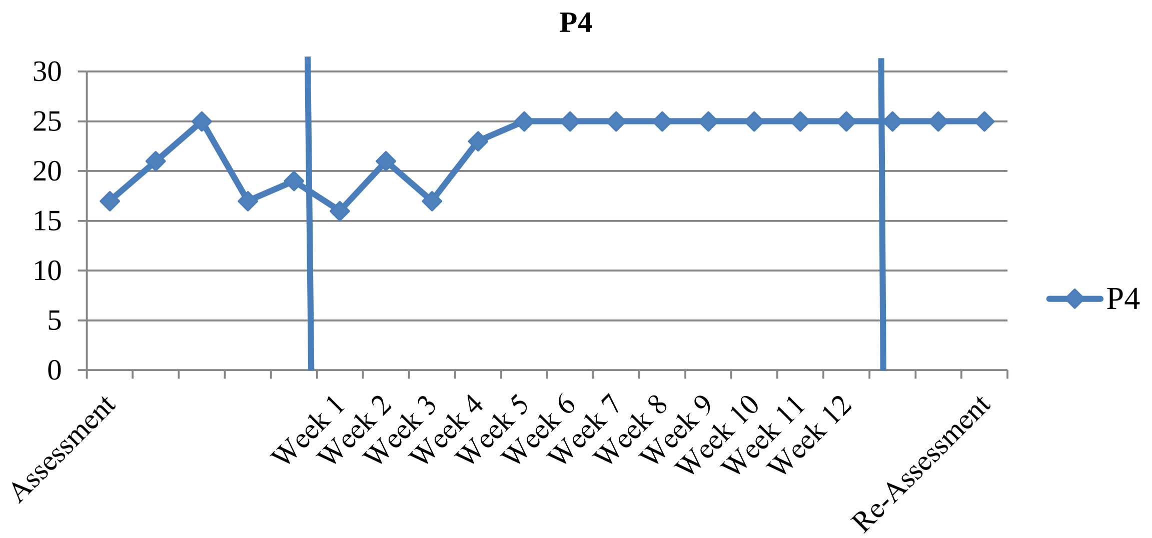

Figure 16: P4's Total Number of Behaviours on WHIM during Assessment, Intervention and Re-assessment

4.8.6.3. CRS-R Re-Assessment

The CRS-R was completed twice over a one week period. The total score obtained was 13/23. CRS-R score pre and post intervention are detailed in Table 24.

CRS-R Total Score Before	CRS-R Total Score After
Total Score 13/23 • Auditory function scale – 2 (localisation to sound) • Visual function scale – 3 (visual pursuit) • Motor function scale – 4 (object manipulation) • Oromotor/verbal function – 2 (vocalisation/oral movement) • Communication Scale – 0 (none) • Arousal Scale – 2 (eye opening w/o stimulation)	Total Score 13/23 • Auditory function scale – 2 (localisation to sound) • Visual function scale – 3 (visual pursuit) • Motor function scale – 4 (object manipulation) • Oromotor/verbal function – 2 (vocalisation/oral movement) • Communication Scale – 0 (none) • Arousal Scale – 2 (eye opening w/o stimulation)

Table 24: P4's Scores on CRS-R Before and After Study

4.8.6.4. SMART Re-Assessment

The SMART was completed on 10 occasions over a three week period. Results from the SMART assessment showed behavioural signs of MCS and a level 4 localising response (auditory and visual). Findings from the re-administration of the SMART are detailed in Table 25 below.

Modality	Type of Response	P4 Highest Level of Response Before	P4 Highest Level of Response After
VISUAL	No Response		
	Reflex Response		
	Withdrawal Response		
	Localising Response	Visual tracking for more than 90 degrees to photo of a baby	Visual tracking for more than 90 degrees to photo of a baby
	Differentiating Response		
AUDTORY	No Response		
	Reflex Response		
	Withdrawal Response		
	Localising Response	Movement of head/eyes towards calling of his name	Movement of head/eyes towards calling of his name

	Differentiating Response	Inconsistent response to pressing AF buzzer switch	Inconsistent response to pressing AF buzzer switch
TACTILE	No Response		
	Reflex Response		
	Withdrawal Response	Movement of stimulated arm away from cold stimulus	Movement of stimulated arm away from cold stimulus
	Localising Response		
	Differentiating Response		
OLFACTORY	No Response		
	Reflex Response		
	Withdrawal Response	Withdrawal response to smell of coffee and garlic	Withdrawal response to smell of coffee and garlic
	Localising Response		
	Differentiating Response		
GUSTATORY	No Response		
	Reflex Response		
	Withdrawal Response	Withdrawal response when swab moved towards mouth	Withdrawal response when swab moved towards mouth
	Localising Response		
	Differentiating Response		
MOTOR FUNCTION	No Response		
	Primitive Reflexive Response		
	Non-Purposeful Spontaneous Movement or Withdrawal Response	Withdrawal response to cold pack, spontaneous movement also observed	Withdrawal response to cold pack, spontaneous movement also observed
	Inconsistent Purposeful movement		
	Consistent Purposeful Response		
FUNCTIONAL COMMUNICATION	No Response		
	Non-specific Response	No specific response observed	No specific response observed
	Specific Response		
	Inconsistent Communication		
	Consistent Communication		
WAKEFULNESS/ AROUSAL	Unarousable		
	Minimal Arousal Level		
	Medium Arousal Level		
	Minimal Prompts Required		Required 2-4 prompts to maintain wakefulness
	Optimum Arousal Level	Remained awake for the majority of assessment sessions	

Table 25: P4's SMART Responses during Assessment and Re-assessment

4.8.6.5. Summary of Standardised Re-Assessment Scales

Differences in scoring between the assessment and re-assessment periods are highlighted in the figure below. No differences between assessment and re-assessment scores on standardised assessments were recorded. There was also no difference in different postural positions.

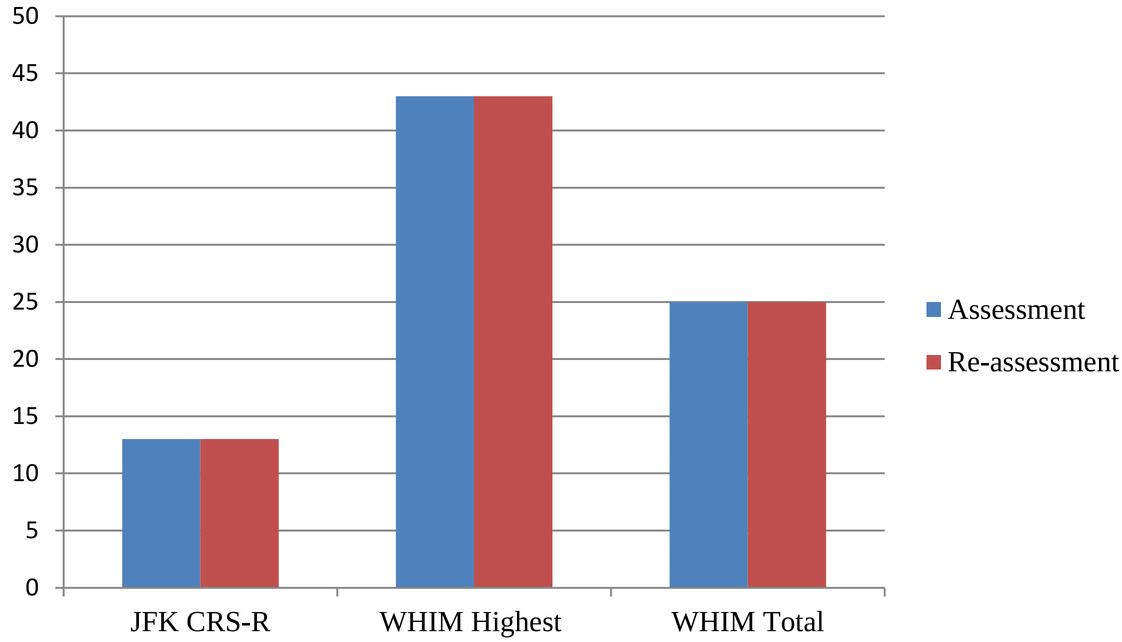

Figure 17: P4's Pre and Post Measures

4.8.6.6. Non Standardised Results

Following the research study P4 was able to take a drink from his flask independently as and when he needed to. This contributed towards increased autonomy and quality of life for P4. Staff and family encouraged him to increase his independence by leaving items on his lap-tray and allowing him the time to pick it up before automatically handing items to him. Tactile stimulation was now left on his lap tray and P4 would sometimes touch these items. This was also used as a means of decreasing his hand sensitivity but at his own pace.

P4's routine changed and he now spent time in different rooms around the unit, in particular the garden. The amount and type of stimulation was managed by staff and they continued to follow the controlled stimulation programme.

4.9. Participant Five

4.9.1. Participant Profile

Background Information	• 59 year old female • 41 months post ictus • Non traumatic brain injury following a subarachnoid bleed • Medical history of meningitis
Diagnosis	• MCS
Family	• Daughter and grandchild visit regularly
Care Location	• Admitted initially to the local regional hospital for emergency care • Transferred to a local medical and stroke rehabilitation unit where she received regular therapeutic input • Transferred to a specialist rehabilitation facility for three months before returning to the medical and stroke rehabilitation unit • Currently cared for in a local brain and spinal cord injury rehabilitation unit
Specialist Assessment and Rehabilitation	• 12 week specialist assessment
Nutritional Status	• Receiving 1800kcal daily (Jevity Plus) • Fed via PEG tube
Respiratory Status	• Independent
Sensory Status	• No known issues
Cognitive Status	• MCS
Physical Status	• No voluntary movement in lower limbs

Table 26: Summary of P5's Clinical Profile

4.9.2. Daily Routine

P5 required full assistance for all ADLS. Every day she spent four hours in the day room with other residents. She did not participate in any activity while in the day room. She slept during the day from 3-5pm. Her family visited regularly and reported that her interests were watching TV and listening to the radio. She had a TV in her room and this was switched on in the evening time.

4.9.3. Therapeutic Services

She received physiotherapy three times weekly for passive stretching to maintain existing ability. She also received SLT on a monthly basis for exploration of functional communication. She was not receiving any OT input at the time of the study. She continued to be seen by the specialist rehabilitation centre for outpatient appointments, with particular focus on her splinting and range of movement needs. Her outpatient appointments were every three months.

4.9.4. Assessment

4.9.4.1. Pre Assessment Intervention

No changes were implemented prior to assessment phase.

4.9.4.2. Standardised Assessments

The assessment period took place over 3 weeks and was broken down as follows;

Week 1: WHIM completed on 5 occasions over one week. The highest score obtained was 38/62, while the highest total number of behaviours was 18/62.

Week 2: JFK completed on 3 occasions over one week. Highest scoring assessment scored 10/23 broken down as follows;

- Auditory function scale – 2 (localisation to sound)
- Visual function scale – 3 (visual pursuit)
- Motor function scale – 1 (abnormal posturing)
- Oromotor/verbal function – 2 (vocalisation/oral movement)
- Communication Scale – 0 (none)
- Arousal Scale – 2 (eye opening w/o stimulation)

Week 3: Trialled SMART assessment on five occasions over 1 week period. P5 was unable to participate in this assessment and was observed to continually close her eyes of fall asleep.

4.9.5. Intervention

A number of intervention strategies were used with P5. These are summarised in Table 27.

Type of Intervention	
SENSORY	
Establishment of a Controlled Sensory Stimulation Environment	YES
Desensitisation Programme	
PHYSICAL	
Biomechanical Interventions (seating, splinting, prevention of further contractures, maintaining range of movement)	
Standing Position	Unable
COMMUNICATION	
Additional Exploration of Functional Communication	YES
Novel Stimuli	YES
Video Analysis	YES
Building Therapeutic Rapport	YES
Standardised Behavioural Assessment	YES
FORMAL PSYCHO-EDUCATION	
Family Education	
Staff Education	YES

Table 27: Types of Intervention Trialled with P5

4.9.5.1. Establishment of a Controlled Sensory Environment

The development of a daily, individual sensory timetable was completed, similar to those described in the previous case studies. Sensory stimuli were provided for 10 minutes at a time followed by a 20 minute rest period. Staff and family were educated on how best to avoid creating over or under stimulating environments.

4.9.5.2. Additional Exploration of Functional Communication

The AF buzzer switch from the SMART assessment kit was trialled over a number of intervention session using P5's hand, head and knee. However no potential for functional communication was seen using this method. Long handled bells (similar to the ones used by P4) were also trialled. Verbal communication was encouraged; however this was seen on an ad-hoc basis and often not as the result of any particular stimulation. Written or symbolic pictures were trialled also but no gestural communication or functional eye pointing was observed.

4.9.5.3. Video Analysis

As with all participants video analysis was completed with P5. No additional behaviours, spontaneous or purposeful, were observed when P4 was alone.

4.9.5.4. Building Therapeutic Rapport

P5 was reported to demonstrate preference to people as it was reported that she would groan loudly with particular staff. This was not observed during the study but building rapport with P5 was used as an intervention strategy. Building rapport involved spending informal time with P5 in a number of locations for a number of activities, e.g. in her room in the evening time, watching her favourite programme with her in the day room, sensory garden and in the snozelen room.

4.9.5.5. Novel Stimuli

During the intervention phase a number of novel stimuli were trialled. These included an adapted paintbrush, comb, toothbrush and fibre optic equipment in the snozelen. P5 demonstrated good ability to use an adapted paintbrush when supported at the elbow joint. She was also able to pick different paints and demonstrate different brush strokes upon verbal instruction once she was facilitated physically. Verbal encouragement was also provided which was found to be beneficial. P5's grand-daughter often brought her paintings and during the painting sessions her family would verbally encourage her to paint something for her grand-daughter. Using a thickened handled comb P5 was also observed to bring the comb to her head on two occasions which indicates potential for functional object use.

Photograph 2: Painting Completed by P5 Using an Adapted Paintbrush

4.9.5.6. Standardised Behavioural Measurements

The WHIM was conducted weekly with P5 during the intervention phase. This was also a source of sensory stimulation. WHIM scores throughout intervention are described in Figures 18 and 19.

4.9.6. Re-assessment

4.9.6.1. Standardised Assessment Results

The re-assessment was completed over a two week period. It was not possible to complete the SMART re assessment owing to eye closure and P5 falling asleep.

4.9.6.2. WHIM Re-assessment

The WHIM was conducted on three occasions over one week. The highest total score obtained was 43/62 (smiles). The highest recorded total number of behaviours was 24/62.

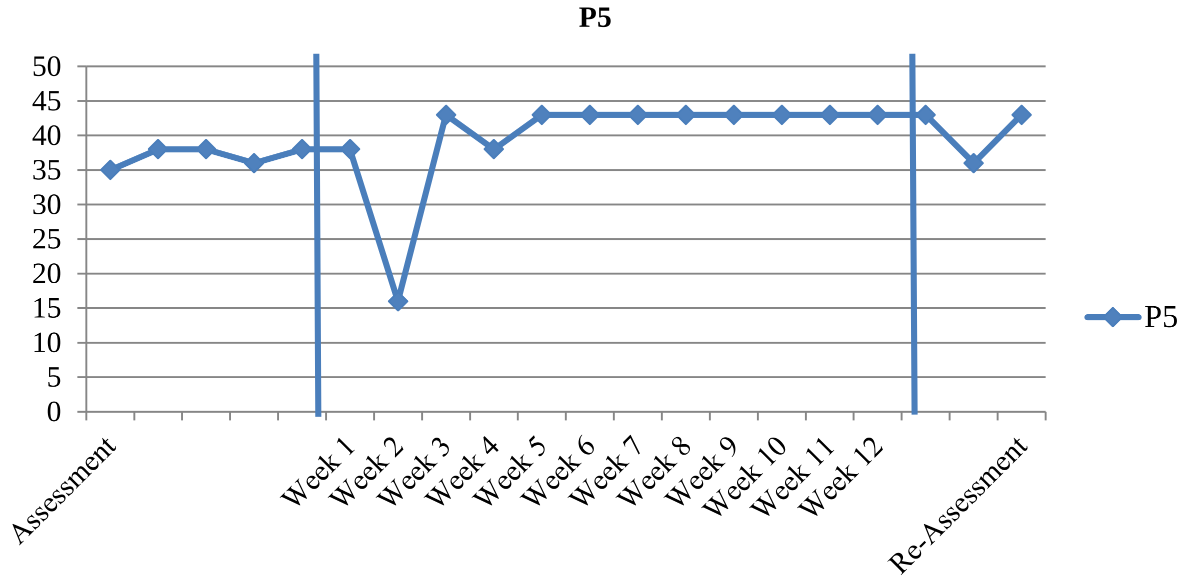

Figure 18: P5's Highest WHIM Scores during Assessment, Intervention and Re-assessment

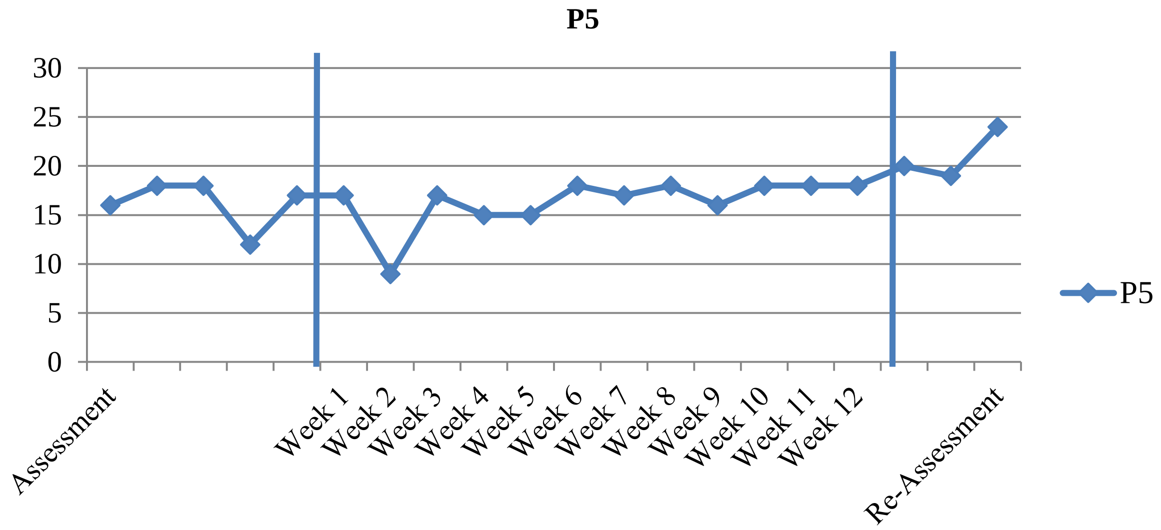

Figure 19: P5's Total Number of Behaviours during Assessment, Intervention and Re-

4.9.6.3. SMART Re-assessment

Could not be completed as was not used in the initial assessment.

4.9.6.4. CRS-R Re-Assessment

The CRS-R was completed twice over a period of one week. The highest total score achieved was 13/23. A breakdown of CRS-R total scores before and after intervention is provided in Table 28.

CRS-R Total Score Before	CRS-R Total Score After
Total Score – 10/23 • Auditory function scale – 2 (localisation to sound) • Visual function scale – 3 (visual pursuit) • Motor function scale – 1 (abnormal posturing) • Oromotor/verbal function – 2 (vocalisation/oral movement) • Communication Scale – 0 (none) • Arousal Scale – 2 (eye opening w/o stimulation)	Total Score - 13/23 • Auditory function scale – 2 (localisation to sound) • Visual function scale – 3 (visual pursuit) • Motor function scale – 6 (functional object use) • Oromotor/verbal function – 2 (vocalisation/oral movement) • Communication Scale – 0 (none) • Arousal Scale – 2 (eye opening w/o stimulation)

Table 28: P5's Scores on CRS-R Before and After Study

4.9.6.5. Summary of Standardised Results

Differences between pre and post WHIM and CRS-R scores were observed. These are detailed in Figure 20 below.

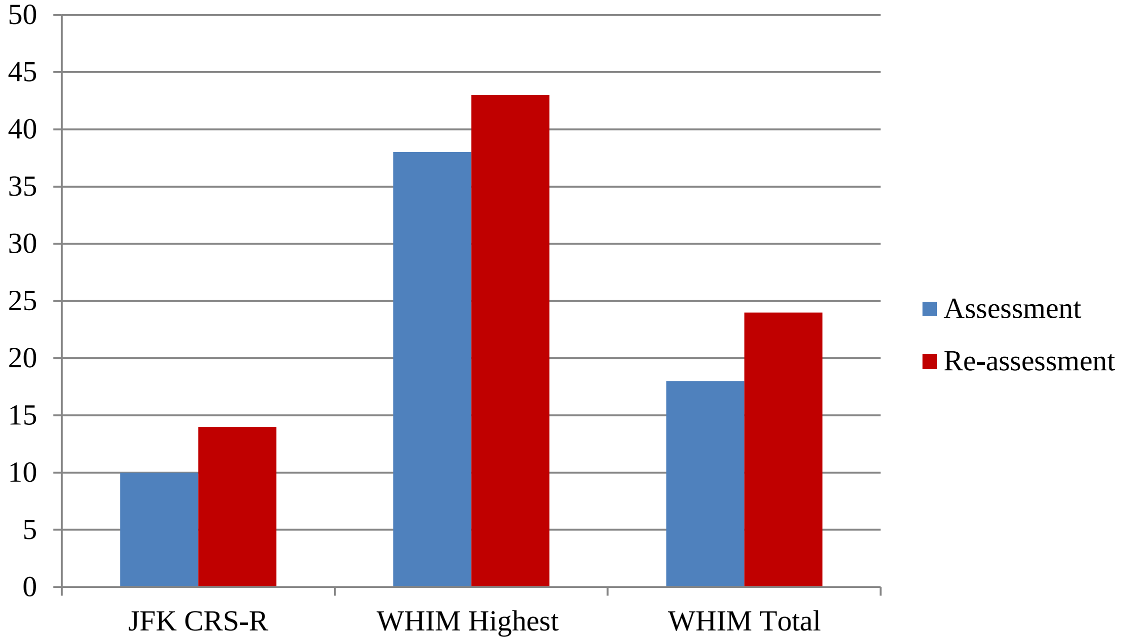

Figure 20: P5's Pre and Post Measures

4.9.6.6. Non Standardised Results

Following the research study P5 was encouraged to participate in an increased number of activities in the day room using adapted equipment, e.g. thickened paint brush handles, thickened pen handles, etc. She continued to paint pictures, particularly with family involvement.

