SHAPING AND SHARING FUTURES IN BRAIN INJURY REHABILITATION

JULIE LATCHEM

DOCTOR OF PHILOSOPHY
CARDIFF UNIVERSITY
2017
DECLARATION

This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award.

Signed … … (candidate) Date…31/05/2017..............

STATEMENT 1

This thesis is being submitted in partial fulfilment of the requirements for the degree of PhD.

Signed…….. (candidate) Date…31/05/2017..............

STATEMENT 2

This thesis is the result of my own independent work/investigation, except where otherwise stated, and the thesis has not been edited by a third party beyond what is permitted by Cardiff University’s Policy on the Use of Third Party Editors by Research Degree Students. Other sources are acknowledged by explicit references. The views expressed are my own.

Signed…….. (candidate) Date…31/05/2017..............

STATEMENT 3

I hereby give consent for my thesis, if accepted, to be available online in the University’s Open Access repository and for inter-library loan, and for the title and summary to be made available to outside organisations.

Signed…….. (candidate) Date..31/05/2017..............
Acknowledgements

First, I would like to thank my loving mother Mary and beloved father David for being perfect parents, for their support and for instilling within me, a quiet determination.

I would like to express my appreciation to all my supervisors - Professor Joanna Latimer, Dr Sara MacBride-Stewart and Professor Jenny Kitzinger. Joanna, thank you for your teaching and guidance through the first half of this doctoral journey. Sara, thank you for constantly pushing me to locate my work more strongly and to leave no sociological stone unturned.

To Professor Jenny Kitzinger – Thank you for encouraging me to think differently, for bringing me to sociology and challenging me to see what I could achieve through academia. Thank you for the time spent battling out our differences and discovering how what divided us was key to finding shared values, ways forward and to making a difference. Thank you for supporting my hybridity and for always protecting my golden thread.

I would like to acknowledge and thank my academic mentor Professor Barbara Adam, whose constant support, wisdom and kindness has been utterly critical to the success of this doctoral research. I would also like to thank my clinical mentor Mrs Gill Donovan, who has journeyed with me the longest. Thank you, Gill, for supporting me through highs and lows and for always being so dependable for that all important crucial advice when it really mattered.

Very special thanks go to my partner, Dr Geraldine Hastings. Thank you for all your love and thoughtfulness. Your care and understanding kept me going when I needed it most.

Finally I would like to thank all those who participated in this research. Thank you everyone for your generosity and care. I had one of the best times of my life with you. I hope this work and everything I do in the future, does you justice.
This thesis is dedicated to the memory of Joanne Woodward.
Abstract

The future is a tricky issue for the sciences because it has not happened yet and therefore is not ‘fact’ (see Adam and Groves 2007) to be studied. Nonetheless the future in and by its intangible nature acts upon us and is brought into the present, shaping both interactions and actions taken in the now. At the same time, futures are continually in the making and already made as actions past shape future lives to come. How futures are made then, how people’s lives to come are shaped, is both a social and political issue which requires attention.

This thesis focusses on the lives of one particular group of people - those who have severe brain injuries. It explores how their futures are being shaped and negotiated, made and constrained by and through rehabilitation in a context of every day care delivery within independent neurological rehabilitative settings.

This research draws on in-depth ethnographic data collected over five months at two neurological rehabilitation settings in England which includes interviews and broad and close observations of day-to-day happenings in the lives of around 60 brain injured residents, families and health care staff. The data was subject to a situational analysis (Clarke 2011), which is underpinned by grounded theory and discourse analysis, to foreground the collective multiplicity of actors in context.

The findings highlight how patients’ futures are imagined depends upon their ability (or not) to demonstrate rehabilitative progress and are imagined in line with their fit to a ‘rehabilitative imaginary’. The dominance of this imaginary simultaneously negates the futures of those unable to fulfil it but enables the ‘good care’ of all in the present. Those that are considered marginal to care - ‘hotel service staff’ (cleaners, cooks, maintenance and administrative staff) are shown to be central to the making of futures of brain injured residents and how differences in the way in which patients’ futures are imagined by patients, their families and HCPs are shown to contribute to tensions between them.

It contributes to the sociological literature by extending temporal analysis to this under-researched condition (brain injury), process (rehabilitation) and place(s) (independent neurological rehabilitation settings in the independent sector) and by illuminating how futures of brain injured residents are imagined and shaped by brain injured residents themselves, by families and HCPs working with them.
Contents

Abstract ........................................................................................................................................ iv
Introduction ...................................................................................................................................... 1
Study implications for policy and practice ................................................................. 7
Biography of the research questions and the rationale for the research focus .......... 8
Neurology – a golden thread ............................................................................................. 8
The triad of patient, family and health care professional relationships .............. 9
Independent sector care – a choice of setting ............................................................. 11
The contribution of unqualified staff and recognising the social ..................... 12
Matron – organisational process and practice ......................................................... 13
Qualitative research and focusing on futures ......................................................... 14
Thesis audience and terms of reference ................................................................. 16
Overall structure of the thesis ..................................................................................... 17
Chapter 1 – Severe brain injury and caring relations .............................................. 19
1.0 What is severe brain injury: classifications, incident, and prognosis ............ 20
  1.0.1 Classification ........................................................................................................ 20
  1.0.2 Incidence, epidemiology and impact ............................................................ 21
  1.0.3 Defining Severe brain injury ........................................................................ 21
  1.0.5 Disorders of Consciousness: Coma, the vegetative and minimally conscious state ................................................................. 23
1.1 The construction of people with severe brain injury in medical, health and sociological literatures, their experiences and approaches to their care .......... 24
  1.1.1 Complexity and range of impairments caused by SBI: distinguishing needs 24
  1.1.2 Brain injury care and treatment – phases and places ................................. 25
    1.1.2.1 Acute care in intensive care units ............................................................... 25
    1.1.2.2 Rehabilitation .......................................................................................... 26
    1.1.2.3 Care ‘in the community’ ........................................................................ 27
    1.1.2.4 Missing people in hidden places ............................................................. 27
  1.1.3 Further approaches to care, treatment and study ....................................... 32
    1.1.3.1 Divided bodies ........................................................................................ 33
    1.1.3.2 Multidisciplinary team working .............................................................. 35
  1.1.4 Experience of people with brain injury: the sociological study of brain injured persons ......................................................................................... 38
    1.1.4.1 Self and Identity ..................................................................................... 38
4.3.3 What is ethnography and how has it been used in the study of health, illness and medicine, and in the study of time? ................................................................. 126
4.3.4 Time and ethnography .................................................................................. 128
4.3.5 Methods of data collection used in ethnography ......................................... 129
  4.3.5.1 Semi-structured interviews ..................................................................... 130
4.4 Locating and differentiating the study methodologically .................................. 131
  4.4.1 Brain injury, rehabilitation and ethnography .............................................. 131
  4.4.2 Families of brain injured people and ethnography ..................................... 133
4.5 Data collection .................................................................................................. 133
  4.5.2 The ethnographic sites – ‘the field’ ............................................................. 135
  4.5.3 Sampling ..................................................................................................... 137
  4.5.4 Recruitment of residents .......................................................................... 138
  4.5.3 Sample demographics ................................................................................ 143
  4.5.5 Ethics - Informed Consent and confidentiality ........................................... 146
  4.5.6 Designing through Ethics .......................................................................... 148
4.6 Doing data collection - Observation and interviewing ....................................... 150
  4.6.1 Broad observations and day-to-day ‘access’ .............................................. 151
  4.6.2 Interviewing ............................................................................................... 154
  4.6.3 Researcher identity, implications and management .................................... 155
  4.6.4 Data collection with residents – a case by case approach ......................... 157
  4.6.5 Data collection with staff and families ....................................................... 160
4.7 Data analysis ..................................................................................................... 161
  4.7.1 Situational analysis .................................................................................... 162
  4.7.2 Social worlds ............................................................................................. 163
  4.7.3 Doing situational analysis ......................................................................... 165
Chapter 5 – Findings 1: ‘Poster boys’ and the rehabilitative dream .................... 169
5.0 Chapter Overview ............................................................................................. 169
5.1 What is ‘rehab’ as defined by those working within it? .................................... 170
  5.1.1 Rehabilitation as restoration ................................................................... 170
  5.1.2 Rehabilitation as time, in time and with time ......................................... 171
  5.1.3 The pervasiveness of the rehabilitative dream/imaginary ....................... 180
  5.1.4 Small gains and big moments .................................................................. 182
5.2 Successful rehabilitative stories ....................................................................... 184
  5.2.1 Poster boys .............................................................................................. 187
    5.2.1.1 Low expectation of further rehabilitative potential ......................... 189
5.2.1.2 The challenge and rejection of a negative prognosis .......... 191
5.2.1.3 Intensity of rehabilitative interventions .......................... 191
5.2.1.4 Persistence and ‘not giving up’ ....................................... 192
5.2.1.5 The demonstration from the patient of consistent progression and improvement in multiple domains ............................ 193
5.2.1.6 Improvement that makes discharge home or into the community possible ................................................................. 193
5.2.1.7 The sustaining of rehabilitative progress ........................................ 195
5.3 Poster boys’ futures ................................................................ 198
5.3.1 Imagined and constructed ..................................................... 198
5.3.2 Unimagined, hampered and constrained ................................. 200
5.4 The futures of non-poster boys ............................................... 205
5.4.1 Cash cows .......................................................................... 210
5.4.2 Complexity of needs ............................................................. 210
5.4.3 Finance .................................................................................. 212
Chapter 6 – Futures in the making – being made ‘rehab-ready’ and rehab-able in and through the everyday ........................................ 215
6.0 Chapter overview .................................................................. 215
6.1 Being ‘rehab ready’ ................................................................. 216
6.1.1 Preventing rehab readiness .................................................... 219
6.1.2 What happens to those who are not rehab ready? .................... 220
6.2 Non-qualified care and therapy workers .................................... 222
6.2.1 Generating ‘response’ through humour .................................... 223
6.2.2 Attending to atmosphere ...................................................... 226
6.3 Hotel service staff do this through the conducting of the everyday ........ 229
6.3.1 Cognition ........................................................................... 229
6.3.2 Orientation ......................................................................... 231
6.3.3 Physical function .................................................................. 233
6.3.4 Occupation ......................................................................... 235
6.3.5 Communication, behaviour and sociability ................................. 236
6.4 The experiences of hotel service staff ....................................... 239
Chapter 7 Future talk – relationships and the temporal in brain injury rehabilitation ................................................................. 245
7.0 Chapter Overview .................................................................. 245
7.1 What future do residents imagine for themselves? ...................... 245
7.2 What is the future about for families? ....................................... 249
7.2.1 Restoration and improvement ................................................................. 249
7.2.2 Restoration of family life/family togetherness ................................. 252
7.2.3 Quality of life ......................................................................................... 253
7.2.4 Discharge home or outside of the care setting ................................. 254
7.2.5 The future as the end of life ................................................................. 256
7.2.6 The painful future of returning to everyday life for family members .. 257
7.2.7 Taking control of the future for their relatives and themselves ...... 258
7.2.8 On hold, stasis, limbo ............................................................... 259

7.3 Temporal tensions in relationships ......................................................... 260
7.3.1 Future imagining mismatches: residents, families and staff .......... 261
7.3.2 ‘There is no future talking’ - Temporal compression and mismatch of
temporal frames for families and staff ...................................................... 262
7.3.3 Families open futures and broaden patient horizons - Staff’s recognition of the role of families in brain injured futures ................. 268
7.3.3.1 Families hamper and endanger futures ........................................ 268
7.3.3.2 Requirement for constant future reimagining and reorganisation ... 270

8.0 Conclusion ............................................................................................... 274
8.1 Opening overview of the discussion ....................................................... 277
8.2 Original contributions: theoretical, substantive and methodological .... 277
8.2.1 Theoretical contributions ................................................................. 277
8.2.1.1 Sociology of time ......................................................................... 278
8.2.1.2 Sociology of health and illness .................................................... 278
8.2.1.3 Health care sciences and rehabilitative literature ....................... 280
8.2.2 Substantive contribution ................................................................. 280
8.2.2.1 Contribution to the Sociology of health and illness .................... 281
8.2.2.2 Contribution to the literature on the Sociology of time .............. 281
8.2.2.3 Contribution to health care sciences and rehabilitative practice ... 282
8.2.3 Methodological reflections and contributions .................................... 283
8.2.3.1 Four key contributions ............................................................... 284
8.2.3.2 Troubling researcher-led recruitment ........................................ 284
8.2.3.3 Researcher-led interviews ......................................................... 285
8.2.3.4 Ethnographic methods and a case by case approach ................. 286
8.2.3.5 The value of hybrid researcher – skilled to interview, confident to include ................................................................. 286
8.3 Implications for policy and practice ....................................................... 287
8.3.1 Extending time for rehabilitation and establishing new patient pathways 287
8.3.2 The importance of imagination .................................................. 288
8.3.3 Respecting present keepers and protecting informal rehabilitative practices .................................................. 289
8.4 Limitations of this study ....................................................................... 290
8.5 Unanswered questions and further work ........................................ 291
8.6 Closing summary ................................................................................. 293
References.................................................................................................. 294
Appendix 1 – Prelude – Good morning Charis ........................................ 330
Appendix 2 – Goal setting ......................................................................... 338
  2.1 Person centred care, service user involvement and participation in goal setting .................................................. 338
Appendix 3 - Methods ............................................................................. 340
  3.1 Patient Consent form ........................................................................ 340
  3.2 Patient participant information sheet ............................................... 343
  3.3 Interview schedule/Topic guide ...................................................... 352
  3.4 Observing and being observed – capturing one another ............... 360
  3.5 Resident-led interviews ................................................................... 362
  3.6 The technicalities of data capture .................................................... 363
Appendix 4 – Postscript ........................................................................... 365
  4.1 Sharing of findings and initial ‘impact’ .............................................. 365
    4.1.1 Audience and Attendance ........................................................ 367
    4.1.2 PhD corner: The work of hotel service staff .............................. 368
    4.1.3 Thematising PhD corner with flowers ..................................... 370
    4.1.4 Family-staff relationships ....................................................... 374
    4.1.5 Engagement and interaction with PhD corner ....................... 375
  4.2 Post event discussions with staff ..................................................... 377
Introduction

Social time theorists argue that we are continually engaged in creating and anticipating our future life trajectories, being heavily invested in the future for ourselves and those close to us (Bell 1996; Adam and Grove 2007; Shirani and Henwood 2011). ‘Unexpected life course events’ then, can cause significant problems – partly through disrupting the playing out of such anticipated, expected life trajectories (Shirani and Henwood 2011, p. 49).

Despite the unknowable nature of what is to come, Adam and Grove (2007) theorise that throughout history, humankind have made multiple attempts to know or foretell the future, to control it and to capitalise on it. They posit that approaches to the future taken by societies and cultures have changed over time. The dominant belief in divinities and their dominion over the temporal domain and individuals’ ‘fate’ present in communities and civilisations past, has given way to a starkly different engagement with the future today – one where both individuals and groups approach the future as theirs to control, make, shape and exploit (Adam and Grove 2007; Adam 2011).

Within this current relationship to the future, social scientists who study social futures argue that attempts to make the future knowable, to ‘tame’ it, are made by relying on patterns seen in the past and anticipating either the reoccurrence of that which has come before, or the next occurrence in any identified sequence (Adam and Grove 2007). In contemporary western society complex predictive models and social analysis of past events are used to forecast anything from developments in medical research (Bender et al. 1969), public health needs (Bezold 1995; Hancock and Garrett 1995), risks in communications and information technologies (Bostrom 2003), European tourism demands (Hassani et al. 2017) to supply chain operational management (Syntetos et al. 2016), renewable energy markets (Kaur et al. 2016) and climate change (Bas et al. 2017).
Technological advances such as the development of the internet and web based applications (such as Skype) have further changed societal approaches to and engagement with the future. Digital technologies enable instant communication across vast distances, compressing the time taken to share knowledge or experience from weeks into an instant. As the development of such technologies make possible the option of immediacy, societal relationships and actions shift, engaging with new temporal frames made available (Adam and Grove 2007). In this way, the future comes into the now enabling lives to be lived in an ‘extended present’\(^1\) (Novotny 1995) rather than a time to come.

Within these contexts of shifting temporalities and much engagement with and investment in making the yet to come knowable, social time theorists argue that time, and the temporality of the future is infused into every part of the social world (Novotny 1995, Adam and Groves 2007). Attempts to make the future knowable, coupled with social and cultural expectations about and imaginings of lives to come, constantly brings the future into the present and therefore forms actions taken in the now. Any study which seeks to understand the present therefore, requires recognition that engagement with what has past and what is to come is central to the shaping of any present.

A stark example of an ‘unexpected life course event’ (Shirani and Henwood 2011, p. 49) and an area of the social world where there is high investment in making and wanting the future to be knowable, is that of severe brain injury. Brain injury is one of the leading causes of death and disability in young adults (aged under 40) in the western world (Maas et al. 2008). Coming without warning and often affecting previously healthy individuals, mortality from severe brain injury ranges from 30% to 50% internationally (Turgeon 2013). However, ever more people with severe brain injury are surviving (Turgeon 2013) and those who do often live with multiple impairments (Schumacher et al. 2016) such as an inability to walk and wash

---

\(^1\) The extended present is a temporal term developed by Helga Nowotny (1994) which refers to how societal developments enable things to be done or experienced in an instance. The future is constantly brought into the now and time is lived in an extended present.
themselves, talk and communicate, eat and drink, remember and plan. They may have extreme changes in behaviour, experience pain and altered or loss of sensation. Their level of awareness and arousal may be affected, and to such an extent that for some people who ‘survive’ brain injury, their body functions in that their heart beats, they breathe and urinate but they are not aware (or only intermittently aware) of themselves or their surroundings.

Historically most people would have died of severe brain injury through apnoea (the cessation of breathing) (Demertzi et al. 2011), however due to modern medical technologies and medico-legal practices this is no longer the case in many countries. Advancement in life sustaining medical technologies such as resuscitation, mechanical ventilation, surgical procedures and innovations in intensive care and neurosurgery mean that many people are now surviving the initial injury (Marshall 2000; Demertzi et al. 2011). The development of techniques, formule and practices in the delivery of respiratory care (such as long-term tracheostomies and portable mechanical ventilators) and nutrition and hydration through artificial means are implicated in the fact that they enable people with severe levels of impairment for many years – even decades (Kaufman 1993; 2000; Kitzinger and Kitzinger 2012).

In this situation where anticipated futures are dramatically ruptured, attempts to make the future knowable are evident in the work of clinicians who try to foretell the post injury outcome of their patients. Prognostication, the attempt to make a prediction of the likely outcome of the state and abilities of a patient following injury, plays a critical role in the way in which medical decision-making is done (Turner-Stokes 2016). Attempts to know the future of patients with severe brain injury are made extensively through a series of key strategies. Foretelling the outcome of people with severe brain injury relies on learning achieved from careful study of past patients (case studies) and the resultant outcomes to any treatments and the development of mechanical technologies. Brain imaging (i.e. magnetic resonance imaging and computerised topography scans) and assessment and measurement technologies such as intracranial pressure monitoring and established outcome measures such as the Glasgow Coma Scale, provide the clinician with a picture of the
previously hidden brain, the damage caused or being caused (Guise et al. 2005). However, despite advancements in tools providing information about the extent of brain injury, clinicians state that there is, nonetheless, ‘no reliable way to predict outcome’ (Turner-Stokes 2016, p.1) early after injury. Subsequently there is both historic and contemporary recognition within medicine that there is a significant level of uncertainty in the prognostication of outcome following severe brain injury – and that the future for these patients is therefore unknowable (Gogstad and Kjellman 1976; Guise et al. 2005; Stevens and Stutter 2013; Brasure et al. 2013; Turner-Stokes 2016).

In this situation of exceptional uncertainty, medical treatment ‘is normally provided during the early stages in the hope and expectation of recovery’ (Turner-Stokes 2016, p.1). It may ‘save’ life and facilitate some form of recovery, but be “futile” in that it may not necessarily restore function to the level that the patient would consider to be a life worth living, either now or in the future (Turner-Stokes 2016). In balancing the probable effectiveness of any given treatment, clinicians must then consider the harm it may cause and the ‘risk of unacceptable badness’ (Gillet et al. 2010, 727). Unacceptable badness is ‘the probability that the patient will end up living in a state that they would describe as intolerable.’ (Turner-Stokes 2016, p.1). The concepts of futility and unacceptable badness have been explored extensively in relation to neurosurgical techniques (Honeybul et al. 2011;2012) conducted in the immediacy following severe brain injury to ‘save’ life, without the benefit of foresight and the eventual outcome of these types of actions taken in the now (Turner-Stokes 2016).

In the case of severe brain injury, within medical literature and clinicians’ own narratives, greater certainty about the eventual outcome for the brain injured person is considered to be achievable in time and with more time, meaning, the closer to the future that is wanted to be known about in the present, the more reliable predictions that are given about the overall ‘long-term’ situation for the person will be (Stevens and Sutter 2013).
How medical decision-making is made following severe brain injury therefore forms the focus of discussion regarding the ‘problem’ of people surviving brain injury (i.e. being treated but then ending up living with high levels of disability that they themselves would find unacceptably bad) from families and clinicians (Holland et al. 2014; Kitzinger and Kitzinger 2012; 2014; 2015). Early and repeated best interest decision-making in the initial phases following injury and improved understanding and engagement with prior expressed value and beliefs within this decision-making process (in line with the Mental Capacity Act 2005) has been identified as an area of concern and in need of improved practice (Chatfield et al. 2017; Kitzinger and Kitzinger 2012; 2016a, 2016b).

However, while the challenge of foretelling futures through prognostication following early stages post severe brain injury is well documented, prognostication gives way to a very different set of temporal foci for those who, through medical treatment have survived severe brain injury and are living with profound and complex impairments in rehabilitation and long-term care settings. Those who survive severe brain injuries are left with significant physical, sensory and cognitive deficits and require long lasting rehabilitation (Schumacher et al. 2016). Rehabilitation is said to be a future orientated process which looks to maximize function, physically, cognitively and socially whilst minimising medical complications and disability (Wressle et al. 1999; Kischka 2004). However, in severe brain injury complete recovery is rare and so, in many cases, despite often prolonged periods of rehabilitation, these people remain impaired and need significant care and support from others in the long-term. The extent and multiplicity of their needs often makes care at home not possible and many reside for prolonged periods of time in rehabilitative and/or long-term care facilities. They are sustained in these places with medical advancements enabling the extension of their life – such as percutaneous endoscopic gastrostomy (PEG) feeding tubes and tracheostomies.

However, not all patients with severe brain injuries have such extreme impairments, but present, nonetheless with a complex range of impairments and with difficulties such as mobilising, planning and speaking. These patients do not require such high
levels of medical care in that they can breathe independently, eat and drink but require extended periods of rehabilitation and around the clock care in the management of the complexity of their needs. Some may, for example, walk with help and speak well but struggle with memory, recalling the sequence of everyday activities such as making a drink or getting dressed. They may have developed extreme changes to their personality and following injury be easily angered and become aggressive. Some such patients are also cared for in long-term care facilities that largely cater for the needs of an elderly population, many however are in places specifically designed for people with brain injuries and/or other types of neurological conditions. Such neurological care centres are predominantly owned and run by independent care companies or charities. Whatever the type and range of their impairments, what those who reside in neurological long-term rehabilitation and care settings have in common is that their needs are complex and multiple and for some reason, they have been unable to rehabilitate substantially enough, or quickly enough, to return home or be supported in a location that does not offer around the clock care and support.

At this stage, these severely brain injured people no longer have an uncertain future in prognostic terms. They are severely brain injured and will, with very little doubt, remain so for the rest of their lives. This thesis contributes to the sociological literature through the empirical illumination of this time, this place and these people, for whom ‘uncertainty’ is much less extreme but where futures of individuals and those around them will now be dramatically different than anticipated. The thesis also contributes to the sociological and healthcare literature through applying a ‘temporal gaze’ (Adam 2000) to the care and rehabilitation of people with severe brain injury. This thesis is about the temporality of care and demonstrates how the past, present and future is at the core of all happenings in the now which surround those with severe brain injuries. It explores how their lives, their futures, are shaped during ‘rehabilitation’, identifies who has a future and how these futures are re-imagined (or in some cases not imagined at all) and by whom. It examines how the future comes into the present to feature in actions taken in the now, and how the
future can be pushed out, bracketed, negated or compressed in the care work with and around these patients.

This thesis addresses two key questions:

1) How are the futures of people with brain injury shaped and negotiated through a) day-to-day interaction and b) organisational process and practice?

2) What role does ‘time’ play and ‘the future’ hold in the development and mediation of relationships between patients with brain injuries, their families and HCPs during rehabilitation?

**Study implications for policy and practice**

The above section has highlighted the theoretical significance of the thesis. This section highlights the significance of the thesis for policy and practice. As such it reflects my hybrid concerns, background and approach to studying these issues (I am both a sociologist and a neurological physiotherapist, see below and chapter 4).

Positive relationships between patients, families and health care professionals [HCPs]² are fundamental to good care (Nolan 2006) and have been identified by people with neurological conditions and their families as the most important element in their rehabilitative experience (Pellat 2004; Latchem and Kitzinger 2012). There is a growing focus on and much wider identification in policy, research and practice of the importance of these relationships “and a growing awareness that staff, patients and families want to provide and receive care...in the context of caring relationships” (Smith et al. 2010, p.5). The magnitude of this need and the importance of these relationships has been highlighted in multiple governmental reports such as the Francis Report (2013) which saw a ‘caring culture’ as critical to improving the quality of care.

² In this thesis ‘Health Care Professional’ is used as a collective term to mean those who are paid to provide health and/or care and have either a professional status i.e. Physiotherapist, Doctor, Nurse or are an aide to a connected profession such as a physiotherapy assistant.
of healthcare³. Although the quality of relationships within healthcare are of the utmost importance, these relationships can become extremely strained during brain injury rehabilitation (Shaw and McMahon 1990; McLaughlin and Carey 1993) as efforts to control the future, to influence the outcome of injury, and to shape the identity and care of a patient with brain injury must be negotiated within the likelihood of long-term disability.

By exploring what happens as efforts to influence the future and outcome of injury are made this thesis delivers a third contribution to the literature. Identifying the ways in which the future of the brain injured person is imagined (or not) by the different groups of actors contributes to knowledge regarding both the challenges and care shown within these relationships.

Biography of the research questions and the rationale for the research focus

In this section I further exploration the origins of the research problems posed and addressed by this thesis and the professional experiences of its writer, which underpin the drive to undertake this research. The topic I explore and the questions I ask in this PhD are motivated through and from my own professional work as a neurological physiotherapist treating and caring for people with neurological conditions.

Neurology – a golden thread

I first came into contact with people with neurological conditions on a work placement with physiotherapists at a Multiple Sclerosis centre. I was deeply affected by what they faced each day, and at the same time, utterly fascinated by how neurological impairments were manifesting in their bodies. The bizarre feeling of a

---

³ There is inconsistency within the literature regarding the use of ‘healthcare’ or ‘health care’ about the care of an individual’s health, the services provided by professionals or an overall service or system. Here I use ‘health care’ to mean a set of actions by a person or persons to maintain or improve the health of a patient/customer and the term ‘healthcare’ to mean a system, industry, or field that facilitates the logistics and delivery of health care for patients/consumers.
spastic limb which at first touch feels solid and stuck, but then with handling dissolves, dissipates and returns to momentary normality. Strange movements with shakes and shudders which render limbs unusable, useless, but with input, weight bearing, exercises can be restored usable. Achieving this was to me a truly worthy pursuit and one in which I followed, becoming a physiotherapist some years later - eventually specialising in neurology.

As a practicing physiotherapist I met all sorts of people with many different types of illnesses and sometimes, subsequent disabilities. In some cases, I felt I made a huge impact upon patients’ recovery or wellbeing and was flooded with the endorphins of triumph as these patients improved, rehabilitated and left hospital either cured or able to live life with less barriers ahead of them than when they came in. However, there are situations where there can be no resolution and where outcomes are unknown. Often, there is no smooth and upward trajectory of ‘recovery’, and instead a journey of ups and downs, improvements, stagnation or even decline. Neurology is much like this. Successes are not often found in the same places as in other clinical areas, mistakes are devastating and often unfixable, treatments are partial. It’s within this messy reality that this PhD is set.

The triad of patient, family and health care professional relationships

“Care has become such a widely used concept that it risks becoming meaningless.” (MacBride-Stewart 2014, p. 85) – the concept and how we use it may be at risk of becoming meaningless but it is however, the very meaningfulness and importance of care, in both its breadth and depth, the multitudes of its manifestations and the giving and receiving of it which is central to my clinical experience and journey to this PhD.

I have worked in lots of different types of care places and treated people with very different ailments. I’ve worked on general medicine and respiratory wards, in intensive care, musculoskeletal outpatients, womens health, elderly rehabilitation, orthopaedics, stroke and neurology. Despite the variation of my clinical case load, there is striking parity in what patients and family members thank you for.
Considering my profession, one might anticipate that what patients say might include ‘thank you for helping me get back on my feet’ or ‘thank you for helping get stronger’ or such like. Instead, messages of thanks more often focus on ‘love and care’ rather than expertise or therapeutic skills. How important these type of relationships between patients and health care professionals are, was made further evident to me when I asked patients with neurological conditions and their families what was most important to them in their rehabilitation or long-term care in my first research study (Latchem and Kitzinger 2012).

I saw the strength and power of good care relationships and how they positively contributed to rehabilitative outcomes. At the other end of the spectrum however, I experienced relationships of much tension, apprehension which at times, rendered me fearful to go into work. In between there were a range of relations which started well and then deteriorated over time or vice versa, relationships that began full of conflict and were settled and eventually resolved. Sadly, not all health care relationships are full of love and care nor resolve from being tense into something therapeutic. Some can be continually difficult and ‘often one that has no smooth trajectory, mistakes are devastating and often unfixable, treatments are partial’ – the same description I gave for Neurology.

I only came across the most extreme, severely tense relationships in neurological care – acute, rehabilitation and long-term care. Interestingly these experiences are matched to a point in the literature, with relationships in brain injury rehabilitation and long-term care frequently identified as being ‘conflict-laden’ (see Chapter 1). How and why these relationships can become so difficult and fraught was something I struggled to understand as a clinician. A will to map the tensions in these troubled relationships to better understand them forms part of the focus of this PhD and plays a part in the choice of the ‘futures’ framing it takes.
Independent sector care – a choice of setting

In December 2008 I left the NHS for a post leading the therapy team at a new neurological centre in the independent care sector. On the 19th January 2009 I walked into a new building, purpose built for the care and rehabilitation of people with neurological conditions. The building wasn’t finished and for the first two weeks of our employment, a group of around 20 of us (a mix of qualified health care professionals, experienced carers and those completely new to care) shared our experiences and knowledge with one another and sketched out the future as we wanted it to be. We made a pledge to one another and to the people we were to care for in the future about how we would do that. This we called our ‘ethos’.

Two weeks in and it was finally possible for us to walk around the rest of the building and see where we would be delivering care. For those of us who had worked in neurological care and knew about the reality of facilities and provision in our local area – this building was, in our eyes beautiful. It was light, spacious and had almost everything we could want. I was full of hope for the future – knowing that the space and the resources that would fill it, would give us the tools to deliver care and therapy like never before. The building at this point was empty – in that we had just walls and flooring. But, as I later came to understand, it was already a crowded space. The future of this building, the service to be developed within it and the future of those who were to come to it were already in the making – and not entirely ours to shape.

My experiences of neurological rehabilitative provision and what impacts it within both the NHS and independent sector has guided this PhD and the motivations behind it – but the focus on independent sector settings comes from the striking absence of research within these places, their growth within the UK and the concentration of people with severe brain injuries being cared for within these places (see chapter 1).
The contribution of unqualified staff and recognising the social

I held the responsibility of setting up the centres therapy team – a team I grew and developed over 18 months from myself and three assistants to a 12 strong multidisciplinary team. For some of my team, they had not come into contact with people with neurological conditions before, let alone treat them. As we began to take patients, each new patient, showed them something utterly new and they faced one challenge after another along with our patients. Like I had done years earlier they experienced for the first time neurological tone and the range of neurological symptoms that manifests in bodies, affecting function and life - only without ‘professional’ training like I had. They were in many ways remarkable, with their therapeutic skills developing quickly, the way in which they built relationships with patients exemplary, but also different.

They often helped me understand the perspectives of others and without the lens and the moulding of a profession, they saw things in a way that I had long forgotten, and they challenged what they saw and were told. They questioned approaches, attitudes, decisions - how death happened and why in that way, how we could promote life in severely disabled states. They sought to understand what achievement and success meant in neurology and how to find it. The way in which they coped and made sense of what was happening around them was something I admired. They were often very brave and also very therapeutically effective. The contribution to rehabilitation and the outcomes they achieved were impressive. These people inspire and motivate this PhD as much as families and patients and the inclusion of both qualified and non-qualified health care workers in this PhD was paramount.

The centre we worked within had to become home for some of the residents. The rules and boundaries that had applied in hospital – the requirement for patients to remain captive, confined in very specific spaces no longer applied so rigidly - in fact it was part of our job to make sure we transcended them. This meant introducing the social world, facilitating a social life into our realm of responsibility – but this was
tricky. Introducing the social with patients, many of who still had complex medical requirements brought significant challenges. How to get patients with needs such as mechanical ventilation, frequent medications, severe physical impairments which affecting how they moved (or didn’t), how they could sit, in what and for how long, neurological fatigue, behavioural outbursts – out into the world, the world beyond our walls or conversely, how could we bring it to them was constantly on our minds. Exploring this – and the times we achieved it became for me one of the highlights of my time there. Such attempts to build lives within long-term care facilities has led me to question – how are the futures of patients in such places shaped, and by whom?

**Matron – organisational process and practice**

In 2010 it was decided that the centre needed a Matron. This was a role that appeared in all other corporate services in the rest of the business. It was a strategic post, put in place in order to align neuro services with the structure of the acute hospital services in the rest of the business. My application was successful and in 2010, I became Matron. Once in post my responsibilities grew heavier and my involvement with external stakeholders intensified. With the new role came an ever-deepening sense of responsibility and will to create an environment that was best for the people in my care. I was however simultaneously becoming more aware of the crushing constraints under which I was working realising that neurological rehabilitation and the ‘independent sector’ was anything but, and was ruled by many other things.

At least 95% of patients that came to our centre were ‘Continuing Care’ (NHS) or Social Care funded. This meant that there was constant communication with funders – then, primarily Primary Care Trust’s (PCTs). Patients could come from far and wide with no ‘out of country’ ‘tariffs’ imposed. This meant that we worked with many different PCT commissioners who all worked in a different way and wanted different things. Most of the time funders would want some form of regular report – often lengthy and detailed. They would request regular ‘review meetings’. These people
seemed to hold much power and multiple rights - rights of entry, to information, to control and governance over what we did and did not do. As an independent centre and an autonomous practitioner this monitoring was experienced, at least by me as intrusive, excessive and often frustrating.

The level and amount of reporting was pressurising and what ‘quality and value’ meant to each stakeholder sat around the table (patient, family, health care professionals, independent sector manager, funder) were certainly different, often incompatible, with these differing positions and agendas consistently clashing with the middle ground often illusive. The effect of external agencies and their role in shaping both the present and the future has also motivated this study and led to the exploration of organisation practice and process.

**Qualitative research and focusing on futures**

Health care provision in England is regulated by the Care Quality Commission. The way in which the regulatory guidelines were written however did not seem to entirely match what was important to the patients we were treating. Carrying out my first qualitative research study to check the discrepancies between Care Quality Commission guidelines and what was important to neurological patients and their families receiving either rehabilitation or long-term care in specialised neurological centres in the independent sector (Latchem and Kitzinger 2012), I had my first opportunity to interview patients as a researcher, not care provider.

Marjorie was my first ever research participant. A pseudonym of course, but behind it, a woman with a neurological disease called motor neurone disease who gave me her time and energy to tell me about her experiences of being cared for and what was most important to her about the care she was receiving. Marjorie was ventilated 24 hours a day and required what is called 1:1 care – meaning that she had a carer with her 24 hours a day who sat by her side to both care for her and in essence provide surveillance, to ensure that the ventilator which, for then was sustaining her
life, kept on doing so. Marjorie spoke to me for around an hour. We had to break in-between for her to have a little care now and again but she continued until she had told me everything she had to say.

At the end of the interview I thanked her sincerely for talking to me. What Marjorie had given me was not just her words, her physical effort and her time, but she’d given me time and space, the opportunity to sit and listen – just to listen. Free of almost all responsibility in that moment (Marjorie was not my patient), I had heard anew. To my surprise Marjorie thanked me back. She asked me if what she had said was useful and I told her that it certainly had been. She then said, as that was the case, then she felt that she had achieved something that day, and that was important to her.

Recognising the value of qualitative research, not only for its findings but as a practice and the potential for its impact upon neurological patients and their rehabilitation, I sought research training and PhD funding. Discussing some ideas with a senior lecturer one late afternoon in November 2012 and identifying something temporal about my topic area, I was advised to speak to Professor Barbara Adam. I met Professor Barbara Adam on the 26th November 2012. She made social futures theory accessible to me in that meeting and I began to think about the temporal in relation to relationships in brain injury rehabilitation. Experientially I reflected on my own avoidance of talking about the future with patients and families, while actively, my professional was fundamentally about improving prospects. I began to question how ‘the future’ contributed to the tensions in these relationships.

During my time in the NHS, the way in which physiotherapy on the wards was being delivered for patients with neurological conditions (notably stroke, MS and brain injury), for how long and how many of us there was to give it, and the provision of rehabilitative services and resources of any kind for these patient groups seemed to be continually diminishing. There was a consistent discourse of concern that this continual reduction in therapy provision was preventing patients reach their rehabilitative potential and the question of whether they were therefore being
condemned unnecessarily to a life of disability was asked frequently. From there, a bigger question came into view – how are the futures of people with neurological conditions being shaped?

The two research questions posed and addressed by this PhD is the result of bringing together my love of neurological rehabilitation, my concerns regarding the difficulty in relationships between patients with brain injury, their families and health care professionals (day to day interaction), what I’d learned while therapy lead and Matron about how services were delivered and how these were influenced by multiple organisational, political, social and financial dynamics and the long voiced concerns of neurological therapists - how loss of service provision impacts future levels of disability.

Carrying out this PhD I’m now in a period of transformation. I was a disciplined care giver – using my body and myself to give care and treatment to others. What is certain is that this is a body of experience – a vessel which holds an array of physical, sensory, social and emotional experiences in practicing clinically and managing within health care settings. It is this body – utilised in the delivery of therapeutic treatment and care which has now become an instrument of research – changed in shape and form maybe but with the same, unchanging goal – to care well.

**Thesis audience and terms of reference**

This thesis is written for both HCPs working with people with severe brain injury and for social scientists interested in the application of futures theory in healthcare. In order to meet the diverse needs of these audiences, the literature review chapters (chapters one, two and three) take on a dual role of reviewing the sociological and healthcare literature relevant to the focus of this thesis and providing the reader with explanation about what brain injury is, how it happens and the effects it has on both patients and their families (chapter 1), providing a potted history of the development of rehabilitation (chapter 3) and providing an overview of the sociology of time and
social futures theory\textsuperscript{4} (chapter 2). For the social science reader/non-health care professional appendix 1 offers a data-inspired snapshot describing the care at the bedside of a person with severe brain injury.

**Overall structure of the thesis**

The thesis is organised into seven chapters. Chapter one gives an overview of the contemporary landscape of severe brain injuries in both clinical and social terms. Focussing on incidence, aetiology and the impact of this condition on individuals, their families and the formation of services in the UK it lays the foundations for this thesis and sets the scene for the research questions posed. Chapter two picks up on the importance of temporality and examines the sociology of time and temporal work on ‘futures’. Concluding with an exploration of the role of ‘time’, and more specifically of ‘futures’, in health care, it identifies current contributions and research gaps.

Having positioned the thesis within the sociology of time and healthcare studies and illuminated both the people and places this thesis explores, Chapter three concentrates further on constructing the field of study and on the specific world of neurological rehabilitation. A brief history of the development of rehabilitation is provided before a critique of the core temporality of this process is presented, pulling out the implicit temporal orientation of neurological rehabilitation evident in one key area of the rehabilitative literature – goal setting.

The thesis then moves on to method and findings. Chapter four details the research questions, the methodological approach taken and how data were collected and analysed. Chapter five is the first of three findings chapters from the empirical work in rehabilitation centres. Beginning with those identified by the ethnography as

\textsuperscript{4} This approach to literature reviews of healthcare literature in areas such as this where sociological analysis is limited has been taken in other doctoral theses which traverse disciplines. For example, see Owen (2014) and Hastings (2013)
spending most time with patients and often in closest proximity to the bed space, the first findings chapter identifies the role of the ‘hotel service staff’ (cleaners, cooks, maintenance and administrative staff) - in the making of futures of brain injured residents.

Chapter six examines the role of those residents who successfully rehabilitate and how even the brightest futures in this context are often negated and compressed. Chapter seven, the final findings chapter, explores the role of the temporal in the relationship between residents, families and staff and explains how temporal mismatches and discrepancies in future imaginings cause tensions and are the source of conflict.

This thesis concludes by discussing how the findings relate to existing theory, their implications for clinical practice, a reflection on methods, plans for additional research and consideration of further work needed in this area.
Chapter 1 – Severe brain injury and caring relations

This thesis focusses on the care and rehabilitation of people with severe brain injury aged between 18-65 years of age. This category of patients are positioned distinctly in terms of both the delivery of care and rehabilitation they are afforded and the relationship they hold between their past, present and future selves within their own imagined life trajectories. The disruption to imagined futures is dramatic for this group of people because they have a past which has shaped their person, a present awareness of that self and an active engagement with what they and others hope for their future.

They have been selected as a group for study for three key reasons. First, due to this dramatic disruption to their anticipated futures selves the importance of the role of the future is amplified. Second, severe brain injuries are predominant within a younger population, and this clinical and social area is distinct from that of aged care. Such a distinction between a younger and older brain injured population is drawn in rehabilitative terms by Turner-Stokes et al. (2011) about the likely difference in goals, adaptability, recovery and societal burden. For example, return to work or parenting is given as an example of goal focus which may be more predominant in a younger population and less relevant in an aged, retired population. Younger adults are considered to be able to learn and adapt over a longer period of time and, in contrast to older adults, may have to live longer with severe disability and/or be cared for within society. Therefore, both they and society may benefit from longer periods of rehabilitation than the older population. Aged care is an area which has and continues to occupy much research attention from both a clinical, social and temporal perspective. This thesis is distinct in its specific illumination of the shaping of futures of this younger population. Third, this younger brain injured population are collectively cared for in distinct places of care which are strikingly under-researched settings.
This chapter focusses on defining the groups of people this thesis is about and draws together the literature which has sought to illuminate the relationships between them. First, I define the clinical classification of severe brain injury and explore the way in which brain injured people are studied and framed in the health, care and sociological literature. Second, I discuss the impact brain injury can have on both patients and their families. Third, I critique the way in which families of people with severe brain injuries, their own needs and the contribution they make to care and rehabilitation is framed by the literature. Working to situate the key concerns underpinning this thesis – the shaping of patient futures and the tensions in relations between patients, families and HCPs, finally, this chapter explores the literature which considers the relationships between these groups. This chapter does not address the care literature as a whole due to its vastness. Relevant care literature in which time and temporalities have been specifically attended to however, are discussed in chapter two in relation to the sociology of time and healthcare research which informs this thesis.

1.0 What is severe brain injury: classifications, incident, and prognosis

1.0.1 Classification

Within medicine brain injuries are continually classified and reclassified with new diagnostic categories being introduced, different types of injuries and patients being brought together or divided. There is much variation in diagnostic criteria and classifications of brain injuries and a lack of consensus within the clinical literature around the world (Bruns and Hauser 2005). However, causes of brain injuries are broadly categorised as ‘traumatic’ (e.g. from a blow to the head), ‘cerebral-vascular’ (e.g. stroke), ‘diffuse axonal’ (the result, for example, of shaking or sudden deceleration) or ‘hypoxic’ (e.g. from strangulation, drowning, or suffocation). All four types of injury are often brought under one umbrella term - ‘acquired brain injury’ (ABI)\(^5\) - a term which draws an important distinction/division between those who

---

\(^5\) Cerebral-vascular events are often separated in the clinical and guidelines literature and in clinical practice - with neurologists leading treatment of people post TBI and old aged medicine or specialist stroke consultants leading treatment for people post stroke.
were born with brain injuries or those that occurred during birth (including hypoxic injuries – such as cord strangulation) and those who ‘acquire’ brain injuries postpartum, during their life time. ABI distinctions however do not stop there. In health and social care – in its organisation, delivery and monitoring of quality - patients with ABI now tend to be divided less by brain injury type and more by need and age, divided into ‘younger or working aged adults aged 16-65\(^6\) and those aged ‘65 and over’ (Turner-Stokes et al. 2005, p.2).

1.0.2 Incidence, epidemiology and impact

In the United Kingdom (UK) approximately 10,000-20,000 people sustain a severe ABI each year, with a person being admitted to hospital with an ABI every 90 seconds (Headway 2014). The prevalence of acquired brain injury is approximately 558 residents per 100,000 of the population and over 1 million people in the UK live with the long-term effects of brain injury. Between 2011-2012 there were 353,059 people admitted to hospital due to an ABI (Headway (2014). Brain injuries can cause mild to catastrophic impairments (Turner-Stokes et al. 2007) including physical, sensory, cognitive and behavioural difficulties which can severely impede activities of daily living (Blake 2008). Approximately 30% of those that survive severe brain injuries are left with significant and long-term neurological impairments (Turgeon 2013).

1.0.3 Defining Severe brain injury

Severity of brain injuries is categorised in the clinical literature (although not consistently or with consensus) as mild, moderate or severe (Brasure et al. 2012). Severe brain injury (SBI) is defined from two points – at the time of insult before the outcome is known and the post injury outcome. For example, acute care clinicians who look after those immediately after injury define SBI as “an insult severe enough to cause an acute and persistent loss of consciousness and to entail a significant

\(^6\) 16-65 is the clinical age range given to younger adults and to draw a distinction between children and adults for service provision in acute care. In the UK, long-term care provision for adults regulated under the Care Quality Commission is specified as 18-65. It is this latter age range based on those residing in long-term rehabilitative/care facilities on which this PhD focusses.
likelihood of death or of long-term disability” (Stevens and Sutter 2013, p. 1104). In comparison, rehabilitation professionals, working with patients who have survived their injury and are at a point where the affect upon their functioning is apparent, define SBI, from the point of view of the injury’s impact on the individual’s ability to conduct ‘activities of daily living’ (e.g. Kelly and Nikopoulos 2010; Bender, Bauch and Grill 2015).

The clinical trajectory of recovery following SBI is considered as three basic processes/stages: 1) the emergence of conscious awareness, 2) the recovery of higher neuropsychological processing, and 3) the return of functional capacity (Stevens 2006; Stevens and Sutter 2013). The rehabilitative focus of this thesis focusses on the stage of care of people for whom their clinical trajectory and the impact of their injury is now apparent. Here SBI refers to a range of patients, who, as the result of brain injury are left with multiple physical, sensory and/or cognitive impairments which prevent them from doing the very basic things of everyday life, such as eating, washing, walking, talking, planning, remembering. What prevents such individuals carrying out such tasks includes damage to areas of the brain which control the contraction of muscles to produce movement and the co-ordination of such movements. For example, in swallowing or speaking, damage to areas of the brain which coordinate and decipher information such as language or visual stimuli and insult to areas of the brain which controls ‘higher functions’ such as thinking and moderate emotions such as anger.

Within the category of SBI are yet a further subset of people – those in a disorder or consciousness (DoC) - an umbrella term which refers to a collection of disorders: coma, the vegetative and minimally conscious state (Bernat 2009; Owen 2008; Demertzi et al. 2011). In this subset of brain injured people, they have not completed stage one highlighted above and have not fully regained conscious awareness. Those in a DoC form a subset of people with severe brain injury, made distinctive by their lack of consciousness as well as profound and multiple physical, sensory and cognitive impairments. In comparison to the broad lack of consensus regarding how brain injuries in general are categorised and defined in the literature, DoC are very
carefully and consistently defined. These different disorders are however distinct. DoCs is important here because these people, people with the most severe of brain injuries, are part of the population on which this thesis focuses.

1.0.5 Disorders of Consciousness: Coma, the vegetative and minimally conscious state

Briefly, ‘coma’ although a term in common parlance to cover a range of disorders of consciousness actually refers to the state of unconsciousness which rarely lasts for more than a few weeks. Most people who remain unconscious (rather than dying or recovering consciousness) after a few weeks enter either a vegetative or minimally conscious state. The vegetative state (VS) is a state in which people:

never regain recognisable mental function, but recover from sleep-like coma in that they have periods of wakefulness when their eyes are open and move; their responsiveness is limited to primitive postural and reflex movements of the limbs (Jennett and Plum 1972, p. 734).

If a patient is in a VS it is deemed ‘permanent’ (with recovery of consciousness highly unlikely) after several months or a year, depending on the nature of the original injury (and considering issues such as infections, medical stability, any trajectory of change) (see Royal College of Physicians guidelines 2003; 2013 and Multi-Society Task Force 1994).

The minimally conscious state (MCS) is the final and newest defined of the conditions under the umbrella of ‘disorders of consciousness’. This is defined as being a condition in which the person shows limited and inconsistent, but clear evidence of awareness (Giacino et al. 2014; Estraneo et al. 2015). Unlike VS patients, people in MCS can sometimes, but not consistently follow simple commands, make verbal or gestural yes/no responses, have some intelligible speech or make purposeful movements. The line between vegetative and minimally consciousness, can often be very small, so much so, that diagnoses of VS or MCS are often contentious.

For a sociological account of how this diagnostic term has been created and contested see Nettleton et al. 2014).
Apart from those with the mildest of brain injuries, most people who sustain brain injuries will require some form of treatment and rehabilitation. SBI causes impairments which require long hospital stays in acute care, prolonged periods of rehabilitation and for some, long-term institutional care (Corrigan et al. 2010).

1.1 The construction of people with severe brain injury in medical, health and sociological literatures, their experiences and approaches to their care

This section further explores the impact of SBI on individuals. It summarises the way in which people with SBI have been studied, and the approaches taken to their care. It explores how their bodies have been divided between health care professions for both study and treatment before being brought back together through multidisciplinary team working, in preparation for ‘reintegration’ into ‘the community’ or discharge into long-term care. Explaining the way in which their care is broken down into phases, illuminating the involvement and range of HCPs involved in their care and identifying the categorisation of the places of care within which they are cared for, this section assists to position the phase and place of care this thesis focuses on, and the people involved in the care of patients with SBI.

After tracing the medical and health care literature around this patient group this section also explores the small body of sociological literature which has begun to draw on the narratives of brain injured people themselves, in the illumination of their experiences. This section is concluded by highlighting the gaps in sociological research in relation to this group, their lives and care. In doing so this section provides an insight into the clinical and social complexity of the care and treatment of this patient group.

1.1.1 Complexity and range of impairments caused by SBI: distinguishing needs

Due to the complexity of the brain and its control over all bodily functions, thoughts and behaviours, people with SBI present with a vast range of impairments and combinations of deficits. As highlighted above, damage to the brain can result in
impacting everything from movement to speech, from comprehension to controlling emotions. However, despite the range, severity and combination of impairments which can be caused, people with SBI do present with similar symptoms and conditions and are considered to have similar needs. The organisation of their treatment and care is divided into key stages, each with specific goals for treatment and delivered in different places. Such organisation and provision of care and treatment is distinct to this patient group and is described in clinical research literature and brain injury care and treatment guidelines. The section that follows summarises this body of literature in describing the key phases and places of this care and its aims. It also highlights what is missing within the care and treatment typography written in the medical and rehabilitative clinical literature and, in doing so, highlights the importance of this study.

1.1.2 Brain injury care and treatment – phases and places

National and international clinical guidelines divide the care and treatment of people with SBI into three key phases – acute care, rehabilitation and community integration (i.e. Royal College of Physicians (RCP) 2013; National Institute for Care Excellence (NICE) 2014) World Health Organization’s International Classification of Functioning (WHO ICF) 2001). The medical and therapeutic literature relating to brain injury also conceptualises post injury care and treatment in these three stages and refers to the transfer between them as the care or patient ‘pathway’ (RCP 2013) or ‘trajectory’ (Curran et al. 2015).

1.1.2.1 Acute care in intensive care units

Following initial injury severely brain injured people are cared for in acute National Health Service (NHS) hospitals within ‘intensive’ or ‘critical’ care units. The primary aim of the acute management following injury is said to be the identification and treatment of ‘secondary injury processes’ - medical complications that are caused because of severe injury to the brain (Hartings 2017, p.94). For example, these include prevention of ischaemia (restriction of oxygen supply to tissues), maintenance of ventilation (the taking in of oxygen through the lungs) and perfusion
(the transfer of blood from arteries to capillaries and into bodily tissues), the management of thermostasis (control of temperature), haemodynamics (blood flow and pressure), intracranial pressure (the level of pressure within the brain) (Hughes 2002; Hartings 2017) and pain (NICE 2014).

Within this acute stage, patients with SBI either die due to the severity of their injuries and the inability of medical intervention to manage secondary injury processes or survive with neurological deficits and subsequent functional impairments. Some who survive do so with the continual assistance of medical technologies such as mechanical ventilation, tracheostomies and nasogastric or PEG feeding tubes, while others survive without the mid to long-term aid of the majority of these interventions. For those who survive, once medically stable enough and able to support life sustaining bodily functions largely independently, patients with severe brain injuries are transferred into post-acute rehabilitation (Das-Gupta and Turner-Stokes 2002).

1.1.2.2 Rehabilitation

Following acute care, and the initial stages of recovery from acute injury people with SBI are likely to require and are provided with a period of intensive inpatient rehabilitation (Turner-Stokes et al. 2005; Brasure et al. 2013) delivered in rehabilitative wards within NHS acute hospitals or NHS run specialist rehabilitation hospitals. This stage of care and treatment is proffered within the literature to aim to help the person regain functional independence and ‘to make the transition from hospital back into the community’ (Turner Stokes et al. 2005, p.3). It is also an important stage in which specialist assessment and complex disability management can be provided for the most severely brain injured (RCP 2013). These post-acute rehabilitative programmes ‘tend to focus on reduction of impairment and disability’ (Turner-Stokes et al. 2005, p.3) and plan for discharge from hospital and/or future care needs (RCP 2013). The aims of and approaches to rehabilitation as discussed in the literature are reviewed in detail in chapter three.
1.1.2.3 Care ‘in the community’

Following rehabilitation and discharge from NHS hospital services into the community either to home or some form of supported living accommodation, care and treatment is said to shift from attention of medical management, managing disability and conducting activities of daily living to ‘social integration, with return to work and financial independence if possible’ (Turner Stokes et al. 2005, p.3). Programmes of care outside of acute or rehabilitative institutionalised care focus on the use of outcome measures which reflect participation in social groups and psychological adaptation as well as functional ability (Muenchberger et al. 2012; Turner Stokes et al. 2005; Curran et al. 2015). Research exploring community care and rehabilitation programmes in the community focuses on the outcome of treatment delivered in outpatient rehabilitation and home-based vocational rehabilitation rather than highlights care and rehabilitation within long-term care settings in the independent sector. For example, in Australia Curran et al. (2015) studied the cognitive, functional and psychological outcomes of patients with moderate – severe brain injury who received a mix of outpatient rehabilitation (including hydrotherapy, directed exercise within a physiotherapy gym within a rehabilitation centre) and goal centred vocational rehabilitation at home or another social setting. Similarly, Muenchberger et al. (2012) studied the outcome of a community outpatient based rehabilitation programme aimed at improving ‘self-management skills’ and in Canada, Gerber and Gargaro (2015) studied the effects of a social and recreational day programme delivered two days a week in an outpatient rehabilitation centre, on social integration.