Following staff education, a behavioural diary was established. Also in her room was placed the WHIM, Behavioural Pain Scale and a Mood Scale. Following staff training each staff member was involved in the daily completion of these documentation.

4.10. Perspectives of Staff

4.10.1. Staff Questionnaires - Demographics

In total 44 staff responded to the questionnaire across the 4 care locations. The percentage response is unclear owing to high staff turnover. The majority of respondents (79.5%, n=35) were female. The remaining 20.5% (n=9) of respondents were male. Ages ranged from 22-64 with a mean age of 35.6 years. During the pilot study 9 participants identified themselves as 'religious' while 75% of respondents did not answer this question.

People who had participated in the staff questionnaires prior to any research intervention were invited to re-take the questionnaire following intervention. In total 37 people participated in the second round of data collection. This consisted of 30 females (81.1%) and 7 males (18.9%). Ages ranged from 23-65 years. 9 people did not give their ages during the second round. 40.5% (n=15) of respondents in the second stage had participated in a formal educational in-service. All of these participants were based in care location 4, the rehabilitation unit.

4.10.2. Job Descriptions

The majority of respondents were Health Care Assistants (54.5%, n=24). Nursing staff, domestic staff and allied health professionals also were among the respondents. The positions of respondents who responded to the post questionnaires was similar to that in round one with the majority of staff (54.1%, n=20) reporting to be health care assistants. One person did not report a job title.

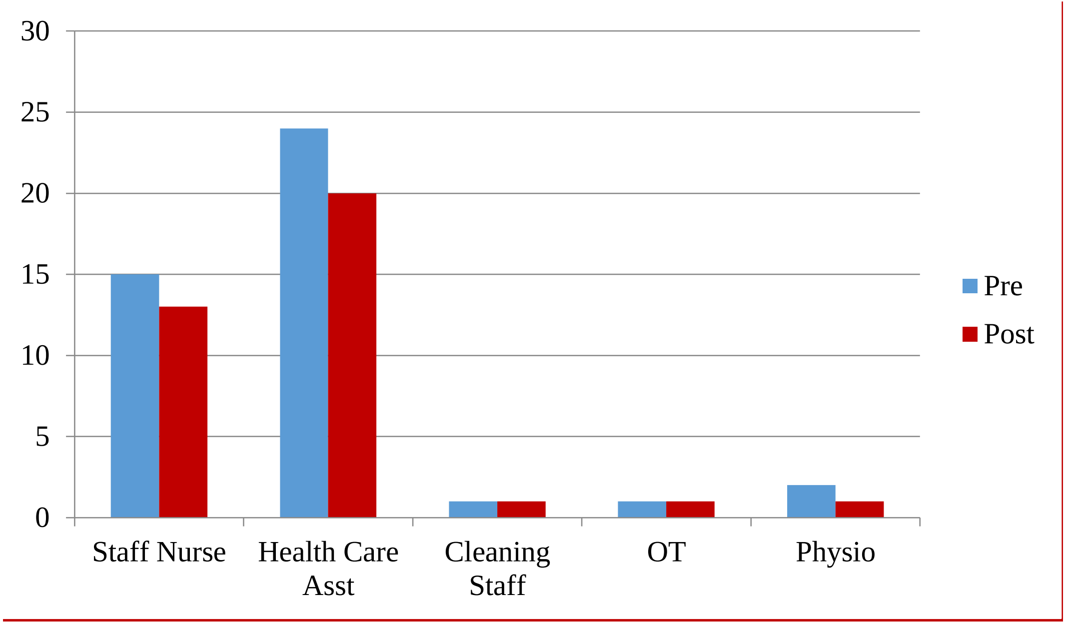

Figure 21: Job Title of Respondents across Care Settings

4.10.3. Care Locations

The four care locations that were surveyed were an acute regional hospital, a community hospital, a residential long-term care setting and a rehabilitation unit for adults. Staff at the rehabilitation unit formed the majority of respondents (40.9%, n=18) to the questionnaire. This was also the setting which cared for two participants in the study. The care location with the least respondents was the nursing home (11.4%, n=5). The acute hospital (27.3%, n=12) and the community hospital (20.5%, n=9) made up the remainder. For the follow up questionnaires the care location of staff was quite similar. The majority of respondents were from the rehabilitative setting. The remaining participants worked across the other care settings, the acute hospital (16.2%, n=6), the community hospital (32.4%, n=12) and the nursing home setting (10.8%, n=5).

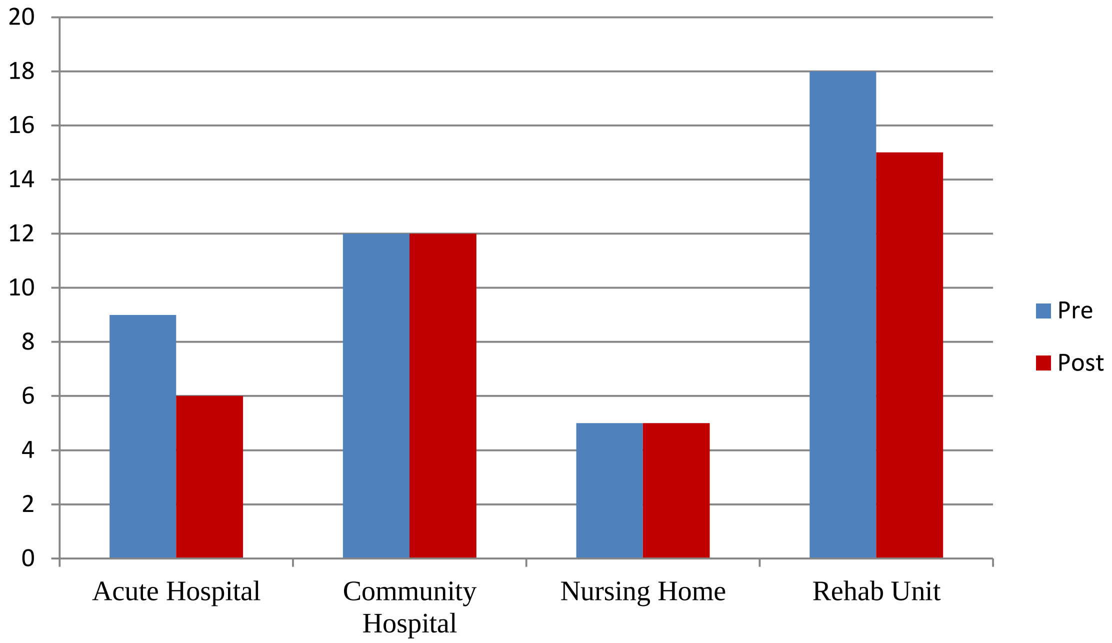

Figure 22: Work Location of Respondents Before and After Study

4.10.4. Clinical Experience

Participants were asked about their experience in terms of working with patients of this nature. They rated their experience on an ordinal scale ranging from 'very limited' to 'very good'. Figure 23 highlights the frequency of responses. Prior to any intervention 36.3% of staff responded that their experience was good or very good while 36.4% rated their experience as limited or very limited. 27.3% (n=12) of respondents rated their experience as sufficient. During the second stage they were asked how they would currently describe their experience and confidence in terms of this work. The vast majority (67.5%, n=25) now reported their experience to be either 'good' or 'very good'. 16.2% (n=6) reported their experience to be either 'limited' or 'very limited' while 6 people (16.2%) reported 'sufficient' experience.

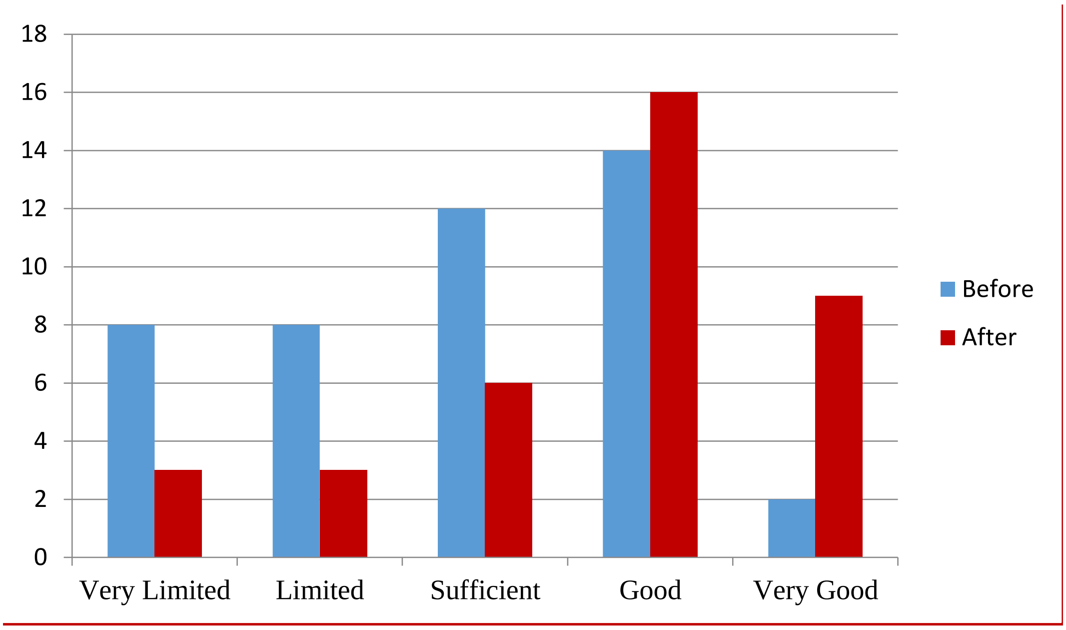

Figure 23: Comparison of Staff Reported Experience Before and After Study

4.10.5. Frequency of Clinical Contact

Staff were asked how frequently they worked with the research patient in clinical practice. Responses were rated on an ordinal scale from 'never' to 'more frequently than 3-4 times weekly'. The most frequent response in the initial round of questioning was that the staff had contact with this patient at least once a month. During the follow up the most frequent response was clinical contact 1-2 times weekly (43.2%, n=16) followed by monthly clinical contact (37.8%, n=14). 18.9% (n=7) of respondents reported working with the patient more than three times weekly.

Number of Clinical Contacts with this Patient	Percentage Before	Percentage After
Never	6.8 (n=3)	0
Monthly	38.6 (n=17)	37.8 (n=14)
1-2 times weekly	31.8 (n=14)	43.2 (n=16)
3-4 times weekly	20.5 (n=9)	0
More frequently	2.3 (n=1)	18.9 (n=7)

Table 29: Staff Reported Clinical Involvement with Person with PDoC

4.10.6. Familiarity with DoC

Participants were asked about their familiarity with the terms 'disorder of consciousness', 'vegetative state' and 'minimally conscious state' pre and post research study. Differences between reported responses are highlighted in the table below.

Question	Percentage Yes (before)	Percentage Yes (after)
Are you familiar with the term Disorders of Consciousness?	38.6% (n=17)	40.5% (n=15)
Are you familiar with the term vegetative state?	81.8% (n=36)	83.8% (n=31)
Are you familiar with the term minimally conscious state?	63.6% (n=28)	91.9% (n=34)

Table 30: Staff Reported Familiarity with DoC Before and After Study

4.10.7. Attitudes and Beliefs Surrounding DoC

The questionnaire explored staff beliefs and attitudes surrounding the person with DoC. These pre and post responses are summarised in the table below.

Question	Yes Response (before)	Yes Response (after)
Do you believe the patient can understand what you are saying?	38.6% (n=17)	89.2% (n=33)
Do you believe the patient has awareness of his/her environment?	47.7% (n=21)	89.2% (n=33)
Do you believe the patient experiences pain?	50% (n=22)	86.5% (n=32)
Do you believe the patient can improve?	11.4% (n=5)	37.8% (n=14)
Do you believe the patient will gradually get worse?	25% (n=11)	8.1% (n=3)
Do you believe the patient would benefit from more rehabilitation?	25% (n=11)	59.5% (n=22)
Do you believe the patient is in an appropriate care setting?	43.2% (n=19)	37.8% (n=14)
Do you believe the patient can get frustrated?	22.7% (n=10)	78.4% (n=29)
Do you believe the patient should be in a busy room with other patients?	31.8% (n=14)	10.8% (n=4)
Do you believe the patient needs to be seated out every day?	27.3% (n=12)	54.1% (n=20)

Table 31: Yes Responses on Staff Questionnaire Before and After Study

McNemar tests were to investigate if differences were significant and a significant difference was found on six of the sub questions. Differences on three of the questions was significant at $p<.00$ ($p<.01$) (the person can understand what I am saying, the person has awareness of his/her environment and the person can get frustrated).

4.10.8. Care Priorities

Staff were asked what they believed were the main care priorities for a patient of this nature. A number of responses were provided and participants could select as many options as they felt applied. They were also provided with an option to write down a care priority should it not be mentioned on the list.

In the responses in the pre questioning the majority of staff felt that comfort was the main priority for a patient of this nature (38.6%, n=17). Only four respondents (9.1%) believed that specialist intensive rehabilitation was a care priority. 11.4% (n=5) reported a care priority of maintaining current function, 13.6% (n=6) believed the patient required general rehabilitation while 2.3% (n=1) reported ‘other’. This other was chiropody. 11 respondents (25%) reported multiple care priorities. These were a combination of comfort and maintenance of current function (18.2%, n=8) and comfort and general rehabilitation (6.8%, n=3). In the follow up questionnaires greater numbers (67.5%, n=25) of participants reported they believed rehabilitation was the main care priority for the patient as opposed to comfort and maintenance of general function (13.5%, n=5).

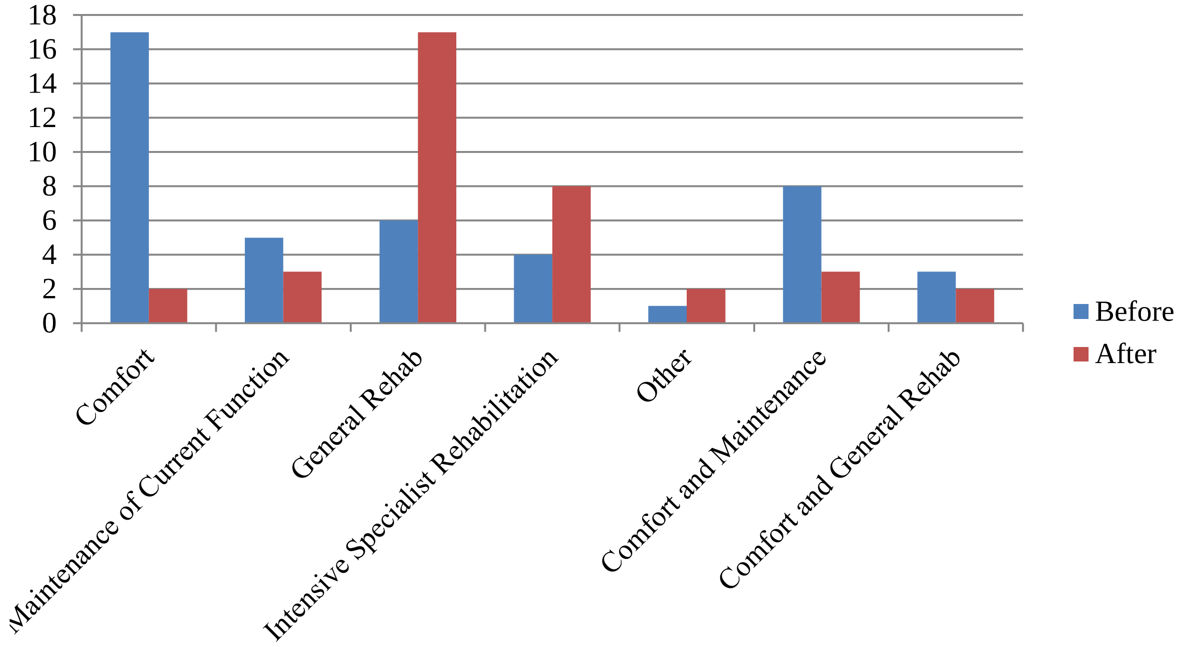

Figure 24: Comparison of Staff Reported Care Priorities Before and After the Study

The reduced difference in beliefs surrounding comfort as a care priority was significantly different p=.00, (p<.01). McNemar tests also found a significant difference (p=.001, p<.01) in beliefs surrounding general rehabilitation as a care priority pre and post the research interventions.

4.10.9. Perceptions of Current Care

The staff perception of current care was also explored via this questionnaire. Staff were asked to rate the care services provided to the patient by this setting. They were provided with an ordinal scale ranging from 'fair' to 'excellent'. The staff reported scores are highlighted in the following table. Before the research study almost half (45.4%, n=20) of the 44 respondents reported the current care of the person with DoC to be good. 31.8% (n=14) of respondents reported their care was 'very good' while 2.3% (n-1) felt it was 'excellent'. Following the research programme no respondent rated the care services as fair. 54.1% (n=20) rated the care services as 'very good' or 'excellent'. The other majority (45.9%, n=17) viewed the services as 'good'.

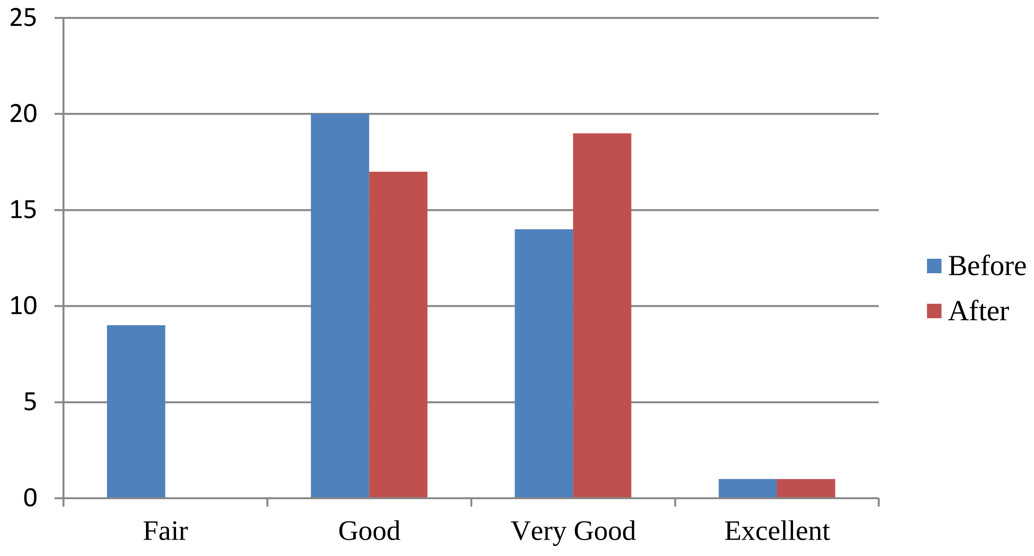

Figure 25: Staff Rating of Care Services Before and After Study

4.11. Perspectives of Family

In total 9 family members participated in pre and post questionnaires. They completed the FSQ and the STAI before and after the research programme. Two thirds of the family members were female (66.7%, n=6). Their relationship to the research participants consisted of mother (22.2%, n=2), father (n=2), sister (n=2), husband (11.1%, n=1), sister-in-law (n=1) and daughter (n=1). Their time spent caring for their relatives with PDoC ranged from 6 months to over 9 years.

The care locations represented that of participants 1-5. One of the family members (11%) cared for somebody living in a nursing home, one frequently visited their relative in a community hospital, three family members (33%) cared for somebody in an acute hospital setting while four family caregivers provided care to somebody in a rehabilitation unit.

4.11.1. Family Strain Questionnaire

The nine family members were asked to complete the Family Strain Questionnaire pre and post intervention. Their total score on this assessment are summarised in the table below. Differences in total scores pre and post intervention were not found to be statistically significant on a Wilcoxon Signed Ranks Test.

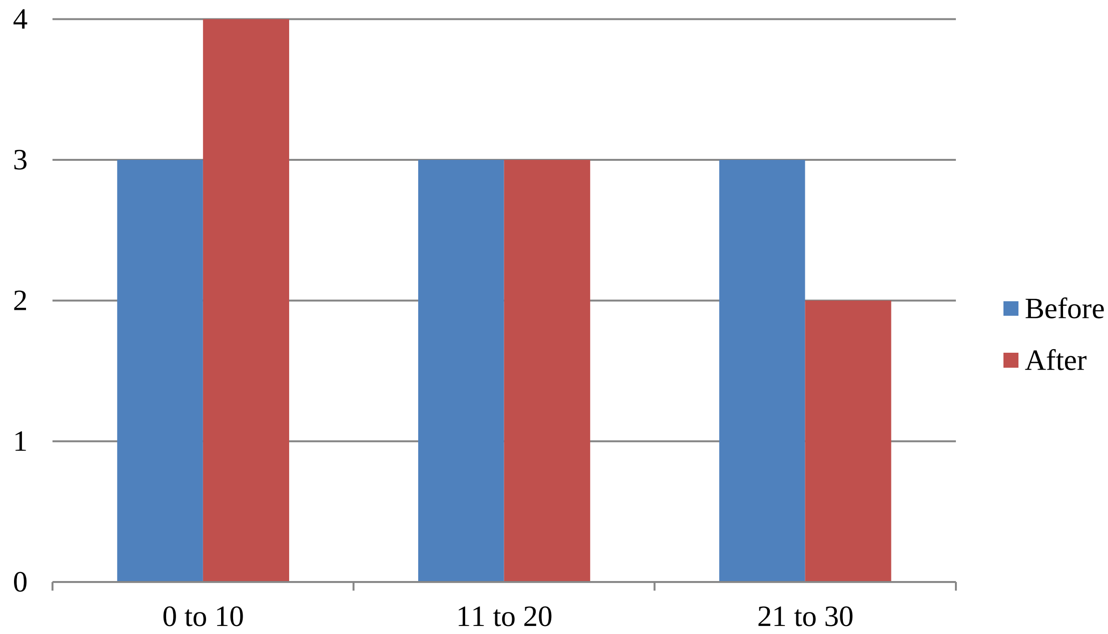

Figure 26: Total Scores on FSQ Before and After Study

Certain items on the scale had a reduction in 'yes' responses. Only one item had an additional yes response – "I feel guilty when I leave the patient alone or with somebody else". All items which had a change in scores are highlighted in the table below.

Table 32: Changes in Responses on FSQ Before and After Study

Question	Frequency of Yes - Before	Frequency of Yes - After	Frequency of No - Before	Frequency of No - After
I feel the need for advice on how to look after the patient	6	4	3	5
I sometimes think about the death of the patient	8	6	1	3
I always think about how things will end	4	3	5	6
I have too many things to think about	7	6	2	3
I wish I could control my emotions better	8	6	1	3
During this period I feel very anxious about the future	6	4	3	5
I have felt very stressed during this period	6	5	3	4
During this period I have not wanted to go out much	5	4	4	5
I feel guilty when I leave the patient alone or with somebody else	3	4	6	5
I am pessimistic about the future	4	2	5	7

4.11.2. State-Trait Anxiety Inventory

Family participants completed the STAI prior to the research intervention and post intervention. Their total scores are shown in Figure 27 below.

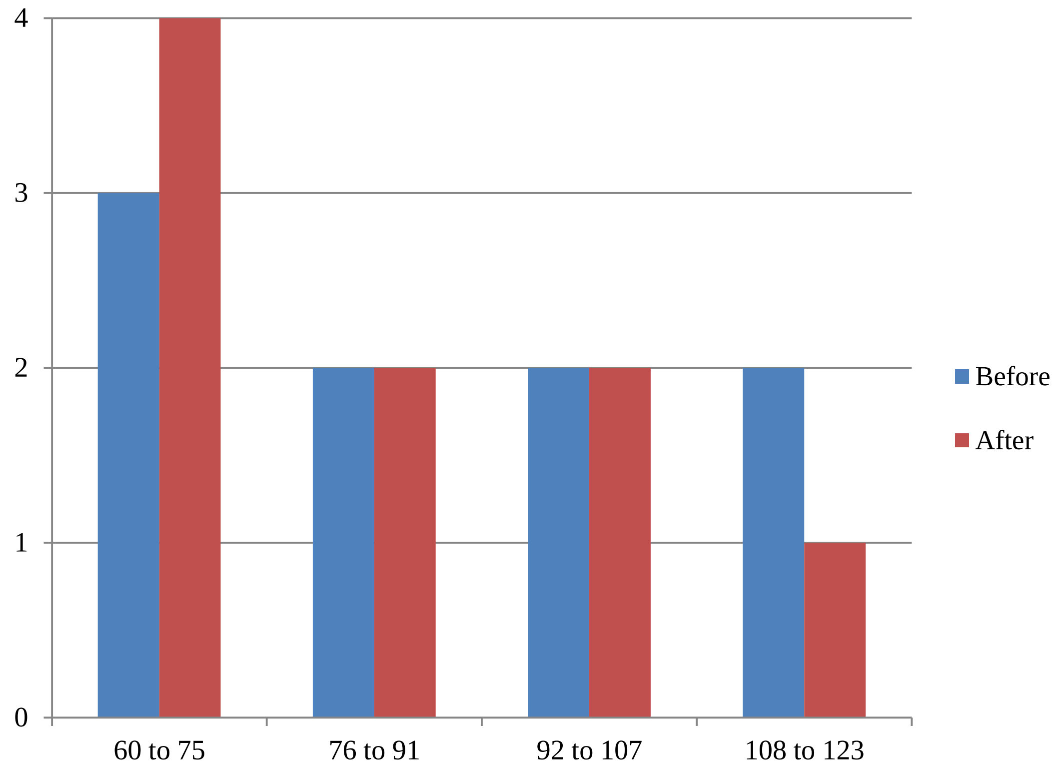

Figure 27: Total Scores on STAI Before and After Study

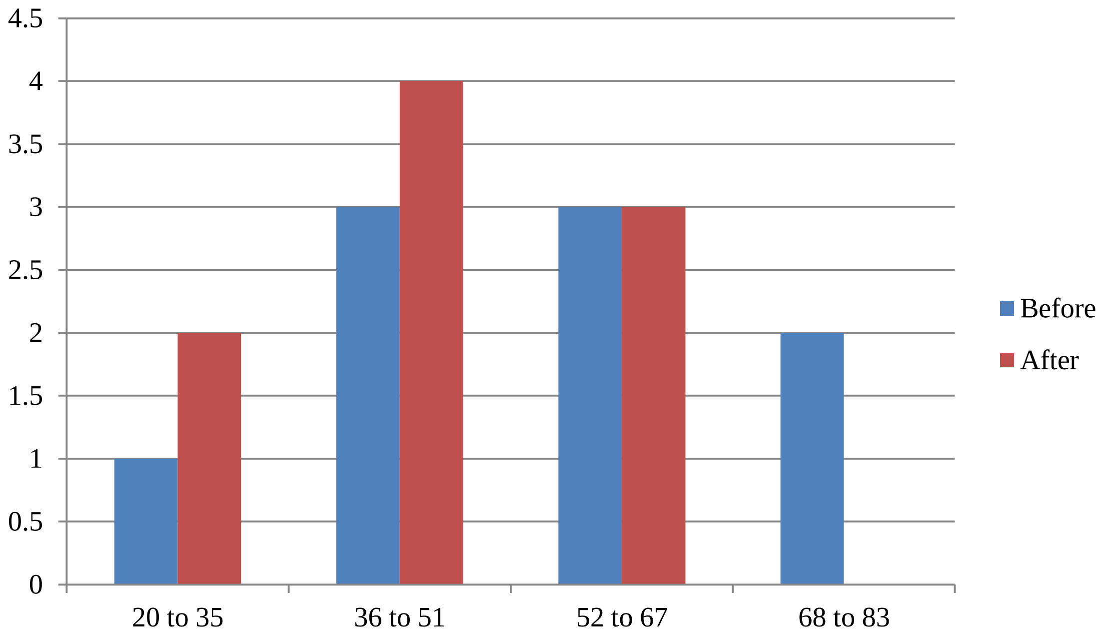

Figure 28: Total Score on the State Scale of the STAI Before and After Study

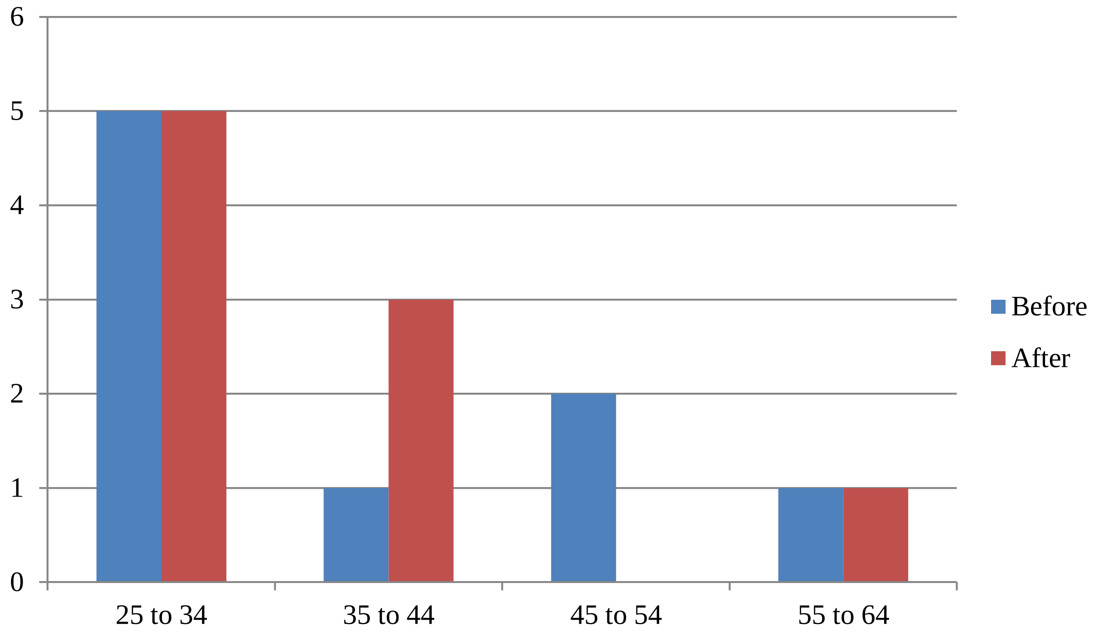

Figure 29: Total Score on the Trait Sale of the STAI Before and After Study

4.12. Research Questions

4.12.1. Phase One

4.12.1.1. What are the current health settings providing care to people in a VS or MCS in Ireland?

A number of healthcare settings responded to the nationwide questionnaire. Specialist wards in acute hospitals and rehabilitation facilities cared for 41.5% (n=17) of people considered to be VS or MCS. Full time residential and nursing home settings cared for 24.4% (n=10) of people while community hospitals accommodated and cared for 21.9% (n=9). Five people (12.2%) were found to be cared for in non specialist wards in acute hospitals including general medical and orthopaedic wards. While time since onset for the DoC ranged from one month to 24 years, this was unrelated to their care setting and no clear pathway could be identified, i.e. people with prolonged conditions were found in acute settings.

4.12.1.2. What are the common aetiologies of disorders of consciousness in this client group?

In the majority of reported cases the aetiology was that of dementia or other neurodegenerative conditions. Excluding those with end-stage neurodegenerative conditions 53.7% (n=22) of people had a traumatic aetiology. Types of traumatic injuries included road traffic accidents, falls, assaults, attempted suicide/parasuicide, drowning and gunshot injury. The remaining 19 people (46.3%) had a non-traumatic aetiology, mainly cerebrovascular conditions and falls.

4.12.1.3. What care services (neurology, occupational therapy, physiotherapy, speech and language therapy, neuropsychology and other) are provided to people PDoC in Ireland?

Specialist medical and therapeutic services were found to be extremely limited. People with MCS were nearly two and a half times more likely to receive specialist or therapeutic services than those considered to be in VS. No people considered to be VS received neuropsychology services. The amount of people receiving some form of clinical service ranged from 0% to 53.7% with huge variability. Physiotherapy was the most common service received with 53.7% (n=22) people considered to be MCS received some form of this form of therapy.

4.12.1.4. Are this client population receiving regular re-assessment of awareness?

This study found variability in the both the timing and nature of cognitive re-assessment. While use of appropriate standardised measures of awareness such as the WHIM and the SMART were reported, measures such as the MMSE which is not appropriate to assess these people were also reported. People considered to be in MCS were more likely to receive regular re-assessment. Three people considered to be in VS had not been re-assessed in over five years.

4.12.2. Phase Two:

Is there clinical benefit to providing an occupational therapy service to people with prolonged DoC in non-specialist long-term care settings?

4.12.2.1. Are there any clinical benefits (cognitive or physical) to the person with PDoC from participating in an individualised therapeutic programme??

Four of the five participants scored higher in the re-assessment phase following intervention. Higher scores were recorded for the WHIM (total number of behaviours and the highest number of behaviour) and the CRS-R. Only P4 scored the same as the initial assessment phase. This indicates that for four participants the number of behaviours they exhibited or were shown to have were increased as the result of provision of an individualised therapeutic programme. No improvement in scores in the SMART was seen for the two participants who completed it in both the assessment and re-assessment phase.

None of the participants had up to date behavioural profiles and so each were provided with an initial comprehensive assessment. This in itself has clinical benefits for the person living with DoC. For P1 the clinical and personal benefits from participation in the study are clear, functional communication which had not been seen previously was identified and established and she now has autonomy and choice when it comes to her daily routine and her medical treatment. While P2 demonstrated a plateau in his level of responsiveness the provision of information of his observed behaviours and his increased ability to demonstrate behaviours in standing to the specialist rehabilitation unit meant that a more comprehensive assessment could be provided. For P4 and P5 the observed behaviours while picking up a flask and painting respectively meant that both now had increased opportunities for interaction and expression. While there was little change to P3's daily routine detailed documentation surrounding her behavioural repertoire was now available and this information could be used throughout her ongoing rehabilitation.

4.12.2.2. What is the benefit to the families of people with PDoC from their family member participating in an individualised therapeutic programme?

Family strain was found to be reduced following the provision of an individualised therapeutic programme as measured by the FSQ.

Caregiver anxiety was showed to be reduced following the implementation of an individualised therapeutic programme as measured by the STAI but not significantly.

4.12.2.3. Are there any benefits to professional care staff from a person with PDoC receiving an individualised therapeutic programme within their long-term care settings?

The majority of professional care staff reported their experience in working with patients of this nature as 'good'. 81.8% of staff reported they were familiar with the term VS while 63.6% of staff reported that they were familiar with the term MCS. A number of incorrect beliefs surrounding the care of a person with DoC were highlighted. Following the study these beliefs were changed, with a significant number of care staff changing beliefs around care.

Prior to the research study the majority of care staff reported comfort as the main care priority for people with DoC. Following the study a significant number of care staff now reported that rehabilitation rather than comfort was considered the main priority. This significance was statistically significant at $p=.00$, $p<.00$ using a Wilcoxin Signed Ranks Test.

5. Discussion

This study has explored important aspects of the care and treatment of people with DoC from acute to long-term care. It consists of two phases. Phase one is a nationwide cross sectional study, exploring the ‘who’, ‘what’, ‘where’ and ‘how’ of care services for people with DoC in Ireland. Phase two provided in-depth case studies of people living with DoC in this country and explored the impact of therapeutic assessment and intervention for people with PDoC.

5.1. Discussion of Methodology of Phase One

Phase one of this study employed a cross sectional descriptive epidemiology design. The choice of a survey was selected in order to best address the research questions and it is one of the most popular data collection measures in social health and epidemiological research (Bowling, 2005). Although surveys are an efficient, inexpensive and flexible method of data collection it is argued that they are becoming less effective of collecting data from physicians due to time restraints and active policies of non-response to surveys (Wiebe, Kaczorowski & MacKay, 2012). Response rates for medical doctors are on average about 10% lower than studies conducted with the general population (Cummings, Savitz & Konrad, 2001). Online surveys were considered; however, response to online questionnaires can be affected by automated (out-of-office) replies, server rejection, spam filters and automated forwarding (Dobrow et al., 2008). In addition, postal addresses were much more accessible and up to date than e-mail addresses and no e-book of current consultants’ and nurse managers’ e-mail addresses was available.

The primary reason for non-response among health care professionals is reported to be time (Sudman, 1985). Low response rates can raise issues like non-response bias or the likelihood that non-response is indicative of physicians different from the population under study. Based on previous findings (VanGeest, Johnson & Welch, 2007; Edwards et al., 2002), a number of measures of improving response rate to postal surveys were used including keeping the questionnaires brief, less than 1,000 participants, personalised envelopes (where possible), use of coloured paper and use of university headed paper. Reminders were not sent but may have improved response rate (Cook, O Dickinson & Eccles, 2009). A survey response rate of approximately 60% is suggested in order to ensure that non-response does not affect the validity of the study (American Medical

Association, 2012; Burns et al., 2008). This was not achieved in this study and the level of bias from this low response rate is not known.

It was not possible on this occasion to survey general practitioners and thus information on people living with VS or MCS who are cared for at home was not collected. No previous study has explored the assessment and management of people with VS or MCS cared or in their home by family and this is an area for future research.

The survey used as part of phase one was not a standardised measure and thus validity must be considered. In order to increase the validity of the survey it was piloted prior to distribution. The use of a cross sectional postal questionnaire meant that this study covered a wide geographical area. In the event of an unclear diagnosis, subjective reporting may have led to inconsistencies in the reported diagnosis of the clinical population being explored. Detailed definitions and examples were provided to all participants in order to increase accuracy. In addition, only directors of nursing and clinical nurse managers were surveyed in residential care settings. This nursing population, in addition to the medical consultants being surveyed would have much clinical expertise and experience and be very familiar with the client population. Furthermore an option to report an unspecified diagnosis (unclear whether it is VS or MCS) was provided.

By expanding on a similar study conducted in Northern Ireland (Wilson et al., 2002) and including additional numbers of medical specialties, every effort was made to capture people with DoC in every possible care setting. The novel venue based model also ensured that each location was considered. The use of this novel venue model of understanding the management of people with PDoC was the first such study to examine care services on a national scale.

5.2. Discussion of Methodology of Phase Two

Little is written about conducting clinical research with this population in a real world clinical setting and thus the methodology had to be flexible to accommodate not only a distinct and complex clinical population but also to be relevant to today's practice and clinical contexts. Multiple case study methodology was selected in order to provide such information. The strengths and limitations of multiple case study design will be discussed in this section.

This population of clients are heterogeneous and present with different symptomology, social environments, secondary complications, care needs, etc. Case study methodology, with its flexible time frames, allowed the researcher to amend and adapt the intervention according to client need. This was also the most ethical method of implementing a therapeutic programme. It allowed for the collection of real world data set in clinical contexts. Other methodologies such as single case experiments would not allow for this level of flexibility and so could have led to constraints in study design and data collection. The duration of intervention varied for each of the five participants but was originally set at approximately sixteen weeks. In the case of P1 the intervention was extended by a further sixteen weeks. This was due to the functional level of awareness identified and the ethical obligation in relation to this finding. An unexpected finding such as this is important to consider when conducting research in clinical settings with people with PDoC. P1 was observed to have high levels of fatigue and so shorter sessions over longer periods of time were provided. The researcher had to be available at different times of the day in order to work with P1 when she was most alert. For example she usually woke late in the morning and so early morning sessions were not possible. When she was found to have consistent communication P1 was provided with a choice at the beginning of each session whether or not she wished to partake in therapy sessions. Often she declined to engage and this was respected. It meant that a number of sessions were re-scheduled and this added to the length of the study. The flexible nature of case study methodology allowed this awareness to be explored in full and a comprehensive handover of care to be made.

The validity and generalisability of case study methodology is often called into question and are seen as key limitations of this methodology (Yin, 1999). In order to improve validity standardised assessments were used where possible. Where this was not possible, such as the staff questionnaires, surveys were developed and piloted. Sampling validity was also considered and using purposive sampling it was ensured to have a broad range of participants to fully explore the phenomena under investigation. The use of an independent assessor also contributed to the validity of the study design and in reducing assessor bias.

Case studies are often considered to be non-generalisable; however Flyvbjerg (2006) believes the opposite to be true, arguing that rich data collected within real world contexts has more merit than drawing conclusions from context independent sources. While case study methodology has limited representatives, multiple cases were chosen in this instance to increase available data. The results are not generalisable to other cases, owing to both the design and heterogeneity of DoC. The findings do however raise important considerations and questions for clinical practice. This exploratory study therefore provides support for further research in this area.

One limitation of this study was the lack of qualitative data collection measures. While this was not possible to implement with the participants themselves the study may have been enhanced by information gained from qualitative data from the perspectives of staff and family members.

5.3. Discussion of Phase One

Apart from a preliminary study exploring three post-acute rehabilitation settings (Ni Lochlainn et al., 2012) there are no demographic data regarding the number of people living with DoC in Ireland. Phase one surveyed every adult residential care setting in the Republic of Ireland as well as surveying consultants from seven medical disciplines. A piloted questionnaire which focused on identifying the number of people living with a DoC under the participants' care was used. Where a person with DoC was identified, questions in relation to aetiology, current care services and re-assessment procedures were asked. This cross sectional nationwide survey identified forty one people who met the criteria for VS or MCS.

5.3.1. The 'Who' Question – Who Are the People Living with DoC and PDoC in Ireland?

The people with DoC discussed from this point on excluded people with end stage dementia and other neurodegenerative conditions. The age range (from 23 to 92 years) was broad and people were identified in all regions of the country. Time since onset ranged from one month to twenty four years. This is an important finding in terms of the care needs of people with DoC. People living with these conditions can and do have a normal life expectancy so the provision of appropriate care across a life time must be considered.