1.1.2.4 Missing people in hidden places

In theory, the movement between the three phases of care detailed above denotes recovery and progression, with the overall aim of return to and re-integration with ‘the community’. However, both guidelines and the literature which reports on this patient group and summarises their care in the phases highlighted above, often fail to identify the existence of those who do not return to the community (either home
or into supported independent living facilities). For those for whom movement through these phases and places of care has meant survival, but not necessarily recovery, they need prolonged opportunities for rehabilitation and/or long-term care (Das-Gupta and Turner-Stokes 2002). Largely missed as a phase and a place, the existence of and needs for these people are repeatedly excluded from the literature. Only very recently have the needs and existence of this population and the non-NHS run places of their care been mentioned in clinical guidelines in the UK.

The British Society of Rehabilitation Medicine (BSRM) (2013) produced guidance for best practice for ‘specialist nursing home care for people with complex neurological disabilities’. This document identifies the existence of places of care which sit outside of the NHS saying: ‘[t]he majority of people with severe physical or cognitive disabilities receive their nursing care in private institutions that operate at a distance from the NHS’ (BSRM 2013; p.5) and refer to these settings as ‘Private rehabilitation Units’8 and ‘Specialist Nursing Homes’9. The BSRM (2013) guidelines recognise the presence of those with severe brain injuries being cared for within them, including ABI in a list of ‘[c]onditions giving rise to complex and profound disability requiring specialist nursing home care’ (see BSRM (2013), p.9 Table 1) and identify the anticipated care needs of this patient population stating that they are a group of people who have survived neurological insult and have a life expectancy of several decades. The BSRM (2013) clinical guidelines also define the clinical work undertaken by these private care settings, defining three different processes – ‘complex disability management’, ‘slow-stream rehabilitation’ and ‘neuro-palliative rehabilitation.’10

8 Private Rehabilitation Units – These places of care are characterised by an active rehabilitation pathway and a short stay, with ‘planning for discharge from the outset’ (INPA 2012)
9 Specialist Nursing Homes - These care settings have younger residents with longer lengths of stay and higher staffing levels, more complex management protocols and more specialist equipment than in standard nursing homes (BSRM 2013).
10Complex Disability Management. This has the aim of both preventing complications and enhancing participation and autonomy despite the restrictions of severe activity limitation. Such patients usually require a postural management program, maintenance physical therapy, the provision of assistive technology and equipment, enteral nutrition and sometimes assisted ventilation. (BSRM 2013, p. 10)
Slow Stream Rehabilitation. This refers to the achievement of rehabilitation goals amongst a subgroup of patients who have the potential to achieve significant functional improvement over a period of six months or more. Such longer-term rehabilitation requires regular, but less frequent, one to one therapy contact, and relies extensively upon the facilitation of skill acquisition and functional improvement by care and rehabilitation assistant staff. The intensity of such a programme increases
In doing so, new potential phases of care for the severely brain injured are defined and a new type of care facility delivering them.

Such identification of the needs of this patient group for slow-stream rehabilitation, complex disability management or neuro-palliation and its delivery within the private or independent sector is also evident within the RCP (2013) guidelines for the care and treatment of PDoC patients and within a small emerging rehabilitative and long-term care literature base. This literature includes research conducted in neurological case management (see Clark-Wilson and Holloway 2015) and previous research conducted within these care settings by the author of this thesis (see Latchem and Kitzinger 2012; 2015) which explores the experiences of patients and families within these settings and their perceptions of what makes for ‘good care’. This literature base and the clinical guidelines are critical here in both identifying and defining the place of care and type of rehabilitative service this thesis focuses on. The existence and place of slow-stream rehabilitation, complex disability management or neuro-palliative rehabilitation and the institutionalised long-term care of severely brain injured people is however vastly unexplored, and does not, to date, include ethnographic exploration of how the lives and futures of this population are shaped within these places.

Examination of the delivery of slow-stream rehabilitation, complex disability management and neuro-palliative rehabilitation within long-term care settings however does appear more readily in the research base of other countries. In the Netherlands for example, a nursing home clinical specialism exists for doctors, named

---

from Rehabilitation predominantly provided by care staff with infrequent but regular therapy review, Rehabilitation provided by trained rehabilitation assistants or technicians supervised by therapists and Hands on treatments by therapist enhanced by care staff using specified approaches at other times. (BSRM 2013, p.10-11)

**Neuro-palliative Rehabilitation.** This refers to the preservation of autonomy and relief of distress of patients with a complex disability, and family members, particularly when close to death. It is work at the interface between Rehabilitation and Palliative Medicine (RCP 2008). As the disease progresses there is increased reliance on skilled nursing and medical management in liaison with palliative care teams. Many professionals may become involved and their work needs to be carefully coordinated. Patient autonomy must be preserved as much as possible in the face of worsening cognitive and communication difficulties through the use of Advance Care Planning. (BSRM 2013, p.11)
‘Physicians in Nursing Home Medicine’ (see Koopmans et al. 2010a; 2010b). Research produced by this group of physicians and connected researchers includes a focus on severely brain injured people within this population. Their work includes the exploration of the long-term outcome of patients with PDoC who have received intensive neurorehabilitation within specialist nursing home facilities (Eilander et al. 2016), the prevalence of this patient population in European countries (Beljaars et al. 2015) and Dutch perspectives of the care and treatment of this population (Van Erp et al. 2016).

The research highlighted above supports the reality that people can live with severe brain injury for decades, cared for within specialised nursing homes. It highlights the range of impairments and clinically defined problems that they can experience and evidences the ongoing medical pursuit to manage or cure secondary complications. This work also details the different ethical and legal approaches taken internationally to PDoC patients, a subset of the patient population this thesis explores. It highlights how the lives and deaths of these patients are managed in other European countries and offers both a contrast with and a question to as the way in which the lives of people with catastrophic injuries and lives of extreme impairments are sustained in the UK.\textsuperscript{11} This literature is useful in that it identifies the presence of this type of care internationally and a potential future outcome for this patient group – that of sustained impairment. It’s purely clinical construction and quantitative reporting however does little however to illuminate how the futures of people in these places are shaped and the contribution care here to making or constraining patients’ futures.

Although the identification of these people, their places of care and their treatment is visible in some European countries, the UK problem identified above of the largely undisclosed and under-researched lives and care of people with severe brain injury in long-term institutionalised setting is also mirrored in the American literature. The

\textsuperscript{11} See Kitzinger and Kitzinger (2016a 2016b) for description of current UK law and clinical practice surrounding life sustaining practices and a full exposé of contemporary case law and practice around applications to the court for the withdrawal of artificial nutrition and hydration.
hidden nature of these patient types and their places of care is explicated in the work of Professor Sharon Kaufman (Kaufman 2000; 2003). One such paper aptly named ‘Hidden places, uncommon people’ (Kaufman 2003) focusses on the care of people in PDoC who are ventilator dependent or dependent upon other medical technologies to sustain their life in long-term care settings in America. She highlights that although these places of care are not a ‘secret’, and may even stand architecturally independent of other buildings, they are places which are entirely internal within care systems and therefore hidden from general view. Kaufman (2003) identifies that one source of anguish within the care of people in PDoC within these places is concern regarding the nature of the person and attempts to maintain personhood in a situation where the patient’s lack of consciousness renders them silent. She highlights how these places of care have a mandate to maintain life and identifies that the question of what classifies as appropriate medical care in the situation where the quality of the lives of people being sustained is itself questionable is not raised.

The work of Kaufman is critical to this thesis in multiple ways. First, her ethnographic work in specialised care environments of the same type as studied here is useful in that it raises important questions regarding the social status of the people cared for in these places, (particularly those in PDoC) and explores the consequences of life saving and sustaining medical treatments. Second her work in this area focusses on death and dying and is worthy of attention as it offers an insight into the futures of some people with severe brain injuries - a life of extended living with severe impairments and the social challenge of both their lives and deaths. How the work of Kaufman makes a third further contribution to the body of literature this thesis contributes to is discussed in chapter two. Finally, critically, Kaufman makes a key contribution to the small body of sociological literature exploring the lives and care of people with severe brain injury, which will be explored in detail in section 1.1.4.2.
1.1.3 Further approaches to care, treatment and study

As can be seen from the exploration of the literature above, care of people with SBI is approached in global ways, breaking down and focusing on phases of their treatment post injury – acute, rehabilitation, slow-stream rehabilitation/long-term care or reintegration into the community. In addition to this, singular attempts to study the needs of this patient population and the outcome of their treatment is conducted with a focus on individual medical issues which occur secondary to the initial injury such as spasticity (Ashford and Turner-Stokes 2013; Zhao et al. 2015; Correas and Saavedra 2016), heterotopic ossification (Achour et al. 2016; Belhaj et al. 2013). Furthermore, while the phases of their care or specific ailments provide focus for the examination of treatment outcomes, brain injured patients are also studied in relation to the time post injury.

The clinical literature is awash with follow-up and longitudinal studies which focus on disability or functional achievements 1 year, 2 years, 5 years and 10 years post injury (e.g. Hillier and Sharpe 1997; Steel et al. 2010; Forslund et al. 2017). These studies look at the long-term outcomes of a particular intervention or service, for example, inpatient rehabilitation without community rehabilitation, outcomes of patients with certain sets of symptoms post injury, such as physical impairments (Andelic et al. 2010), emotional distress (Sigurdardottir et al. 2014), resilience (Flemming and Tooth 1999; Hanks et al. 2016), difficulty with community integration (Doig et al. 2001, Sandhaug et al. 2015), social or psychological wellbeing (e.g. Resch et al. 2009) or vocational return (Lundqvist et al. 2008; Arango-Lasprilla et al. 2011; Dahm and Ponsford 2015). Sandhaug et al. (2015) for example studied community integration in those with severe brain injury following inpatient rehabilitation two years after their injury. Their research identified that those who lived with a spouse, had access to longer periods of inpatient rehabilitation and less severe brain injuries had significantly higher levels of community integration (as defined by outcome measure - ‘Community Integration Questionnaire’) than those who lived alone, had more severe brain injuries and shorter inpatient rehabilitation times. These studies tend
to focus on those who are severely injured but who eventually return home, and therefore sit outside of the attentions of this thesis.

The clinical literature summarised in part above provides a detailed view of the plethora of medical conditions, psychosocial problems and long-term impact and presence of multiple impairments suffered by those with severe brain injury. In doing so it provides a particular view through time of the lives of people with severe brain injuries, their impairments, needs and the interventions provided for them. However, this body of work does not explore the subjective experience of people with severe brain injuries, their families or those caring for them. Neither do these studies provide much insight into how the social world shapes their futures, the relationships between them and others or the way in which they themselves engage with the future – as is the aim of this thesis.

1.1.3.1 Divided bodies

Tracing the literature about people with SBI illuminates how these people have been and are studied. It also demonstrates how these people and their bodies are divided up and moved between places of care, treated and cared for in a multitude of ways. What has not been highlighted so far however is how they are treated through the gazes of a range of professions who take an interest in a particular ailment or deficit, by which their specialism or specialist area is (or at least is now) defined. For example, within the literature discussed above, psychologists attend to issues of psychological and cognitive functioning, wellbeing and emotional distress while physiotherapists focus on physical functioning, exercise and movement and occupational therapists on vocational outcome and community integration. The phenomena of dividing up of the body for study and treatment and the development of medical and health care specialisms around specific mind or body foci have long been identified by medical sociologists as central to medicine and healthcare organisation (Struhkamp et al. 2009).
The diverse ways in which bodies are divided in relation to illness and disease, assessment and medical management has been explored particularly within the sociology of the body and in sociological and historical exploration of the development of medical and caring professions. For example, in her doctoral thesis and subsequent publications, Nettleton (1988; 1989) explains how the head became separated from the body, in and through the development of dentistry and subsequent divisions between medicine and dentistry.

Similarly, Crotty (1993, p. 109) wrote that ‘the act of swallowing divides nutrition’s “two cultures”, the post swallowing world of biology, physiology, biochemistry and pathology, and the pre-swallowing domain of behaviour, culture, society and experience.’ Concepts such as ‘body work’ (Twigg et al. 2011) and ‘body boundaries’ have been developed, used to define and divide the work of some professional groups over others – highlighting for example the management of bodily fluids by nurses (Lawler 1991) and the therapeutic touch at the heart of the allied health profession of physiotherapy (Nicholls and Holme 2012; Hastings 2013). Furthermore, Mol (2002) who studied how the disease of atherosclerosis is diagnosed and treated in a Dutch hospital, illuminated how bodies are divided through examination, radiographic investigation and treatment.

The body divisions through the development of specialisms and the diagnostic divisions can also be seen in the research explored and care given to people with brain injuries, whose bodies are also divided into phases of recovery to move them into and through different places of care, with a view to eventual ‘disposal’ of the patient from medical care (Latimer 2000). Critically for those with neurological impairments the division of these bodies in and by clinical practice is recognised and identified as problematic. Despite the sociological attention to dividing practices in medicine and healthcare, efforts to bring the body back together forms the focus of professional working in the field of neurological rehabilitation, in a type of professional working known as ‘multidisciplinary team working’. This is a process in which all those who have taken elements of the body for their particular attention
and treatment, come together to share information and to, in theory, treat and care for the person as one.

1.1.3.2 Multidisciplinary team working

Multidisciplinary team (MDT) working is defined as the bringing together of different professions who assess and treat the patient collectively and simultaneously, working in parallel to achieve a holistic view of the patient’s needs, maximise improvement/recovery and provide high quality care (Barnes 1999, Körner 2010, Karol 2014). This style of working is recorded within the literature in the acute care (Atwal and Caudwell 2006; Hickman et al. 2015) and the long-term care (Bernardi and Maher 1995; Johansson and Harkey 2014) of multiple types of patients e.g. in mental health (Jones 2006), Type 1 Diabetes (Brierley et al. 2012), Myocardial infarction (Coons and Fera 2007) and between teams, such as acute care nurses and aged care assessment teams (Robinson and Street 2004) and primary and community care teams (Xyrichis and Lowton 2008). However, much literature about MDT working is focussed around rehabilitation, and is particularly prevalent in the neurological rehabilitation literature.

The multidisciplinary team within brain injury and/or medical rehabilitation is said to include a physician, psychologist, occupational therapist, physiotherapist, nurse and social worker (Monaghan et al. 2005; Körner 2010). MDT working is considered to be the foundation of the conduct of neuro-rehabilitation (Barnes 1999), a key phase of care of brain injured patients. MDT working in the rehabilitation of brain injured people is proffered to enable the establishment of a holistic view of patients’ problems (Körner 2010) and facilitate multipronged change through the intervention(s) of multiple providers treating a certain or closely related deficits simultaneously (Karol 2014). Barnes (1999) gives deficits of cognition as an example of multipronged treatment of a particular deficit, highlighting that cognition is attended to by Occupational Therapists, Psychologists and speech and language therapists. MDT working is considered to be critical in maximising patients’ rehabilitative potential and reducing the impact of impairments post neurological insult (Monaghan et al. 2005). To be effective, MDT therapeutic input must be
coordinated as individual therapeutic interventions that are uncoordinated are argued to be insufficient to achieve improvement (Sinclair et al. 2009).

The bulk of research about multidisciplinary team working in brain injury rehabilitation focusses on clinical effectiveness (Poncet et al. 2017), models of team working (Körner 2010), efficacy of various team practices such as the MDT meeting (see Monaghan et al. 2005) and/or barriers to effective MDT working, such as communication between team members (e.g. Körner 2010). Research about MDT working which explores its effectiveness in relation to clinical effectiveness and impact upon patients’ rehabilitative outcomes repeatedly concludes that a multidisciplinary approach to rehabilitation improves rehabilitative outcomes. For example, Momsen et al.’s (2012) review of MDT effectiveness studies published after 2000 found that MDT working improved rehabilitative outcomes for people post brain injury in several ways – increased survival following injury, increased chances of living independently at home one year after injury and reduced need for long-term institutionalised care. They concluded however that these results drew on small participant numbers and further research was required to further qualify these claims.

Research exploring barriers to MDT working uncovers tensions in the perspectives of professionals about their team members and multiple factors which pose challenges to effective communication between them. Dalley and Sim’s (2001) study of nurses’ perceptions of physiotherapists as team members, although highlighting that nurses value physiotherapists as part of the team, uncovered that nurses felt that their physiotherapy colleagues lacked an understanding of the pressures of nursing work and did not recognise nurses’ autonomy in decision-making within rehabilitation.

Research about MDT working in neurological rehabilitation repeatedly highlights the need for ‘good’ MDT input and collaborative working but equally reports concerns about provision and delivery. For example, in a review of clinical outcomes for PVS and MCS patients in the UK, Wilson et al. (2002) highlight first in their recommendations the critical need for MDT working for this patient group for the
establishment of accurate diagnosis, appropriate medical management and the maximisation of ‘quality of life’ but highlight poor and inconsistent provision of such care and subsequent problems. They detail how patients without specialist and multidisciplinary output were misdiagnosed, often being considered vegetative when they had emerged and now had communicative abilities - and were therefore being inappropriately cared for, even harmed.

Research about collaborative MDT working also explores the experiences of professionals in terms of challenges to professional identity, job satisfaction and in dealing with certain aspects of care or sensitive issues. Ostermann et al (2010) explored the effects MDT working in a neurological rehabilitative environment had on professionals’ perceptions about their working environment, professional identity and job satisfaction. They found that staff felt better equipped and able to resolve conflict through the development of MDT working but had increased self-reported feelings of nervousness and concerns over the maintenance of professional identity. Taking the holistic approach proffered by MDT working did not change professionals’ perceptions of work load or working environment. Dyer and Nair (2014) explored MDT members’ perceptions and experiences of talking about sexual dysfunction with brain injured patients and illuminated how these professionals considered this area to be ‘specialist’ despite their access to multiple disciplines within their own team and outside of their rehabilitative remit. They raised concerns regarding risk and safeguarding of patients and others around this issue.

Despite the amount of research conducted about multidisciplinary team working within neurological rehabilitation, recent work on the subject argues that the process(es) of MDT working and rehabilitative programmes, its components and the roles of individual therapists within them are poorly described (Poncet et al. 2017) and that further work is required in the examination of MDT effectiveness in relation to clinical outcomes (Momsen et al. 2012). However, the literature about MDT working to date is useful here in that it offers an insight into how brain injured people are cared for and treated and by whom. It goes some way to explicate the experiences of the professionals working within these teams in terms of their ability to and
difficulties in working with one another and coping with the management of certain aspects of brain injury care and rehabilitation. It recognises that there are significant challenges in the delivery of a multipronged approach to brain injury rehabilitation and provides a backdrop of concern about the efficacy of brain injury rehabilitation and the resultant outcomes for patients with brain injury. This problematisation of care and treatment and ‘outcomes’ or futures is useful in that it supports the concerns addressed by this thesis.

Although this body of work focusses on the experiences of professionals and the relationship between successful multidisciplinary team working and clinical outcomes of patients, it fails to address the experiences of brain injured people and the effects their injury has on their identity and social status. There is however a small sociological literature base which addresses this and considers in part how brain injury affects individuals’ sense of self and identity and explores their own self-expressed experience of being cared for.

1.1.4 Experience of people with brain injury: the sociological study of brain injured persons

1.1.4.1 Self and Identity

The attention paid by sociology in relation to the condition of brain injury is focussed in two main areas – the subjective experiences of people with brain injury (specifically problems of ‘identity’ and the disruption of ‘self’) and loss of ‘personhood’ in relation to those whose consciousness has been altered following brain injury (in the case of those in a PDoC). Multiple sociological studies note that brain injured people experience a “loss of self” (Lewisham 1993; Pollack 1994; Nochi 1998; Lorenz 2010) following injury\(^\text{12}\) or in psychological terms, experience ‘subjective changes’ (Gracey et al. 2008, p. 627). Any injury or disease which causes disability has the potential to

\(^{12}\) ‘Loss of self’, ‘self-identity’ and ‘identity work’ – concepts repeatedly referred to in the sociological literature about people with brain injury are not defined in most of the papers which focus on these notions referenced here. Only Gracey et al. (2008) study refer to the definition of the constructs of “self and Identity” they are drawing on. They do so by stating that they are using definitions from Social Identity Theory detailed by Turner (1982). They do not however detail how this theory defines self and identity.
challenge notions of ‘self-identity’ (Mattingly 1998 p. 118), but ‘identity work’ for those post brain injury is recognised as particularly difficult (Lorenz 2010).

Sociological and psychological research which employs qualitative research methods, explores how brain injured people make sense of and construe themselves following brain injury, why they see themselves the way they do and what the challenges to self-identity are following brain injury. Nochi (1998) posits that negative images of brain injured people in the public domain contribute to challenging brain injured individuals’ perception of self. Through the examination of images in the public domain of brain injured people and the exploration of these images with brain injured people themselves, Nochi (1998) highlights how negative images of brain injured people in society which suggest brain injured people have lost the key elements of their character which defined them prior to injury, position them as abnormal and powerless and contradicts the self-image brain injured people hold of themselves. Nochi (1998) suggests that brain injured people use various strategies to try and rid themselves of these, what they perceive as stigmatising, constructions of them. They do this by limiting social contact to those they perceive are non-judgemental, highlighting how any abnormality or impairment does not affect their ability to carry out certain tasks or foregrounding that they can do the same as everyone else or replacing terms about them which hold negative connotations for those which they perceive reframe them in a more positive or ‘normal’ light.

Gracey et al.’s (2008) interview study of brain injured patients undergoing a neuropsychological rehabilitation programme suggests that the way in which people following brain injury make sense of their brain injured self and reconstruct their identity is based most significantly on their ability to do things which reinforce their pre-injured self and/or enable them to be part of social activities or groups. They therefore suggest that sense making of self is developed through and overtly linked to doing. Lorenz (2010, p.863) highlights how people with brain injury have difficulty in learning the new post brain injured self and building a new identity which incorporates ‘(a) the new brain injured self, (b) an old self (with residual strengths), and (c) a self who does meaningful activities (e.g. parenting, partnering, art,
gardening, volunteering, or paid work).’ Through examining one photovoice project with a brain injured person, ‘Judy’, Lorenz (2010) suggests that photovoice projects can assist brain injured people to consider the biographical disruption caused by brain injury as part of their life lived and incorporate it into their life history/biography.

This sociological work is useful here in that it introduces temporal based concepts including biographical disruption and the effect disruption to imagined life courses caused by brain injury has on individuals. What this literature however does not offer is the explicit examination of the role of time and the temporal in the experiences of brain injured people. The work referred to above also focusses on those who have largely suffered moderate not severe brain injuries and who are able to speak well and express their emotions and thoughts.

1.1.4.2 Existence without consciousness: The troubling of life, death and ontological state of the person

However, for those severely brain injured people who are unable to express their experience, those in a PDoC – this group of patients challenge the very ontology of what it is to be human and person and have also provided academic fodder for sociologists and philosophers in the exploration of concepts such as personhood, life and death. Unable to study the experience of these patients as perceived by themselves, there is a body of work which explores the experiences and perceptions of people who work with or have relatives in PDoC, and the general public (Gray et al. 2011; Kitzinger and Kitzinger 2014; Holland et al. 2014). When asked about their experiences of having a relative in a PDoC, or given the definitions of PDoCs and asked to think about this state, participants immediately question the ontological status of a person in a PDoC, especially those in a vegetative state – and ask - are they dead or alive? Holland et al. (2014, p. 416) argue that the vegetative state is an ontological state all of its own with people in PVS “neither straightforwardly alive nor yet dead.” This questioning about ontological status can be seen repeatedly in interviews with family members. Drawing on extracts from Kitzinger and Kitzinger’s

---

13 Photovoice is a systematic, collaborative investigation by which people represent their lives, point of view, and experience using photographs and written narratives (Lorenz 2010, pp. 863)
extensive interview study with families of people with a PDoC, describing the vegetative state reported in Holland et al. (2014) and Kitzinger and Kitzinger (2014), a brother says of his sister:

It’s between life and death. You’re in no man’s land basically. The Zoe I knew died four years ago.

Also, Ann speaking about her daughter in PVS says ‘She did really die in the quarry, didn’t she? She drowned.’ And a father talking about his son says: ‘He’s already dead. The only reason he’s not dead is because his heart pumps.’ (Holland et al. p. 417).

Similarly, Gray et al. (2011) inform that people in PVS can be perceived by the general public as ‘more dead than dead.’ In this study participants were found to consider people in PVS to have less mind than the dead and to be in a state ‘worse’ than death. Gray et al. (2011) highlight how the dead hold a certain ‘presence’, whether they are thought of as being in some form of afterlife or recalling their being from our own memories. Conversely, a person in PVS, can be seen as a body without a mind, falling ‘biologically between life and death’ and ‘seen as mindless bodies while the dead may be seen as disembodied minds.’

Using these ontological challenges Kitzinger and Kitzinger (2014) highlight how ‘death’ can be socially constructed and is more than the biological definition - ‘the irreversible breakdown in the functioning of the organism as a whole’ leaves out another key component of death – ‘the irreversible loss of the capacity for consciousness’ (Veatch, 1975). They argue that the fact that modern medicine can enable the long-term survival of the body without conscious awareness of themselves or surroundings (PVS) challenges the purely biological notion of death. Through the ontological challenges and questioning of the state and whereabouts of the person asked by families of people in a PDoC, Kitzinger and Kitzinger proffer that people in a PDoC are subject to a ‘social death’, biologically alive and physically present but socially dead, unable to be in or interact with the world.
Further work which highlights the challenge to personhood posed by PDoC explores the connect between personhood and place. Kaufman (2003) highlights how places of care are implicated in either the preservation or loss of personhood. Her ethnographic study of a long-term care facility caring for people in a PDoC in America explores ‘how relations among persons who care for and interact with those patients are understood and how the agency and subjectivity of the person who is a patient are approached, known, and enabled’ (Kaufman 2000, p.2250). Kaufman (2003) observes the interactions with people in a PDoC by clinical staff caring for them and their families and notes how the person is given presence through the speech of those around the bed. She highlights how staff members use knowledge about the person prior to injury to construct an ongoing identity in the now. Kaufman (2003) however challenges the reality status of this construction considering the questionable ontological status of a person who is not aware of themselves and their surroundings and cannot purposefully interact with anyone or anything.

The sociological and philosophical literature which explores PDoC discussed here is important to this study as it identifies the socially constructed nature of and the challenges to social and philosophical understandings of what it means to live and die, to be alive or dead, and to be a person. This literature provides an indication of the relational and clinical complexities around the care and existence and maintenance of the most severely brain injured – those who are under study here. However, despite these insights, sociological work does not overtly employ a temporal gaze and consider the role the future plays in the lives and care of these people and the interactions that go on around them.

In this section I have introduced the main group of people under study here, those with severe brain injuries and reviewed how they are studied and what is known about them. I have demonstrated that there is a vast clinical literature base which explores the care and treatment of these people and a small but critical body of sociological work. I have highlighted however that while this work provides useful context for this study, the literature reviewed here is devoid of overt temporal engagement and application of a temporal lens.
1.2 The impact of severe brain injury on families: focussing on health care and sociological literature.