Prognostic studies suggest that younger people and people with a traumatic aetiology have a better prognosis than older people with DoC or those with a non-traumatic brain injury (Whyte & Nakase-Richardson 2013; Luaute et al 2010; Lammi et al 2005). The majority of people identified in this study were male and 53.7% had a traumatic aetiology, both in keeping with international findings (Godbolt et al., 2013; Ni Lochlainn et al., 2012; Whyte et al., 2005). While Ni Lochlainn et al (2012) found a predominantly younger population, the results of phase one found a higher average mean age of 49.43 years. This may reflect a higher number of younger people receiving inpatient neurological rehabilitation in the three rehabilitation centres surveyed by Ni Lochlainn et al., It may also be possible that a higher percentage of younger people are cared for in their own homes instead of residential care settings. Alternatively this result may be indicative of people who sustained a brain injury in their youth and have survived with chronic conditions for longer. Despite a higher mean age found in this study it seems that Ireland has a significant number of young people with brain injuries of a traumatic aetiology.

People with DoC in Ireland are a heterogeneous group in terms of age, gender, aetiology and geographical location. The healthcare responsibilities of treating and rehabilitating people with DoC are therefore a national concern. In addition no epidemiological data or statistics are available for children aged 18 and under living with DoC. With no specialist paediatric DoC service in existence in this country the true picture of 'who' is affected by DoC requires further research.

5.3.2. The 'Where' Question – Where are People Living with DoC and PDoC in Ireland cared for?

There is one specialist rehabilitation centre in Ireland for people with DoC and this accounted for 7.32% (n=3) of people identified via the survey. The majority of people living with DoC in Ireland (48.8%, n=20) are cared for in either rehabilitation settings or in full time residential care (mainly nursing homes). Contrasting perceptions of what rehabilitation constitutes for this population were reported in the survey. Non-specialist acute hospital wards referred to themselves as ‘rehabilitation settings’. Similarly nursing home settings reported providing rehabilitation to people with DoC. This reflected the fact that therapeutic services were available upon request. Many centres reported providing rehabilitation to people with DoC but the nature and frequency of appropriate services is not known.

There is a lack of specialist care available in residential care units. The Health Information and Quality Authority (HIQA) govern the care provided in these units. Its National Quality Standards for Residential Care Settings for Older People Report (2008) highlights the importance of people in residential care units having access to allied health professionals. A recent Health Service Executive (HSE) audit of service provision (2013) found that one third of residents in private and voluntary nursing homes have access to publicly funded occupational therapy. Half of people in public homes can access occupational therapy. Community hospitals report providing care to 21.9% (n=9) of the sample. Community hospitals may or may not be led by a consultant and the level of therapeutic services available varies. Occupational therapists working in the community and in primary care are responsible for providing care in residential units and community hospitals. Often it is these therapists who will be providing therapeutic input for people with PDoC if they receive a referral to do so. However, currently they receive no formal training or education, other than as undergraduates, in working with this population. No professional guidelines specific to occupational therapy are available and the quality and quantity of care is location and therapist specific.

Acute care settings reported caring for 29.3% (n=12) of the reported population. This is not unusual considering the medical needs of people with acute DoC. However, in this sample the time since onset of injury ranged from 6 to 108 months. The rehabilitative, personal and familial impact of remaining in an acute hospital for long periods of time, often while awaiting a specialist bed is not known. Early rehabilitation and intervention can lead to better outcomes for people with DoC (Nakase-Richardson et al., 2012). The impact on services and the functional outcomes for people with DoC may be affected as this group of patients appear to remain in acute hospitals for long periods of time.

The limited availability of specialist care is identified in phase one with under 8% of people living with DoC residing in a designated rehabilitation unit. Once discharged from this centre their rehabilitation input is unknown and re-admission is rare. It also must be considered that the only specialist rehabilitation is available in the capital of the country, thus highlighting that the 'where' of specialist care is geographically distant for a large proportion of the population.

5.3.3. The 'What' Question – What Care Services do People with DoC and PDoC Receive in Ireland?

People living with both VS and MCS were under the care of a variety of consultants. In Ireland, on entry to an accident and emergency department, a person is cared for automatically by the consultant on call. Once medically stable that person can then be referred to other specialties for continuing care needs. It is clear that people with DoC may be under differing medical specialities even after the acute phase. This may be for different reasons; that at the time of the survey the person was temporarily under the care of a particular consultant due to need, e.g. under the care of a consultant orthopaedic surgeon due to a recent fracture; that this person was not referred to neurological or rehabilitation services; that they are currently on the waiting list for neurological services or they have been discharged from these services. Thirteen patients were identified by consultants in neurology, neurosurgery, geriatric medicine, orthopaedics, cardiology and rehabilitation medicine.

Early intervention and intensive early therapeutic interventions have shown to be of benefit following traumatic brain injury (Browne et al., 2013; Gelling, 2004; Oh & Seo, 2003). In this context there is a lack of therapeutic services for the person with DoC even in the acute stages. The results indicate that physiotherapy is the most common therapeutic intervention provided to people with DoC in this country while neuropsychology is least available. In terms of occupational therapy, 17% (n=7) of people considered to be a VS received occupational therapy services and 39% (n=16) of people considered to be in a MCS received occupational therapy. None of the participants with an unspecified diagnosis received occupational therapy input. The frequency and timing of occupational therapy services was not explored in detail. It is also unclear if people were reporting that occupational therapy was available to these patients or if they were actually receiving input.

The delivery of occupational therapy services was found to be determined by the aetiology and current care setting of the person with DoC and PDoC. People reported to be in VS received less occupational therapy. The role of occupational therapy for people with DoC is not well established (Munday, 2005). The standard of treatment and rehabilitation for people with DoC in Ireland remains undetermined.

People with DoC are not active participants in rehabilitation and it can take time and resources to establish their true behavioural baseline and level of consciousness before intervention can take place. Currently in Ireland, people are provided with a twelve week assessment period in the specialist centre and then a follow up programme is provided to the continuing care centre. A twelve week programme may not be appropriate for people with DoC as their progress can be over longer periods of time, often with smaller gains to be made (Whyte & Nakase-Richardson, 2013). People with DoC can often lose contact with specialist services and services as they move into long term care (Berube et al., 2011). Therefore without support of people who advocate for services on behalf of the person, a large number of people with DoC never re-engage with appropriate rehabilitation services. This was demonstrated in phase two of the study where just one participant of the five continued to be seen by a rehabilitative consultant as an outpatient.

5.3.4. The 'How' Question – How are People with DoC and PDoC followed up in terms of treatment and rehabilitation?

Less than half of questionnaires returned contained information regarding the time since re-assessment of level of consciousness. This may indicate a misunderstanding regarding the question or perhaps evidence that it does not occur routinely. It is important to note that this survey took place prior to the publication of the RCP Guidelines around PDoC (2013). Therefore no guidance for the purposes of re-assessment was available and the practice of re-assessment was dependent on the consultant. These guidelines have since been published; however they have not been adopted by the Irish rehabilitation services and so there remains no onus on practitioners to conduct such regular re-assessment.

Though not asked for explicitly, some centres provided information on the type of assessment tool they were using in order to assess consciousness. While two assessments mentioned were appropriate (WHIM and SMART), one setting reported use of the Mini Mental State Examination to assess a person's level of consciousness. Use of this assessment was reported by a long term residential care setting. This assessment tool is inappropriate for use with a person in PDoC and could be indicative of a lack of knowledge surrounding appropriate assessment with this clinical population. An alternative explanation may be that this assessment was appropriate as the person had progressed in levels of awareness and no longer had a DoC. This is less likely but raises the issue of the negative and long-term consequences of labelling.

The RCP (2013) state that clinical re-evaluations should be carried out six and twelve months post injury and every year thereafter by an appropriately skilled team. This is considered best practice. This study shows that not only is this not taking place but the type of re-assessment being undertaken may be inappropriate. In this study it was found that nearly half of patients deemed to be in a VS had not been re-assessed in over five years. The majority of people in MCS were reportedly re-assessed every six months with one centre highlighting a person in MCS who had not been re-assessed in over three years. People with MCS have been shown to have a better rehabilitation potential than those considered to be VS (Luaute et al., 2010) and therefore they may be more likely to be referred to re-assessment services.

Lack of appropriate re-assessment and follow up can have serious consequences for the person with DoC and impacts directly on the care and rehabilitation they may receive. This study highlights the need for further investigation into the type and amount of re-assessment received by people with DoC in this country. Not only was lack of re-assessment identified but the type of re-assessment also proved a cause of concern. In the second phase of this study the benefits of multiple forms of behavioural assessment are highlighted. However in phase one care centres reported that they were using one tool or that they were using an inappropriate tool in order to measure consciousness. It is not known by whom and how these assessments were being administered and this is an area for further research. People with VS were reported not have been reassessed in over five years. This is an alarming statistic when studies show that people in VS can show improvement after eighteen months (Wilson, Dhamapurkar & Rose, 2016) and after five years (Estraneo et al, 2010).

5.3.5. Conclusion

Three specialist rehabilitation beds are designated for people with DoC in this country. Underestimation of the prevalence and incidence of these conditions in this country may contribute to this allocation. Phase one of this study highlights a large number of cases who require formal assessment and regular re-assessment. At present the rehabilitation services allocated for people with PDoC do not appear to be meeting these needs.

5.4. Discussion of Phase Two

The study found that following the programme there was a change to each participant's clinical presentation. This change was measured in different ways; by an increase in score on neurobehavioural assessments, demonstration of a new behaviours, an improved clinical environment such as increased therapeutic input or a combination of these changes. In this section findings from each case study will be discussed in detail. Following individual discussion of each case, emergent themes across multiple cases will be discussed.

5.4.1. Participant One

P1 was a 55 year old female, nine years post ictus with a hypoxic nTBI diagnosed as being in a vegetative state. She had been cared for in a local regional hospital for nine years and had subsequently been transferred to a community hospital. She had multiple physical limitations, limited family involvement and had never received any specific assessment or intervention regarding her diagnosis of VS. The main areas for discussion include misdiagnosis, the issue of labelling in PDoC, the role and function of an AF buzzer switch in assessment and the importance of an up to date and comprehensive personal history.

5.4.1.1. Misdiagnosis

During this study P1 demonstrated consistent functional communication, indicative of a person with EMCS. This finding demonstrated that she had been misdiagnosed. Misdiagnosis, as described in the literature review remains a significant concern in DoC management (Schnakers et al., 2009; Childs, Mercer & Childs, 1994; Andrews et al., 1997). This case of misdiagnosis may be attributed to a lack of specialist diagnostic assessment initially, inaccurate follow up and assessment or due to slow emergence of recovery over time. No theory can be proven or disproven and so to state a reason for this finding would be speculative. P1's case demonstrated the serious implications for people living with misdiagnosis and the impact this has on a person's quality of life and care (Giacino et al., 2004; Andrews et al, 1996; Childs, Mercer & Childs, 1993; Tresch et al., 1991). The lack of rigour and clarity surrounding re-assessment means that there is no guarantee cases such as this are unique. The prognostic parameters for nTBI (American Academy of Neurology, 2011; Multi Society Task Force, 1994) are called into question with this case. Important decisions are made based upon diagnosis (Wild, 2007) and P1 received no rehabilitative services apart from passive range of movement exercises. At the beginning of the study her nutritional intake was poor at 1000kcal daily and despite referral no changes were made. Once functional communication was found this nutritional intake was increased by 250kcals daily. The decision to increase therefore was based on perceived increase in function.

5.4.1.2. Labelling

P1 had been diagnosed with VS while still in ICU. In her medical chart there was no evidence of formal diagnostic assessment or systematic behavioural review. This diagnosis was accepted by her treating team and no referral to a specialist centre for formal diagnostic assessment was sent. It is professionally and socially accepted that the term vegetative carries with it negative connotations (Von Wild et al., 2012; Laureys et al., 2010) and contributes the therapeutic nihilism surrounding PDoC (Laureys & Boly, 2008). When working with people with PDoC labelling is a serious concern with widespread consequences. For P1 this meant that she received no follow up, a limited nutritional intake, reduced family contact and no rehabilitative input. Even when it was apparent that functional communication was present it took a period of time to change attitudes towards her care and encourage staff to facilitate her to make choices.

5.4.1.3. Use of AF Buzzer Switch

Use of an AF buzzer switch is indicated in one standardised neurobehavioural assessment only, the SMART. The SMART also provides this buzzer switch. Use of the switch for P1 had major consequences, demonstrating that she was capable of consistent functional communication. This functional communication was not demonstrated using the WHIM or CRS-R assessments. This highlighted the importance of such assistive technology during assessment and intervention for people with PDoC.

During the initial assessment the SMART protocol is to select the body part with the most voluntary movement to trial the switch. Due to her physical limitations P1's head was the only body part with visible voluntary movement. This head movement was used during the ten assessment sessions to explore her ability to press the switch. No consistency was found in pressing the switch using her head. This may have been due to her auditory sensitivity. However due to the limited voluntary movement elsewhere head movement was chosen as the best method for trialling the switch.

It was not until the intervention stage that the limited movement in her right hand was used to trial the switch. This movement was limited to a few degrees of wrist extension. This limited movement was evident despite contractures on the wrist and fingers of her right hand. With this movement P1 was able to press the buzzer switch.

Once consistent functional communication was identified, P1's scores on the WHIM, CRS-R and the SMART all increased. This was in the communication subsets of each scale. Scores on both the WHIM and CRS-R increased using the buzzer switch. This is interesting as neither scale explicitly state to trial such a switch but were augmented by its use in this case. No other behavioural evidence of awareness was demonstrated as no other functional movement was observed. If this consistent communication had not been discovered, then all scores on would have remained the same. In this case study the choice of the right hand was not the first choice and possibly may not have been trialled at all if this slight movement had not been explored. It is possible that a clinician may not have explored this movement owing to time and resource pressures, yet this was lead to a significant and important finding for P1.

Exploration of P1's functional communication also discovered a number of her cognitive issues. While she demonstrated good autobiographical memory her working and short term memory were impaired. She was unable to remember things said to her after approximately one hour. This supports the recommendation that people working with PDoC should allow for poor memory and introduce themselves and their reason for being there at the beginning of every session (Wilson, Gracey & Bainbridge, 2001).

5.4.1.4. Collating Personal History

As stated in the results section when functional communication was established P1 was able to confirm her interests and likes. In this case it was clear that the information on file regarding these preferences were incorrect. While it was originally recorded in her medical chart that she liked country music, this was refuted by P1 herself who was able to later report she preferred classical music. Over the past ten years country music had played in her room almost daily. The original documentation was based on a report from her husband while she was in ICU care. Recorded personal preferences are important as they help guide selection of sensory stimuli in therapy sessions. Some researchers find personal and meaningful stimuli are more likely to produce a response (Di Stefano et al., 2012). If these personalised stimuli are inappropriate then this response may be affected. This study recommends that personal histories be compiled from multiple sources. Peers and friends, in addition to family members should be included in collating personal histories. For example a mother, older brother and friend all might have different opinions about what the person likes depending on their relationship to that person. A variety of stimuli should always be presented during assessment and intervention.

5.4.1.5. P1 Conclusion

P1 was a case whereby functional communication was discovered ten years post injury. This finding is important as it highlights the vulnerability of people with PDoC in the absence of clear protocol surrounding diagnostic assessment, re-assessment and follow up. The negative consequences of misdiagnosis and labelling were clearly evident in this case. In addition the importance of repeat measures of functional communication status using different methods and different parts of the body was highlighted.

5.4.2. Participant Two

P2 was a 23 year old male, cared for in an acute hospital and had the shortest time post ictus. He was the victim of a traumatic assault six months prior to commencement of the study. P2 was awaiting a place in a specialist rehabilitation hospital. While he demonstrated some initial progress and fluctuating levels of awareness he then had a plateau in his rehabilitation. In this case example early intervention, the assessment and management of PDoC in acute hospital settings, the importance of multidisciplinary team working and patterns of recovery will be discussed.

5.4.2.1. Early Intervention

In the absence of clear protocols decisions regarding early rehabilitation are physician dependent. Since initial admission P2' care was overseen by a consultant general surgeon. He was referred to neurology for botulinum injections for his left elbow. Despite this involvement with neurology services there was no recommendation to transfer his care to neurology. He was managed by a multidisciplinary team on a general medical ward and waited one year for a bed in the specialist rehabilitation centre. Early intervention and rehabilitation have been shown to lead to better outcomes and reduced disability following brain injury (Browne et al., 2013; Gelling, 2004; Oh & Seo, 2003). With limited specialist rehabilitation services there are long waiting lists for such services. In this case example P2 was cared for in a general medical ward in a regional hospital while he awaited a place at a national rehabilitation hospital. This waiting time was a minimum of one year. There is an opportunity cost involved in such long waiting times, whereby the individual can miss out on the benefits of early rehabilitation, leading to increased secondary complications and increased disability long-term (Fins, 2013). Where possible rehabilitation interventions should commence once the person is medically stable in order to maximise the chances of some recovery. Acute hospital beds are valuable commodities in healthcare systems across the world and thus the focus in acute care environments is on discharge from hospital. At the commencement of this study P2 was receiving OT for maintenance of his range of movement on a needs basis and physiotherapy twice weekly to improve his respiratory status. These therapeutic services were reduced after three months due to increased demand on discharge planning for other service users.

5.4.2.2. Assessment and Management in Acute Care

While advantages were seen in implementing such a programme in an acute care environment there were also difficulties. Firstly it was difficult to control for external noise and environmental influences in a busy hospital environment. These influences needed to be recorded during formal assessment sessions as they also provided sensory stimulation. P2 was overstimulated in this environment. This overstimulation was controlled as part of this individualised programme by reducing visual stimulation in his room, educating staff on limiting the times the radio/TV were on for, managing the amount of visitors and allowing regular rest periods. Secondly, there was a high rate of staff turnover, in particular with the nursing staff. This meant that P2 had a number of different nurses caring for him over a short period of time. Staff involvement is important for all therapeutic programmes and with such a high turnover it was difficult to build knowledge and establish consistency in implementing the programme, particularly maintaining this controlled sensory environment. The impact of overstimulation for people in the early stages of PDoC is unknown but overstimulation has been associated with habituation (Tolle & Reimer, 2003) which can impact performance on neurobehavioural assessment. In addition overstimulation can lead to increased levels of neurofatigue which also can have an impact on behavioural performance.

Thirdly, the presence of acute medical conditions also limited the frequency and duration of therapeutic programmes. P2 had a craniotomy which meant that he had positioning limitations, i.e. he could not be in any position that would apply pressure to the right hand side of his head. He also had a hospital acquired infection and so he could only be assessed in a particular clinic room within the hospital. His respiratory needs also meant that he require multiple staff members to facilitate functional transfers and transportation within the hospital. Thus, such a programme requires input from all members of the multidisciplinary team in order to be conducted efficiently.

5.4.2.3. Plateau in Rehabilitation – Patterns of Recovery

P2 demonstrated consistent use of the AF buzzer switch during a number of sessions and was able to answer some basic comprehension questions correctly. He was observed to move his hand, arm and leg to verbal and written command. This was not established consistently. His highly fluctuating behaviours meant that it was difficult to establish a behavioural baseline. During the programme P2 demonstrated behaviours indicative of VS, MCS and EMCS at different times but not consistently. His presentation of fluctuating behaviours then plateaued prior to the re-assessment phase. The reason behind this was unknown. It has previously been suggested that people with PDoC demonstrated different patterns of recovery (Shiel, 1999) with some showing early recovery of behaviours, some continuing to fluctuate in behavioural presentation and some people demonstrating late recovery of behaviours. P2’s presentation may reflect a person who demonstrated early recovery of high level behaviours prior to a decrease and then subsequent plateau in behavioural demonstrations. No clear rationale behind this plateau was found. As per the SMART protocol of factors which may impact on performance there had been no change to his dietary or medication status, no issues with infection or other medical issue, no change to his bowel management programme and his sensory environment was appropriate. In order to promote an increased level of awareness a standing programme was conducted. Standing has been shown to increase behavioural demonstrations of awareness and increase brain arousal (Krewer et al 2015; Berget et al., 2014; Symons, 2008; Elliott et al., 2005). While this was effective in increasing his behavioural repertoire the high level functional behaviours seen earlier in the programme did not re-emerge.

5.4.2.4. Multidisciplinary Working

Prior to the study P2's level of awareness was assessed using the Glasgow Coma Scale. There was no multidisciplinary care plan in place and all health professionals worked separately. P2 had a hospital acquired infection which limited the time of day and clinical rooms in which P2 could be seen. During the standing study joint physiotherapy and OT sessions were developed and implemented. This standing programme was shown to be beneficial for P2, the therapy professionals and for the service. For P2 the standing programme increased wakefulness by fifteen to twenty minutes, and he demonstrated 11.3% (n=7) more behaviours on the WHIM when compared to sitting. For the staff involved there was an exchange of knowledge and skills which contributed towards continuous professional development. Finally for the service the standing programme was shown to be more cost effective than individual therapy sessions. Individual therapy sessions cost the service €164.58 per session while multi professional joint session was costed at €74.64, less than half the cost. Due to the complex presentation of PDoC collaborative working and joint therapy sessions are recommended for people with PDoC in acute hospital settings.

5.4.2.5. P2 Conclusion

Scores across all three behavioural assessments improved for P2 following the study. In addition detailed information regarding behaviours and assessments were provided to the specialist rehabilitation hospital P2 was transferred to after the study. This case study has shown that there is an opportunity to intervene quicker for people with PDoC by providing specialist programmes in acute, regional hospitals. Not only will this maximise further rehabilitation input but will work towards reducing secondary complications and disability, both of which ultimately increase the cost of long-term care and management.

5.4.3. Participant Three

P3 was a 68 year old female who was eighteen months post brain injury following a road traffic accident. Her husband was very involved and supportive, visiting P3 up to three times daily. She had received formal rehabilitation available to her and at the time of the study was cared for in a nursing home. One of the main findings from this case study was the discovery of inconsistent functional communication. These findings led to P3 having increased scores across all neurobehavioural assessment tools post study and will be discussed in this section.

5.4.3.1. Choice v Islets of Functional Communication

The behaviours observed in this third case study are indicative of a person who is making a choice regarding participation in a therapeutic programme. Her formal diagnosis was MCS- reflecting inconsistent low level behaviours. During the study behaviours indicated of EMCS such as functional communication were found. P3 was able to consistently comprehend questions and verbalise appropriate short responses. This was originally thought to be islets of responsiveness; however using video analysis evidence was collated that P3 was making a choice. She was clearly observed to close her eyes each time the researcher entered the room, anticipating time of entry appropriately and visually tracking as she walked out of the room. Each time a formal assessment environment was established P3 closed her eyes to all stimuli and did not respond.

Due to this proposed selective engagement with stimuli, P3 demonstrated fluctuating WHIM scores throughout the intervention phase. These behaviours ranged from no response to high level functional communication. On occasion she whispered short, relevant responses and eye pointed appropriately while more often there was no communicative response. Functional communication was only demonstrated during informal sessions using novel stimuli while there was eye closure and withdrawal to all formal assessment procedures.

One reason for this finding may be the time spent developing a therapeutic rapport with P3. This included reading to her, watching her favourite TV shows, gently encouraging conversation and spending time with her where no demands for engagement were made. Portraying empathy and spending time with a person are the two of the key elements of developing therapeutic rapport (Cole & McLean, 2003). The importance of strong therapeutic relationships in improving functional outcome has been documented extensively (Radomski & Trombly Latham, 2008; Scanlon, 2006; Leach, 2005). The development and maintenance of therapeutic relationships when working with people with PDoC has never been explored. This is despite assessment guidelines (Gill-Thwaites & Munday, 2004; RCP, 2013; Shiel et al., 2000) identifying that it is possible for a person with PDoC to demonstrate a preferred response to different people. P3 did not ever demonstrate functional communication in the presence of her husband, despite his increased contact time with her and the informal approach he had with her. Again this may perhaps reflect some choice on behalf of P3.

The behaviours observed may be representative of P3 making a choice as previously discussed or her fluctuating awareness may reflect the presence of islets of awareness. While she was clearly observed to opt out of some sessions whether or not she was making a choice regarding level of functional communication expressed remains unknown. More research is needed to better identify why these behaviours fluctuate and what can be done to promote consistency.

5.4.3.2. Follow Up

In this case example there was no involvement of any professional care staff who declined to be involved in any education session, training or to participate in any way in the study. Therefore while the findings were reported to all staff the follow up in relation to her rehabilitation programme is questioned. The effectiveness of any rehabilitation programme is reduced when there is limited follow up from staff working with the person daily. These important findings cannot be further explored without interested, skilled staff who understand the aims and objectives of such intervention and who wish to be involved. In the absence of clinical standards and policy there is no onus on professional care staff to provide rehabilitation programmes such as this to people with PDoC in nursing home settings.

5.4.3.3. P3 Conclusion

In this case example the person with PDoC appeared to be making a choice whether or not to engage in a rehabilitation programme. This has not previously been explored in medical literature and is an interesting case. It is speculative to suggest what may be causing this but the development of a strong therapeutic rapport, novel stimuli and informal presentation are suggested for consideration and exploration in future research.

5.4.4. Participant Four

P4 was a 31 year old male with a nTBI six years post injury. He had received a formal diagnosis of MCS by a rehabilitation multidisciplinary team. He was no longer receiving follow up from this team and was cared for in a long-term residential unit.

5.4.4.1. Co-morbidities

P2 had co-morbidities of epilepsy and diabetes and had hypersensitivity of his upper limbs bilaterally. Epilepsy and diabetes have a number of symptoms which could potentially impact on demonstration of awareness including lack of concentration, fatigue, reduced energy, blurred vision and tiredness (Engel 2013; Bilous & Donnelly 2010). There are no guidelines or accepted criteria for assessment and management of DoC with co-morbidities of epilepsy and diabetes. This is an important area of further research as the number and type of co-morbidities may be contributing to the high rates of misdiagnosis (Schnakers et al., 2009). As discussed in the literature review neurobehavioural assessment has a number of limitations (Giacino et al., 2014; Formisano et al., 2011; Gill-Thwaites, 2006; Majerus et al., 2005; Shiel, 2004; Giacino et al., 2002). The presence of specific co-morbidities and co-diagnoses has not been explored previously. Their presence may have a significant impact on neurobehavioural assessment and their management may greatly aid clinical neurobehavioural assessment.

5.4.4.2. Timing

P4 demonstrated a new behaviour after a considerable length of time. Using video analysis he was observed to pick up an object after 18 minutes. The results of this case highlight the importance of allowing varying lengths of time for a person to demonstrate a behaviour. The SMART allows up to one minute for a persons to demonstrate a behaviour, the CRS-R allows ten seconds while the WHIM does not specify time lengths. However, even when using the WHIM it is the decision of the clinician to decide the length of response time allowed. This can lead to discrepancies between clinical sites and clinicians working with people with PDoC.

5.4.4.3. Reduction of Secondary Physical Complications

P4 had full range of movement in all limbs and was able to tolerate standing for long periods. He received regular physiotherapy on a sustained basis over a number of years.

This was important to consider in relation to his results. The importance of postural positioning, in particular standing, in relation to eliciting behaviours was previously discussed in the literature review. In this case study it was possible to assess P4 in standing. While this did not result in any associated increase in awareness it does mean that P4 was able to undergo a comprehensive assessment of awareness, incorporating multiple postural positions as specified by the current guidelines (RCP, 2013). This was not possible in other case studies (P1, P3 and P5) due to secondary physical complication, particularly contractures and inversion of the feet. Thus, when secondary complications are present, and the person cannot be assessed in standing, this further limits the extent and effectiveness of neurobehavioural tools in clinical practice. In addition secondary complications of the upper and lower limbs can restrict movement and limit the type and nature of stimuli which can be presented. An example of this is if contractures of the upper limb are present then as person cannot reach out to take a ball as detailed in the CRS-R, they may be unable to press an AF buzzer switch as described in the SMART and are unable to turn pages of a magazine or pick up objects as assessed in the WHIM. The extent to which neurobehavioural assessment and individual neurobehavioural assessment tools are hindered by secondary physical complications is unknown. In this study participants with moderate to severe physical limitations were limited in which stimuli they could engage with and the postural positions in which they could be assessed. This is a major limitation for neurobehavioural assessment in clinical practice. Therapeutic interventions should be made available to people with PDoC throughout their care so as to reduce or avoid physical complications. This will also ensure that people who demonstrate awareness at later stages of their recovery will not be restricted in demonstrating this awareness using motor function.

The maintenance of full range of movement can also contribute towards the person's quality of life further along their recovery. P4 went swimming weekly with members of his family and this would not have been possible if he had severe physical complications as they would not have been able to transport him in the family car or manage his dressing or transfer needs in and out of the pool. In addition the level of physical limitations affects the amount of nursing intervention required to manage their basic care needs. Therefore by increasing focus on maintaining full range of movement the intensity of nursing need and ultimately the cost of health care required can be reduced.

5.4.4.4. *P4 Conclusion*

P4 demonstrated a new functional behaviour (picking up a flask and drinking) as well as a new non-functional behaviour (spontaneous smiling) five years after he had reached a plateau in his rehabilitation. He had no physical complications, his diet was well managed and he required no pre-assessment intervention. Other than residing in an under stimulating environment P4's management was very appropriate. The role this played in supporting the late emergence of these behaviours is not clear, however this case study highlights the importance of the provision of optimum care environments for people with PDoC long-term.

5.4.5. *Participant Five*

P5 was a 59 year old female, 41 months post ictus with a formal diagnosis of MCS. P5 had also been through all formal rehabilitation channels and continued to be seen as an outpatient at the rehabilitation hospital. In relation to the findings of this case study the following will be discussed; the choice and role of adapted equipment, P5's difficulties engaging with the SMART, the use of video recording for family involvement and the importance of consistent documentation.

5.4.5.1. *Adapted Equipment*

P5 was observed to have a number of spontaneous behaviours with her upper limb, particularly in her left hand. Using an adapted paintbrush this spontaneous movement was shown to be purposeful. She was able to bring the brush to canvas and make shapes with the paint. Upon verbal instruction she was able to dip the brush into different coloured paints. This functional behaviour was observed with some consistency and led to an increase in her CRS-R scores. This increase in scores was seen solely in the motor function scale. Being able to explore spontaneous behaviours in terms of their potential to demonstrate purposeful or functional movement is an important aspect of therapeutic intervention. Practitioners need to think outside the box in terms of adapting equipment to make it suitable for exploring all types of spontaneous behaviours observed. There are no set rules surrounding how to best do this and it is dependent on each clinician. Without clear guidance and clear standards in place aspects of care which are clinician dependent can be open to a range of variability.

5.4.5.2. *Difficulties Engaging with SMART*

P5 was not initially assessed using the SMART assessment due to her inability to engage with this assessment. She would close her eyes or fall asleep during sessions despite prompting and no full assessment session could be conducted despite ten attempts. This may be because of high levels of neurofatigue. However P5 was observed to maintain wakefulness for up to one hour in more informal settings. Therefore the impact of habituation to this detailed assessment must also be considered. P5's formal diagnostic assessment in a specialist case setting was made using the SMART. The SMART is a detailed assessment and is conducted in a formal manner over a period of three to twelve weeks. The hypothesis that people with some level of awareness may, on some level, demonstrate signs of habituation to an assessment is possible but difficult to prove. An alternative hypothesis is that as people progress through their care journey their ability to engage with a lengthy, formal assessment may be affected. This study has found two case examples of older female participants who had been assessed previously using the SMART assessment without any difficulty and during this study would not engage with this assessment. Their higher level of awareness (observed functional communication with P3 and functional movement with P5) may support the hypothesis that these participants may also be making a choice not to engage.

5.4.5.3. *Use of Video Analysis for Family Involvement*

Each session with P5 was video recorded for later analysis. In this case example another advantage to video record keeping was identified. P5's daughter was involved in her care. Her daughter was working and had a young child. She reported that she found it difficult to be present for some of her mother's therapy sessions which took place during working hours. P5's daughter often requested to see recorded sessions so she could be more involved in her therapeutic programme. This method of record keeping may be beneficial in reducing carer burden and strain. This is particularly true for people like P5 who demonstrate fluctuating behaviours as it lessens the pressure for families to be present for all therapy appointments. It also means that family members are less likely to miss observing less frequent behaviours.

Video recording sessions can also be used for staff and family training. It allows them to clearly see how stimuli are administered, the environmental set up and the response times allowed. Previous studies (Taylor, Mayell, Vandenburg, Blanchard & Parshuram, 2011;

Ellis et al., 1999) have shown that video recording has value in education, performance assessment, quality improvement and clinical care in acute hospital settings. The benefits of video analysis can contribute to increasing knowledge about DoC and is a useful pedagogy in staff and family education in long-term care contexts. It is something that should be considered in clinical practice with this population after the issues of personnel and time resources and confidentiality are addressed (Brown, 2003).

5.4.5.4. Importance of Consistent Documentation

During week two of the interventions phase P5's highest WHIM score decreased from thirty nine the week before to a score of fifteen. Her total number of behaviours on the WHIM assessment also dropped from sixteen to nine. When this was further explored using a urine dip test it was discovered that P5 had a urinary tract infection. Thus use of consistent and regular assessment and documentation could contribute towards early identification of infection. It is important that the pattern of behaviour responses be monitored on assessments such as the WHIM so as to identify as early as possible potential signs of infection.

5.4.5.5. P5 Conclusion

P5 demonstrated that, despite chronicity, a rehabilitation programme can continue to have benefits for the individual and their family. Increased family involvement due to video recording methods, increased activities through painting, consistent monitoring for potential infections prior to P5 becoming very unwell and preferences for assessment and stimuli were all recording following the individualised therapeutic programme.

5.5. Discussion of All Case Studies

5.5.1. Importance of Consistent Contemporaneous Documentation

In each of the case studies, even when participants were receiving therapy services there was no assessment or treatment protocol around intervention to increase levels of awareness. During phase one it was found that the majority of people with PDoC in this country are cared for in nursing home settings. This is not uncommon and long-term care is nursing homes is widely reported as the norm across different countries (Berube et al., 2011; Lavrijsen et al., 2005; Stepan et al., 2004). People with PDoC who live in long-term residential care units should have follow up by a skilled multidisciplinary team (RCP, 2013). This is to provide a formal follow up assessment of awareness levels and monitor changes in their clinical presentation. In order for this formal re-assessment to be effective up-to-date medical information must be available from long-term care units. Across all five case examples there was no transparent system of establishing and maintaining consistent, relevant documentation in relation to behavioural awareness. The system established as part of this study included monitoring pain and mood, weekly use of the WHIM, educating staff and family members on its use and the importance of their involvement in documenting behaviours observed and an informal diary which was used for family, friends, visitors and other care staff to record behaviours they had seen and the context and nature of this behaviour. Not only is this documentation important in terms of re-assessment and follow up but also has important implications for the people with PDoC. Understanding patterns of behavioural response can help identify changes in the person's presentation. If these changes are positive, i.e. increased behavioural responsiveness then they can be used to advocate for increased rehabilitation services. If they show a decrease in behavioural response this may help identify a medical or possibly psycho-social issue for the person. This is important for people with PDoC who are unable to communicate their needs.

5.5.2. Variability in Care

Due to the purposive sampling employed, there was wide variability in the demographic information of all participants. One common factor among all participants was that they were all from the same geographical region. Despite this, all presented with different care experiences, varying access to specialist services and were cared for in different care settings. These case examples highlight the variability and uncertainty surrounding the care and treatment of people with PDoC in this country.

Three of the five participants (P3, P4, and P5) had received the twelve week formal diagnosis in the national specialist centre. Only one (P5) was continued to be seen by the specialist centre as an outpatient. This raises concern regarding appropriate follow up and aftercare available to people with PDoC in this country. From the results it is clear that each participant would have benefitted from such follow up and each were shown to have developed increased behavioural repertoires from the individualised therapeutic programme.

P4 was the only participant without any contractures or who was not receiving intervention to improve muscle tightness. The impact of physical limitations and contractures on behavioural demonstration of awareness remains unknown. P1 was so limited by her physical contractures that she was unable to demonstrate a high level of awareness. The importance of maintaining range of movement for people with PDoC through multiple care locations is an important issue which requires a systematic approach across multidisciplinary teams.

5.5.3. Controlling Sensory Environment

In all five case examples interventions were conducted around establishing a controlled sensory environment. There are no set rules around how best to establish such an environment because it is dependent on person and environmental factors. One of the main aims of controlling sensory stimulation is to avoid over and under stimulation, the effects of which can impact on the person's ability to respond to stimuli. Over or under stimulation can lead to withdrawal or habituation from stimulation (Rankin et al., 2009) and this may impact on the ability to respond to stimuli in the context of formal behavioural assessment. Controlling the sensory environment involves the provision of a number of types of stimuli including active, passive, uni and multi-modal stimulation. It also involves controlling the length of time a stimulus is provided for and incorporating regular rest periods. P1 and P2 were found to experience over stimulation while P3, P4 and P5 all experienced under stimulation.

Establishing and maintaining a controlled sensory environment requires regular monitoring and needs to be re-assessed and updated at regular intervals. In this study it was observed that the establishment and upkeep of a controlled sensory environment is a simple and relevant intervention for people with PDoC.

5.5.4. Statistical v Clinical Significance

In-depth case studies such as these require time and resources. Each participant received between 12 and 24 weeks of assessment and intervention. This is a significant investment of clinical time. Following the study an increased behavioural repertoire was identified for all participants. Both P4 and P5 demonstrated new consistent functional behaviours, i.e. lifting a flask to drink and using an adapted paintbrush respectively. In the case of P4 scores on standardised tests did not change at all as this new behaviour was not identified by any standardised test. It can be argued that this investment of time is not justified in these cases where one new behaviour is seen. The ethical principal of distributive justice in a resource limited healthcare system must also be considered. Statistically significant findings are not the primary focus of case study methodology, particularly with chronic conditions. These type of findings do not address the ‘how’ and ‘why’ questions. This study explored not only changes that can be measured by statistical testing but also the clinical/meaningful significance of this programme to the participants and their families. Taking a drink from a flask independently appears minor in terms of the hours of intervention which P4 received. It is, however, a significant milestone in terms of his rehabilitation. Firstly it demonstrates that he is capable to developing new behaviours years following injury. It also is the only functional task he can complete independently and thus his autonomy has increased. For P5 the addition of painting means that she can complete an activity with her grandchildren. The impact for both families is also positive. When completing research with people with PDoC and their families, the clinically meaningful significance and promotion of quality of life must also be considered. This is particularly true owing to the limitations of neurobehavioural assessment and the lack of agreement surrounding prognosis.

5.5.5. Scope of Therapeutic Interventions

Different interventions were effective in different case examples. This highlights the need for individualised programmes for each person with PDoC due to the wide variability of presentation and secondary complications. P1 was found to press a buzzer switch consistently 11 weeks into the study after a number of verbal, non-verbal and written explorations of functional communication. P3 was observed to verbalise following informal interactions. P4 picked up a flask following approximately 20 minutes. P5’s spontaneous arm movement was found to be purposeful following trials of different adapted equipment. Following a rehabilitation plateau P2 was observed to increase his behaviours during a standing study. None of the therapeutic techniques above were specified by any guideline or assessment tool. There were the result of trial and error techniques, video analysis, increased intervention time and clinical reasoning. This does not make the intervention protocol easy to replicate for other practitioners. It also raises the complex clinical questions of how many types of stimuli/equipment should be trialled and for how long? It is difficult for the clinician to determine which methods will be selected for trial, how long they will be trialled and in how many ways will they be trialled? (e.g., extra timing, non-verbal or gestural). Presently it remains clinician dependent and as highlighted this can lead to variability in care. It may also be a cause of distress to staff who find it difficult to establish boundaries in what they should do for this client group and the extent to which this should be done.

5.6. Complementary Clinical Usability

This study has employed the use of three neurobehavioural assessments for the first time in a single study. This has generated valuable data on the clinical usability, differences and potential for a complimentary relationship between all three. In this section this will be discussed further. In this study all three assessments were used for the purposes of assessment and re-assessment. During the study the WHIM was used weekly to obtain measure of performance throughout the programme. Complimentary use of more than one assessment tool best equips the practitioner for comprehensive and detailed assessment of awareness. While increasing effectiveness it is acknowledged that they are still limits to the behaviours which can be captured. This is clear in P4's case. It is proposed that rather than be classifying the SMART, WHIM and CRS-R, according to their psychometric properties, they should be considered in terms of their clinical usability, i.e. based on person and environmental factors.

The complimentary use of all three will be discussed under design, aims, implementation in practice, assessment environment and stimuli. These factors are summarised in Table 32. It appears that a strong complimentary relationship exists between joint use of the SMART and WHIM owing to their contrasting design. The CRS-R is similar in aims to the SMART, is used less frequently and for shorter duration which may be more suitable to people with PDoC presenting with fatigue, habituation or medical concerns. Through use of all three at regular, appropriate intervals a number of aspects of awareness were discovered for all participants in this study. Therefore, it is suggested that the limitations of one assessment can be reduced by the strengths of an alternative tool.

5.6.1. Design and Aims

The SMART is a diagnostic tool. By categorising and documenting both inconsistent and consistent behaviours systematically the results of the assessment can help distinguish between VS and MCS patients. The CRS-R is also used for the purposes of diagnostic assessment, with the frequency of administration prior to making a diagnosis less clearly defined. The CRS-R has the added advantage of exploring the person's reflexive responses prior to assessment. The WHIM is designed to monitor and document observed behaviours from coma to emergence from posttraumatic amnesia (PTA). While both the SMART and CRS-R may be used to clarify the differential diagnosis the WHIM can aid the continued monitoring and exploration of behaviours, thereby feeding into the overall evidence. The WHIM also tracks recovery or possible regression quickly, contributing to diagnostic information. These distinct aims support the proposed complementary relationship.

The SMART is designed to be used for an initial assessment period, followed by an eight week treatment period and then follow up assessment. This is then followed by a defined intervention dependent on time. However, the SMART is not designed to be used on an on-going and consistent basis over a long period of time. The CRS-R, while also serving a diagnostic purpose can be used on multiple occasions as it is much shorter in duration and less intensive than the SMART. It does not specifically state a time of day or assessment environment in which to use it and this is advantageous in busy clinical environments. The WHIM allows quick monitoring and recording of change over long periods of time. This continued assessment and regular reassessment is central to the care and management of the DoC patient in continuing care environments. It is important both for the patient and to increase knowledge of recovery patterns in DoC. Comprehensive assessment and monitoring are necessary for this patient population so that changes are not missed. Employing the WHIM, CRS-R and the SMART allows for detailed assessment, long term monitoring, re-assessment and follow-up.

5.6.2. *Implementation in practice*

The SMART takes up to 60 minutes to complete. The CRS-R takes approximately 30 minutes to complete. The length and frequency of assessment are not specified with WHIM. Administration times can vary from 10 to 90 minutes where appropriate. The differences in administration time mean that each assessment could be used at different times and circumstances of the patient's assessment. For instance the SMART may be difficult to employ in situations where medical instability, high fatigue levels and fluctuating regimes (e.g. for medication/positioning, etc) are an issue. Therefore if a diagnostic assessment was sought the CRS-R may be better places to assess this individual. The shorter WHIM sessions also allow the clinician to work with such patients who may not be able to participate in longer sessions. In addition, with the WHIM there is flexibility to provide regular rest periods throughout a session and also to run short, frequent sessions throughout the day.