In this next section I introduce another group of people whom this study includes. As brain injuries affect not only the individual with the injury – but those who care about and for them this section focusses on the literature concerning family members of people with severe brain injuries. It reviews the literature which exposes the effects of brain injury on individual family members and family life and explores the literature on sociological and health care perspectives of the role of family members within care.

1.2.1 Carers as category

Care relations are complex, potentially multiple, socially, culturally and politically shaped (James 1992). The label of ‘carer’ is problematic (James 1992) due to the multiplicity of this single term. Carers can be paid professionals or non-professionals, unpaid family, friends or neighbours. Carers can provide singular or multiple types of ‘care’ from basic domestic chores to total physical, psychological, emotional and social support. They may also hold multiple caring roles. The qualified nurse can provide ‘formal’ care to others and ‘informal’ care for their parents for example. Carers can be both carer and cared for, and those dependent on others for care, take on and fulfil an active social role as patient (see Parsons 1951).

In this section I divide this ‘category’ of informal carers who are family members, into ‘family caregivers’, by whom I mean family members who provide regular (full or partial) physical, psychological or emotional care to a person within the family home and ‘relatives’, family members who care about a person with severe brain injuries but do not carry out the physical care themselves – in this context, because their loved one resides in a neurological rehabilitation and long-term care facility. I use the more generic term ‘carer’ when discussing the wider literature on informal carers – those who provide care but are not employed to do so and do not take a regular wage for providing this care.
1.2.2 Care as burden and experiences pathologized: the impact of brain injury on families

There is a large body of literature which focuses on the experiences of family caregivers of people with brain injury. Research about this group consistently reports that family caregivers experience a plethora of emotional, psychological and social problems following the injury of their loved one and the requirements for their care and support (Boschen 2007; Blake 2008). Such problems include depression, anxiety (Douglas and Spellacy, 2000; Rivera et al. 2007; Leonardi et al. 2012) and grief (Calvete and Lopez de Arroyabe 2012); with the nature of the brain injured person's symptoms determining the level of stress and psychological factors identified within family members i.e. the worse challenging behaviours are, the higher the levels of stress and depression for family members (Riley 2007).

Alongside stress and the identification of specific psychological issues reported in the literature, the well-being of family caregivers is also severely impacted due to the social interruption caring for a loved one causes. Reduction in leisure time (Leonardi et al. 2012) and less contact with friends, loneliness and feelings of isolation are reported by family caregivers of people with brain injury (Romano 1974; Lezak 1988). The burden of caring is considered to not only affect the well-being of the caregiver (Foster 2012) but more broadly, impacting on the functioning of the whole family (Degeneffe et al. 2013; Frain et al. 2014).

Chiambretto et al. (2001) who explored problems experienced by relatives of people in a permanent vegetative state (PVS) with long-term hospital stays found that relatives experienced emotional distress which increased over time, including depressive symptoms and anxiety. They also reported that 70% of the sample felt socially isolated, had limited interests and low participation in leisure activities. Similarly, in a large study investigating the burden of care in 487 family caregivers of people in PVS or MCS, Leonardi et al. (2012) reported that over half of participants had high levels of depressive symptoms with around a third meeting the criteria for so-called ‘Prolonged Grief Disorder’. This ‘disorder’ was first named by Prigerson et al. (2009) to refer to observations by Stern et al. (1988) who found that relatives can
consider PVS an ‘emotional paradox’. This is because they are unable to mourn conventionally because the person in PVS is in many ways irretrievably ‘gone’ and their life has ended, but the person is not biologically dead (for a sociological/philosophical discussion of this see Holland et al., 2014). Distress is compounded by the fact that a person in PVS can present with movements (albeit involuntary) and as they become less reliant on medical interventions and intensive care, they can be considered to be ‘improving’ (Chiambretto et al. 2010). Many other studies published over the last decade examine psychological or emotional ‘symptoms’ experienced by families such as Norup et al. 2013; – all of which use psychological questionnaires and testing and conclude with analyses which position and describe families as ‘at risk’, or in clinical terms, with patient based terms, in need of psychological support or treatment of some form.

Research has examined how family members’ “coping mechanisms” vary (i.e. reframing and seeking spiritual support as coping strategies) (Verhaeghe et al, 2005; Calvette et al, 2011) and are influenced by factors such as gender and the amount of professional support provided (Verhaeghe et al, 2005). This body of work calls for improved social networks and professional support (Arango-Lasprilla et al. 2010; Calvette et al. 2011), highlights the need for avoiding conflict between families and HCPs and developing models for long-term support of family carers (Verhaeghe et al. 2005).

As can be seen through this literature, such a focus of family caregivers being stressed and burdened renders carers as a group either ‘at risk’ of developing health problems, in particular, mental health problems or already having developed them, such as stress or newly labelled psychological conditions such as ‘prolonged grief disorder’. Such framing pathologises caring by family members, positioning it as a condition (or at least, a risk factor for illness) rather than an activity or role and subsequently extends the ‘medical gaze’ to include not just those being cared for, but their carers too. This extension of the medical gaze is also evident in the long-term care literature which reports how family caregivers have been considered and are treated by HCPs as ‘hidden patients’ (Hills 1998). Kitzinger and Kitzinger (2014)
however argue that what families of people with severe brain injury need is not psychological framing of their experiences but information and involvement in decision-making. They argue that the risk of ‘pathologising’ family members’ behaviours is that the cause for their distress, such as poor provision of care, can be ignored and passed off as ‘stress’.

To further highlight the extent of the pathologisation of families within the brain injury literature a series of studies by Norup et al. (2010;2012;2013) studying families of people with severe brain injury mirrors the clinical rehabilitative literature in terms of the title, methodological approach, analytical frame and temporal ordering. As with research about patients, which uses the time post injury to explore remaining impairments, impact of injury on function, ‘activities of daily living’ and effect of interventions – Norup et al’s research uses the same post injury ‘phases’ to explore family experience, ‘symptoms’ and psychological states. For example, the clinical literature post brain injury is characterised by the review of symptoms, impairments and the impact of treatments – one year post injury, two years post injury, five years post injury, sub acutely and chronically (or ‘long-term’). Furthermore, there are multiple studies which overtly research the ‘treatment’ of families of people with brain injuries or explore the provision of various ‘interventions’, or ‘family focussed therapies’ (see Bowen 2007; Dausch and Saliman 2009; Heslin et al. 2016).

1.2.3 Ignoring reciprocity and multiplicity

The idea that caring is inherently burdensome, stressful and risks the well-being of the caregiver however assumes a uni-directional notion of care giving and fails to consider how care relationships can be reciprocal and co-constructions (Henderson and Forbat 2002). The dominating construction that caregiving is a negative experience is challenged however, especially in the sociological literature. However, studies of caregivers’ experiences highlight how for some, caring can be an empowering experience. Care can be multidimensional and multidirectional as roles within families can remain shared but have to be reorganised to accommodate ill health and impairment. Radcliffe et al. (2013) who held joint biographical interviews
with 13 older stroke survivors and their partners identified that for some, caring relationships were considered to be positive, with impairments caused by stroke accommodated and overcome by couples working together. The achievement of this self-reliant management was discussed with pride.

Reorganisation following illness and impairment can be seen not just between couples, as is predominantly focussed on within the literature, but within entire families as roles and responsibilities are reshuffled through multiple generations or broaden to include more distant relatives, bringing them into day-to-day caring roles that they would not normally or previously had been involved in or party to. Research investigating the experiences of family caregivers of people with brain injury highlight how significant changes to roles and relationships are often experienced in families as parents may revert back to caring for their adult son or daughter and partners take on both caring responsibilities for their partner and have to do the practical tasks, including those that would normally have been carried out by their partner prior to injury (Blake 2008) (e.g. domestic chores, looking after children, dealing with finance or seeking employment (McKinlay et al. 1981; Chan 2007).

Although it is important to consider and identify appropriate support for those that care for others, framing caring as fundamentally negative, negates the flexibility and resilience within families to absorb caring activities and re-distribute roles, overlooks the cultural and historic nature of care in the home and does not account for narratives of individual carers that talk of embracing care responsibilities and successfully and positively co-constructing or reconstructing identities. Instead, caring relationships can be considered in terms of a normal life course transition – as changes to identities and roles occur as a response to illness, and are managed through biographical work and reconstruction just as any change in our lives such as divorce, redundancy etc. require. This body of literature is helpful here as it highlights the extent of the impact brain injury has on family members. It provides a critical context of concern, highlighting the extreme challenges experienced by families and the problems which can arise for them in the care for or about a loved one in severe
brain injury. Again however, this literature does not consider if the temporal has a role within the forming of these experiences.

1.2.4 Exposing medical, legal, social and ethical issues through examining family experience

In response to the pathologised body of literature, more nuanced work about the experiences of family members has been conducted by sociologists who, through the experience of families, highlight core medico-legal, social, ethical and political concerns regarding the care of people with the most severe brain injuries, those with a PDoC.

Kitzinger and Kitzinger (2012) explore the experiences of family members who have a relative with a PDoC who they believe would rather be dead than sustained in such a state. They explore how uncertainty regarding prognosis drives medical treatment to keep the person alive in the acute stage following injury, a time where the ‘window of opportunity’ to die is most open, in that the withholding or withdrawing of ventilation or decisions not to manage intracranial pressure or fit a tracheostomy would allow patients to die at this time. However, once prognostic certainty is established – and in the case of PDoC – that the person will be severely disabled for the rest of their lives, the physiological stability of the patient is higher and their medical condition stable and the window of opportunity for death much narrower. Kitzinger and Kitzinger (2012) highlight how families are not always consulted in best interest decision-making in acute care and that people with severe brain injuries are surviving brain injuries in circumstances where survival is not what they would have wanted.

In relation to ongoing care of people with severe brain injuries, including those with PDoC, Latchem and Kitzinger (2012) explored what families consider constitutes ‘good care’ and what was most important in the care of their relative within long-term care facilities. This research highlights how care quality for families includes staff’s recognition of their role in both knowing the person before injury and the
contribution they make to the everyday care of the person following brain injury by sustaining their identity and meeting the majority of the patients’ social needs.

Kitzinger and Kitzinger (2014) also explore family perspectives of the nature in which patients in a PDoC who do not die in acute care eventually die in long-term care. For those who are sustained in a PDoC in long-term care, their opportunity for death is minimal as they often receive high quality nursing care. The withholding of antibiotics for urinary or respiratory tract infections is one possibility for death, but these infections may be few and far between. The withdrawal of artificial nutrition and hydration from people with a PDoC is legally permitted in the UK but requires an application to the court of protection. Kitzinger and Kitzinger (2016) highlight that many families consider a death by starvation and dehydration to be inhumane, the consequence of which being that people with a PDoC are being administered life prolonging treatments even though this treatment may not be in the patient’s best interests and can be considered as futile.

For those applications that do go to court proposing the withdrawal of artificial nutrition and hydration many are subject to significant delays, taking years to go through. In their review of one such case Kitzinger and Kitzinger (2016) identified a series of causes for delay in the application and court process(es) and identify practice concerns regarding best interest decision-making, prevision in the inspection of the care review for these patients and misunderstanding about the law.

1.2.5 The role of the family in neurological rehabilitation: the perspective of health care professionals

In this section I briefly summarise the way in which families are viewed by HCPs and how families are framed within the health and social care literature. I use three key concepts (carers as commodities, co-workers and co-opters) identified by Twigg (1989) to understand the key ways in which families are viewed by professionals within the rehabilitation process and the roles they play.
1.2.5.1 Carers as commodities

Within the health and social care literature relating to family carers, this group can be considered as ‘resources’, in that they are able to provide various support to the patient and potentially care at home, outside of the clinic. Although ‘carers as commodities’ is seen more prolifically in relation to care in the community – predominantly relating to domestic care, family caregivers can also be seen as commodities throughout the health care chain including long-term care and within neurological rehabilitation institutions. For example, in aged care research suggests that family involvement in aged long-term care can influence the quality of care residents receive (Rowles and High, 1996; Kellett, 1999), aid the maintenance of residents’ personhood and identity and ensure more personalised care (Hertzberg 2000). Within these environments families are considered as resources in terms of their ability to provide social interaction and information about the patient (Cooney et al. 2009).

Within the neurological rehabilitation literature family members are also considered as critical to a patient’s wellbeing, maintaining and providing the patients social interaction (Baker 2010). They are argued to be important advocates within decision-making processes (Stein 2006) and facilitators of communication between patients and HCPs (Wagner and Stein 2006). Families are also seen as potential future care providers within the home and critical to the facilitation of discharge (Visser-Meily et al. 2006). Szmukler and Holloway (2001, p.58) also argue that family caregivers “can play a prominent role in helping supervise medication, encouraging participation in treatment programmes, and generally providing an environment conducive to progress.” This is supported by research which explicitly examines the roles of families in rehabilitation by Evans et al. (1992) who highlight that families provide motivational and emotional support to patients during their rehabilitation.
1.2.5.2 Carers – co-workers, co-opters and hidden patients

Alongside the construction of families as a resource, or as a potential resource, from which care or support within the rehabilitative process can be gained, the way in which health and social care workers see their relationship with families can, in some situations be one of ‘co-worker’ or someone who can be co-opted, either in the provision of care or the management of the patient in some way (Montgomery, 1983; Rosenthal et al., 1980; Bauer 2003 p50-51). Within the neurological rehabilitation literature, Evans et al. (1992) explain that families can take on an ‘enabler role’ where the influence of family is used to reinforce desired behaviour taught to the patient by professionals. Similarly, families are seen as a way to monitor the actions and behaviours of patients in the absence of HCPs (Duncan and Morgan 1994). In this way, families can extend the medical gaze beyond the direct interaction between health care professional and patient. The construction of families as co-workers is strengthened by research which suggests that patients whose families are actively involved in their rehabilitation or who form positive relationships with HCPs have better rehabilitative outcomes compared to those patients who don’t have families or who have families who are not engaged with their rehabilitation (Chua et al. 2007; Sherer et al. 2007).

As already highlighted above in section 1.12, families can be considered by professionals as ‘hidden patients’, burdened and in need (Bauer 2003). However, within the rehabilitative literature, although families are often seen as burdened and in need, work which explores the effectiveness of family orientated rehabilitation approaches reframes patients and family members from individuals to a family unit and considers the needs of the family as a unit. Within these approaches, families are seen as in need of education, information, training (Gan et al. 2010) and support (Campbell 1988) in order to preserve both the functioning of the family and achieve the best rehabilitative outcomes for the patients (Foster et al. 2012).
1.2.5.3 Carers constructed as ‘problem’

Although Twigg’s (1989) frames of reference provide a useful map on which to group much of literature about carers/families widely and in terms of rehabilitation, these frames of reference are not all-encompassing. Beyond the categories offered by Twigg (1989), one further construction of families in the literature is carers as ‘problem’ – as resource user, a contributor to making, being and forming additional work for health care staff and as the sources of conflict. Hertzberg et al. (2003 p.431), exploring registered nurses’ views and experiences of relatives of residents in nursing homes, found that ‘Relatives were seen as a resource (with some restrictions) and nice, although demanding. The RNs saw relatives as part of their work – a part that could be time consuming and had low priority.’

In long-term aged care staff-relatives relationships have repeatedly been documented as being a ‘fraught’ experience for relatives (Bauer 2003, Friedemann et al. 1997, Haesler et al. 2006, Sandberg 2002) and both relatives and staff have reported dissatisfaction, tensions within and difficulties in forming relationships (Marziali et al., 2006, Shuttlesworth 1982, Schwartz 1990) ‘and in some cases the interactions between the two groups have been known to become dysfunctional’ (Bauer 2003, p. 214). Despite, and perhaps made self-evident by these tensions, research suggests that these relationships play a key part in the care experience and delivery of quality care (Duncan and Morgan 1994).

The potential sources for conflict within rehabilitative patient, family and staff relations are explored in detail in the following section. This literature is useful here in that it begins to form a picture of the way in which families are seen and experienced by HCPs. It identifies a co-reliance between health care professionals and families, while at the same time drawing attention to the potential for and existence of conflict. This literature supports the second question and concerns of this thesis – the relationships between the groups under study here. This literature, while useful for context – again does not overtly address or consider the role of time in the development of, and the living out of these relationships of care.
1.3 Tensions in relationships

Having highlighted the stark and varied experiences of brain injured patients and the challenges they face in their recovery from, or life with, severe brain injury, the experience of families and how they are viewed by HCPs, I bring these experiences together in an initial exploration of the literature about the relationships between these groups and open up one of the key concerns of this thesis – the tension in relationships between them. In the final section of this chapter I review the neurological rehabilitation literature which explicitly considers the challenges between the relationships of health care professional and families.

1.2.5.1 Triad relations in brain injury rehabilitation

Within the area of brain injury rehabilitation, although the literature is limited, there are a few papers which consider why relationships between patients, families and HCPs can become strained. First, this body of work highlights that care and treatments and those who provide them are primarily focused on the individual who has sustained injury or illness and are less concerned with involvement of the family in providing care (Kendall et al. 2000; Lawler and Mattingly 1998). It is not surprising then that the first tension in these relationships that is identified is that families can often feel excluded by HCPs in the care or rehabilitation of their relative (Clarke et al. 2009; Jumisko et al. 2007a).

Health research highlights that professionals often have difficulty in establishing meaningful relations with brain injured individuals and their families (Lefebre et al. 2005). McLaughlin and Carey (1993, p. 45) explain that this may in part be due to the need of staff working with patients with brain injuries and their families to balance supporting rehabilitative efforts ‘while simultaneously communicating often negative realities about prognosis.’ McLaughlin and Scaffer (1985) and Levack et al. (2011) suggest that the aims of patients and their family can at times run counter to the goals set by the therapeutic team and McLaughlin and Carey (1993) highlight that in families where the patient has exceeded medical expectations (prior to the
rehabilitative phase), a lack of trust in medical and therapeutic expertise may lead to team/family conflicts.

Prognosis, progression or lack of it, hopes and expectations are considered central to the development or breakdown in patient-family-staff relations. Carberry (1990) suggests that if a patient does not progress as expected then the family may be used as a scapegoat by the rehabilitative team to account for the lack of progress or conversely, the rehabilitative team may be blamed for the lack of the individual’s progress. From the moment of injury, throughout the patients’ trajectory, patients with acquired brain injury, their relatives and HCPs ‘develop hopes for the recovery and future of the patient’ (Gebhardt et al. 2011, p.3). HCPs have identified that there can be a mismatch between clinicians’ own expectations of the patient’s recovery and those of patients and their relatives (Wade 2009; Gebhardt 2011; Latchem 2013). Furthermore, how relatives of people with brain injury envisage the future to pan out can be influenced by things other than medical information, such as the media (e.g. images of miracle recoveries) (Wijdicks and Wijdicks 2006; Latchem 2013). A mismatch between HCP, patient and family expectations of recovery has been problematized as ‘without a clear understanding of the similarities and differences related to the hopes that caregivers and nurses have, it is difficult to plan realistic patient care for discharge and develop pragmatic plans for the future of the patient with ABI’ (Gebhardt 2011, p.3).

Misunderstandings between patients, families and staff aside from expectations of the patient’s progression have been evidenced in other work. Latchem et al. (2015) highlight the mismatches in understandings of treatment aims between families of people in a disorder of consciousness and physiotherapists. For example, they highlight how physiotherapy interventions can facilitate momentary moments of increased arousal which can inadvertently and incorrectly communicate to families that the patient’s level of awareness is improving. Other work which has explored the experiences of relatives of people in disorders of consciousness has highlighted the existence of problematic encounters between relatives and clinicians during medical decision-making processes, and the difficulties some families confront when
trying to ensure their relatives’ prior expressed wishes are respected (Kaufman 2006; Kitzinger and Kitzinger 2013). Relatives of people in disorders of consciousness face significant challenges during decision-making processes as they battle and attempt to reconcile respecting the prior expressed values and beliefs of the person prior to injury, recognising the needs of the person that is now and the person that will be in the future (Kitzinger and Kitzinger 2013). Shaw and McMahon (1990, p. 88) conclude that each party (patients, families and HCPs) ‘contribute’ to the tensions in the relationships between them and note that ‘[G]iven the stressors imposed both on family and staff as well as the intense needs of family members, the existence of conflict in the rehabilitation setting would appear inevitable.’

Conclusion

Although tensions in relations between these groups is suggested as both understandable given the context, and ‘inevitable’ and the literature here provides a wealth of reasons for such difficulties, considering that research also repeatedly highlights that these relationships play a key part in the care experience and delivery of quality care (Duncan and Morgan 1994), in order to improve care quality and the experience of neurological rehabilitation for all those involved in it, it is critical to further explore and attempt to establish greater understanding of the forming of and causes for tensions in these triad of relations in neuro rehabilitation. As part of the exploration of these relations in brain injury, this thesis seeks to understand the role that time – and more specifically the future, plays in the conduct of these relationships in the very specific situation of brain injury rehabilitation.

Through mapping the literature about brain injured people and those who care for and about them I have introduced the three key groups of people this thesis focusses on. I have highlighted the ‘problem’ of the fractured lives and the long-term potentiality of living with severe brain injury and explained the phases of care that they are exposed to. I have illuminated a phase and place of care – slow stream rehabilitation and independent sector neurological rehabilitation centres or
‘specialised neurological nursing homes’ and positioned this thesis within the happenings of these places. I have discussed the way in which brain injured people and their families are constructed within the literature and begun to introduce the HCPs who treat them – and the approaches taken to the care of both patients and families in brain injury rehabilitation. Finally, I have introduced the tense and often fraught nature of the relationships between these groups during rehabilitation and in doing so detailed the second concern this thesis addresses. I have highlighted how despite the wealth of knowledge offered by the literature reviewed here, this work is devoid of explicit attention to the role of the temporal and I posit that the application of this lens is important to explicate how the lives of people with severe brain injuries are shaped during rehabilitation.

In Chapter 2, I explore the literature which does pay attention to the role of time in everyday life and focus explicitly on how the temporal domain of the future has been explored and researched. I illuminate how time has been used within health care and position this thesis not just within the world of neurological rehabilitation but within the broader study of time and futures and the role of temporality in the social world.
Chapter 2: Time, temporality and futures in everyday life: a critical examination of the social analysis of time

Through reviewing a broad range of ‘time’ based literature, this chapter explains how time and temporality are constructed concepts, central to the social world and everyday life. Positioning the thesis within the sociology of time and healthcare sciences this chapter highlights how time and temporality have been used in both theoretical and empirical based social science and health care study. In this chapter I identify gaps in this body of work and discuss how this thesis contributes to addressing such gaps.

2.0 The mutual implication of time and of temporalities

There is no singular definition of ‘time’, but instead a multitude of times which form a central part to the experience, expression and organising of everyday life. ‘Time’ to many people refers to the time of day, to the clock, or to time as measurement (the length of time something took). However, time is more than the clock and a measure, it is also memory and takes on form through processes such as anticipation. Critically, time can be both explicit (in its use as clock time for example), or implicit, in terms of ‘matters of timing, sequencing and prioritising’ (Adam 1995, p. 12) – both make up the social nature of time, but often sit separated, with clock time dominating over the other and the implicit nature of the experience of time in everyday life left without attention or critical examination. In this thesis, the specific mechanical and measurable notion of ‘time’ is specifically referred to on occasion, but the word ‘time’ is used to refer more broadly to both the measurable and immeasurable conceptualisations of time, critically seeing it as not an external singular ‘truth’ but a socially constituted concept (Durkheim 1915) – embedded in the shaping and experiencing of the social world.

Time and temporality are mutually related, but they are not the same. Temporality refers to the temporal positions of past, present and future – the movement between and lived experience, perception and usage of these ‘times’ in the context of social and personal lives (Costas and Grey 2014). It is argued that the past, present and
future are all mutually implicated, in that they all act upon one another (Adam 1995; Adam and Groves 2007). The present, is both dependent on what has come before, and sits in anticipation of what is to come. The present is defined by social time theorists, as the sum of all that has come before, the result of latent impacts of actions taken both recently and long ago (Novotny 1994; Adam and Groves 2007). The future is arguably engaged with in the present as actions taken in the now, are based, not on achieving an immediate result but to do, get, be or have something at a later time. The ability of human beings to move between and engage simultaneously with multiple temporal positions is noted by Adam (1995, p. 18) who argues that:

\[ \text{[I]}t \text{ is within the power of the human mind to visit past events, to re-invent them, create alternative versions and plan a multitude of futures. We are able to imagine the world in a projected future-present upon which we can reflect and make our choices} \text{ (Adam 1995, p. 18).} \]

The future in this perspective therefore comes into the present and acts upon the now, on the making of decisions and the taking of actions. The future therefore can be said to shape the lived experience of every ‘today’ as much as the past does. The past is said to be acted upon by both the future and the present. The past, although often considered ‘fact’ – as, there are ‘no future facts and no past possibilities’ (Brumbaugh 1966, p. 649; Bell and Mau 1971, p. 9) is not as ‘factual’ as it might first appear. As new knowledges, artefacts and other materials emerge in the present from the past, the way the past is known and understood changes. With each new ‘find’, in the archaeological sense comes undiscovered building types, materials, artefacts and the like which tell us something new about a civilisation of the past. A single piece of pottery with a different glaze or shape can disrupt the chronology of cultural and scientific development as it had been mapped and reorder it entirely. New accounts of abuse from adults reporting experiences as children can alter how we think of individuals in public life – the case of Jimmy Saville for example. New tests for banned substances can force a revisiting of who obtained medals at the London Olympics! The past therefore is ‘fact’ in that it has already happened, but the way in which we know and understand what has gone before, in the now changes and can
be changed. The present and future can therefore unsettle the past as it is continually reinterpreted. It is also argued in both the ‘hard’ sciences and social sciences that both the past and present are implicated in the future. This is argued to be the case because the happenings that have gone before and decisions and action taken in the now will be continually impacting a future state for millennia to come. There is then a perpetual latency to all actions in the past and those taken now (Adam and Grove 2007), and in this way the future is both continually in the making and much to come is already made.

2.1 Temporality in everyday life – time as socially constructed

Time is a central element of human life (Durkheim 1964). Everything people do is conducted in and through time (Mead 1969), making it an escapable part of our existence and the experience of everyday life (Shirani and Henwood 2011). Time is critical to social organisation. For organised social life, actions are required to be co-ordinated in and through time, and to follow some temporal order(ing) (Bordieu 1977). All human acts are understood not as movements in an already existing time, but as emerging events that first constitute a present with a past and future horizon (Mead 1969). People competently move in-between, in and out of the past, present and future as they navigate through life and construct the social world around them (Adam 1995). The extraordinary ease in which this is done signals the imbedded, central and inescapable nature of time in our lives and denotes its very taken-for-granted presence (Daly 1996). Time is so integral to our lives that time itself is rarely acknowledged or reflected upon (Adam 1995; Nowotny 1994) and it is difficult to get beneath this taken-for-granted part of our lives, to think and to talk about time and especially challenging to get beyond the structured ‘clock time’ associations we have in contemporary society (Adam 1995).