The CRS-R is the only assessment of the three available for free online. This makes it the most accessible. While the WHIM must be purchased there is no statutory training required to use it. This makes the WHIM available for use by a variety of clinicians and supports its implementation at night, during weekends and by carers and family. Attendance at a training course and follow up accreditation process is required to use the SMART. This training ensures that the assessment is administered in the structured manner required and that SMART assessors have the skills required to conduct the assessment systematically. It is conducted by the SMART trained assessor only and findings are produced by one assessor. This is similar to the CRS-R where carers and family observations feed into the assessment but they are not encouraged to administer the assessment themselves. While the SMART allows for controlled reporting of behaviours and structured release of findings the WHIM captures and reports on behaviours on a more regular basis by a wider variety of staff. Both styles of reporting are important for an unbiased and broad picture of behavioural repertoire.

Frequently monitoring all responses, both observed and reported, builds up a picture of the patient's responsiveness over time and helps to identify the instances where the patient responsiveness level improves or deteriorates. The SMART assessment allows for changes in position, nutrition and medication status to be monitored and their effect on behavioural responses to be explored. This can provide important information as to the optimal conditions needed for responsiveness. By recording small subtle changes the SMART can identify and report smaller, less consistent responses. When using the WHIM if behaviours do not meet the operational definitions provided, the behaviour is not recorded. This means that there is a possibility that significant but inconsistent responses will fall outside of defined behaviour. On the other hand, this also means that the WHIM can provide total scores. The CRS-R is similar to the WHIM in this regard as it has strict operational definitions and produces a total score. The use of numbers as opposed to descriptive information allows a drop in score to be quickly identified and reported. Possible reasons for deterioration e.g. infection can then be promptly explored. This can be seen as a valued contribution to clinical care as SMART findings are reported following the three week assessment period while WHIM/CRS-R can be reported immediately. When employed together both the numerical and descriptive information provides comprehensive monitoring of improvement and deterioration.

	WHIM (Shiel et al., 2000)	**SMART (Gill Thwaites & Munday, 1988)**	**JFK CRS-R (Giacino et al., 2004)**
Aim	An observational tool that may contribute to an overall diagnosis. Designed to monitor behavioural responses from coma through to emergence from post-traumatic amnesia	It is both an assessment and treatment tool. Instigates and identifies behavioural responses in order to determine the VS from the MCS	Designed to aid discrimination between VS/UWS and MCS and MCS from EMCS. Consists of 25 hierarchically arranged items.
Subscales	No specific subscales. Comprises visual, auditory, tactile, motor and communicative items No specific olfactory or gustatory modalities	Five senses/modalities covered: visual, auditory, tactile, olfactory and gustatory. Also has motor function, functional communication and wakefulness subsets.	Comprises of 6 subscales: • Auditory Function • Visual Function • Motor Function • Oromotor Function • Communication Scale • Arousal Scale
Time to Administer	Not specified – can vary from 10-60 minutes	Up to 60 minutes	Approx. 30 minutes
Training Required	No formal training required	Formal training required	No formal training required
Availability	Available for purchase from publishers	Available for purchase following completion of training	Accessible free online

Table 33: Assessment Characteristics of the SMART, WHIM and CRS-R

5.6.3. *Assessment Environment*

In the assessment phase of SMART a structured environment is created where external or confounding factors are controlled. Clear guidelines are provided on how to structure the environment and how to position both assessor and patient. This is to ensure consistency by eliminating confounding variables. While the CRS-R does not specify a particular assessment environment it requires a quiet space free from distraction. The WHIM can be used in any environment. It facilitates information gathering from observing the client in a variety of scenarios, e.g. during personal care, during therapy sessions or with staff and other patients. When both assessments are used information is obtained on behaviours in both structured and natural environments. This is useful in compiling the complete behavioural repertoire of the patient.

SMART incorporates observational periods throughout assessment where the patient's behavioural baseline at complete rest is documented. This contributes to the distinction between reflexive, spontaneous and purposeful behaviour. While each assessment should be interpreted separately the information from all three, regarding baseline behaviours at rest and during natural, day to day interaction is important to determine motivation of the client to demonstrate behaviour.

5.6.4. *Stimuli*

In each SMART assessment session the sensory stimuli used are standardised and remain constant throughout the ten sessions. The method by which the stimuli are presented is also standardised, including defined dialogue to be used by the SMART assessor. Familiar stimuli can be introduced following the three week assessment period. The stimuli are administered in a structured manner to ascertain and document any consistent behavioural response from the patient. The CRS-R provides instruction as to how to administer defined stimuli, but does not provide stimuli. Similarly it provides guidance around presenting the stimuli but does not provide the same level of standardised instructions as the SMART. The WHIM uses a variety of stimuli in a less structured manner. Selecting and obtaining stimuli for use with the WHIM can involve family and staff and salient stimuli are used from the first session. It is not necessary that these stimuli remain consistent over time. The WHIM also does not have a defined dialogue which may be more advantageous for patients with language impairment. Therefore the use of both tools provides the patient with familiar and structured stimuli in both a standardised and natural environment. Used together, they offer increased opportunity for patient response which can then be compared to ascertain the type of stimuli which can elicit the most meaningful responses.

The merits of complex stimulation within different environments for the person with DoC have been shown (Di Stefano et al., 2012). The use of more than one behavioural scale, when applied appropriately, could identify a detailed behavioural repertoire for persons with DoC. All three assessments provide the person with PDoC with varying sensory stimulation in different contexts. When regulated appropriately the use of more than one provides the patient with increased opportunity to respond, with different assessments exploring different behaviours at different cut-off points.

5.6.5. Clinical Regulation

Sensory bombardment and over stimulation should be avoided, therefore it is important to note that use of more than one assessment should be paced and controlled appropriately. Similarly consistency of use incorporating clear patient goals is essential to facilitate maximum responsiveness. Failure to do so may result in confusion and unclear communication for the DoC patient. Take functional communication for example; if functional gestures, e.g. the ability to give a 'thumbs up' is being explored during WHIM assessment as a method of potential communication while in SMART it is done using a AF switch then this inconsistency may prove confusing to the patient. Each communication pathway should be fully explored before trialling alternative pathways. The clinical team working with the patient need to establish clear communication pathways and goals to ensure that each functional communication method is trialled systematically.

5.6.6. Conclusion

This section outlines the position of the WHIM, the CRS-R and the SMART as standardised measures of behavioural assessment. Their compatibility in terms of eliciting and documenting behaviours, implementation in different environments and use of stimuli have been explored. The SMART, CRS-R and the WHIM are all useful, clinically relevant and should be used initially and on an on-going basis to ensure the patient's level of awareness is monitored and behavioural responses recorded frequently. Their complementary aims and properties provide the DoC patient with a wider opportunity to demonstrate any functional behaviour in acute, post-acute and long-term care.

5.7. Additional Considerations for Exploring Consciousness in Clinical Practice

Consciousness is an abstract concept and understanding of it remains limited. It continues to be a subject of intense philosophical, medical and ethical debate. As discussed in the literature review, neurobehavioural assessment with people with DoC can be difficult and there are a number of factors which must be considered. The research to date has focused primarily on 'person' factors, i.e. internal processes impeding demonstration of awareness. This includes motor disorders, sensory disabilities, mood disorders and cognitive impairments. The importance of the assessment environment is discussed less but is identified as an important aspect of uncovering a true baseline of behavioural response (Gill-Thwaites, 2005). While personal and increasingly environmental factors are recognised as impacting on assessment performance, there may be other considerations which being overlooked.

During this study, eight additional considerations, not previously discussed in relation to people with DoC were identified. In this section these additional factors which may impede neurobehavioural assessment will be discussed. It is proposed that these factors are important areas of future research in addition to having serious clinical consequences in the assessment and treatment of people with DoC. The additional considerations under review are; neuronal panpsychism, post traumatic growth, boredom, habituation, social relationships, the role of observer and the rehabilitation relationship. The next section comprises a discussion of each of these considerations in relation to their potential impact for people with DoC and the need for further exploration into these concepts.

5.7.1. Neuronal Panpsychism and DoC

The neuroscientific theory that consciousness arises when a particular level of cortical connectivity is reached (Laureys et al, 2013; Owen, 2011) is widely accepted in the DoC literature. This theory states that it is only when a 'threshold' of cortical connectivity is reached can the individual have a conscious experience. Where consciousness cannot be measured behaviourally there is scope that neuroimaging techniques could detect this conscious awareness. This neuroscientific theory finds that any cortical activity that falls below the 'threshold' is not registered by the individual as a conscious experience.

On the contrary in 1890 William James proposed that single neuron may carry with them individual consciousness. He explained his theory by adding that such as the brain is a collection of fibres and cells, so is the cell made up of individual atoms and small molecules. It is therefore possible that every brain cell has its own specific consciousness which is separate from all other neurons. This is known as the single neuron theory of consciousness.

It remains unknown how this type of consciousness is demonstrated. It is suggested that each individual neuron produces a higher set of consciousness that can be measured (Zeki & Bartels, 1999) and this would fit in with the neuroscientific theory mentioned previously. However, it is also suggested that multiple separate neurons may summate their outputs to produce the illusion of a single mind when it is in fact comprised of multiple separate conscious outputs (Sevush, 2002).

Panpsychism is a philosophical view that everything has a mental life. Neuronal panpsychism (Williams, 2014) proposes that each individual neuron is a locus of mental experience. This notion again proposes that the 'macro' conscious experience of adults is comprised of 'micro' experiences of individual neurons (Williams, 2014). It views consciousness not as an all or nothing phenomenon but as a state of awareness that does not have a unique threshold. This is similar to the single neuron theory. This is an interesting perspective when DoC is considered, in particular the transition between states of consciousness. Neuronal panpsychism states that each individual neuron contributes to consciousness. Thus, depending on the type of injury the presence of consciousness will be experienced and demonstrated differently.

It is interesting to consider how different types of collective 'macro' responses can then be produced and demonstrated. This becomes more complex for the injured brain which can produce a varied pattern of conscious responses based on the number of neurons which are damaged or remain intact. It is possible, based on this theory that different conscious responses can be produced by individuals to the same stimulus. This has ramifications for the assessment and unmasking of awareness. Standardised behavioural assessments may fall short in looking for many different patterns and mediums through which people may experience stimuli and subsequently elicit a response. Similarly the single neuron theory and neuronal panpsychism may highlight the issue of small levels of consciousness which may be undetectable using today's assessment technology. If each single neuron carries with it individual consciousness this would call into question the diagnostic criteria surrounding the vegetative state, where a person is found to have no conscious experience of any internal of external stimuli. This theory proposes that consciousness could exist for the person in VS; however the knowledge or technology does not exist to capture its existence. It is important to consider both theories when assessing and exploring consciousness.

5.7.2. Post Traumatic Growth

Sustaining a severe brain injury is no doubt a traumatic life event. Living with complex disability challenges a person's sense of self and is also greatly traumatic. Trauma, however, does not always have all negative consequences (Joseph, 2012). Post-traumatic growth is a psychological term used to describe positive changes that can happen as the result of trauma and life challenges (Lindley and Joseph, 2004). People with brain injury report changes in self-identity (Gracey & Ownsworth, 2012). Two of the key features of post traumatic growth are that the person reports a change in views about themselves and also reports a change in their life philosophy. Post traumatic growth is related to older age, longer time since injury and lower levels of depression (Grace et al., 2015). Detecting the presence of post traumatic growth requires insight and an ability to communicate this changed philosophical stance – therefore it is not possible to measure this explicitly for people in true MCS or EMCS. However, should awareness be present, the possibility of a changed life philosophy and perspective cannot be ruled out completely. People commonly believe that people with chronic locked in syndrome have a poor quality of life, however it has been shown that this client population report meaningful quality of life and their demand for euthanasia is surprisingly low (Laureys et al., 2005). The person surviving with MCS or EMCS they may also experience changed perspectives on what they value and what is important to them. This is important to consider in terms of providing optimum assessment and treatment. The importance of using personal and meaningful stimuli to elicit a response was discussed in a previous section and if this is considered in terms of changed life perspectives it becomes even more difficult to determine what is now meaningful to the person with DoC. Determining what stimuli are meaningful to the person is predominantly based on their likes and preferences prior to the brain injury and so it may be true that the level of meaningfulness around these activities/stimuli have changed.

5.7.3. Boredom

"*Boredom is the experience of dissatisfaction and disinclination to action; a state of longing and an inability to designate what is longed for; a sense of emptiness; a passive, expectant attitude with the hope that the external world will supply the satisfaction.*" Greenson (1953, p.7)

An important distinction must be made. Boredom is not merely the lack of activity. Boredom can exist even while a person engages in an activity or occupation. If the occupation or activity is not meaningful to the person or does not have the right balance of skills and challenge then this can lead to boredom (Csikszentmihalyi, 1992). Greenson's definition is one of the most widely used definitions of boredom and highlights the complexity of the conflicting impulses associated with this state. Boredom in relation to DoC (in particular MCS and EMCS) has never been explored in academic literature. In the absence of consistent communication it is difficult to determine whether or not boredom is a clinical concern for people with DoC.

This study suggests that boredom is a consideration that must be taken into account during assessment and treatment for this client population. It also emphasises boredom as an important clinical issue for occupational therapists. Martin (2009) reported that occupational therapists need to increase their understanding of boredom as an important barrier to therapeutic engagement. Many occupational scientists suggest boredom to be the direct result of occupational deprivation (Wilcock 2006; Whiteford 1997; Farnworth 1988).

Greenson (1951) described two types of bored state –apathetic and agitated. In the agitated boredom prone individual, boredom is experienced as an aggressively dissatisfying affect. This individual is willing to engage with stimulation. However attempts to do so do not satisfy them. This may be seen as inappropriate stimulation and stems from the external environment. In the apathetic boredom prone individual, all stimulation is seen as ineffective or monotonous. In this instance, the individual is unmotivated to do anything about this and has no internal desire to alter their experiences. Boredom and depression are commonly associated but are separate entities (Goldberg & Danckert, 2013). Boredom presents significant barriers to rehabilitation (Glenn et al 2002; Chervinsky et al 1998).

Goldberg & Danckert (2013) found higher levels of proneness to boredom in people with moderate to severe TBI when compared to mild TBI and healthy controls. In this study the researchers used to Boredom Proneness Scale (BPS). The BPS developed in 1988 (Farmer & Sundberg) is the most commonly used and psychometrically sound measure of susceptibility to boredom but requires a high level of self-reporting and insight. This is not possible in a group of people with DoC. However it is naive to think that just because something cannot be proven does not mean it does not exist. It is proposed that the null hypothesis theory must be considered in this instance. In Goldberg and Danckert's study higher levels of boredom were associated with an increase in severity of brain injury. Brain injuries resulting in PDoC are the most severe and thus it must be considered that it is possible that people in a MCS with appropriate awareness may experience high levels of boredom.

Boredom can present in different ways with different individuals. Boredom may also be associated with the individual's premorbid levels of boredom. In Greenson's definition of the agitated boredom prone individual there is a willingness to engage and as such engagement in increased occupations may be futile. Therapists must be cognisant that matching the person's level of ability, regardless of how limited, to the right occupations is a key aspect of our work for people with DoC.

5.7.4. The Rehabilitation Relationship

When family members engage in a person's rehabilitation it is associated with better outcomes for the person (Foster et al., 2012). Family members involved in this study were observed to spend many hours involved in the daily care of their family members including nutrition, personal care, positioning, splinting and pressure care. As part of this study training workshops were offered to family members to teach them to administer behavioural assessments and controlled sensory stimulation interventions. There was little uptake (n=1) on this offer of workshops and no family member was observed to regularly engage with their family member around objective behavioural assessment without supervision.

This finding identifies the difficulty family members have in establishing a 'rehabilitation relationship' with their loved ones living with DoC. It was unexpected that so few family members would engage in formal learning about rehabilitation measures. This may be for many reasons. Family members may lack confidence in their ability to measure behaviours objectively, they may not wish to be involved in this aspect of their family members care so as to maintain familial relationships, or they feel they do not have enough time as they are heavily involved in self-care.

The findings suggest that the development of a ‘rehabilitation relationship’ is difficult when working with families of people with PDoC. It can be argued that parents and siblings of those in a PDoC wish to retain their familial relationship status with the person. This was particularly true of mothers who were observed to engage in practical caregiving, e.g. washing, dressing, toileting, and bed positioning. The suggestion that parental and familial rehabilitation relationships may be difficult to form has been documented in paediatric literature. It has been reported that parents find it difficult to engage in therapeutic activities initially as they come to grips with the diagnosis but once they have accepted the condition their level of participation increases (Piggot, Paterson & Hocking, 2002). This may be true also for families of people with DoC who have received limited information and support around coming to terms with a devastating diagnosis. It is suggested that this may be the case despite years since onset of injury. If increased involvement of family members is beneficial for the person, paediatric literature supports the notion of providing increased support, education and time for families around grieving and acceptance.

5.7.5. Habituation

Habituation reflects a reduction in behavioural response as a result of repeated stimulation and is distinct from sensory adaptation/sensory fatigue or motor fatigue (Thompson & Spencer, 1966). Motor neuron activity, muscle contraction, simple reflexes and nervous system outputs can all be affected by habituation (Rankin et al., 2009). During behavioural assessment, sensory stimuli are used to elicit a behavioural response from the person with DoC. There are no clear recommendations regarding the frequency or intensity of presenting stimulation this client population. Similarly, there is no consensus on the type of environment and daily stimulation the person with DoC should experience. Lack of clinical agreement in these instances can have a direct impact of the level of habituation. Weak and/or frequent stimulation result in a more pronounced reduction in behavioural response (Rankin et al 2009; Thompson & Spencer 1996). This can include leaving a radio or television playing all day. Intense stimulation has also been shown to cause a habituation response (Ponce et al., 2011).

The findings of this study show that each of the five case studies required intervention around controlling the sensory environment, with each participant residing in different environment with different level of daily and therapeutic stimulation. There is a need to explore the short and long-term impacts of habituation to these different sensory environments. The effect of habituation for people with DoC is an important clinical issue and can impact the results of standardised neurobehavioural testing greatly.

Short term habituation has been shown to be a greater issue for people with DoC than previously thought and it is also observed in people with VS (Camanducci et al., 2014). Interestingly short term habituation was found in a population of people with VS who went on to become MCS but not in a population who remained in VS, suggesting a prognostic value in measuring habituation (Camanducci et al., 2014). Longer term habituation may also have a more prolonged duration than previously thought (Rankin et al., 2009). Understanding habituation and dishabituation in this client population is important in terms of assessment and also for the long-term care environment. Frequent stimulation and stimuli with sudden onsets over short or long periods have been shown to lower the threshold of conscious perception (Dehaene & Changeux, 2006) and both the nature of and presentation of stimuli must be considered when attempting to assess something as complex as consciousness.

5.7.6. Social Relationships

Maintaining strong familial relationships and friendships is important following traumatic brain injury (Callaway, Sloan & Winkler, 2005). International literature reports that the majority of people who sustain traumatic brain injuries are young males. In phase one a number of young people surviving with severe brain injuries are reported. Thus, their brain injury occurs at a time of their lives when they value friendship greatly and choose to spend a great deal of time interacting with and socialising with friends (Hartley, 1994). For the person surviving with DoC their ability to understand and participate in social relationships is unknown. However that is not to say that intervening around social relationships is futile. The WHIM records whether the person with DoC responds differently to different people and this is not an uncommon behaviour to observe. The

RCP guidelines state that family and friends need to be involved in diagnostic assessment. This is because it is not uncommon for family members and friends to elicit behavioural responses that would not be observed otherwise. Thus, it must be considered that the person with DoC, most typically MCS is its defined state, can identify and participate in some basic form of social relationships. Models of occupational therapy practice, particularly the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Townsend & Polatajko, 2007) support this consideration highlighting the social environment as an important factor in occupational participation.

Facilitating shared occupations between people with DoC and family/friends is an area of intervention for occupational therapists and this will encourage the deepening of social relationships. This is important not only for the person with DoC but also for family members and friends coming to terms with changed relationships. In the second phase of this study changes in attitudes among staff members was reported. This is important as this led to changed social relationships between staff members and the person with DoC. This renewed social relationship created an expectation of the person with DoC and provided an appropriate environment and time in which to develop new shared occupations. This is a further area of involvement for the occupational therapist.

5.7.7. Role of Observer

In 1951 Talcott Parsons conceptualised the ‘sick role’ (p.244) whereby a person or patient adheres to the social role of being sick and allows others to control important aspects of their life. This may be viewed in direct response to losing other valuable life roles such as worker, provider, etc. Following severe brain injury the person loses many of their previous life roles. Occupational therapy literature acknowledges that roles are important to people and add value and meaning to their lives (Taylor, Lee, Kielhofner & Ketkar 2009). The sociological term of the sick role has since been widely refuted with scholars arguing that it is this role is given to the person by the medical establishment and environmental limitations rather than the person assuming a role (Burnham, 2014). As health care moves away from the medical model and towards a health and well-being model this term is used less and less. It is proposed that this identity of the sick and unable patient continues to permeate clinical care for the DoC population. People may be cared for by professionals who underestimate or misunderstand the person’s level of ability or potential. While it is not suggested that people with DoC assume a sick role it is proposed that without appropriate and timely stimulation the person may assume the role of observer that is, a person who adheres to the role of being unable to participate and is not encouraged to. When a person cannot participate, by means of a physical, occupation or environmental constraint, over time this could lead them becoming an ‘observer of life’. This role is one where the person becomes accustomed to watching and observing life as it happens.

It was observed that health professionals and family assume control of every aspect of the dependent person’s life, moving the agency of power from the individual, something similar to what is defined by the sick role. In most cases this makes complete sense; if the person cannot communicate then decisions must be made on their behalf. The person with DoC cannot make clear choices and thus choice is frequently not offered. However it must be considered that if no choice or encouragement is provided to the person with DoC to participate at their level of response, then over weeks, months and years should further recovery occur or a higher level of responsiveness emerge then the engrained role of observer may be a difficult barrier to overcome. For the purposes of holistic assessment and creation of optimum environments, an atmosphere of participation must be encouraged. This involves creating an air of expectation to encourage the client to get involved when and where appropriate. An example of this is whereby the person demonstrating spontaneous behaviour in their arm is asked to use this behaviour to make a choice, e.g. ‘move your arm towards the shirt you wish to wear today’. This not only assesses purposeful behaviour but encourages participation. When healthcare professionals and family create such an environment over time then this role of observer will not be as difficult to overcome should further recovery occur. This type of social interaction should be encouraged in clinical practice. This finding is supported by the previous consideration of maintaining and developing social relationships as an important area of intervention.

5.7.8. Conclusion

In 1906 Dmitri Mendeleev won the Nobel Prize in chemistry for his version of the Periodic Table which left spaces for elements not yet discovered. By acknowledging that spaces should be left for what is not yet known he remains one of the great chemists in history. This style of thinking should be applied to consciousness – an area of study where not everything is known and understood. Aspects of consciousness and factors that impede consciousness that have yet to be uncovered should be allowed for. In this section additional considerations for working with people with DoC are discussed. The additional considerations are important as they explore a deeper level of understanding around working with consciousness. Each of these considerations has never been explored in relation to DoC. Research studies do not include these factors as confounding variables, nor do clinical studies or guidelines recommend their inclusion. However they are factors which may play a part in assessment of consciousness and cannot be overlooked until proven otherwise.

5.8. Impact of Research

The impact of this study will be discussed using the Research Impact Framework (Kurvilla et al., 2006). Both phases of this study make valuable contributions to knowledge and research surrounding rehabilitation for PDoC. In this section these contributions will be discussed under research, policy, service and societal impacts.

5.8.1. Research Impacts

This study had a significant research impact. The research questions posed were relevant and important in terms of therapy research. It explored an under-researched aspect of the care and treatment of DoC, namely the current management and long-term care structures in place for this complex client population. This research study is the first to explore a holistic therapy programme for people with DoC. Previous studies have explored physiotherapy outcomes (Latchem, Kitzinger & Kitzinger 2016; Wheatly-Smith et al 2012; Pilon, Sullivan & Coulombe 1998) but none to date have investigated outcome from an awareness and functional perspective. This research study makes a valuable contribution to the literature as it evaluated outcomes from three perspectives – the person, family members and professional care staff. This triangulation of results is achieved through a case study methodological design. By setting phase two in a non-specialist care setting valuable data was collected regarding potential rehabilitation techniques for people living with these conditions long-term and their families. The novel approach taken in phase one identified important issues in relation to management and re-assessment for this population. Similarly the use of three neurobehavioural assessments enriched data collection and allowed to direct comparison of these assessment methods. A study of this nature has not been seen previously in the literature and thus these findings will make an impact in our understanding and knowledge of caring for these conditions. In addition the selection and application of these research methods contributes to research.

To date the study has produced one peer-reviewed paper and 7 conference presentations both nationally and internationally. Similarly two international conference presentations were also invited, one as part of a larger symposium on DoC. The paper and conference presentations are detailed below. More peer reviewed articles will be published from this study.

Invited Paper

1. Morrissey AM, Gill-Thwaites H, Leonard R, Pundole A, McLellan L, Wilson B & Shiel A (2015). Review of Neurobehavioural Assessment of Consciousness: Are we Casting the Net Far Enough? Neuropsychological Rehabilitation (In preparation)

Conference Presentations

1. Morrissey AM & Shiel A (2016). Workshop: Clinical Interventions for Disorders of Consciousness. COTEC-ENOTHE Joint Congress, Galway.
2. Morrissey AM (2015). Behavioural Assessment of Consciousness. Central England Rehabilitation Unit Conference on Prolonged Disorders of Consciousness. Stratford-upon-Avon, UK. (Invited Speaker).
3. Morrissey AM & Shiel A (2016). Workshop: OT for PDoC. Association of Occupational Therapists of Ireland National Conference, Galway.
4. Morrissey AM & Shiel A (2014). Assessment and Intervention for Long-Term Disorder of Consciousness. World Federation of NeuroRehabilitation, Istanbul. (Invited Speaker).
5. Morrissey AM & Shiel A (2013)**.** Long Term Severely Brain Injured Service Users in Ireland: A Survey of Current Location and Care. Heath and Social Care Professionals Inaugural Research Conference Developing HSCP services through Research, Stewarts Hospital, Palmerstown, Dublin.

6. Morrissey AM & Shiel A (2013). Benefitting Client, Family and Care Staff: Implementation of an Individualised Therapeutic Programme for a Long-Term

Disorder of Consciousness Patient. The 11th Conference on Neuropsychological Rehabilitation, Maastricht, The Netherlands.

7. Morrissey AM & Shiel (2012). Disorder of Consciousness Patients in the Republic of Ireland: Employing a Venue Model to Determine Prevalence for Vegetative State and Minimally Conscious State from Acute to Long-Term Care. International Brain Injury Association Ninth Annual World Congress, Edinburgh, Scotland.

5.8.2. Policy Impacts

Impacting and changing policy is the most difficult task for research studies (Kurvilla et al., 2006). While this study to date has made no contributions to national rehabilitation policy it has contribution to local policy for residential care settings. The majority of care settings adapted their care policy during and following this study to enhance the participants' rehabilitation. His meant introducing new assessment measures as part of daily care, maintaining optimal therapeutic environments, inclusion of the people with PDoC in activities in the settings and improved communication strategies for staff when working with people with PDoC. Through further dissemination the impact on local rehabilitation policy may increase and in turn impact on national policy to some extent.

5.8.3. Service Impacts

This research study provides evidence to support the establishment of a national register for people with DoC. With increasing numbers of people surviving with DoC (Tan et al., 2012) the issue of long term care and follow up re-assessment will grow. Setting up a national register will help the identification of people surviving with this condition long-term. It will also provide a system of recording re-assessment and rehabilitation needs. Agreed guidelines (RCP, 2013) state that people with PDoC should receive regular re-assessment at least annually. These guidelines provide a strong framework within which the data base could identify people who may be at risk of misdiagnosis, have not been seen by the specialist team or who require follow up. Such a register will also provide invaluable information regarding the epidemiology and long term prognosis of people with PDoC. Opportunities exist in Ireland to have this be a cross border initiative.

This research study was the first of its kind to employ all three neurobehavioural assessments. It has found disparities in measurements and the areas of behaviour that each of the three explore. It has also described ways in which the three assessments complement each other in clinical practice. This has implications for clinical service. This study suggests that research using only one measure of behavioural assessment may be limiting assessment. This is something which must be considered in clinical practice.

This is an emerging area of practice and requires an increased focus owing to the increasing prevalence of these conditions. The effectiveness of therapeutic programmes in these settings is rarely explored as it is not common practice that people with prolonged or chronic conditions of this nature receive regular therapeutic input.

5.8.4. Societal Impacts

This study provides data to support the provision of rehabilitation programmes in the person's own local community. The provision of services at a community level has many advantages for the individual and their families. It means that the person can live in their local community, thus enabling further engagement with local relatives and friends. It may also lessen the burden of care. Community supports will need to be developed in order to do this effectively. This movement away from specialist regional centres must be done without losing specialist knowledge and skills. The establishment of regional specialist teams which cover local community care units and homes may be a potential answer to this issue. The team, comprising rehabilitative medical and therapeutic specialists, may also be involved in the provision of educational and training for professional and informal care staff. This would also allow regional statistics and data surrounding the care and services for people with PDoC to be more formally maintained. Regional areas may also be linked with academic institutions such as universities as recommended by the Mohonk Report (Berube et al., 2011). This could lend itself to increased research output for this client population. Telerehabilitation should also be considered. Telerehabilitation could help provide support for families caring for loved one with PDoC in the community. It has shown some initial benefits in terms of bridging the transition between residential care to home environments (Hauber & Jones, 2002).

The most effective method by which to provide this client population with appropriate assessment, treatment and follow up is an issue for further discussion and debate. What is known, and supported by this research study, is that the current provision of services is inappropriate and a cause of concern for both people diagnosed with PDoC, their families and formal caregivers

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Appendix A: Ethical Approval for Phase One of Study

O'Connell, Eithne <eithne.oconnell@nuigalway.ie>

19/04/2011

Sent on behalf of Dr Brian McGuire, Vice Chair, Research Ethics Committee.

Dear Ms Morrissey

RE: Ethical Approval for "Epidemiological survey of people in a vegetative and minimally conscious state in the Republic of Ireland"

I write to you regarding the above proposal which was submitted for Ethical review. Having reviewed your response to my letter, I am pleased to inform you that your proposal has been granted **APPROVAL**.

Please note, the issue of ethnicity should be treated with due sensitivity, especially if reporting results based on a small population. It is advised that a "standard" version of ethnic descriptors is used, for example, from CSO.

All NUI Galway Research Ethic Committee approval is given subject to the Principal Investigator submitting an annual report to the Committee. The first report is due on or before 31st March 2012. Please see section 7 of the REC's Standard Operating Procedures for further details which also includes other instances where you are required to report to the REC.

Yours Sincerely

Dr Brian McGuire
Vice Chair - Research Ethics Committee

Appendix B: Questionnaire Distributed to Consultants

NUI Galway
OÉ Gaillimh

Dear Consultant,

I am a PhD research student at the National University of Ireland, Galway. As part of my research I am conducting a nationwide survey on the prevalence of vegetative and minimally conscious patients in Ireland.
As research of this nature has never been conducted in this country and would yield very valuable information, your participation is valuable and worthwhile.

What it involves...

1. **Read carefully the definitions of both vegetative and minimally conscious states that are under research in this study.**
2. **Should any patients currently under your care match either of these diagnoses, please complete the enclosed questionnaire for each patient.**
3. **Should there be no patient under your care that comes under either of these diagnoses I would be grateful if you would indicate this on the survey and return the questionnaire.**
4. **Please return completed questionnaires as soon as possible to:**
   Ann-Marie Morrissey, Room 230, Department of Occupational Therapy, Áras Moyola, National University of Ireland, Galway.

All applicable consultants and residential care settings will be asked to complete the questionnaire. All issues surrounding ethics and confidentiality have been adhered to (page 2).

If you have any further questions or queries please do not hesitate to contact me by e-mail (a.morrissey2@nuigalway.ie) or telephone (087) 7611819. Should you wish to receive the results of this survey please indicate this on page three of the questionnaire.

Thank you so much in advance for taking the time to complete this survey.

Kind Regards,

____

Ann-Marie Morrissey (B.Sc OT/PhD student)

Ethical Approval

- Full ethical approval was obtained from the Ethics Committee, NUI Galway.

Confidentiality

- All information provided will be stored under lock at the University and will not leave its premises. Only the two primary researchers mentioned will have access to completed surveys. All data will be made anonymous and the key to this anonymity will only be known to the two primary researchers.

Vegetative State Criteria

All of the below criteria must be met to establish the diagnosis of VS:

- Patients in VS demonstrate intermittent wakefulness as evidenced by eye-opening or sleep-wake cycles on EEG
- They fail to produce any purposeful or voluntary behaviour in response to auditory, visual, tactile or noxious stimulation
- They do not exhibit any sign of language comprehension or expression
- There are generalized physiologic responses to pain (e.g., abnormal posturing, tachypnea, diaphoresis) and roving eye movements that may be misinterpreted as visual pursuit unless careful examination is conducted.
- Cranial nerve functions are variable and there is double incontinence (Giacino, 2004)

The diagnosis of VS typically requires serial bedside examination and should not rely solely on neuroimaging or lab studies (Aspen Workgroup, 2000).

Minimally Conscious Criteria

The minimally conscious state is a condition of severely altered consciousness in which minimal but definite behavioural evidence of self or environmental awareness is demonstrated (Giacino et al., 2002).

To make the diagnosis of MCS, limited but clearly discernible evidence of self or environmental awareness must be demonstrated on a reproducible or sustained basis by one or more of the following behaviours:

- Following simple commands.
- Gestural or verbal yes/no responses (regardless of accuracy).
- Intelligible verbalization.
- Purposeful behaviour, including movements or affective behaviours that occur in contingent relation to relevant environmental stimuli and are not due to reflexive activity.

Some examples of qualifying purposeful behaviour include:

a) appropriate smiling or crying in response to the linguistic or visual content of emotional but not to neutral topics or stimuli
b) vocalizations or gestures that occur in direct response to the linguistic content of questions
c) reaching for objects that demonstrates a clear relationship between object location and direction of reach
d) touching or holding objects in a manner that accommodates the size and shape of the object
e) pursuit eye movement or sustained fixation that occurs in direct response to moving or salient stimuli (Giacino et al., 2002)

QUESTIONNAIRE

PLEASE COMPLETE THE FOLLOWING QUESTIONS...

Name of Consultant: ________________________ Date: _______

Place of Work/Speciality: ___________________________

Number of Patients in care setting that match the definition of Vegetative State = __

Number of Patients that match the definition of Minimally Conscious State = __

- Would you like to be provided with a copy of the results: YES / NO (please circle)

(Address/Contact Details for Correspondence: ___________________________________)

- Do you think that the families of these patients would grant their permission for these patients to be assessed? (Please circle) YES / NO

Please complete for each patient circling whether their diagnosis matches a Vegetative State or Minimally Conscious State.

PATIENT ONE (Vegetative State / Minimally Conscious State)

Age: ___________	**Time Since Onset:** ____________
Sex: Male / Female	**Time Since Last Assessment** (of their Level of Consciousness): ______
Ethnicity: (please circle) Irish Travelling community African Asian Other: ________________	**Aetiology:** (please circle) Cardiovascular Road Traffic Accident Fall Assault Suicide / Parasuicide Neurodegenerative Dementia Other: ______________________
Current Place of Care: (please circle) Acute Hospital (Specialist Ward) Acute Hospital (Non-specialist ward) Rehabilitation Facility Community Hospital (respite or full-time) Residential Care (respite or full-time) Own Home Other: _______________________	**Are they currently in receipt of any of the following;** Neurology/Neurosurgery YES / NO Occupational Therapy YES / NO Physiotherapy YES / NO Speech and Language Therapy YES / NO Neuropsychology YES / NO Other: ____________________________

PATIENT TWO (Vegetative State / Minimally Conscious State) (Please circle)

Age: ___________ ______________

Sex: Male / Female

Ethnicity: (please circle)
Irish
Travelling community
African
Asian
Other: _______________

Current Place of Care: (please circle)
Acute Hospital (Specialist Ward)
Acute Hospital (Non-specialist Ward)
Rehabilitation Facility
Community Hospital (respite or full-time)
Residential Care Home (respite or full-time)
Own Home

Other: ______________________

Time Since Onset:

Time Since Last Assessment (of their Level of Consciousness): __________

Aetiology: (please circle)
Road Traffic Accident Fall
Assault Neurodegenerative
Suicide/Parasuicide Cardiovascular
Dementia
Other: _____________________

Are they currently in receipt of any of the following:

Neurology/Neurosurgery	YES / NO
Occupational Therapy	YES / NO
Physiotherapy	YES / NO
Speech and Language Therapy	YES / NO
Neuropsychology	YES / NO

Other: ____________

PATIENT THREE (Vegetative State / Minimally Conscious State) (Please circle)

Age: ___________

Sex: Male / Female

Ethnicity: (please circle)
Irish
Travelling community
African
Asian
Other: _______________

Current Place of Care: (please circle)
Acute Hospital (Specialist Ward)
Acute Hospital (Non-specialist Ward)
Rehabilitation Facility
Community Hospital (respite or full-time)
Residential Care Home (respite or full-time)
Own Home

Other: ______________________

Time Since Onset: _____________

Time Since Last Assessment (of their Level of Consciousness): ____

Aetiology:
Road Traffic Accident Fall
Assault Neurodegenerative
Suicide/Parasuicide Cardiovascular
Dementia
Other: _____________________

Are they currently in receipt of any of the following:

Neurology/Neurosurgery	YES / NO
Occupational Therapy	YES / NO
Physiotherapy	YES / NO
Speech and Language Therapy	YES / NO
Neuropsychology	YES / NO

Other: ____________

Appendix C: Questionnaire Distributed to Residential Care Settings

Dear Sir/Madam,

I am a postgraduate research student at the National University of Ireland, Galway. As part of my research I am conducting a nationwide survey of the prevalence of vegetative and minimally conscious patients in Ireland.
As research of this nature has never been conducted in this country and would yield very valuable information, your participation is valuable and worthwhile. All issues surrounding ethics and confidentiality have been adhered to (see page 2).

What it involves...

1. **Read carefully the definitions of both vegetative and minimally conscious states that are under research in this study.**
2. **Should any patients currently under your care come under either of these diagnoses please complete the enclosed questionnaire for each patient.**
3. **Should there be no patient under your care that comes under either of these diagnoses I would be grateful if you would indicate this on the survey and return the questionnaire.**
4. **Please return completed questionnaires as soon as possible to: Ann-Marie Morrissey, Room 230, Department of Occupational Therapy, Áras Moyola, National University of Ireland, Galway.**

All residential care settings and applicable consultants will be asked to complete the questionnaire. If you have any further questions or queries please do not hesitate to contact me by e-mail (a.morrissey2@nuigalway.ie) or telephone (087) 7611819. Should you wish to receive the results of this survey please indicate this on page three of the questionnaire.

Thank you so much in advance for taking the time to complete this survey.

Kind Regards,
Ann-Marie Morrissey

Ethical Approval

- Full ethical approval was obtained from the Ethics Committee, NUI Galway.

Confidentiality

- All information provided will be stored under lock at the University and will not leave its premises. Only the two primary researchers mentioned will have access to completed surveys. All data will be made anonymous and the key to this anonymity will only be known to the two primary researchers.

Vegetative State Criteria

All of the below criteria must be met to establish the diagnosis of VS:

- Patients in VS demonstrate intermittent wakefulness as evidenced by eye-opening or sleep-wake cycles on EEG
- They fail to produce any purposeful or voluntary behaviour in response to auditory, visual, tactile or noxious stimulation
- They do not exhibit any sign of language comprehension or expression
- There are generalized physiologic responses to pain (e.g., abnormal posturing, tachypnea, diaphoresis) and roving eye movements that may be misinterpreted as visual pursuit unless careful examination is conducted.
- Cranial nerve functions are variable and there is double incontinence (Giacino, 2004)

The diagnosis of VS typically requires serial bedside examination and should not rely solely or neuroimaging or lab studies Aspen Workgroup (2000).

Minimally Conscious Criteria

The minimally conscious state is a condition of severely altered consciousness in which minimal but definite behavioural evidence of self or environmental awareness is demonstrated (Giacino et al., 2002).

To make the diagnosis of MCS, limited but clearly discernible evidence of self or environmental awareness must be demonstrated on a reproducible or sustained basis by one or more of the following behaviours:

- Following simple commands.
- Gestural or verbal yes/no responses (regardless of accuracy).
- Intelligible verbalization.
- Purposeful behaviour, including movements or affective behaviors that occur in contingent relation to relevant environmental stimuli and are not due to reflexive activity.

Some examples of qualifying purposeful behaviour include:

f) appropriate smiling or crying in response to the linguistic or visual content of emotional but not to neutral topics or stimuli
g) vocalizations or gestures that occur in direct response to the linguistic content of questions
h) reaching for objects that demonstrates a clear relationship between object location and direction of reach
i) touching or holding objects in a manner that accommodates the size and shape of the object
j) pursuit eye movement or sustained fixation that occurs in direct response to moving or salient stimuli (Giacino et al., 2002)

QUESTIONNAIRE

PLEASE COMPLETE THE FOLLOWING QUESTIONS...

Name: ________________________ Date: _______

Place of Work/Location: ___________________________

Number of Patients in care setting that match the definition of Vegetative State = __

Number of Patients that match the definition of Minimally Conscious State = __

- Would you like to be provided with a copy of the results: YES / NO (please circle)

(Address/Contact Details for Correspondence: ___________________________________)

- Do you think that the families of these patients would grant their permission for these patients to be assessed? (Please circle) YES / NO

Please complete for each patient circling whether their diagnosis matches a Vegetative State or Minimally Conscious State.