2.1.1 Clock time and other time

When asked ‘what is time?’, empirical research which explores peoples experience and understanding of time within the context of their own lives highlights that the clock is quickly referred to, or the measurable aspects of time, its standardisation
(Adam 1995); but the clock is not ‘time’ itself, it is a construction and a measuring device, enabling ‘time’ to be more accurately used as a commodity – to be bought, sold or exchanged. Within sociology, the commodification of time is argued to be critical in the establishing and running of the labour market for example, – the buying and selling of workers’ time (see Giddens 1981 p. 130-134). The ‘clock’ however is not a modern invention, as attempts to measure and capture time has a long history. One of the earliest measurements of time was the calculation of 30 days between full moons, beginning the formation of a year made up of 12 months (12 cycles of the moon) and 360 days – evident within the Babylonian calendar 800 years BC (Bruton 2002). Among the first clocks are Egyptian water-clocks existing in the 15th century BC, and the first mechanical clock is thought to be that invented in China by Yi Xing, a Buddhist monk and mathematician of the Tang Dynasty, 618 - 907 AD (Bruton 2002). The production of the twenty-four-hour clock in the 18th century, the introduction of ‘standard time’ (the synchronization of clocks within a geographical area or region to a single time standard) established in the 19th century and the extension of standard time globally in the twentieth century asserts a powerful influence upon the way in which daily life is ordered, not only in the UK, but across the world.

Clock time however, does not tell us about ‘my time’, ‘your time’, ‘our time’, ‘lived time’ and ‘other time’, all of which are an entirely different, and argued by social scientists to be an unescapably connected part of our lives (Adam 1995; Adam and Groves 2007; Shirani and Henwood 2011). Time and temporality is much more than the clock and ‘the existence of clock time, no matter how dominant, does not obliterate the rich sources of local, idiosyncratic and context-dependent time awareness which are rooted in the social and organic rhythms of everyday life’ (Adam 1995, p. 21). It is the experience and existence of this ‘other time’, time lived and our experience of it (temporality), the way in which the past, present and future, our concurrent use of and movement between them that shapes our social world and our experience of it which is of particular interest here.
This ‘other time’ – a non-clock, lived time, can only be seen, thought and talked about when we bring ‘time’ as taken-for-granted to the forefront of our minds. In doing so, and only in doing so, ‘the spell of clock time is broken. The invisible is given form’ (Adam 1995, p.6). Over the past 50 years sociologists and anthropologists have made extensive efforts to do just this – to lift the obscuring dominance of clock time, to identify and explore its social construction, its use, place and role in societal organisation. In doing so extensive social analysis of time (e.g. Adam 1995, Nowotny 1994, Grosz 1999), social theories of time (e.g. Heidegger (1927), Luhrmann 1978;1979;1982; Adam and Groves 2007) and studies which use time as a lens to explicate areas of everyday life have been produced. It is this literature which explicitly theorises the socially constructed nature of time, identifies its multiplicities within the social world and seeks to explicate the experience and role of ‘time’ in everyday life, the latter of which is of interest here and is reviewed below.

2.1.2 Time and society: variety and extent of the temporal literature

The utilisation of the use of ‘time’ in the study of matters of both everyday life and those of significant societal concerns is extensive and traverses many disciplinary fields (Bergmann 1992). The exploration of the use of time is particularly prevalent contemporarily however in the fields of environmental social science, energy usage, finance and public health. For example, the doctoral and postdoctoral work of Dr Catherine Butler illuminates the role of temporality in processes of environmental governance in relation to flood prevention planning (and post environmental disaster responses). She highlights how understandings of flooding in the UK and pre-emptive approaches are mediated through estimations of the future risk of flooding and explains how these understandings are destabilised and subsequently shift with emerging knowledge about anticipated climate change(s) (Butler 2008). The impact of and concerns about the present and future impacts of nuclear power have also been explored through a temporal lens. For example, Venebles et al. (2012) explore the presence of ‘risk’ in relation to environmental disaster and energy production in the narratives of people who live near nuclear power plants and describe the impact the building of the powerplant has had upon individual and community futures. The
development of sustainable energy, explorations of individual energy usage and attitudes towards future practical changes required for environmental preservation have been explored with a temporal focus (see Groves et al. 2016; Henwood et al. 2016). This work identifies the interplay between envisaged futures, risk, personal and community identities.

The temporal position of ‘future’ within this environmental and energy work which integrate the exploration of personal biographies in the context of large scale policy development and decision making draws out the recognition (or dismissal) that the future comes into the present and acts upon the now. The ‘yet to come’ is conceived as exerting influence on what actions are and are not taken in the now. Recognising that actions taken in the now shape the future for both self and others (or the absence of this) provides a moral framework around which decisions taken in the now are both shaped, judged and challenged – and enable the raising of key ethical questions - who is this decision for? People now or people to come? – and how do decisions taken for people now, affect me now, me in the future or those to come?

Building upon these ideas and areas of work – but applying them to one specific area - the ‘lived future’ and how that forms the experience and production of neurological rehabilitation is of key concern here. How engagement with the future shapes care and rehabilitation of people with severe brain injuries and when it does not, when it is compressed and negated is the story told here.14

As highlighted in the introduction of this thesis, multiple predictive models have been developed in efforts to predict the future of financial markets (e.g. Pyrlik 2013; Tay and Shen 2002). These models rely upon reviewing past facts, identifying patterns and subsequently making a prediction that what comes next will follow the pattern where ‘the accurate prediction of the future states [is] based on the identification of

---

14 Although the concepts of risk and uncertainty have been referred to in this section, they are not pursued further within this thesis. This is because this thesis focuses on the lives of people with the most severe brain injuries at a stage when risks of surgery and uncertainty about their functional outcomes has largely passed and the outcome of the severity of their impairments is now known to be long term and mostly irreversible.
patterns in the historical data’ (Tay and Shen 2002 p. 641). Similarly, within Public Health, models based upon past patterns mixed with contemporary demographical knowledge are brought together to forecast needs for health services and what are now everyday medicines – such as the ‘flu jab’ (see Graham-Rowe 2011; Centers for Disease, Control and Prevention (CDC) 2016).

A further substantial area of social science time based investigation is in the study of ‘work.’ This includes studies by authors such as Zucchermaglio and Talamo (2000) who explore how time is defined within the context of project work in a national bank. Zucchermaglio and Talamo (2000) illuminate complex tacit sociotemporal understandings that are negotiated through discourse in project meetings and highlight how the establishment of multiple ‘times’ are central to the organisation of the project work. Other time and work focussed literature includes theoretical and empirical work which explores how, for example, the separation between ‘leisure time’ and ‘work time’ is narrowing - shifting as work is brought into domestic spaces and into social time. This merging of work and leisure time is mediated by remote technologies (Offe et al. 1992; Martin and Mason 1998; Crow and Heath 2002). Another important area which time and work literature illuminates is the construction of gender, gender based divisions of labour and differences in how the time of women and men is spent. For example, such research highlights that although women work less paid hours then men, due to their domestic responsibilities and the expectations upon them to fulfil multiple caring roles, women have less leisure time than men (e.g. Beechey and Perkins 1987; Shelton 1992; Benschop et al. 2013).

The reference to these bodies of work is made for three main reasons. First it highlights the range of subject areas to which ‘time’ has been explored within or applied as a lens. Second, it positions time firmly within the exploration of contemporary political, social and ethical concerns. The use of a lens which has the power to explicate social, political and ethical concerns is critical in this thesis, which explores the very serious business of the shaping of lives of severely disabled people. Third, it provides examples of how ‘time’ has been utilised within theoretical and empirical social science research, both separately and collaboratively. For example,
the work of Shirani and Henwood (2011), Venables et al. (2012) and Groves (2016) combines social theory and empirical study. Their work accepts the socially constructed nature of time, utilises concepts of ‘latency’ and expectations of time-based life experiences (e.g. anticipated life trajectories, standardised life cycles) as a base from which to empirically explore individual lives and communities. It is within this tradition of time-based social science research that this thesis is positioned.

Although the temporal work discussed above usefully demonstrates the value of applying and developing the social theory of time, and utilising a temporal lens to explicate lived experience and core societal concerns, this work does not illuminate the topic under study here. Neither does it specifically or explicitly focus on the temporal dimension under study – the future. A more detailed review of this broader work is not useful. Therefore, the remainder of this chapter focusses on the sociological work on ‘lived time’ and how time has been explored in relation to health and illness. Attention is paid to research which considers the role of the future in health care relations and how the future is disrupted, effected or remade in the context of illness.

2.2 Lived time

Temporality is our utilisation of, ability to and experience of moving between the domains of past, present and future. This way in which we do this and exist in the world temporally is lived time and sits in opposition to an objective, singular time as measured. Lived experience or lived time is a different kind of time: time as we live it’ (Stone 2012, p. 1). The experience of time and how we perceive and conceptualise that experience varies and is argued to be dependent upon context (Adam 1995). Temporality and the role of lived time in our lives has been widely explored, used, for example, to explicate experiences of care and caring and to explain discrepancies in care delivery models and perceived well-being of individual patients.
Before I turn to explore the literature which examines the role of time and temporality in medicine, health care practice and the experience of health and illness, I first discuss a series of temporal sociological concepts. The temporal concepts discussed below are concerned with the explanation of the broad shaping of the living of lives and the way in which lives are divided in and by time, and are anticipated to be lived out in a certain temporal ordering. These concepts require exploration here as they underpin the core medical sociological concepts explored later in section 2.2.2.

2.2.1 Futures, selves and society

Social time theorists argue that we are continually projecting ourselves into “the realm of the not yet” (Adam and Groves 2007, p. xviii), learning how to imagine our futures from early childhood and extending our temporal horizons into the past and the future as we grow (Bell 1996; Stone 2012). We make plans, and are encouraged to do so - to think about what we want to be when we grow up and to make wishes for what we want to happen or to have (Markus and Nurius 1986; Adam and Groves 2007). ‘[D]uring each present the past we have already lived and the future we still expect to live play a central role in the way we experience, plan and act. Not only that, we have a relationship to our past, present and future; we take an attitude to our origin and destiny’ (Adam 1995, p. 19). This ability and constant interaction with the future is argued to be implicit (Adam and Grove 2007), can be taken for granted, is overlooked and rarely analysed explicitly (Adam 1995; Grosz 1999; Shirani and Henwood 2011).

It is suggested that we assume that our lives will follow an ordered trajectory (Järvenien 2004) and that the life we anticipate for ourselves is imagined dependent on our perception of ‘biographical certainty’ (Zinn 2004). In his book ‘Modernity and Self-Identity’ Giddens (1991) explains that whilst questions such as “What to do? How to act? Who to be? ... all of us answer either discursively or through day-to-day social behaviour” (Giddens 1991, p. 70), making something of ourselves is “dependent on the reconstructive endeavours in which she or he engages” (Giddens 1991, p. 75).
This is achieved through engaging the reflexive self in an aim to build a consistent and stable sense of identity, using “key reference points [that] are set ‘from the inside’, in terms of how the individual constructs/reconstructs his life history” (Giddens 1991, p. 80).

Giddens explains that the ‘reflexive self’ grounds and organises itself through considering the trajectory of its lifespan, reflecting and learning from past experiences and then anticipating what is required for an “organised future” (Giddens 1991, p. 75). He details that in order to be reflexive, a level of self-awareness is required; the ability to be aware of oneself in the present, to be aware of both physical and emotional sensations. He also considers that in order to sustain and maintain self-identity coherence is required and this is achieved through the crafting of a continual narrative of self.

Giddens discusses the temporal element of the trajectory of the self, the importance of a continually reflexive narrative and explains how the reflexive self is crucial for the navigation and survival of various life events. He states:

“Negotiating a significant transition in life, leaving home, getting a new job, facing up to unemployment, forming a new relationship...all mean running consciously entertained risks in order to grasp the new opportunities which personal crises open up...such transitions are drawn into, and surmounted by

15 The self, according to Giddens is a ‘reflective project’, its formation reliant upon the reflection of experiences, actualised through the skills of an individual to navigate its social world and create and maintain a coherent narrative. However, in order to achieve all of this the highest level of cognitive skill is required. For example, in order to reflect upon experience, build and sustain a narrative one is reliant on memory. This however can be highly problematic for people with SBI as memory loss and/or the ability to form new memories is common (Potvin et al. 2011; Palacios et al. 2012). Although a person with SBI may be able to remember their narrative before injury, they may not be able to build on it any further as they cannot remember any new experiences. This in turn would halt their progress towards self-actualisation. This however can only relate to those who have consciousness. Those in PVS or MCS are unable to sustain a sense of self at all. It is this problematic nature of the need for cognition that renders Giddens notion of reflexivity problematic within the topic and focus of this thesis.
means of, the reflexively mobilised trajectory of self-actualisation” (Giddens 1991, p.79).

Shirani and Henwood (2011) argue that the planning of ones’ own future is likely to be relatively unproblematic when our lives pan out the way we plan, but when something unexpected occurs that causes a disruption to the anticipated life course or is deviant to an envisaged possible self consequently forces a reorganisation and reimagining of the future. This can unsettle a sense of self and identity as ‘such experiences challenge an individual’s ontological security derived from a sense of continuity regarding one’s life events’ (Shirani and Henwood 2011, p. 50).

The imagining of one’s own future is also argued to be based upon a ‘standardized life cycle’\textsuperscript{16,} an ordering of life events and decisions which reflect societal norms, values and expectations. The level of standardisation of life cycles within modern society is however debated within the literature (Shirani and Henwood 2011). Elchardus and Smits (2006, p. 303) question to what extent standardized life cycles have been replaced with what they term as an ‘individualised life course’. Beck and Beck-Gernsheim (1995) and Neale and Flowerdew (2003) argue that traditional norms have been replaced with life courses which emphasise individuality and personal choice. Elchardus and Smit (2006) however dispute this, concluding that the evidence overwhelmingly supports the continual dominance of a standardized life course. Conversely Markus and Nurius (1986) argue that the imagining of possible selves is both individualized and socially influenced, in that possible selves are envisaged and crafted from a range of possibilities derived from sociocultural contexts, media and immediate individual social experiences. Therefore, cultural traditions may still influence elements of an individual’s anticipated future, possible

---

\textsuperscript{16} A life cycle is a phenomenon has been conceptualised by sociologists as “a normatively anchored, man-made phenomenon that imposes regularity on life’s events and life’s decisions” (Elchardus and Smits 2006, p. 303). Within the literature, the level of standardization of the lifestyle is discussed in relation to different historical periods. The industrial era is highlighted as a period of “strong standardization and homogenization”, resulting in what Elchardus and Smits (2006) call a standardized lifecycle. “The structuration of the life cycle is said to become characterized by the increasingly strict sequence of education, work and retirement, or of the pre-active, active and post-active life stages” (Elchardus and Smits 2006, p. 304).
self or expected life trajectory, but these are likely to be predominately built in relation to individual circumstances.

Although we may imagine how our own lives will pan out, and dream for things we want for ourselves, how we anticipate our future is likely to involve others and we may anticipate and have expectations of what we think the future holds for them too (Duggleby et al. 2010). Although it is argued that we may no longer be completely influenced by our shared cultural traditions (Mark and Nurius 1986) with regards to how we build and construct our imagined futures, I have argued elsewhere that ‘not in our wildest imaginings would we ever conceive of ourselves or our loved ones sustaining a severe brain injury. This catastrophic ‘unexpected event’ however is the reality for some people and their families who experience huge upheaval of their own lives in the present and find themselves faced with an enormous discrepancy between the future that they imagined for their family member and themselves and the actual outcome’ (Latchem 2013, p. 19). It is within this context of a future never imagined and the intense disruption of planned lives that this thesis is set.

While expectant mothers imagine a standardised life cycle ahead for their unborn child, the life imagined for children born with brain injuries is quickly reimagined and adjusted for them by others, taking into account the impairments they have. These children do not have a pre-injured self and so there is no fracturing of a past and present self – and no big shift (other than at birth) in terms of their future. This however does not mean that futures are not imagined for them, but that the major future adjustment is made at birth. Similarly, for those who are over 65 and are then injured, they have already had the opportunity to live out the future that they or others anticipated. While they may have foreseen and made plans for retirement for example, the major rites of passage (or the opportunity for them) have passed. For those who are aged between 18-65, those deemed ‘working age adults’, they have an established self, with both a past, a present and a well thought out imagined future. It is within this context of an established past and much ahead in an imagined future, the fracture between these two selves and the impact on individuals and their families that is of interest here.
The way in which futures are imagined, how these are socially influenced (irrelevant of the extent to which this is individualised or standardised) and the problematisation of disruption to the actualisation of imagined lives are conceptualisations which are taken up and used to explain experiences of health and illness.

A further body of work which highlights the relationship between futures and selves can be found within the body of work which explores eugenics and medical ethics (e.g. Turnbull 2000). These papers bring together the role of futures in shaping self and connect self and society through temporal concerns. They demonstrate the embedded temporality in both decision making for both individuals and societal concerns and actions (risk taking) taken in the now based upon a projected future. These papers are really useful as a demonstration of the way in which futures are lived in the now, shape action in the now and is one body of literature to which this thesis contributes. What this literature however does not show is how multiple actors’ future projections act on others within the same situation. This type of work has not previously been applied to brain injury. But, what do we know about care, time and health? – what does the literature contribute to understandings of caring and medical practices that may be useful here?

2.2.2 The exploration of lived time in everyday life: care, medicine and health care

2.2.2.1 Time and health, illness and wellbeing

Exploring how time organises, and what part it plays in experience, has been applied to the study of medicine and health care in the defining of wellbeing and disease and to explicate the experience of illness.

2.2.2.2 Biology, time and psychological wellbeing

The temporal has been found to be a central part to understanding medicine, health, healthcare and its practice(s). In relation to health and wellbeing, studies have examined how ‘time’ interacts with and is part of our biology, our bodily functioning
and malfunction and its role in health and being healthy. Concepts such as the ‘body clock’, the role of ‘circadian rhythms’, the phenomenon of jetlag and the existence of time based disorders such as seasonal affective disorder (SAD) (Kurlansik and Ibay 2012) are all examples of efforts to explain our biological relationship with time and its affect upon us as human beings. Alongside explanations of time based interactions with biology and physical healthiness, the role of time has also been described and investigated in relation to mental health and psychological wellbeing. For example the concept of ‘time perspective’ – a notion defined by Zimbardo and Boyd (1999) as ‘the often nonconscious process whereby the continual flows of personal and social experiences are assigned to temporal categories, or time frames, that help to give order, coherence, and meaning to those events’ (p. 1271), has been applied to understandings of the experience of aging (Chernus 2011) and to highlight differences in gender (Ely and Mercurio 2010). Having a ‘Balanced Time Perspective’ is considered important for healthiness (Drake et al. 2008) and a positive contributor to life satisfaction (Stolarski et al. 2016). Equally, any disorder of temporal perceptions, are offered in the literature as contributory to ill health, the experience of negative moods (Stolarski et al. 2014) and certain health related behaviours (e.g. Lawton 2002). Furthermore, the effects of ‘time’ on our wellbeing has also been explored in relation to how we ‘use’ our personal, social time (Cipriani 2013) with misuse of time or an inability to ‘take time out’ or away from the routinisation of work for example, being considered as ‘bad’ for our health and wellbeing (Southernton and Tomlison 2005).

2.2.2.3 Time and medicine

Within medicine and the development of its practices, the usefulness of time and its centrality of the understanding of illness, diagnosis and treatment has long been recognised. This is demonstrated by early epidemiological work and in the publication of edited collections such as Frankenberg’s (1982) ‘Time, health and Medicine’ which draw together a broad selection of nuanced work which carefully considers the role of time in medical practice(s) and knowledge. Furthermore, the extent of the medical sociological work published within the time based journal ‘Time
and Society’ since its inception until today, such as Roth’s (1992) work on the history of medicine in 19th century France, Lynch’s (2000) work on the representation of AIDs, Waterworths’ (2003) research on time and the organisation of nursing work, Hauge’s (2015) exploration of time perception of cancer patients in relation to treatments and Ferrie and Wiseman’s (2016) work on the experience of motor neurone disease is testament to the importance of studying time in relation to medicine and health care.

Within these literatures and the continuation of scholarly exploration of time and medicine today, time has been used to explore doctor-patient interactions, describe illness and its impact and illuminate the way in which medicine is practiced. For example, research exploring reproductive medicine discusses the interconnection between human reproductive, time and timing and the *disjuncture* between medically organised time and reproductive timing (Thomas 1992). Temporal work also highlights how understanding time and timings of illness is critical to knowledge about illness. Knowing if conditions are short or long-lasting, the phase of the condition (e.g. acute or chronic), its anticipated trajectory or pattern is critical for diagnosis (see Beck-Nielson 2015), influences and effects treatment decisions, the urgency for treatment and the incarceration or discharge of patients (Roth 1963). Patient care is prioritised based on the type of illness of a patient and the requirement for timeliness of treatment in relation to its potential for harm over time. For example, people with respiratory conditions are prioritised for physiotherapy treatment over those with ambulatory difficulties due to the life threatening impact of respiratory illness if left too long without treatment. This importance of ‘timing’ is clearly expressed in the context of emergency medicine where the synchronisation of the ‘right treatment’ for the ‘right patient’ by the ‘right people’ has been explicitly linked to reducing morbidity and mortality (Mazur and Ellis 2014). Here Mazur and Ellis (2014) highlight how speed of information sharing between first response individuals (e.g. emergency call handlers and paramedics) and emergency medicine clinicians is critical to saving lives or reducing the impact of illness. They argue that the sooner medical professionals can intervene in the patient’s illness, the more effective their medical intervention will be. Here, time,
illness and outcome are intimately related and the way in which time organises health care work and the attentions of medical care explicated.

Time and temporality has also been identified as central to the identity of acute medical doctors, shapes discourses of professionalism and illuminates gendered differences and implications within the profession. Ozbiligin et al. (2011) who interviewed 20 acute medical doctors in Wales explored the doctors’ shared feelings of nostalgia and loss of (or deterioration of) ‘all hours work’. All hours work refers to doctors’ temporal commitment to be available for work night and day and to work beyond their contractual agreement. Ozbiligin et al. (2011) found that such temporal commitment is a highly regarded, dominant temporal norm in the medical profession today – but that it has significant gendered implications. This ‘all hours culture’ flourishes within full-time work, which favours male workers over female due to the cultural expectations upon women to balance working life with needs of the family. This paper (and others including Lewis 2010) reinforces that the temporal commitments and culture within which medicine is practiced favours men and prevents women participating as fully in the profession. The work of other doctors outside of emergency medicine is also explicated through the lens of time. For example, Macbride-Stewart (2013) highlights how the giving of time by GPs to patients in a way that sits outside of limitations imposed by appointment timeslots is conceptualised by GPs as the provision of quality care and is therefore a ‘gift’.

2.2.2.4 Time and care

Work which explores ‘care’ is located within the broader time literature explored earlier – arguing that ‘care’ takes place in and through time and that socially constructed notions of how time should be ‘spent’ and the value placed on different times impact upon beliefs about and how care is practiced (Bowlby et al. 2010). For example, lived time sits as the core conceptual framework through which experiences such as being and becoming a mother (Stone 2012) or father (Finn and Henwood 2009) are located. What constitutes work time, social time and family time, how these are defined, separated and interact form ideals of healthy work-life balances. Equally, values placed upon how time should be spent renders those
forced by social-economic circumstance to work ‘unsociable’ hours as ‘bad’ parents, unable to spend time as a family, in the same ways as others who work within standard ‘working hours’ (Folbre and Bittman 2004).

The way in which the dominance of measurability within society places value only upon time that can be quantifiable (Adam 2006) is considered to reify capitalist structures of work and working. In doing so, it impacts upon care, imposing clock-time structures of working upon an area characterised by irregularity and individuality. Clock time imposes uniformity and mechanistic ordering – a strategy utilised in models of nursing care for example, where routinized daily activities are structurally forced onto patients and carers, which sits in opposition to the more irregular flow of human experience (Reed 2002). Such routinisation of everyday tasks and functioning, such as washing and sleeping impose a kind of “structural violence” (Farmer et al 2006), interrupting the lived time of both carer and the cared for and rupturing the inclination for intimacy that such relationships can offer (Gass 2004).

Temporal concepts such as timing, synchronisation and rhythm are considered central to defining different types of care – for example care needs may be short lived and intermittent such as taking someone to see the doctor, or repeated and regular, such as feeding a child; and concepts of care and caring sit within notions of life courses which highlight particular points within lives where care is more likely to be needed and given. For example, we are considered as entirely ‘dependent’ as babies, reliant upon the care of adults. As children we navigate and explore the boundaries of care and responsibility and as teenagers begin to attempt to define ourselves as independent and pull away from being cared for. As adults we shape what care we receive and give in the context of new and past relationships and what we plan for the future. In older age we attempt to keep control of our ability to care for ourselves and others, while the changes of aging may render us once again in need of care to meet everyday needs (Bowlby et al. 2010). Charting care conceptualisations within and throughout the life course draws out notions of dependency, interdependency, intergenerational relational and social structures. A full discussion of care, time and the lifecourse has been made elsewhere (see Bowlby et al. 2010).
2.2.2.5 Time, healthcare organisation and the allied health professions

There is an extensive array of studies which explore time in relation to health care practice, organisation of services and work. For example, the temporal landscape of healthcare service organisation and the way in which the introduction of new technologies can shift how health care work is prioritised, allocated, synchronised and co-ordinated is illuminated (Georgio et al. 2011; Wray 2013). Georgio et al. (2011) explores the impact of a new ehealth system on a pathology service. They argue that the introduction of a new ehealth system alters the way in which time is conceived of and demonstrate how such new conceptions of time restructured work within the department. For example, they explain that the new system changed the way in which specimens were tracked and monitored within the laboratory and how information was communicated and work divided.

Studies of time and its organising properties have been utilised particularly in the study of the practice, professional development and identity of nursing. This work highlights how time is key within the configuration of conceptualisations of ‘care quality’ and the requirement for nursing at any given time. The time of day or night and the time of year, for example, impacts nursing shift patterns and staff numbers as patients’ nursing needs fluctuate (e.g. Grant 1979; National Quality board 2013. Time based work in nursing also focusses on how nursing time is ‘used’ or ‘spent’ in general (e.g. Pediani 1998; Duffield et al. 2008) and within specific clinical areas such as surgery (Sharma et al. 2010), post-surgery (Cook 2015) and respiratory care (Melkko et al. 2013). Other work seeks to identify factors which impact upon ‘nursing time’ and there is an extensive array of literature evaluating projects which aim to ‘free up’ the time of nurses such as hands free mobile communication systems (see Pemmasani et al. 2014). These papers and sociologically based research on how time organises nursing time, such as Allen (2015) repeatedly reflects how over time, the way in which nursing time is used has changed. Charting the impacts of medicalisation, hospital structures (Duffield et al. 2008), clinical governance (Allen 2015), economics and demographics (Duffield et al. 2008), this work demonstrates how these processes take nurses away from the bedside and reduce the time nurses
spend providing ‘direct clinical care’ (Sharma et al. 2010), ‘compassionate care’ or ‘holistic care’ (Jones 2010). All of which is proffered as equating to ‘quality care’. Time therefore plays a critical role in the shaping and distinguishing of health care professional work, value and identity. There is however a dearth of temporal research which explores the practices or experiences of other allied health professionals such as physiotherapists, occupational therapists, dieticians, speech and language therapists.

2.2.2.6 Time and patient-health care professional relations

A small subset of temporal research in medicine and health care practice considers and highlights the temporal components of relations and how the differing ‘times’ of patients and doctors (Pritchard 1992), of women and institutions (Pizzini 1992) shape these relations and experiences. This work is particularly useful here as it highlights how the temporal plays a major role in the shaping of control, power and knowledge within these relations. For example patients ‘wait’ for doctors, who control when they see patients, where, for how long and in what order through systems of appointments, medical places of care and discourses during consultations (Jespersen and Jenson 2012).

Furthermore, a number of writers attend, in detail to the way in which patients and HCPs talk about time during their interactions. Applying discourse analyse to ethnographic data, Davies (1994) identifies tensions between ‘process time’ and ‘clock time’ in care-work of young children. Furthermore both Fahlgren (2009) who explores time in the discourses of social work and Juhila et al. (2015) who examines ‘timetalk’ in mental health rehabilitation goal setting meetings identify discrepancies between and in discourses of time between patients and health care workers. They highlight that these temporal mismatches impact caring relations between patient and health care worker and/or the patients’ experience of illness. Juhila et al. (2015) also specifically highlight that mis-matches of time discourses and temporalities between patients and HCPs produces conflict and tensions within these relations and highlight that it is important that HCPs recognise the existence of alternative and
different time discourses as an important part of understanding clients and their needs and their relationships with them. This work is important here as it signals that ‘time’ has a significant part to play in the relationships between patients and HCPs and indicates its contribution to the causing of tensions within these relationships.

2.2.2.7 Time, the experience of illness, of death and dying

Alongside interaction between patients and health care professionals and the organisation of HCPs working practices, medical sociology’s use of time and temporality in the exploration of illness experience is also strong, deeply embedded and long-lived. Many “core” medical sociology concepts worked up to explicate the impact of illness on lives and communities are temporal (Williams 2000) in that they rely upon and are about time and temporality. For example, the concept of ‘biographical disruption’ (Bury 1982) is the term afforded to the phenomena experienced by people with chronic illness, where the illness ‘undermines the structures of everyday life and the forms of knowledge which underpin them’ (Bury 1982, p. 169) and in doing so, alters a person’s biography, their concept of ‘self’ and the future they had envisaged for themselves (Bell et al. 2016). The concept of biographical disruption is deemed particularly applicable to chronic illness, because the progressive and continual functional loss caused by illness impact upon social functioning and in doing so hamper opportunities for the establishment of alternative ‘self’ of value (Charmaz 1983). This temporally based concept has been used in the exploration of the experience of many different types of illness including sensory impairment, multiple sclerosis, stroke, cancer and Meniere’s disease (Dyck, 1995; Leveälahti et al., 2007; Grassman et al., 2012; Hannum and Rubinstein, 2016; Bell et al. 2016).

Similarly, concepts developed in the study of the experience of aging, are temporally based. ‘Biographical pain’, a concept to describe the emotional pain of recalling the extremes of experiences in lives lived – moments of elation, of success and joy, coupled with memories of profound pain and loss (Johnson 2016) is said to be
heightened in older age, when people frequently review decisions made, opportunities taken or missed in a context when their lives are nearing an end. This is argued to be particularly prevalent today because, within modernity, our lives are measured by length of time and is caught up in moral judgements regarding whether or not our time has been ‘well spent’.

In a contemporary western world, there are continuous efforts to extend the ‘time’ people do have to live through, pursued primarily through the development of life saving and sustaining medical technologies and research about how to stay young and slow down the ageing process (Lu 2015). However, it is not only the time and timing of lives that are studied, but also deaths. The process of dying, the timing of and the temporal components of our experiences of dying have also been studied and is explored below.

There is much sociological work which investigates the temporal in relation to life prolongation, life extension, and how death has now become ‘timed’. This work brings to the fore how, through attempts to safe and prolong life, ‘improved’ medical technologies have brought with them a number of new cultural discourses and shaped the way we think about life expectancy, ageing and our choices regarding how we live and what life and living is. Kaufman (2010, p. 226) explains how the improvement and accuracy of diagnosis and screening programmes means that life choices and the timing of both living and dying can be made and taken in certain situations:

‘Medical treatment at all ages is more complex than ever before, a result of the proliferation of diagnostic techniques. Greater diagnostic capability leads to ever more finely tuned therapeutic intervention which, in turn, often requires repeated decision making about whether to pursue aggressive, possibly life-prolonging treatments. In addition, medicine now offers many older persons a dual offering – the choice between (potentially) life-extending and palliative options. These developments open up a reflexive, ethical field in which clinical options give rise to two pressing questions in which the management of life itself is increasingly understood (for many) as an
How we live, how long for and when we die then is orientated to ‘time’ being given or taken by the clinic and the medicine and medical technologies it can offer to extend lives which are threatened by aging, illness or disease.

In certain situations, the pursuit and achievement of life extension is destabilising ‘life’ and understandings of what it means to ‘live’ and be human (see chapter one). The findings from the literature explored in chapter one, section 1.1.4.2 and the temporal component of it, is important here both in terms of contextualisation about who this thesis is about but also in the demonstration that human orientation to and experience of time is central to the creation of one type of severely brain injured persons that this thesis includes – those in a PDoC.

The temporal concepts developed (such as biographical disruption, illness trajectories, imagined futures and standardised life cycles), the type of time based health explorations discussed above and their findings are visible and evidently influential in the small literature base which utilises time as topic or lens in the study of brain injury and neurological rehabilitation. The section that follows now discusses and critiques time and temporal study that focuses on brain injury and neurological rehabilitation.

2.3 Time and temporality in brain injury and neurological rehabilitation

Time within the practices of neurological rehabilitation are evident within the literature, in that much attention is given to a series of key time related processes – in particular ‘goal setting’ and ‘orientation of the patient’. Goal setting is a future orientated process through which goals for medical or therapeutic treatment are made by HCPs in conjunction with the patient and their family. The importance of goal setting, how it is done, how it could be done better and its effects on clinical outcomes are explored at length within the literature. Goal setting is so pervasive within the rehabilitative literature that it warrants closer in-depth examination. A
Another time-based part of neurological rehabilitation evident within the literature is the pursuit of assessing and re-establishing ‘orientation’. Following brain injury, posttraumatic amnesia is common. The duration of this loss of memory is one of the best indicators of the severity of the patient’s future recovery and/or lasting impairment (Nakase-Richardson et al. 2009). Posttraumatic amnesia is ‘the impaired ability to remember events after the trauma, and it is defined as the period from injury until resumption of the ability to store new memories after TBI’ (Langhorn et al. 2009, p. E2). Following loss of consciousness, and on wakening (apart from in the case of PDoC), the patients’ orientation to the time of day, the place they are in and events happening after their brain injury are poor. These memory problems can effect interactions with others, ability to carry out everyday tasks (because they may not be able to conduct a task in the order and sequence it requires) hinder or delay rehabilitation and result in prolonged hospital stays (Cicerone et al., 2005; Nakase-Richardson et al., 2009). ‘Orientation’ then becomes a critical part of rehabilitation. Knowing the time of day or night, year and month and how these times relate to where they are in both their own lives and the current situation that faces them is therefore a significant rehabilitative aim. Literature exploring strategies, programmes and treatments for these cognitive issues is reported on extensively within the literature (e.g. Novack et al. 2000; Alderson and Novack 2002; Langhorn et al. 2009). This time focus however looks at the re-establishment of clock time and the understanding of routine, rather than on any type of lived time or experience.

However, while time related elements of rehabilitative practice are evident in the literature if you go looking for it, the explicit exploration of brain injury rehabilitation through the lens of time is something quite different. There are a small group of authors who have looked at aspects of brain injury or the care of brain injured people through or with the use of temporal lens – nurse and social scientist Sharon Kaufman, social anthropologist Margaret Lock and myself, in earlier work.
Lock (1996) uses the temporal to explore constructions of death and how new medical technologies which sustain ‘life’ in certain ways, shift understandings of life and death across different cultural discourses. Drawing on recent historical medical documents, media sources, medical and philosophical publications, Lock (1996) traces how, due to the introduction of medical technologies such as mechanical ventilators, the sustaining of bodily functions in the absence of a functioning brain has become possible and redefined the point of death to include ‘brain death’. She explains how this reconceptualization of death has been required to support the sustaining of the body of a brain dead person, in order to harvest their organs successfully for use in patients who are currently alive. This work provides a useful narrative of medical, cultural, ethical and legal interplay regarding how our definition of life and death are constantly being re-made, and offers a useful reminder here of a clinical situation which is often confused with PDoC or talked about as another potential outcome of severe brain injury. However, although this work includes problematising definitions between those who are truly brain dead, and those who are in a prolonged disorder of consciousness, the brain dead diagnosis sits outside of the severely brain injured patient group focussed on here – those who are clinically alive and have potential for some improvement.

As referred to in Chapter one, Kaufman (2003) illuminates how health care staff and families caring for people in a PDoC in long-term care settings in America, maintain the personhood of a person with a PDoC through discourse and action around the bedside. Through ethnographic observation she unpacks the complex and often conflicting projections of person upon the body made by conscious others about a person who is unable to interact with the world around them and is in effect, not in the world as they are not aware of themselves or their surroundings. She explains how to maintain the person in the now, family and staff draw on information known about the person prior to injury to construct imagined responses or preferences in the present. This paper offers the closest insight into the groups of people this thesis is about and the care afforded to the most severely brain injured. Kaufman’s (2003) work does not however focus on rehabilitation, the care of different types of severely brain injured people or explicitly focus on the future. However, building upon this
work, and other work by Kaufmann (2005; 2011) focussing on the problematisation of life extension through life sustain technologies, Jain and Kaufmann (2011) explore how hope and promise influence how treatment options and medical decisions are presented in the future in the context of chronic illness. This paper is useful here because it provides a useful demonstration of how the future comes into the present and shapes the now, and does so in a context closer to that of this thesis than other futures work. It does not however explore brain injury rehabilitation and how the future shapes lives in that context.

In my own work (Latchem and Kitzinger 2012; Latchem 2013) I have explored the experiences of severely brain injured people (and those with other neurological conditions) and their families in institutionalised care in independent neuro rehabilitation centres. Within this work timing was critical to the delivery of what patients and families considered as individualised care. For example, being able to get up and washed and dressed when they wanted or was normal for them and not having to wait was of great importance to patients. Similarly, they highlighted that eating at a time they wanted rather than being forced into living with the routines of the institution was significant to giving them a sense of independence or conversely, served to be a reminder of their dependence.

I have explicitly used the lens of time in work which examines how relatives of people in a disorder of consciousness talk about the future. In this study, I explore families’ future talk, considering their relationship to the future utilising the four key future assumptions of future as fate, fortune, fiction and fact held by societies in and through time as identified by Adam and Groves (2007) and discussed in the opening of this thesis. While Adam and Groves (2007) separate the four positions in order to explain them and the gross shifts over large time spans of civilisation, they also posit that multiple assumptions about the future can and are held simultaneously (albeit in hierarchical relation) and utilised according to context. In my own work analysing the future talk of families (Latchem 2013), I show how multiple future positions are held and utilised simultaneously by families and add a fifth future position to Adam
and Groves’s (2007) conceptualisations – future as transcendence.\textsuperscript{17} Alongside my own work highlighted above, the multiplicity of times is highlighted in other work mentioned earlier, in for example the relationships between doctors and patients and through the ideas of alternative futures. Considering multiplicity of times and futures may then also be important in the study of brain injury rehabilitation and how patient futures are shaped.

So far the literature discussed that which is related to brain injury and the broader time-based exploration within medicine and healthcare, highlights the embedded nature of time investigation within health and illness, medicine and healthcare experience, practice and organisation. I have shown that the temporalities within this work are varied as studies move between the three main temporal positions of past, present and future. The literature reviewed also explicates the variety and multiplicity of lived times and other times in the experience of patients and professionals. However, aside from the way in which illness disrupts imagined futures, as touched on earlier embedded within the concept of ‘biographical disruption’ and the work of the three authors identified in this section, there has been little explicit focus on brain injury rehabilitation or rehabilitation as constructed in and through the clinical rehabilitation literature with time as lens or as topic, and even less which focusses on futures. This thesis contributes to this gap through its explicit futures focus.

2.4 Futures work critique and theoretical positioning

The key ‘problem’ however with much of the empirical futures work detailed above is that within this work, the lens itself is taken-for-granted and ‘time’ is often used without it being critically examined itself; a critique offered by Barbara Adam (1995), Elizabeth Grosz (1999) and Helga Nowotny (1994). This critique can, for example, be

\textsuperscript{17} ‘The way in which relatives talked about the future was not just limited to the ‘life span’. Talk included a sense of continuum, going beyond that of the living. This was expressed in a number of ways and generated reflections about personhood, life and death and the location of a person in PVS's soul.’ (Latchem (2013, p54)
applied to the work of Sharon Kaufman, whose many publications frequently examine multiple places of care and illness experiences and centre on time. This is most noticeable in her prize-winning book titled ‘And a Time to Die’ – an ethnography of American Hospitals which illuminates how medical technology has changed when, where and how people die. This enlightening book however makes no methodological note or overt recognition that time has been her lens nor is ‘time’ in and of itself or its construction overtly examined, in spite of the title. Furthermore, much of the theoretical futures work, or that which relies upon notions of prediction based on past fact, considers ‘future’ as fortune, knowable, controllable and therefore profitable. This work however negates the lived experience, latency and the foreshadowing of futures as highlighted as key ethical concerns of approaching the future as fortune by Adam and Groves (2007).

The work by Adam (1995; 2011), and by Adam and Groves (2007; 2011), however overcome these two critiques. These authors are explicit in their use of and analysis of time by carefully defining each temporal term and concept they use and making temporality the central frame for analysis. Others, such as Kaufman, do not methodologically or overtly highlight the lens of time and a vocabulary of time is unspecified in their work. By contrast, the work by Adam (1995; 2011) and Adam and Groves (2007; 2011), through their conceptualisation of multiple future positions and the identification that futures are always in the making, foreground lived and multiple futures and centralise the ethical and moral nature of futures studies. However, Adam and Groves’ theories are ‘grand’ and sit largely without direct application to empirical data. Conversely Kaufman (2003; 2005; 2010) and Jain and Kaufman (2011), utilise the lens of time in empirical work to illuminate the workings of various healthcare based problems.

This thesis therefore seeks to find a middle ground between the work of Adam and Groves and Kaufman by taking some of the theoretical work of Adam and Groves, for example their carefully conceptualised futures and temporal language, but with the application of this work, to empirical data. This thesis draws on the theoretical work of Adam (1995; 2011) and Adam and Groves (2007; 2011), in that it takes on board
the problem with taking time for granted, the multiplicity of times and the ability of people to simultaneously hold multiple assumptions about the future in their interactions and meaning making. It utilises Adam and Groves’s (2007) concept of ‘lived futures’ and their underpinning futures positions as a jumping off point to examine brain injury rehabilitation and patient, family and health professional relations. It is this lived time and not ‘foresight’, projection and other forms of measured attempts to ‘tame’ an already in motion future which is the focus here and what is meant by futures. ‘Futures’ requires specific critical engagement and is not to be taken-for-granted but requires the specific recognition that time and temporality is lived, and constructed and means more than ‘clock time’. By not taking time and temporality as a given and as singular, it can open up an entirely new way of seeing and understanding the social world.

While recognising the mutual implication of all temporal arenas of past, present and future, in seeking to understand the contemporary condition of neurological rehabilitation – this thesis focusses on the role of ‘future’ in this process, and the lived experience of patient, family and staff and how the future comes into and acts upon the now. Futures are not singular and so this PhD seeks to involve and collect the experiences of these three different groups of actors. It also considers how the future is always in motion and is shaped before it arrives, because of the latency that is the inherent result of every action. Therefore, this PhD also seeks to understand the latencies which have and do contribute to the present that is brain injury rehabilitation in the UK – looking beyond interactional, individual relations and considering broader working practice, organisational and political influence.

2.5 The methodological problem of researching futures

As highlighted in the abstract of this thesis – researching the future poses a problem for scientific exploration because the future is ‘yet to come’, it cannot be seen because it has not yet happened. It cannot be held or touched, because it does not yet exist. Studying the future then poses a complex methodological problem. How can the ‘not yet’ be studied? As highlighted above, there have been a broad range
of attempts to make the future knowable throughout human history. It is argued that those that attempt to know the future, through approaches such as predictive modelling and forecasting which rely on what has gone before fail because no two times can ever be the same. The past does not repeat itself. Critiquing the way in which the future has been attempted to be known by generations in the past and the problem of predictive methodologies, Adam and Groves (2007) argue that although the future does not have a reality status in the now, how people engage with a time ahead in the everyday, does. Therefore, the future acts upon the now, and it is this engagement with the future in the present and how it shapes actions in the now that can and is studied here, applied in the context and exploration of brain injury rehabilitation.

The chapter that follows begins the temporal exploration of neurological rehabilitation. First, it says more about what rehabilitation is said to be and how it was developed in clinical terms before providing a close examination of the most explicit temporal component of rehabilitation discussed within the rehabilitative literature – the practice of goal setting. It is followed by chapter four, which explains the conduct(ing) of this research study, discussing research design and methods and ethics.
Chapter 3: Constructing the field: neurological rehabilitation and its’ temporal orientation

This thesis so far, has focussed on the people this research is about, the way in which their lives will be looked at and where they are being cared for – the who, the how and the where. What has not yet been given full attention however is what neurological rehabilitation actually is (or at least what it is proffered to be within the clinical literature). Therefore, this chapter opens with a brief history of brain injury rehabilitation before the exploration of the contemporary conceptualisation of rehabilitation within the health care literature, with a focus on neurological rehabilitation. Next this chapter explores what the process of rehabilitation consists of, what it is reported to offer patients and who it involves. As highlighted in chapter two, there are a couple of overt, time based areas within the rehabilitative literature – namely that of goal setting. The work on goal setting is so dominant with the rehabilitative literature that is requires detailed attention. Therefore, focussing on this one central tenet of neurological rehabilitative practice ‘goal setting’, this chapter concludes with a detailed critique of the rehabilitative goal setting literature. Using this overtly temporal part of the rehabilitative process this chapter questions the temporal orientation of rehabilitation in practice and initiates the critique of its’ ‘future’ nature.

3.0 Rehabilitation – a brief history

Rehabilitation, initially conceived of as ‘an art and science’ was only established and became considered as a core part of medical treatment following the national organisation and policies instituted following the second world war (Eagger 1960). Rehabilitative pioneers had demonstrated the possibilities of rehabilitative practices and the benefits of rehabilitative programmes during and following the first world war. These early programmes focussed primarily on orthopaedic injuries and blindness. The field of neurological rehabilitation, the learning of both the symptoms and care required for those with severe brain injuries also developed during this time as many returned home with traumatic brain injuries from bomb blasts and bullet wounds (Boake and Diller 2005; Atenalov et al. 2015).
Boake and Diller (2005) explain that prior to World War I, it is estimated that 70% of penetrating traumatic brain injuries sustained in war were fatal. Only developments in neurotrauma care made during World War I made survival from brain injuries a possibility and hence the subsequent need for brain injury rehabilitation. Brain injury rehabilitation is therefore a 20th century development, emerging from militarism (Boake and Diller 2005; Atenalov et al. 2015).

Although early rehabilitation programmes focussed on orthopaedic conditions such as the need for prosthesis following amputations and blindness, brain injury rehabilitation programmes and the first brain injury rehabilitative centres were established during World War I - in Germany and Austria (Poser et al. 1996). Awareness of these centres and their innovative work comes from translated writings from two key directors of Rehabilitation Centres in Frankfurt – Kurt Goldstein (1942) and Walther Poppelreuter (1917/1990). The contribution of neuropsychological problems to disability post injury was the initial focus pursued by Goldstein and Poppelreuter who arranged for patients to undergo clinical tests focussing on memory, visual perception and speech and language comprehension. The limitations of psychologically based testing were soon identified by these early rehabilitationists and so Goldstein and Poppelreuter insisted upon both clinical testing and the observation of functional abilities within vocational workshops (Boake and Diller 2005).

Alongside clinical testing and observation, Goldstein and Poppelreuter instigated a therapeutic approach of adapting strategies to work around impairments (see ‘the adaptive approach’ discussed later) and focussed on employment as the main aim and hopeful outcome of their rehabilitation programmes (Boake and Diller 2005). These approaches and rehabilitative aims fit most closely with the modern-day underpinnings on the allied health profession of occupational therapy.

Following the second world war rehabilitation took its place as a co-ordinated effort made across the world to support those with both temporary and permanent physical impairment. People with disabilities were constructed as both a problem
for society but also a potential resource – a resource much needed following the loss of a generation of working aged men and many working aged women (Eagger 1960). The development of brain injury rehabilitation was resumed and centres specialising in the care and rehabilitation of people with brain injuries were established in the UK (Babington 1954; Zangwill 1979), the Soviet Union (Luria 1979) and within military hospitals in the United States of America (Atenalov et al. 2015). In 1951 the world’s first university-affiliated comprehensive rehabilitation centre was founded by Dr Howard Rusk at New York University which was later renamed the Howard A. Rusk Institute of Rehabilitation Medicine (Atenalov et al. 2015).

At that time, compensatory strategies were employed rather than thoughts of cure or influencing physiological change. Vocation and predictors for returning to work were the focus of rehabilitative programmes, alongside an interest in the development of other medical post brain injury complications such as epilepsy and posttraumatic amnesia. Also, during this post war period, the beginning of multi-professional working in brain injury rehabilitation was initiated, with psychologists and speech and language therapists coming together to take responsibility for both cognitive and communication disorders (Boake and Diller 2005).

Post war research sought to establish the numbers of people within the populous with long-term disabilities in order to plan provision for those in need. At that time, there was a slow recognition that ‘the community has a moral responsibility for the disabled’ (Eagger 1960, p. 31) Rehabilitative efforts following the second world war focussed on the restoration of mobility for those with loss of limbs and burns, the re-education of those with loss of eyesight and the rehabilitation of those with brain injuries. In response to the vast numbers and needs of post war veterans, the professions of physical therapy (physiotherapy), occupational therapy, psychiatry, psychology, speech and language pathology (speech and language therapy) underwent vast and rapid development (Gritzer and ArLuke 1985). These professions began to all work together in the rehabilitation of amputees, post stroke and brain injured patients in the 1950s and 1960s in newly formed rehabilitative centres (Boake and Diller 2005).
According to Boake and Diller (2005), the 1970s saw a rapid rise in the interest in brain injuries. Again, stimulated by need, interest grew as the severity of brain injuries (and people’s survival with such injuries) increased. With the development of faster cars, unregulated speed limits (in 1965 for the UK) and motorways came high speed crashes and subsequent complex and severe brain injuries sustained through high speed impacts. Neurosurgeons became more interested in the eventual outcomes of and for their patients and recognition of traumatic brain injury (now included with the term acquired brain injury) as a public health problem grew. As a result, there was growth and further developments in rehabilitative programmes dedicated to TBI (Evans 1981; Hook 1972). In particular, this period saw the development of organised outpatient programmes (Boake and Diller 2005).

In the 1990s the changes and developments in brain injury rehabilitation follow developments in material technologies, innovation of therapeutic equipment and the growth of singular intervention effect trials (such as the randomised control trial). The changes seen in rehabilitation practice during this period, which also underpin rehabilitative work in the 21st century, are also the result of organisational changes in health care more broadly. For example, in the United States of America (USA), the 1990s brought a shift towards ‘efficiency’ and cost reduction of rehabilitation services. As a result rehabilitative length of stays shortened and the need for the measurement of patient outcomes and rehabilitative effectiveness increased (Boake and Diller 2005). This latter shift was also required to satisfy third party funders of medical and health care in the USA; and in the UK, was the impact of a ‘managed care’ approach18. These changes can also been seen in a UK context where the effect of ‘baby boomers’ on the population, the resultant extension of life expectancy, subsequent pressures on finance and NHS provision of resources and the expansion of the hospital to include managers alongside clinicians has shifted the focus of services from just clinical or functional improvement of the patient, to cost effectiveness and value for money.

---

18 Managed care is an approach to financing and delivering health care that seeks to control costs and ensure or improve quality of care through a variety of systems such as quality assurance (NAMI 2011).
A dominant effect of this shift in health care towards demonstration of clinical effectiveness as well as economic value, is the measurement of outcomes and the extensive subsequent development of ‘outcome measures’ or ‘functional rating scales’ to capture both clinical concerns relating specifically to neurological conditions and to assist in the evidencing of progress or decline (Turner-Stokes 1992; Tyson et al. 2012). More focussed, specifically targeted measures evolved from more global scales used in general medicine (Boake and Diller 2005) and were developed by both rehabilitationists and individual nursing and allied health professions. These measures hold a critical and pervasive presence in contemporary justification and provision of rehabilitation services.

In the 21st century ‘rehabilitation medicine’ is a field dominated by concentrated efforts to support people with neurological diseases and impairments – both acquired and progressive. The next section of this chapter discusses modern day rehabilitative definitions and the formation of neurological rehabilitation in practice.

3.1 Rehabilitation – What is it? General and clinical definitions

3.1.1 Rehabilitation as restoration and return to

Rehabilitation – ‘restore to health or normal life by training and therapy after imprisonment, addiction or illness. Restore the standing or reputation of. Restore to a former condition.’ (The Oxford Dictionary 2011 p. 959). As can be seen from the generic English dictionary definition, rehabilitation is conceived of as a process of restoration, recovery and return to a previous state or way of living. Early and contemporary definitions of rehabilitation focus on its restorative aims. For example, a 1943 definition of rehabilitation devised by The Baruch Committee on Physical Medicine defines rehabilitation as ‘the restoration of people handicapped by disease, injury, or malformation as nearly as possible to a normal physical and mental state’ (Folz et al. 1997, p. 447). The presence of restoration in contemporary definitions of neurological rehabilitation is also seen extensively in the rehabilitation literature, often with a focus on the restoration of a full and functioning life – which offers some
level of quality, for the individual. For example, drawing on Cicerone et al. (2008), Evans (2012, p. 651) defines brain injury rehabilitation thus:

*Brain injury rehabilitation is ultimately concerned with the establishment of a meaningful and satisfactory life for people with brain injury. Thus, put simply, rehabilitation is about improving wellbeing.*

Furthermore, in current international and UK rehabilitation guidelines the focus of what rehabilitation achieves for a brain injury person also draws out this idea of restoring functional abilities. For example, The World Health Organisation defines rehabilitation as a process that is ‘intended to enable people with disabilities to reach and maintain optimal physical, sensory, intellectual, psychological and/or social function’ (WHO 2017).

The definitions of rehabilitation and its aims evident within the clinical neurological rehabilitative literature matches the Oxford dictionary definition, but in addition, offers an alternative focus of minimisation of the impacts of illness rather than restoration and defines rehabilitation as a process.

**3.1.2 Rehabilitation as minimisation and optimisation not restoration**

Although the conceptualisation of rehabilitation in the literature focusses mainly on its restorative qualities, rehabilitation is also conversely conceptualised as a practice of reducing the impact of problems/impairments or optimisation of health and functional abilities in the face of chronic or increasing neurological impairment (Kischka 2004; Foley 2008). These two rehabilitative foci of optimisation/minimisation and restoration are identified in partnership within the field of neurological rehabilitation in particular and considered as differing approaches of rehabilitation – the ‘restorative rehabilitation approach’ and the ‘adaptive rehabilitation approach’ (Gladman et al. 2007). The minimising and optimising definitions over restoration are found predominantly within the therapeutic literature written by the allied health professions and that of consultant rehabilitationists, from those early on in the development of the field and those who
practice today. With the establishment of the social model of disability\textsuperscript{19}, within the adaptive approach to rehabilitation is the inclusion of the appropriate adaptation of the environment in order to reduce the impact of any impairments in terms of social access (Barnes 2003).

**3.1.3 Rehabilitation as process**

Alongside the dictionary definition of rehabilitation as restoration and the therapeutic approaches of minimising the effects of impairments and maximising function, rehabilitation is also defined as a process. This notion of process is found in the definitions and descriptions offered by the literature written by consultant rehabilitationists – Derick Wade (2005; 2015), Lynne Turner Stokes (2007; 2015), Christopher Ward (2013), Michael Barnes (2000; 2003) and Udo Kischka (2004).

These rehabilitationists, amongst other writers, define rehabilitation as a well organised problem solving process (Wressle 1999), conducted by specialists consisting of assessment, planning, intervention(s) and evaluation (Barnes 2003; Kischka 2004). With the added description of rehabilitative aims and what makes for ‘good’ rehabilitation including work in partnership with the disabled person and their family, the provision of accurate information and advice regarding the extent of impairments and overall prognosis, working with other professional colleagues in an interdisciplinary fashion, to liaise as necessary with key carers and advocates (Barnes 2003; Ward 2013) and the involvement of the patient (and the family, where appropriate) in the setting of meaningful, challenging and achievable short-term and long-term goals (Kischka 2004).