PATIENT ONE (Vegetative State / Minimally Conscious State)

Age: ___________	**Time Since Onset:** ____________
Sex: Male / Female	**Time Since Last Assessment** (of their Level Of Consciousness): ______
Ethnicity: (please circle) Irish Travelling community African Asian Other: ________________	**Aetiology:** (please circle) Cardiovascular Road Traffic Accident Fall Assault Suicide / Parasuicide Neurodegenerative Dementia Other: ______________________
Current Place of Care: (please circle) Acute Hospital (Specialist Ward) Acute Hospital (Non-specialist ward) Rehabilitation Facility Community Hospital (respite or full-time) Residential Care (respite or full-time) Own Home Other: _______________________	**Are they currently in receipt of any of the following;** Neurology/Neurosurgery YES / NO Occupational Therapy YES / NO Physiotherapy YES / NO Speech and Language Therapy YES / NO Neuropsychology YES / NO Other: ____________________________

Appendix D: Ethical Approval for Phase Two of Study

From: O'Connell, Eithne

Sent: 04 July 2012 17:06

To: 'Morrissey, Ann-marie'

Cc: McGuire, Brian; Shiel, Agnes

Subject: Ethics Reference: 12/JUNE/03

Sent on behalf of Dr Brian McGuire, Research Ethics Committee

Dear Ms Morrissey

Re: Ethics Application: Carer and Patent Perspectives of the Implementation of an Individualised Therapeutic Programme for long-term Disorder of Consciousness: A Case study Approach

I write to you regarding the above proposal which was submitted for Ethical review. Having reviewed your response to my letter, I am pleased to inform you that your proposal has been granted **APPROVAL**

All NUI Galway Research Ethic Committee approval is given subject to the Principal Investigator submitting an annual report to the Committee. The first report is due on or before 31st June 2013. Please see section 7 of the REC's Standard Operating Procedures for further details which also includes other instances where you are required to report to the REC.

Yours Sincerely

Brian McGuire

Research Ethics Committee

Appendix E: Participant Information Sheet

NUI Galway
OÉ Gaillimh

National University of Ireland, Galway

Participant Information Sheet

Study Title: The Effectiveness of an Individualised Therapeutic Programme for Individuals with a Disorder of Consciousness
Principal Investigator: Ms Ann-Marie Morrissey
We are inviting your next-of-kin to take part in a research project. Before you agree you must understand why we are conducting this study and what will be expected of those who agree to participate. This information sheet will explain the study but if you have any queries or questions after reading this please feel free to ask us.

What is the purpose of this study?

A Disorder of Consciousness (DoC) occurs after a severe head injury. It results in the person having limited awareness of themselves and their surroundings. There exist limited specialised support services for a person with this condition. This study aims to target people with a DoC in long-term care. We are inviting your next-of-kin to participate in a research project which aims to determine if people with a disorder of consciousness would benefit from receiving an individualised therapeutic programme which they would not commonly receive. The therapeutic programme will consist of education of family and care staff, a sensory programme (SMART), environmental modification and seating and positioning advice.

Why have I (or my next-of kin) been chosen?

Your next-of-kin has been chosen as participants must meet criteria for a Disorder of Consciousness.

Do I have to Participate?

Participation in this research is entirely voluntary. Your next-of-kin does not have to take part. If you choose not to take part this will not in any way affect the care that your next-of-kin receives from your medical team.

If you do agree to take part you will be asked to sign a consent form. However your next-of-kin is free to withdraw from the study at any stage despite signing the form.

What is required if I take Part?

If you agree (on behalf of your next-of-kin) to participate in this research study you will be asked to sign a consent form. Your next-of -kin will then go through an screening phase which will consist of the researcher meeting with you, your next-of-kin and their care team. The screening process will also involve the researcher reading your next-of-kin's medical notes. This is so as to determine the person's suitability for this particular study. It is important to note that your next-of-kin may not progress to the next stage of this study.

Should they be deemed eligible following the screening process an individual therapeutic programme will be implemented over the following 12-16 weeks. Following the therapy sessions the participant will be re-assessed to determine the amount, if any, of improvement has occurred.

By agreeing to participate you are also consenting to complete family assessment forms, meet with the researcher and be involved in the rehabilitation programme.

Are There any Risks Involved in participating in this study?

There is no risk associated with participation in this study. All treatment provided will be non-invasive and evidence based.

What will I do if I have more questions?

If you have any more questions about any aspect of this study you should contact the Principal Investigator named at the end of this sheet. She will address any of your concerns and provide any further information that you may require.

Will participation in this study be confidential?

All information collected will be stored anonymously and stored securely. All information will be stored on University campus. Only authorised personnel will have access to this information. Any of the co-researchers viewing the information will have a duty of confidentiality to the participant and will sign a code of Confidentiality.

What will happen to the results of this study?

The results of this study will be published as part of a research thesis. The researcher also aims to publish the results in a medical journal. At no time will a participant in this study be identified in any report or publication.

What happens after the study is completed?

Following the study the researcher will provide you with a home treatment programme which will consists of techniques and advice regarding the care of your next-of-kin. However it is important to note that the researcher will not be available to provide any form of intervention following the study. Should you wish this is something which you would need to do privately of your own accord.

Who has reviewed the study?

This study has been reviewed and approved by NUI Galway's Research Ethics Committee.

For addition information now or in the future please contact:

Prof Agnes Shiel,
Department of Occupational Therapy,
Áras Moyola,
NUI Galway
(091) 492957

Ann-Marie Morrissey
Address: Room 230, Áras na Coiribe, NUI Galway
Phone Number: (087) 7611819

Appendix F: Participant Consent Form

NUI Galway
OÉ Gaillimh

Consent Form

The Effectiveness of an Individualised Therapeutic Programme for Individuals with Long-Term Vegetative State/Minimally Conscious State

- I have read and understood the background and methodology of the above mentioned research study
- I (as legal next-of-kin) declare that I grant my permission for ________________________ to participate in this research project
- I agree to partake in the rehabilitation programme and complete all necessary interviews/questionnaires
- I understand that following this study the researcher is under no obligation to provide further intervention/treatment.
- I accept that this study have not have any effect on awareness levels of my next-of-kin and also that my next-of-kin must undergo a screening process to deem eligibility in this study
- I provide my consent to have the treatment sessions video recorded for rigour and analysis purposes. I also provide my consent for clinical photographs to be taken if and when necessary.

Signed:______________________ Date: _____________________
Name (Block Capitals): ______________________________
On Behalf of: _______________________
Relation:_______________________________
Witness: _______________________ Date: ___________________

I additionally provide my consent for the video recordings to be used for education and training purposes

Signed:__________________________ Date: _____________________
Name (Block Capitals): ___________________________
On Behalf of: _______________________ Relation:_______________________
Witness: ___________________ Date: ___________________

Appendix G: Staff Information Sheet

National University of Ireland, Galway

Staff Information Sheet

Study Title: An Evaluation of an Individualised Therapeutic Programme for a Person with a Long-Term Disorder of Consciousness: a Case Study Approach.

Principal Investigator: Ms Ann-Marie Morrissey

What is the purpose of this study? A Disorder of Consciousness (DoC) occurs after a severe head injury. It results in the person having limited awareness of themselves and their surroundings. There exist limited specialised support services for a person with this condition. This study aims to target people with a DoC in long-term care and provide a specialist treatment programme. The therapeutic programme will consist of education of family and care staff, a sensory programme (SMART), environmental modification and seating and positioning advice.

Why has this care setting been chosen? You have been chosen as one of the residents of this care facility has had a disorder of consciousness long-term.

Do I have to Participate? Participation in this research is entirely voluntary. You will be asked to participate if you care for the aforementioned patients at any time during the study. If you do agree to take part you will be asked to sign a consent form. However you are free to withdraw from the study at any stage despite signing the form.

What is required if I take Part? If you agree to participate in this research study you will be asked to document any changes/movements you observed from the patient while you were working with them. This can consist of verbal or written feedback. You may also be asked to feedback to the researcher as to how you believe the intervention is working from your perspective, this can be verbally or via an evaluation form. You will also be invited to undergo additional training and education regarding working with this specialist client group.

Are There any Risks Involved in participating in this study? There is no risk associated with participation in this study.

What will I do if I have more questions? If you have any more questions about any aspect of this study you should contact the Principal Investigator named at the end of this sheet. She will address any of your concerns and provide any further information that you may require.

Will participation in this study be confidential? All information collected will be stored anonymously and stored securely. All information will be stored on University campus. Only authorised personnel will have access to this information. Any of the co-researchers viewing the information will have a duty of confidentiality to the participant and will sign a code of Confidentiality.

What will happen to the results of this study? The results of this study will be published as part of a research thesis. The researcher also aims to publish the results in a medical journal. At no time will a participant in this study be identified in any report or publication.

Who has reviewed the study? This study has been reviewed and approved by NUI Galway's Research Ethics Committee.

For addition information now or in the future please contact:

Prof Agnes Shiel,
Department of Occupational Therapy,
Áras Moyola,
NUI Galway
(091) 492957

Ann-Marie Morrissey
Address: Room 203, Áras na Coiribe, NUI Galway
Phone Number: (087) 7611819

Appendix H: Staff Workshop Handout

NUI Galway
OÉ Gaillimh

Disorders of Consciousness: Assessment and Rehabilitation in Long-Term Care

Staff Workshop

Outline of Workshop

- **Part One**: Background to Disorders of Consciousness, Behaviours and Sensory Stimulation
- Break
- **Part Two**: Individual Goals and Interventions
- Break
- **Part Three**: Wessex Head Injury Matrix and Scoring

Goals of Workshop

- Fun informative session
- Promote rehabilitation techniques for DoC
- Address any questions
- Standardised behavioural assessment - WHIM

Disorders of Consciousness

- Patients may survive severe brain insult with a Disorder of Consciousness (DoC) in the form of Vegetative State (VS) or Minimally Conscious State (MCS)

  (Godbolt et al., 2012)

- Umbrella Term
- DoC are increasing yet relatively new phenomena

Vegetative State (VS)

- Eye-opening or sleep-wake cycles on EEG
- They fail to produce any purposeful or voluntary behaviour in response to auditory, visual, tactile or noxious stimulation
- They do not exhibit any sign of language comprehension or expression
- There are generalized physiologic responses to pain (e.g., abnormal posturing, tachypnea, diaphoresis) and roving eye movements that may be misinterpreted as visual pursuit unless careful examination is conducted.
- Cranial nerve functions are variable and there is double incontinence (Giacino, 2004)

Minimally Conscious State

- Demonstrated on a reproducible or sustained basis <u>one or more</u> of the following behaviours:

- Following simple commands.
- Gestural or verbal yes/no responses (regardless of accuracy).
- Intelligible verbalization.
- Purposeful behaviour, including movements or affective behaviours that occur in contingent relation to relevant environmental stimuli and are not due to reflexive activity
  (Giacino et al., 2002)

- Some examples of qualifying purposeful behaviour include:
- appropriate smiling or crying
- vocalizations or gestures that occur in direct response to the linguistic content of questions
- reaching for objects that demonstrates a clear relationship between object location and direction of reach
- touching or holding objects in a manner that accommodates the size and shape of the object
- pursuit eye movement or sustained fixation that occurs in direct response to moving or salient stimuli

(Giacino et al., 2002)

Unresponsive Wakefulness Syndrome

Laureys *et al. BMC Medicine* 2010, **8**:68
http://www.biomedcentral.com/1741-7015/8/68

BMC Medicine

DEBATE **Open Access**

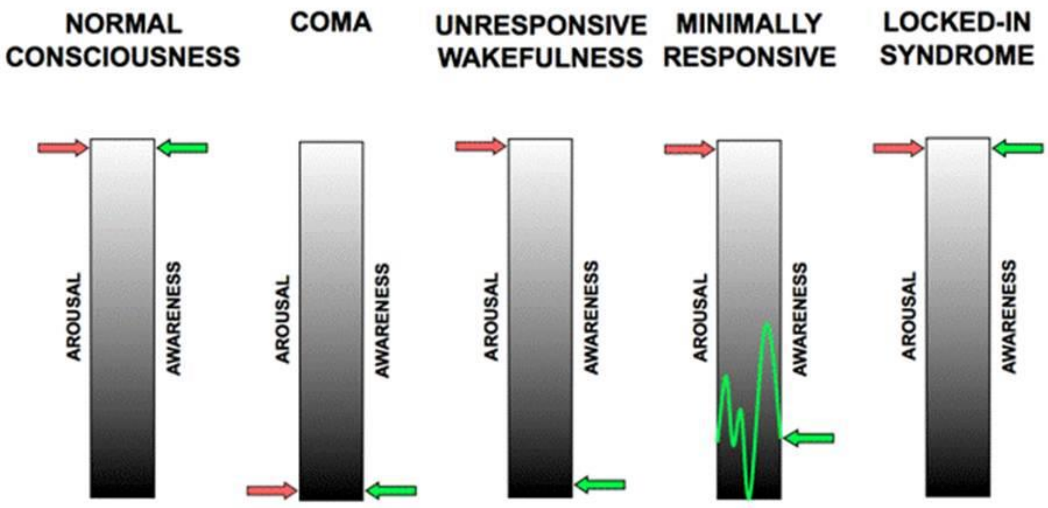
Unresponsive wakefulness syndrome: a new name for the vegetative state or apallic syndrome

Steven Laureys[1*], Gastone G Celesia[2], Francois Cohadon[3], Jan Lavrijsen[4], José León-Carrión[5], Walter G Sannita[6,7], Leon Sazbon[8], Erich Schmutzhard[9], Klaus R von Wild[10,11], Adam Zeman[12], Giuliano Dolce[13], the European Task Force on Disorders of Consciousness[1]

Abstract

Background: Some patients *awaken* from coma (that is, open the eyes) but remain unresponsive (that is, only showing reflex movements without response to command). This syndrome has been coined *vegetative state*. We here present a new name for this challenging neurological condition: *unresponsive wakefulness syndrome* (abbreviated UWS).

Discussion: Many clinicians feel uncomfortable when referring to patients as *vegetative*. Indeed, to most of the lay public and media *vegetative state* has a pejorative connotation and seems inappropriately to refer to these patients as being *vegetable-like*. Some political and religious groups have hence felt the need to emphasize these vulnerable patients' rights as human beings. Moreover, since its first description over 35 years ago, an increasing number of functional neuroimaging and cognitive evoked potential studies have shown that physicians should be cautious to make strong claims about awareness in some patients without behavioral responses to command. Given these concerns regarding the negative associations intrinsic to the term *vegetative state* as well as the diagnostic errors and their potential effect on the treatment and care for these patients (who sometimes never recover behavioral signs of consciousness but often recover to what was recently coined a *minimally conscious state*) we here propose to replace the name.



(Laureys et al., 2002)

Assessments

Assessments

- Coma Near Coma Scale (CNC)
- **Wessex Head Injury Matrix (WHIM)**
- Western Neuro Sensory Stimulation Profile (WNSSP)
- Sensory Stimulation Assessment Measure (SSAM)
- **Coma Recovery Scale Revised (CRS-R)**
- **Sensory Modality Assessment and Rehabilitation Technique (SMART)**

The JFK Coma Recovery Scale – Revised (Kalmar & Giacino, 2005)

- Six subscales: auditory, visual, motor, oromotor, communication and arousal
- Reflexive response means a lower number
- More purposive response means a higher score
- Found to be an effective tool for predicting outcome for severe BI (Giacino et al., 1991)

Wessex Head Injury Matrix – WHIM (Shiel et al., 2000)

- Behavioural observation tool
- Monitors the sequences of the VS patients' recovery
- Can be used in collaboration with SMART to [redacted]

Sensory Modality Assessment and Rehabilitation Technique (SMART)

- Introduced in 1988
- Developed by Occupational Therapists!
- Both assessment and treatment
- Visual, tactile, auditory, olfactory, gustatory, as well as the person's wakefulness, motor and communicative ability are assessed
- 24 hour approach

- Sensory Instigation Programme
- Three week assessment period – ten session
- 6-8 week treatment phase
- Three week re-assessment Phase

Sensory Stimulation

Five Senses

- Sight - Visual
- Hearing - Auditory
- Touch - Tactile
- Smell - Olfactory
- Taste – Gustatory

Presenting Stimuli

- Verbal
- Written
- Gestural
- Uni-Modal v Multi-Modal

Sensory Stimulation

- Under and Over Stimulation

- Rest periods

- Goal orientated

- Passive Stimulation

- Active Stimulation

- Good variety, clear documentation and team approach

Observations / Behaviours

Types of Behaviour

- Reflexive
- Spontaneous
- Purposeful

5 Levels of Responses

1. No response
2. Reflex Response
3. Withdrawal Response
4. Localising Response
5. Differentiating Response (SMART Programme)

Things to Consider Prior to Session

- Nutritional status
- Medical status
- Hearing aids/ Glasses
- Bowel Movements
- Rest Period
- Remove splints/positioning aids where appropriate

Things to consider during session

- Position of assessor
- Position of client
- Presentation of stimuli
- Rest periods
- Providing instructions to client
- Observations and documentation
- Arousal techniques

Posture

- Effect of posture on levels of arousal and awareness in vegetative and minimally conscious state patients: a preliminary investigation
  (Elliott et al., 2004)

- Replication of study (2012)

General Considerations

- Timing of session
- Regular Breaks
- Allow time for responses
- Clear short sentences
- Avoid over stimulation
- Provide instruction (written, verbal and/or gestural)

Wilson et al, 2001

- "they treated me as if I was stupid"
- "my stay..was absolute hell they never told me anything"
- "they used to suction me through my mouth, never told me why"
- "I can't tell you how frightening it was"
- "you need to be told where you are everyday"
- "Tell them things every time you do it, especially if it hurts"
- "Don't laugh, I found it offensive"
- "all I could hear was noise – not words"

References

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Appendix I – Staff Questionniare

Please Note: This questionnaire is for research purposes and all answers are confidential. There are no right or wrong answers so please be honest with your responses.

Name:_________________________ Gender: Male [ ] Female [ ]

Age: _____ Job Title: ____________________________

1. Are you familiar with the term "Disorders of Consciousness"? Yes [ ] No [ ]

Can you briefly describe what is meant by this term _______________________

____

2. Are you familiar with the term "Vegetative State"? Yes [ ] No [ ]

Can you briefly describe what is meant by this term _______________________

____

3. Are you familiar with the term "Minimally Conscious State"? Yes [ ] No [ ]

Can you briefly describe what is meant by this term ______________________

____

4. Have you ever worked in a specialist neuro-rehabilitation ward? Yes [ ] No [ ]

If yes for how long ____________________

5. Have you ever worked with a patient like _______ before? Yes [ ] No [ ]

If yes for how long ____________________

6. How would you describe your experience in terms of working with patients of this nature?
   Very Limited [ ] Limited [ ] Sufficient [ ] Good [ ] Very Good [ ]

7. How frequently do you work with this patient?
   Never [ ] Monthly [ ] 1-2 times weekly [ ] 3-4 times weekly [ ]
   More often [ ]

8. Do you believe that this patient .... (please tick for each one)

I. Can understand what you are saying Yes [ ] No [ ] Don't Know [ ]

II. Has awareness of the environment on some level ……………………………………………………...Yes [ ] No [ ] Don't Know [ ]

III. Experiences pain Yes [ ] No [ ] Don't Know [ ]

IV. Can improve Yes [ ] No [ ] Don't Know [ ]

V. Will gradually get worse Yes [ ] No [ ] Don't Know [ ]

VI. Would benefit from more rehabilitation Yes [ ] No [ ] Don't Know [ ]

VII. Is in an appropriate care setting Yes [ ] No [ ] Don't Know [ ]

VIII. Can get frustrated Yes [ ] No [ ] Don't Know [ ]

IX. Should be in a busy room with other patients Yes [ ] No [ ] Don't Know [ ]

X. Needs to be seated out every day Yes [ ] No [ ] Don't Know [ ]

9. What, in your view, are the main care priorities for this patient?
Comfort [ ] Maintenance of current function [ ] General Rehabilitation [ ]
Intensive Specialist Rehabilitation [ ] Other [ ] ____________________

10. How would you rate the care services received by this patient thus far?
Poor [ ] Fair [ ] Good [ ] Very Good [ ] Excellent [ ]

11. Would you be interested in attending an in-service on working with patients with a brain injury? Yes [ ] No [ ] Don't Know [ ]

12. In this section please write down any thoughts/feelings/beliefs/experiences you have surrounding care of a brain injured adult that were not captured by the questions above.

____

____

Appendix J - STAI Scale Scores

Item on State Scale	Before Not at All	Before Some what	Before Moderately So	Before Very Much So	After Not at All	After Some what	Before Moderately So	After Very Much So
I feel tense	1	4	1	3	1	7	0	1
I feel strained	3	0	3	3	3	2	4	0
I am presently worrying over possible misfortunes	3	2	2	2	5	2	1	1
I feel satisfied	3	3	3	0	1	3	5	0
I feel frightened	4	0	3	2	5	1	2	1
I feel comfortable	5	2	1	1	1	6	1	1
I feel indecisive	1	4	1	3	1	4	4	0
I am relaxed	3	2	4	0	2	2	4	1
I feel content	3	3	3	0	2	2	5	0
I am worried	0	5	2	2	0	7	2	0
I feel confused	4	1	2	2	3	3	2	1

Differences in Pre and Post Scoring on Aspects of the State Scale of the STAI

Item on Trait Scale	Before Almost Never	Before Sometimes	Before Often	Before Almost Always	After Almost Never	After Sometimes	Before Often	After Almost Always
I feel nervous and restless	6	1	1	1	7	1	1	0
I feel satisfied with myself	0	4	4	1	0	2	7	0
I feel like a failure	6	2	1	0	9	0	0	0
I feel rested	1	5	3	0	0	3	6	0
I am happy	2	3	2	2	1	2	5	1
I make decisions easily	3	0	4	2	1	2	5	1
I feel inadequate	5	2	2	0	7	2	0	0
I am content	1	1	6	1	1	1	7	0
Some unimportant thought runs through my mind and bothers me	5	3	1	0	7	2	0	0
I get in a state of tension or turmoil as I think over my recent concerns and interests	3	4	1	1	4	3	2	0

Differences in Pre and Post Scoring on Aspects of the Trait Scale of the STAI