\textsuperscript{19}The social model of disability focusses on the ways in which disability is socially produced and has succeeded in shifting debates about disability from a biomedical dominated definition and model of disability to discourses about politics and citizenship. (Hughes and Patterson 1997).
3.2 The who of neurological rehabilitation

3.2.1 The multidisciplinary team

As noted earlier, and in chapter one, the early formation of rehabilitative practice was characterised by the collaboration between multiple professions – especially in relation to brain injury rehabilitation. Contemporarily neurological rehabilitation is considered to be a process and service delivered by a ‘multidisciplinary team that usually comprises doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, clinical neuropsychologists and social workers’ (Kischka 2004, p. 83). The benefits of this collaborative professional working for the patient is proffered to be that instead of separate goal setting and treatment delivery focused on what can be provided by individual disciplines, roles become ‘blurred’ and therapeutic work is guided by the needs of the individual (Barnes 2003).

3.2.2 Who is rehabilitation for?

Rehabilitation is considered to be a process suitable to and useful for only certain types of people and patients. Barnes (2003) asserts that rehabilitation is appropriate for five different categories of patient:

1. People who will make a spontaneous full improvement over a short period of time—for example, people with mild stroke
2. People who will improve steadily and may or may not return to pre-morbid function—for example, moderate stroke or traumatic brain injury
3. People who will not improve greatly and who can expect a residual level of disability, but in whom some progress is possible—for example, severe stroke or traumatic brain injury
4. People who will deteriorate slowly over time—for example, multiple sclerosis or Parkinson’s disease
5. People who will unfortunately progress steadily and rapidly—for example, motor neuron disease or malignant glioma
The categories recorded here clearly show the presence of the two approaches and therefore possible aims of rehabilitation – both restoration and adaptation/optimization, even in the face of decline. For example the categories include people who have a small and singular insult where neurological damage is limited (such as mild stroke) and minor intervention will support full recovery. In these cases, rehabilitative aims are restorative and focus on enabling the person to return to their pre-morbid self. Conversely, Barnes’s (2003) categories also include those with motor neuron disease or aggressive malignant brain tumors where cure is not possible. In both situations, the patient will continue to decline and eventually die from their disease. In these cases, the aims of rehabilitation focus on optimising the patient’s functional abilities for as long as possible and then adapting to impairments which come as a result of neurological disease.

Rehabilitation as it is largely constructed in the literature, is a process involving specific types of professionals, sets of practices, routines and interactional work. It is held up and heralded as a process which can and does provide the injured and impaired with the hope of and chance for improvement, recovery and return to either a full or partial self-that-was prior to injury (Gilbertson and Aldridge 2008).

3.3 Rehabilitation and sociological thinking: the problem of examining theories about and conceptualisations of rehabilitation

This chapter so far, aside from the humanities’ contribution of the historical context surrounding the development of brain injury rehabilitation, has stuck closely to the clinical literature about rehabilitation. Although this is critical to define rehabilitative approaches as conceptualised by the medical and health care professions, it is largely devoid of sociological thinking or analysis. This is not however without design. Theoretical discussions about rehabilitation present a challenge because of the origins of its development and the very functional and pragmatic focus of its practice. Siegert et al. (2005, p. 1493) explicitly highlight that rehabilitation is a “hybrid discipline”, in that its theoretical heritage is to be found within the parent disciplines on which it is founded, including medicine, nursing, occupational therapy, physiotherapy and psychology. To understand (and be able to offer a critique of)
the contemporary practices of neurological rehabilitation and its theoretical underpinnings in any depth would require the tracing and explication of an even greater range of disciplines. This is because each of rehabilitation’s contemporary disciplinary make up are theoretically founded upon a range of further disciplines. For example ‘*physiotherapy requires knowledge of anatomy, physiology, neurology and kinesiology*’ (Siegert et al. 2005, p. 1494). Unpicking and mapping rehabilitation’s theoretical roots is complex enough, let alone applying a further disciplinary gaze. This complexity may explain why rehabilitation is largely devoid of sociological analysis and why what has been conducted focusses on very specific areas of rehabilitation, a particular condition or practice. For example, Fadyl et al. (2015) use a Foucauldian perspective to analyse the way in which vocational rehabilitation practices in New Zealand reproduce discourses of employee value. Ville (2005) explores the biographical work of spinal cord injured patients in the process of returning to work following rehabilitation and Robertson, Kay and Moore (2010) explore masculine embodiment through interviews with men receiving cardiac rehabilitation. Although this work provides a useful example of how parts of rehabilitation have been sociologically analysed, the relevancy of biographical disruption and reconstruction has been discussed in chapter two, return to work in general is an aspiration which is largely out of reach for the severely brain injured population under study here and most sociological studies about rehabilitation focus on patient groups other than brain injury. Making any attempt to apply sociological thinking to rehabilitative theory, its conceptualisations and form then is difficult due to the extent of its origins and practices and the dearth of sociological work about rehabilitation on which to draw. Such an endeavour would be a thesis within itself and beyond the scope of work here.

Instead, here, sociological analysis is applied in two ways – first, in the exploration of how the clinical literature on rehabilitation is presented, with a focus of time and the temporal and in the application of a temporal lens on one particular group of people (those with severe brain injuries), receiving rehabilitation and long-term care in independent rehabilitation settings. Such temporal sociological examination begins here by first critiquing one specific area of neurological rehabilitation – goal setting.
Despite the largely devoid sociological analysis of neurological rehabilitation there is hybrid health care – social science work in a special issue of Disability and Rehabilitation, which examines person centred care and goal setting (see Disability and Rehabilitation, 2007, 29(20-21). This work is drawn upon here alongside broader clinical neurological rehabilitative literature about goal setting.

3.4 Goal setting in brain injury rehabilitation

One of the most overt temporal practices involved in rehabilitative work is that of ‘goal setting’. A goal is an intended or desired future state which requires action and effort in order for it to become reality (Playford et al. 2009; Wade 2009; Day and Tosey 2011). As object and process, goal setting is therefore future oriented. However, the overt temporal status of goal setting is questionable due to its very explicitness, as time and temporality is often implicit in discourse, knowledge and social practice (Grosz 1999). This section examines and questions the temporality of both a ‘goal’ and ‘goal setting’ and argues that goal setting is not a process of future making but is instead a technology to limit the possibility of failure and manage uncertainty in the present.

The idea of ‘goals’ and goal setting processes has been discussed in the clinical rehabilitative literature for around 40 years (Levack 2006). Goal setting, sometimes known as ‘goal planning’ (terms which are used interchangeably) is the formal process where a multidisciplinary team (MDT) of HCPs, patients and families set a series of goals which are intended to be met during the rehabilitation of the patient (Playford et al. 2009; Wade 2009). Goal setting is widely considered as a central component of brain injury rehabilitation (Barnes 2003; Evans 2012, Playford et al. 2009, Simpson et al. 2005; Wade 2009) and neurological rehabilitation more broadly (Lawler et al. 1999; Halliday et al. 2005; McPherson et al. 2009). Yet, despite its ‘best practice’ and central status within rehabilitative practice, I argue that the clinical literature on goal setting is characterised by uncertainty and lacks consensus regarding how to do it, what it achieves and who it is for. For example, goal setting for people with neurological conditions (irrespective of phase of care) is frequently aligned with ‘person centred’ models of care and integrated into discourses which
claim the critical importance of involving patients and families in decision making. However, McPherson and Siegert (2007, p. 1551) challenge the assumption that goal setting is person centred in practice and suggest that patient involvement in goal setting is more ‘rhetoric than reality’ and there is recognition that the goal setting process serves many – including the multidisciplinary team and the organisation within which rehabilitation services sit – raising the question ‘whose goal is it anyway’?

This section will therefore also discuss how the process of goal setting serves multiple agendas. Here I argue that as there is such limited evidence which underpins the clinical effectiveness of goal setting and due to its fit with ‘patient centredness’ (a concept central to health and social care process and policy discourse), goal setting fulfils a primarily performative role. It is used as a technology through which to demonstrate ‘gold standard’ rehabilitation rather than, to necessarily achieve the best clinical outcomes for patients.

3.4.1 What is a goal?

The Oxford English Dictionary (1989, 2010) defines a goal as: ‘The object to which effort or ambition is directed; the destination of a (more or less laborious) journey [...] An end or result towards which behaviour is consciously or unconsciously directed.’ Applying the Oxford English Dictionary definition of a goal to rehabilitation, Wade (2009, p. 291) states that:

...goals have two characteristics. First a goal is an intended future state; this will usually involve a change from the current situation although, in some circumstances, maintenance of a current state in the face of expected deterioration might be a goal. Second, and of equal importance, a goal refers to the intended consequence of actions undertaken by the rehabilitation team. A goal is not nor should be a simple prediction of what will happen; it should be the intended result of some intervention(s).

The future is unknowable, a quality that allows for and opens up potential and possibilities (Adam and Groves 2007), yet the latter section of Wade’s (2009, p.291) definition of goal setting discloses a planned and expected nature of goal attainment.
in rehabilitation – anticipated and dependent upon a series of certain actions. Conducting goal setting in this manner becomes then, an attempt to make more certain what is to happen, to ‘control’ or ‘tame’ the future. Such attempts to control and know the future in turn reduces possibility and sets limits – with futures then becoming limited or dependent upon our own expectations or merely the ‘intended result of some intervention(s)’ (Wade (2009, p. 291).

Interestingly, the origins, the etymology of the word ‘goal’ highlights this potential for limitation and boundary. While the more modern definitions of the word ‘goal’ include ‘the result or achievement toward which effort is directed’, ‘the terminal point in a race’, ‘an area, basket, cage, or other object or structure toward or into which players of various games attempt to throw, kick, hit, a ball, puck etc. to score a point or points’ (Dictionary.com 2017), the origins of the word ‘goal’ are suggested to come from the 13th–14th century middle English noun ‘gol’ meaning ‘boundary, limit’ and the Old English ‘gaelan’ meaning ‘to hinder or impede’ (Dictionary.com 2017). In practice then, does the setting of goals within neurological rehabilitation open up the future for people with brain injury, enabling them to maximise their rehabilitative potential or does it instead restrict and close down the future, performing the more bounded and limited origins of the meaning of a ‘goal’? This question is returned to later in the chapter and the thesis as a whole. Here, I will argue that goal setting is both a set of material practices and discursive approach in neurological rehabilitation.

3.4.2 How it is meant to be done: SMART goal setting and objective measures

There has been significant attention given to how goal setting should be conducted in the literature, in particular by neurologists and neurological rehabilitation consultants in the UK such as Professor Derick Wade (2009), Professor Lynne Turner-Stokes (2009) and Professor Diane Playford (2009). Wade (2009) explains that the first step in goal setting is for the multidisciplinary team (MDT) to establish ‘what goals are important for the patient’, the wishes and expectations of patients, family members or significant others – which may include funders and the rehabilitative team. He highlights that in conjunction with establishing the importance, wishes and
expectations of the stakeholders, it is critical to establish the potential for change, what changes are and are not possible and their likelihood. Following these ‘preparatory stages’ a series of goals are set through a process of information sharing and negotiation between the team, the patient and their family (Wade 2009, p.293).

There is however much more detailed guidance within the literature regarding how the ideal goal should be set. This guidance takes form of a longstanding standardised goal setting format called SMART\(^{20}\) which is promoted by multiple clinicians and academics. Although the date and inventor of the SMART goal formation is uncertain, the first known publication utilising this acronym was Doran (1981). The formation of goals, targets or objectives originated in business and management contexts (Doran 1981; Locke and Latham 2002), evolving from the ‘management by objectives’ movement (Raia 1965). SMART stands for Specific, Measurable, Achievable, Realistic and Timed in the UK (Wade 2009; Ward 2013), although there are variations in the words within the acronym reported in the wider literature (Wade 2009; Playford et al. 2009). Discursively and in practice ensuring that every goal set fulfils all of these things makes it a ‘SMART goal’ and is the gold standard format of setting goals in clinical rehabilitation (Wade 2009).

Setting goals which require these five elements is challenging however and both solves and creates problems. SMART goal setting is a technology - a ‘program for conduct’ (see Latimer 2000) which is formed of a particular set of practices (discussed below). How SMART is constructed and utilised in practice both creates and makes visible a certain way of viewing outcomes and therefore contributes to the way in which futures of people with brain injuries (and other neurological conditions) can be viewed. The next section interrogates how SMART constructs a way of seeing the world of rehabilitation and programmes conduct. It considers what the consequences of rehabilitating by objectives might be, highlighting what is being made visible through SMART goal setting but also, and most importantly, what is

\(^{20}\) Not to be confused with SMART testing [Sensory Modality Assessment] ‘developed to assess the levels of awareness, functional, sensory and communicative abilities of adults in vegetative (VS) or minimally-conscious states following severe brain injury.’ (Tennant and Gill-Twaites 2017, pp. 185)
being marginalised, prevented and devalued as a result of utilising this goal setting model.

3.4.2.1 What does SMART do?

Specific, Measurable, Achievable, Realistic and Timed

The first component of SMART goal setting is making the goal specific. Locke and Latham (2002) and Schut and Stam (1994) suggest that a specific goal is more motivating than a goal that is not precisely defined and highlight the importance of motivation in goal attainment. However, the predominant importance of goal specificity is to ensure that they can be measured (Schmidt and Wrisberg 2007; Wade 2009). Alongside being specific, the SMART model details that goals should be attainable and realistic. They are to be difficult or at least challenging, but critically within an individual’s capabilities. If a requirement of a goal is that it is to be achievable, this suggests that a goal is merely the predicted and expected outcome following a set of actions and are in essence set specifically to eliminate the risk of failure and provide ‘opportunities for mastery and minimizing anxiety’ (Playford et al. 2009, p. 341) rather than a desired and hoped for, but unknowable outcome. This therefore places a challenge to the future orientated notion of goals. If goals are to be achievable, then goals are less future orientated and more focussed within a closer temporal frame – more like the extended present as defined by Nowotny (1994). Fitting closely with this knowable quality of goal setting, goals within the SMART framing, are also required to be ‘realistic’. The detailing of the need to set ‘realistic’ goals is understood as playing a critical role in managing patient expectations, which are often considered to be ‘unrealistic’ (Playford et al. 2009). This component of goal setting therefore enables patient expectation to be brought in line with those of clinicians. The issues surrounding such ‘management’ of expectations is discussed further later.

Goals are also required to be ‘timed’. Most goals are set within short time frames and must be achievable within the near future - again suggestive of an extended present rather than future orientation. In acute settings the writing of short-term
goals (in this case over a fortnight) have been used to predict the need for rehabilitative services and to predict the likelihood that patients will be discharged on the ‘estimated date of discharge’ set on admission. As Black et al. (2010, p. 374) explain:

If patients achieve their short-term goals, this suggests that they are making satisfactory progress towards achieving their goals for discharge. If they have not achieved their short-term goals, then perhaps the goals for discharge are too optimistic for the patient’s potential ability, the rehabilitation resources utilized or the proposed timeframe of their length of stay. In this case, it may become necessary to do one or more of the following: review the therapy provision, investigate factors that may be impeding progress, amend the expectations of the patient’s abilities at discharge and/or extend the anticipated length of stay.

In this instance, goal setting is being utilised as a technology of prognosis, and to predict the level, type of resources and length of stay required. How goal setting controls and shapes rehabilitative time is considered further later. These four SMART goal setting elements, specific, achievable, realistic and timed however achieve one main critical thing - they enable and ensure the final element of SMART goal setting, measurability can be achieved.

The methodology of a SMART goal demands that it be measureable, in order to both determine that it has been achieved and therefore demonstrate that progress has been made. The importance of goal setting and having ‘targets for rehabilitation’ is seen as important but ‘this raises the question of how outcome is best measured’ (McMillian and Sparkes 1999, p. 250), what measurement means and how it is understood. Playford et al. (2009, p. 339), reporting on a two day conference exploring controversies in goal setting highlight this dilemma, stating that:

Although the ‘M’ in ‘SMART’ goals tends to refer to a goal being ‘measurable’ there was considerable discussion about what was understood by the term ‘measurable’. Two concepts emerged: first, measurement as a tool that enables a quantitative representation of patient experience, and second, measurement for the evaluation of goal performance.
With regards to the aim of evaluating goal performance, a plethora of outcome measures (Turner-Stokes et al. 2014), tools, have been designed specifically to enable the measurement of certain types of impairments or disabilities, many of which are utilised within neurological rehabilitation. These outcome measures include the Neurological Impairment Scale (Turner-Stokes et al. 2014), the Oxford Case Complexity Assessment Measure (Troigros et al. 2014) and Wessex Head Injury Matrix (Wilson et al. 2009) to name but a few. Such measurement tools are considered to be extremely useful and ‘have great value in examining impairment and activity limitations following brain injury’, however in determining ‘the outcome of rehabilitation they may not always be sensitive to important behavioural changes’ (McMillian and Sparkes p. 242). There is recognition therefore that outcome measures, while good at measuring specific type and severity of impairment following injury, lack sensitivity when it comes to measuring all neurological changes – especially those which are cognitive, behavioural or social.

How outcomes are measured in neurological rehabilitation is considered to be different to patients being cared for in acute phases of illness as during these phases, ‘impairment’ is the focus of measurement, which is easy to measure objectively (McMillan and Sparkes 1999). This acute focus can be seen in the measuring tools themselves – most of which measure impairment not ability. This focus of measuring impairment however is in opposition to the aims and practices of neurological rehabilitation and the discourses within it, which primarily focus on restoring function. Measurement within neurological rehabilitation and:

*establishing effectiveness has proved to be more difficult than in some other areas because [...] most interventions in neurorehabilitation are aimed towards reducing [my emphasis] disability/handicap, which in turn reflect quality of life issues more directly, are often multifactorial and at least partly subjective in nature* (McMillian and Sparkes 1999, p. 242).

Certain types of outcome therefore are more easily measured than others. The measurement of physical impairments and tracing their restoration for example are much easier to accomplish in practice than behavioural changes or social functioning. How ease of measuring impacts goal setting practices is discussed later. The reason
for the use and amount of outcome measures is similar to the purposes of goal setting itself which is also explored in detail throughout the rest of this chapter. However, in brief, McMillian and Sparkes (1999, p. 241-242) succinctly highlight the key drivers behind the rise of measurement in neurological rehabilitation, explaining that:

*Throughout the 1990s there has been increasing emphasis on the development and use of outcome measures in neurorehabilitation as tools for estimating effectiveness. Cost pressures in health and social services have led to reorganisation of services, restrictions on their development, and actual cuts. The general heightening of perception that there are limits to resources, would seem to have gone hand in hand with an increasing emphasis on the need to demonstrate that all clinical interventions are effective, in order that this can be taken into account in the planning of health care.*

Playford et al. (2009, p. 340) highlight how the quantitative measurement of goals are not, in the main, of interest to patients, but are ‘*of interest to clinicians, purchasers and researchers because of its perceived potential to enable comparison between patients and services.*’ Furthermore, the need to ensure that the right patients receive the right services has also become of paramount importance in health care management. This can be seen in the development of certain types of outcome measures. While many have been developed to measure often very specific (dis)abilities, some outcome measure tools such as the Rehabilitation Complexity Score, have been developed exclusively to identify and distinguish between the need of individual patients for specialised services (Troigros et al. 2014).

The importance of and need for ‘measurement’ of all outcomes can be demonstrated by the attempts in neurological rehabilitation, to measure the unmeasurable. For example, returning to Playford et al’s (2009, p. 339) first concept of ‘*measurement as a tool that enables a quantitative representation of patient experience*’, this notion is visible in the multiple quality of life outcome measures which have designed in an attempt to quantify this highly subjective and complex concept. A tension exists therefore between ‘*setting goals that are meaningful to patients yet meeting the “SMART goal” requirement to be measurable*’ (Evans 2012, p. 653).
There is recognition that the outcomes of rehabilitation should and do go beyond what can be objectively measured, but in order for service provision to be funded, evidencing to justify its value is critical (Turner-Stokes 1999; Turner-Stokes et al. 2012a,b). The dominance of and need for measuring leads to the prioritising of the things which can be measured and pushes away, or marginalises those changes which are unmeasurable but critical to quality of life – social functioning. This can be seen for example in studies where mismatches in patient goals and clinician goals cannot be aligned due to the problem of measurement (Gardner et al. 2015). The unmeasurable therefore becomes relegated as it cannot be demonstrated. This point is returned to later. Applying SMART to the learning of students in secondary and further education, Day and Tosey (2011 p. 517) warn that ‘there is a danger that SMART targets can be employed in an instrumental manner and divorced from students’ active engagement and reflection on their practice.’ I return to issues of engagement later but Day and Tosey’s (2011) concern regarding the risk of goal setting being used instrumentally is one in which I wish to highlight here. SMART goal setting is a standardised model. This model and other similar technologies which mobilise or seek to enforce ‘standardised’ practice, while important in isolation, risk eliminating any individuality and therefore a person centred focus of neurological rehabilitation. The pressures of measurability therefore risk turning the holistic and individualised process neurological rehabilitation often proffers to consist of, into merely the standardised reproduction of measuring practices. As pointed out by Wade (2009) this warning was also given by SMART’s originator who stated:

*In certain situations it is not realistic to attempt quantification [...] Practicing managers and corporations can lose the benefit of a more abstract objective in order to obtain quantification* (Doran 1981, p. 35).

Despite the prevalence and longstanding guidance offered by the SMART model, there ‘does not appear to be one standardized method of goal setting, or consensus on how goal setting should be undertaken, especially with people with cognitive and communication problems’ (Sugavanam et al. 2013, p. 188) and there is significant variation in the practice of goal setting. The challenges of, and therefore tensions within, goal setting with people with brain injuries are discussed later.
3.4.3 What is goal setting thought to achieve for patients and how might it work?

Theories from psychology and the ‘science of wellbeing’ suggest that striving for and achieving goals contribute to wellbeing (Evans 2012). Several key theories underpin the use of goal setting in neurological rehabilitation (Sugavanam et al. 2013; Evans 2012) - Bandura’s Social Cognitive Theory (1986) which focusses on the role of ‘self-efficacy’ and Locke and Latham’s (2002) ‘Goal setting theory’ which emphasizes the importance of setting specific and attainable goals. However, Levack et al. (2011) argue that there is little empirical evidence that theories ‘imported from psychology’ are applicable within a rehabilitation context.

Goal setting however is argued to offer psycho-social benefits including increased motivation, sense of control and a reduction in anxiety (Stuifbergen et al. 2003; McGrath and Adams 1999; Alexy 1985; Berquist and Jacket 1993; Wade 2009) and is regularly cited as a means through which to increase patient engagement with rehabilitation (Dalton et al. 2011; Evans 2012; Simmons et al, 2005). Goal setting is also proffered to improve task performance in people post stroke (Wade 1999) and brain injury (Doig et al. 2011). However, there is also a lack of empirical evidence which underpins the practice of goal setting (Wade 2009) and its effectiveness in relation to clinical outcomes (Levack et al. 2006b). This lack of evidence persists, being a repeated conclusion in recent systematic literature reviews which have evaluated the evidence of goal setting clinical effectiveness in neurological rehabilitation, including the rehabilitation of multiple neurological conditions (Levack et al. 2006; Rosewilliams et al. 2011), or focussing on single aetiologies such as stroke (Sugavanam et al. 2013). There is some evidence which suggests that goal-directed therapy improves the outcomes of people with traumatic brain injury (Doig et al. 2011) but this review is fraught with design issues and the conclusions made by Levack et al. (2006b) are more representative of the clinical rehabilitation goal setting reviews. Following a substantial systematic literature review of goal setting with adults with postacute or chronic disabling conditions, Levack et al. (2006b) concluded that the evidence linking the use of goal setting to improved patient outcomes is small, inconsistent and limited further by inadequate methodological quality.
Despite a lack of clinical evidence and variation in practice, goal setting is recommended in multiple contemporary clinical, rehabilitation and service delivery guidelines for people with brain injuries in the UK (Royal College of Physicians (RCP) 2003; The National Managed Clinical Network for Acquired Brain Injury (NMCN), 2009; Scottish Intercollegiate Guidelines Network (SIGN), 2013; and internationally, for example, in New Zealand (The New Zealand Guideline Group (NZGG) 2006). However, interestingly, none of these guidelines suggest that goal setting improves clinical outcomes or refers to the psychosocial benefits of goal setting for patients but, instead, detail the role of goal planning as a means of evaluation, ‘demonstrating progress’ (RCP 2003, p. 22), aiding communication (RCP 2003; SIGN 2013), ‘structuring planning and decision making’ (SIGN 2013, p. 3) and in some cases simply stating the importance of patient and family involvement in goal setting (NMCN 2009; RABIIG [no date]) – thereby emphasising its regulatory mechanisms. This is an analytical point that will be returned to and expanded upon later.

**3.4.3.1 Patient inclusion of goal setting**

In order to achieve the psycho-social benefits of goal setting discussed above such as increasing patient motivation and engagement with rehabilitation, the inclusion and facilitation of patient and family participation in goal setting is considered key (Trieschmann, 1974; Webb and Gluekauf 1994; Conneeley, 2004; Kuipers et al 2004). The inclusion of patients in goal setting is also considered to improve their functional outcomes in comparison to those who are not actively involved in the goal setting process (Ponte-Allan and Giles, 1999; Trombly, Radomski and Davis, 1998; Trombly, Randomski, Trexel, & Burnett-Smith, 2002). However, following a systematic literature review, Lewin (2001) concluded that the evidence that involving patients in goal setting improves their overall function is sketchy and inconsistent. Despite the growing strength of person centred care and service user involvement in health and social care policies in the UK (see appendix 2), Bright et al. (2012) suggest that there has been much lip service given to person centred care and service user involvement in practice and highlight that many services are still not delivered in a patient centred way.
The need to recognise the holistic needs of patients, their motivations and social situations is identified as another central component of rehabilitation (Lewin et al. 2001; Cott 2008) and facilitating patient participation in goal setting (however that can be achieved) the focus of person-centred care and contemporary rehabilitative practice (Tickle-Degnen, 2002; Conneeley, 2004; Kuipers et al. 2004) but quite how central the patient is in this process is questionable (Levack et al. 2011). Townsend and Polatajko (2007) highlight that achieving collaboration and person centredness, requires enabling and supporting the patient to make decisions, goals and changes for themselves instead of prescribing and making choices for them. However, a study by Leach et al. (2010) found that only one out of 15 therapists setting goals with patients fully involved them in the goal setting process, with ten involving patients to some extent and four dominating the process with the minimal inclusion of patients. These findings are supported by Rosewilliam et al. (2011) in their systematic review of neurological patients’ involvement in goal setting who concluded that patient involvement in goal setting practice was minimal. Similarly, in a systematic review of goal setting with stroke patients, Sugavanam et al. (2013) highlighted that there was a discrepancy in the perception of levels of patient involvement in goal setting and their actual inclusion.

Lack of patient participation in goal setting may be due to the challenges of working with people with severe brain injuries, many of whom will have severe communication and cognitive impairments (Holland and Halper 1996) and in non-specialised teams professionals may lack the skills and time to maximise the communicative abilities of these patients. Lack of motivation and difficulties with executive functioning are common symptoms following brain injury which impact the ability to participate in goal setting in the crucial ways which are outlined in the literature as being the main beneficial component of goal setting (Dalton et al. 2011). For example ‘[i]f goals are to influence behaviour, there is a basic requirement that they are remembered. However, in brain injury rehabilitation this is not something that can be necessarily relied upon’ (Evans 2012 p. 253).
Difficulties with patient participation in goal setting however is not limited to patient capabilities, but has been suggested to be impacted by organisationally imposed limitations such as finances and patient length of stay (Wressle 1999; Playford 2000; Baker 2001), clinician skills in relation to goal making or patient education (Playford 2000; Baker 2001; Conneeley 2004; Wottrich 2004). Dalton et al. (2011) highlight that this mismatch between guidelines and the reality of practice will continue while there is a lack of evidence to support recommendations. They highlight that people with brain injury will continue to be at risk of being excluded from goal setting due to resources and the continual perception that they lack the cognitive abilities to participate in the process. There is therefore a ‘lack of fit’ between the rigid goal setting practices used within general neurological rehabilitation and the needs of patients with severe brain injuries requiring rehabilitation.

Considering there is so little evidence about what goal setting does for patient rehabilitative outcomes, the psycho-social benefits of goal setting are ignored in clinical guidelines and despite the rhetoric of service user involvement, this is not achieved in practice - why is goal setting repeatedly recommended? What else might it be achieving and for who?

3.4.4 Who else might goal setting be for?

3.4.4.1 Collaboration, team working and organisation

There is identification that goal setting fulfils a multitude of purposes, functions and benefits within rehabilitation which can at times be in conflict with one another (Levak et al. 2006; 2011). Goal setting is considered to provide multiple benefits for both patients and professionals (Schut and Stam 1994). Most professionals themselves ‘report benefits from the goal-setting process, including better multidisciplinary Teamwork’ (Playford 2009, p.335) and team organisation (Levack et al. 2006). The setting of shared goals is said to provide a focus for the collaborating team (Playford et al. 2000; Levack et al. 2006), and ensures that important clinical, rehabilitative or social actions or interventions are not over looked (Wade 2009). Goal setting is also thought to act as a motivator for clinicians. Bright et al. 2012 (p.
109) for example note that reflecting on practice, the action of listening to the wants and needs of patients intently ‘leads to a renewed sense of purpose and meaning in their own clinical practice.’ Furthermore, Evans (2012) suggests that the use of goals drives the performance of clinicians. The meeting of goals enables professionals to prove the impact of their clinical effectiveness (Wade 2009) as individual clinicians, their profession (Levack et al. 2006) and the rehabilitation service as a whole. Proving clinical effectiveness is critical in a context of growing financial pressure where rehabilitative costs are high and professionals may have to justify both their service, the admission and length of stay of individual patients to funders (Turner-Stokes 2007). How economic, intervention effectiveness and professional identity pressures impact day-to-day working practices and the rehabilitation of people with severe brain injuries however is largely unexplored. Goals therefore encapsulate more than the expression of patients’ wishes and their therapeutic aims. They are influenced and mediated by much more than the needs of individual patients (Simpson et al. 2005), including the MDT and service providers (MacPherson et al. 1999; Playford et al. 2000).

3.4.4.2 Goal prioritisation and the meeting of organisational needs

An ethnographic study of goal planning in the rehabilitation of acute stroke patients conducted by Levack et al. (2011) illuminated how certain issues were ‘privileged’ by HCPs, considered as more important which consequently constructed and dominated goals set. These privileged goals tended to have ‘an orientation towards physical functioning [...] short timeframes for their achievement, and [...] conservative estimates of progress’ (Levack et al. 2011, p. 210). However, considering the elements of SMART goal setting as discussed earlier, the goals that are privileged could be, not those that are deemed most important as Levack et al (2011) suggests, but those which are more easily measurable and can therefore assist with meeting professional and organisational needs - proving and demonstrating effectiveness. This argument is supported by Levack et al’s (2011) observation of a lack of goal setting in relation to social and psychological functioning (areas which are more difficult to objectively measure), despite these areas being frequently raised as issues and concerns by HCPs and discussed at length by the MDT. The aims of privileged
goals highlighted above were considered by Levack et al. (2011, p. 210) to reflect one main objective, ‘to return the patient to the community as quickly and as safely as possible.’ Although Levack et al. (2011, p. 210) consider this objective to be reflective of ‘clinicians’ over-riding sense of responsibility’ they omit to highlight that this aim is perfectly in line with broader health care organisations’ (especially acute services) consistent and recurring aim: to ensure regular and continual patient throughput. Continual and rising pressure on services with hospitals repeatedly having ‘bed crisis’ where there is no room for new admissions is a contemporary (and also longstanding) reality for health care services and bed managers. Goal setting can again be seen as a technology which is mobilised to assist with the disposal of patients (Latimer 1995). In this case, to discharge from an NHS rehabilitation service into the community. This organisational aim was imbued within the talk of Levack et al’s (2011, p.210) health care professional informants as demonstrated by a Physician who said:

In order for the process [of goal setting] to work it’s necessary to bring things down from a long-term – what people are going to get out of their life kind of level – which is how I like to see it, down to the nuts and bolts of what is required to get somebody out of hospital. And clearly it’s possible to use the term goal planning right down to that level but for me that’s really more of the issue of task allocation and completion.

The influence of organisational aims and objectives on goal setting has been identified and discussed elsewhere. Simpson et al. (2005) analysed goal setting statements in two brain injury community rehabilitation services. They speculated that organisational objectives explained the differences between the goals being set. They found that the content of goals differed significantly between services and that in one service they changed over time. They concluded that organisational change and its extent was influential in generating these discrepancies. They also highlighted how the differences between organisational agendas, structure and service provision were visible through the goals being set, thus stating that:

‘while goal statements may be reflective of client expressed need and the client/service provider relationship, the data indicate that goal setting may also be understood as an organizational activity embedded within unique
Simpson et al. (2005) therefore suggest that goal setting can be, and is, utilised differently by differing organisations. Goal setting can be manipulated, moulded to fit with a given set of organisational aims. The flexibility of goal setting therefore may explain the longevity of its use. Simpson et al. (2005) do recognise however that other factors could have accounted for the differences they saw, including the severity of individual patient impairments, professional background and experience of individual clinicians and their relationships with patients.

Simpson et al. (2005, p.902), citing Kuipers et al. (2003), theorise that goal setting is ‘representative of the interface between the organization/service provider and the person with ABI.’ Similarly, Alve et al. (2013, p. 156) highlight that planning processes, more specifically patient participation in treatment plans (including goal setting) can provide a focus for interactions between patients and service providers, becoming a tool to facilitate ‘collaboration between the client, public services, and different service providers.’ Simpson et al. (2005, p. 902) also suggest that the governance, accountability requirements, the expectations of funding bodies and the pressures they place on organisations heavily influence goal setting practices. They discuss an array of potential uses of analysing and tracking patient goals for organisational purposes, suggesting that goals provide ‘a means for benchmarking, moving beyond audits of ‘activities’ or ‘occasions of service’ to examine the content of issues addressed in rehabilitation service delivery.’ They also consider how looking at goals set over time can be set against the goals of the organisation, their ethos and aims.

Stilwell et al. (1998) raise how benchmarking through goal setting allows services to evaluate themselves and compare themselves against other services and organisations. Whether this is for quality control, service development, market driven reasons or any others, is not stated. Wressle et al. (1999, p. 80) citing Swedish Health and Welfare regulations however do make a direct link between goal setting
and measuring service quality stating that ‘[q]uality can be defined as the degree of goal fulfilment.’ However, governance and accountability requirements ‘creates tensions for the goal setting process’ (Simpson et al. 2005, p. 902) in particular because they move away from the moral aims and discourse surrounding this technology – that of patient centred practice.

3.4.4.3 Goal setting as a performative technology to evidence patient involvement

As highlighted in the opening of this chapter and subsequently demonstrated, there is limited evidence to suggest that goal setting is clinically effective in neurological rehabilitation and goals are much ‘more than statements of client-expressed need’ (Simpson et al. 2005, p. 902), serving team, individual professional and organisational agendas. It would seem therefore that goal setting has a primarily performative function, being used as a means through which to demonstrate ‘gold standard’ rehabilitation in a variety of ways, rather than to achieve the best clinical outcomes.

One key aspect of ‘gold standard’ rehabilitation that goal setting aids to perform and make visible is that of patient centredness and patient centred practice. Patient involvement in goal setting is presented in the literature as one way (if not the primary way) of enhancing patient-centeredness in rehabilitation contexts. The idea that goal setting performs patient-centredness is supported by the work of Barnard et al. (2010, p.247) who conducted conversational analysis of the patient/professional interactions within multidisciplinary goal setting meetings. They consider that the goal setting meeting ‘represented a kind of participation’, and had a role in performing participation even though ‘the concept of participation is actually rather loose’ and significant collaboration between patient and HCPs was not shown to be the case in practice. The mismatch between the rhetoric of patient-centredness and the practice reality finding is also supported by Hammell (2013). Multiple studies highlight how professionals remain committed to a participatory agenda but Levack et al. (2006) highlight that there is not always explicit recognition that goal setting is utilised for multiple purposes. While ‘there is a genuine desire to focus on what matters to the individual […] this may be constrained by the
organizational culture’ (Bright et al. 2012, p. 1002). In practice health care practitioners have been repeatedly shown to employ strategies to modify goals whilst upholding the appearance that collaborative decision making has occurred (Maynard 1991; Barnard et al. 2010). Goal setting therefore is also a technology which enables professionals to demonstrate and make visible patient participation within both their own individual practice and the rehabilitative service as a whole whilst retaining overall dominance and control in practice (Gwyn and Elwyn 1999; Levack et al. 2006; Barnard et al. 2010).

Tennant (2007) highlights the importance of measuring and evidencing ‘person-centredness’ in rehabilitation and McPherson and Siegert (2007) highlight the central role that goal setting and the measurement of goal attainment plays in achieving this. But why is demonstrating person-centredness so important? First, as highlighted earlier, there has been a significant rise in patient involvement in both their own care and in seeking and ensuring lay participation in service planning, provision and research - which now forms the central tenet in many contemporary policies. Second, the focus on increasing and ensuring patient participation in decisions about their own care, goal setting and health and social care services more broadly is considered to be ‘right morally’ (Evans 2012, p. 653). Cott (2008) highlights that there is a moral discourse which exists surrounding patient involvement. As collaborative goal setting is, in theory a person-centred practice, or at least a process through which person-centredness can be performed, I argue that collaborative goal setting has therefore become, in part, a moral practice.

Goal setting’s link with ‘person-centred care’ positions it safely within the contemporary and popular participatory and involvement discourses and may also explain the maintenance of its centrality in rehabilitative practice guidelines. Considering the extensive and ongoing critique that much lip service is paid to service user involvement and patient centredness, practising collaborative goal setting may serve to protect rehabilitation services against a non-participatory critique, acting as a mechanism through which both person-centredness and the moral practice of service user participation is performed, made visible and subsequently evidenced for
multiple purposes, e.g. to fulfil governance requirements (i.e. the care quality commissions ‘Essential Standards’ 2010). This is important within the current socio-political and financial environment of contemporary health care services – a period of rising health care needs due to many factors, including an ageing population and a period of austerity, privatisation and the development of a health care marketplace in England (and to a lesser extent Wales, Scotland and Ireland), subsequent contractual agreements and commissioning are driving levels of accountability and competition between services (Peate 2013). In this context, goal setting (one part of delivering a ‘gold standard’ rehabilitation service) becomes a mechanism by which service quality and accountability (Levack et al. 2006) can be demonstrated to external funders or stakeholders. The financial pressures and the need for rehabilitative services to prove both cost effectiveness and person centredness is discussed by Turner-Stokes (2007, p.1021) who states:

> it becomes important to be able demonstrate the cost-efficiency of rehabilitation at the same time as addressing the person-centred goals that we know to be important. If we cannot convince purchasers that rehabilitation is a cost-efficient option – they quite simply will not buy services.

How these tensions play out, impact and whether or not they are visible in day-to-day rehabilitation practices will be addressed by this thesis.

### 3.4.4.4 Patient/professional interactions in goal setting meetings

The types of goals set, the level of involvement (or not) of patients and families, the multiple purposes goal setting fulfils and the evidence regarding its clinical effectiveness has predominantly been under scrutiny so far, but there is also a growing interest in the actual multidisciplinary goal setting meeting itself, and more specifically, the interactions that occur between HCPs, patients and families attending it (e.g. Monaghan et al. 2005). The study of these interactions has been conducted with a view to better understand how goal setting and collaboration in goal setting is done (Barnard et al. 2010). Looking at this research aids to further illuminate how goal setting is utilised and the mobilisation of and achievement of the motives highlighted previously is achieved.
Discrepancies between the choice of goals and expectations regarding achievability between patients, families and professionals or the multidisciplinary team are repeatedly highlighted in the neurological rehabilitation literature (e.g. Bloom et al. 2006; Stein et al. 2003). Patients’ own goals are repeatedly framed with the potential of being unrealistic and requiring modification by the therapeutic team (Levack et al. 2011), especially in relation to patients with brain injury, due to lack of insight or awareness of their impairments (Prignato and Schater 1991; Fischer et al. 2004). Goal setting in practice therefore is widely understood as a process of negotiation between the treating team, patients and families (Slade 1994; Wade 2009; Levack et al. 2011) with the identification that patient/professional collaborative decision making often involves a number of key persuasive tactics (Karhila et al. 2003; Pilnick and Coleman, 2003).

This process of negotiation and tactics of persuasion are illuminated by the work of Barnard et al. (2010) who audio and video recorded six multidisciplinary goal setting meetings in a neurological rehabilitation unit in a London hospital and found that patients’ own wishes were rarely translated directly into goals and that the goals identified by patients were modified predominantly by the professionals present. They highlight how goals were modified heavily until they were deemed appropriately achievable by the team and identify six strategies enlisted to achieve this (Barnard et al. 2010). Professionals frame goals not in the long-term but around the admission time frame ‘thus enabling modification of a goal without denying the possibility of its eventual achievement’ Barnard et al (2010, p. 246). They identify that HCPs ‘presenting information in a step-wise fashion’ is both ‘designed to elicit agreement’ but also indicates to the patient ‘that the goal is essentially non-negotiable.’ The goal setting process is further controlled by HCPs by collaborating with one another to move on to the next goal to close down difficult conversations where the goal of the patient and health care professional may differ (Barnard et al. 2010). In Barnard et al’s (2010) research patients also demonstrated an awareness of the achievability requirement of goal setting by moderating their own more ambitious goals themselves. At times however they resisted making goals realistic or achievable and used humour when perspectives differed significantly between
them and the team in a way that that researchers interpreted was in order to ‘save face’ (Barnard et al. 2010, p.246). When patients resisted the SMART goal setting aims, this triggered a clinically reasoned response by professionals. Patients did achieve some control over goal setting however by raising practical difficulties with proposed goals (Barnard et al. 2010).

3.4.4.5 The negative impacts of goal setting

Despite the recognition of the limitations of empirical evidence underpinning goal setting and the discrepancies in patient involvement set against participatory ideals, goal setting remains to be presented as a positive and useful process for patients, professionals and organisations. There are however several papers that discuss potential negative impacts and consequences of goal setting for rehabilitating individuals. These include Conrad et al. (2010 p. 432) who suggest that motivation of a patient to participate in rehabilitation is dependent on ‘concurrence between the treatment goals and the participant’s life goals.’ Therefore, the prioritisation of goals and constant team modification of goals to fit the SMART model may lessen focus on patients’ own life goals - preventing the individualisation required in rehabilitation to improve patient quality of life, a concern raised earlier in the chapter.

3.5 The role of goal setting in shaping futures

This review of the literature identifies many tensions emanating from clinical and organisational sources, patient-professional interactions and the current political and economic landscape which suggest limits/barriers to and influences of the way in which goals are set with and for patients with neurological conditions (in particular, those with brain injuries). In the final section of this chapter, by reflecting on the literature and analysis, so far I question the temporality of this process.

As highlighted earlier, establishing the potential for change for patients with brain injuries, what changes are and are not possible and their likelihood is critical before setting goals, which, if adhering to the SMART model, must be achievable (Wade 2009). Goals therefore are based not on what might be but on what is already known.
or can be predicted within a high level of certainty. There is also recognition within
the literature following ethnographic work, that formal goal setting processes tend
to focus on short-term goals (Conrad et al. 2010), with goals often framed within the
rehabilitative admission period (often days and weeks not months or years) and not
beyond (Barnard et al. 2010). Setting predominantly short term goals could be seen
as a tactic used by HCPs to ensure that goals are achievable but also ensure a focus
on key functions that are more likely to resolve quickly and that enable safe discharge
from hospital or the rehabilitation setting. This often means therefore that physical
goals are privileged (as highlighted by Levack 2011) and may explain why psycho-
social goals are often omitted – because their ‘Timed’ component is beyond that of
days or weeks (and as highlighted previously, they are also difficult to measure). Goal
setting is then arguably set within a temporal frame of an ‘extended present’, rather
than being future orientated.

As highlighted above, goals set are those which are deemed to be achievable for the
patient and therefore likely to be attained. Research suggests that larger or long-
term goals are immediately broken down into smaller ones, with a step by step
approach taken to goal setting and rehabilitation (Barnard et al. 2010). Does the
setting of goals then serve to help manage uncertainty in a situation of high
uncertainty? This is particularly relevant in the case of severe brain injury, where
recovery and eventual outcomes are unknown and difficult to predict (Owen 2008;
Lingsma 2013; Turgeon 2013). Could such a step by step approach enable and
generate a continual focus in the present which prevents patients and families
looking too far into the future - where uncertainty cannot be managed? Could goal
setting then be a technology utilised to manage uncertainty through this temporal
compression? If so, goal setting would again be a process which helps set and hold
rehabilitation in an extended present rather than the future. If this is the case, could
achieving this be helpful? Could these goal setting strategies provide a sense of
control for patients and families as some level of certainty is restored? Does ensuring
parity between predicted outcomes and achieved outcome build or restores trust
between team, patient and family?, or is such a step by step approach merely the
solution to the problem of measurement?
I have suggested that goal setting is a technology, used to fulfil a plethora of purposes other than achieving the best clinical outcomes for patients. Most notably I suggest that goal setting is a way through which person-centredness is ‘performed’ and person-centred care is demonstrated which in turn enables rehabilitation teams to prove they deliver a high-quality service. I consider that goal setting can also be used as a tool to enable the disposal of patients from acute settings into the community and to manage relations between HCPs, families and patients. I discuss more broadly how goal setting fits with and can be manipulated to aid the achievement of organisational aims – some of which I identify above. I have discussed at length what the SMART goal setting model of goal setting makes visible and what it marginalises – illuminating how ‘the problem of measurement’ is both solved and made through the goal setting process.

Despite the centrality of goal setting in neurological rehabilitation what it achieves remains uncertain and relatively unexplored in relation to patients with severe brain injury. How the issues raised here influence and play out in practice, how they impact day-to-day working practices in neurological rehabilitation settings and subsequently the care, treatment and futures of people with severe brain injury is also unknown. I have suggested that goal setting could contribute to managing uncertainty in rehabilitation but in doing so might screen the future out of the goal setting process. To what extent these considerations have importance, presence and relevance to how futures of severely brain injured patients are shaped during their rehabilitation will be asked of the data collected (which is detailed next) and addressed in the findings of this thesis.
Chapter 4 - Methodology

4.0 Chapter Overview

This chapter explains the methodology and conduct of this ethnographic study. Examining existing examples of ethnography in the field of brain injury neurological rehabilitation and related areas, I locate this study methodologically in the broader literature. In doing so I highlight how there is both precedent for ethnographic work in this area, but also significant gaps, which this project helps to address.

I discuss the choices of methodological approach and study design and acknowledge the pros and cons of these decisions and explain how ethical considerations both led and shaped the design. I discuss the key methodological challenges and successes, in-particular focusing on my own status as a ‘native ethnographer’ and hybrid researcher, and reflecting on the inclusion of people with severe brain injury and those who lack capacity to consent on their own behalf.

4.1 Aims and research questions

This research studies the interactions between patients with severe brain injuries, their families and HCPs within neurological rehabilitative institutional settings and the organisational practices within these places. It focusses on the role that time, and more specifically the role the future has in rehabilitative processes and relationships. Examining how patients, families, and HCP’s think and talk about the future (or not) and how time and the temporal organises and influences actions, this PhD explores how future orientated concerns are shaped by, or shape, interaction and rehabilitation. In particular, it seeks to establish how relationships between patients, their families and HCPs are mediated by understandings of time and the future and how the future of the patient is shaped through the rehabilitation process.

As highlighted in the introduction of this thesis, this research addresses two key questions:
1) How are the futures of people with brain injury shaped and negotiated through a) day-to-day interaction and b) organisational process and practice?

2) What role does ‘time’ play and ‘the future’ hold in the development and mediation of relationships between patients with brain injuries, their families and HCPs during rehabilitation?

The importance and relevance of these questions and the approaches taken to this research were considered in consultation with family members of people with SBI, HCPs and representatives working in social services and public services.

4.2 Research consultation

Within healthcare, there has been a drive over the past fifteen years to involve and consult with patients and the public ('Public, patient involvement') throughout the research process, as a mechanism to improve eventual impact and develop better grounded research studies. This sits alongside the Research Excellence Framework impact agenda where the impact of research on non-academic audiences is now a major element within the measurement of the quality of research – and has a direct effect on how universities and units of assessment (e.g. subject departments, schools, etc.) are funded. With both these contemporaneous topical and developing areas of research practice and policy and with a REF year coinciding with the beginning of this thesis, there has been careful consideration of and a commitment to public engagement and potential for impact throughout the design of this doctoral research, its conduct and the ongoing dissemination process. Therefore, an extensive consultation process was conducted to inform the research design.

4.2.1 The consultation process

The stakeholders of this research include patients, their families and healthcare professionals, health care managers in both the NHS and independent sector, commissioners and related charities.
Three types of consultation activity were carried out:

1) 1:1 consultations with individual stakeholders
2) a consultation with a multidisciplinary specialist health professional team
3) an evening consultation event

I met face-to-face or spoke over the phone with ten individual ‘stakeholders’. These included family members of people with severe brain injury, paid carers and health care professionals with experience of working with or whose work was connected to the rehabilitation and long-term care of people with severe brain injuries. I also spoke with seven members of a local health care professional team who specialise in the care and rehabilitation of people with brain injuries for an hour in their workplace. I told each individual and the group about my research, asked them if they felt there was a need for my research and if it was important, what they felt were the main issues in the area, how they felt I could best involve people with severe brain injuries in my research and other questions specific to my research concerns. Individual consultations lasted between 1 and 2.5 hours each.

I also organised an evening consultation event and invited a range of stakeholders to attend. 15 people including health care managers, members of the public and health care professionals attended. The evening was devoted to discussing in more depth and expanding on issues which had arisen during the 1:1 and team consultation. I also asked attendees their thoughts and views on more targeted areas which I felt may be important in my research and invited them to consider the practical challenges I may face during access and data collection and advise me on ways to overcome potential problems.

The event was held at a local hotel that was accessible to those attending. I secured free room hire and support from the ESRC Wales DTC for costs of food and drinks which I used as an incentive for attendance. The event was scheduled to last two hours but actually lasted over 5 hours.
4.2.2 How the consultations impacted the research

Consultees supported both the key research area and reinforced the importance of the research questions. Consultees all felt that research which looked at the care and rehabilitation of people with severe brain injuries was an important area of work. Most commented on the need for research which focussed not just on the initial acute or post-acute stage following brain injury and looked beyond, to the experience of rehabilitation and care over the longer term was key. They instantly linked patients’ relationships with professionals and families as critical to either positive outcomes for patients or conversely, hampered progression. They felt that looking at staff, patient and family relationships within these situations was critical and were forthcoming in sharing their experiences and often frustrations with either the difficulties they faced working with patients, with one another or with families.

Staff and family consultees quickly picked up on the need to focus on staff-family relationships. Recounting both positive and challenging relations they had had with staff or with families, consultees reflected on the complexity of these relations and expressed a need for improved understanding of one another. Most consultees offered immediate thoughts about what causes relational tensions including the potential mis-match of professional and lay understandings, responsibilities and viewpoints and pondered on the impact of broader social debates around death, dying and disability and the role of the media in setting expectations about recovery.

The consultations were influential in the way in which the research was designed and enacted. Consultation provided evidence for and demonstrated that there was both an interest in and a need for this research. All consulted expressed that they felt the inclusion of people with brain injuries was important – they felt this for a range of reasons including – they felt that people with brain injuries often lacked voice, in that they were often excluded from research conducted on not with them and that what they had to say and offer could be insightful – ‘they might have a lot to say’. One professional noted that she felt the research had a place in promoting good
communication with brain injured people. This was particular important in the supporting of the research ethics application.

Consultees were asked how the voices of people with brain injury could be best collected and how best to involve them in the research process. Most consultees identified that the inclusion of people with multiple and varied impairments would be challenging and that a singular method or approach would not work nor be appropriate. Consultees spoke at length about communication aids, creative ways of enabling expression and referred to the variety of sensorial ways of knowing. They talked about the use of communication aids, pictorial talking mats, ‘emotion’ faces and reflected on innovative or unusual ways in which patients they had worked with in the past had expressed themselves and the way they felt.

On asking one woman how best to and the importance of including people with severe brain injuries in the research she said ‘by any means possible’. This quote/comment, reinforced and reminded me of both the need for and the importance of taking a tailored approach to working with people with brain injuries and to move away from attempting any singular approach.

4.3 Methodological approach and design

4.3.1 Ontology and epistemology

Due to the restraints of a PhD study, following people prospectively from a time now into a future of consequence over several years, was not possible. This study therefore has investigated how the future comes into the present, or is bracketed out of experience and action taken in the now. It considers the implications of whether or not the future is present in the interactions between patients, families and health professionals, the actions they and others take, and what that means for the lives of those with severe brain injuries.

Exploring the intangible concepts of futures and temporality and how they shape lives and work in neurological rehabilitation settings, immediately removes some
ontological precepts and methodological approaches and foregrounds others. Exploring social time and interaction between multiple actors requires an approach which accepts the multiplicity and relativity of realities. Interpretivism rejects a singular and external reality, foregrounds perception and experience and accepts these as reality for the sensing individual subject or social group (Williams 2000). An interpretivist approach was therefore selected for this study.

Recognising the reality status of perception and experience and how these shape social action is critical in the understanding of the socially constructed worlds of brain injury rehabilitation settings – and therefore how the futures of people with severe brain injuries are made. The lived experience shapes social action because ‘[p]eople act on their individual perceptions, and those actions have real consequences – thus the subjective reality each individual sees is no less real than an objectively defined and measured reality.’ (Fetterman 2010, p. 5). This study explores both the experience and perception of patients, families and health care staff but also the interactions between them and the organisational structures within which they work. Interpretivism enables the adoption of methods which enable the researcher to capture and make sense of meanings in human interaction (Carlson et al. 2001; Black 2006).

This research study, its questions and aims, have been informed by the clinical experiences of the researcher as a neurological physiotherapist and health care manager. Knowledge of the setting type and context of the research ‘problems’ was therefore held prior to the commencement of the study. Exploration of the problems posed are complex and multiple in that they involve multiple groups of actors and the intangibility and nebulous notion of time. Therefore, taking a positivist approach and fixed research design was viewed as insufficient to illuminate the phenomenon under study. I entered the field with prior insight of the research setting and phenomenon, which fits with the description Hudson and Ozanne (1988) give of the ‘interpretivist researcher’. They explain that the interpretivist researcher adopts an emergent and collaborative approach to data collection and the development of new knowledge, remaining open to new knowledge and ways of knowing throughout the
study. She allows the development of understanding with and through interaction with research participants. An interpretivist approach both enables and illuminates recognition of the changeability and adaptability of social realities and that knowledge is and can only be gained in time and context bound situations. This doctoral research was conducted with the three key elements described above by Hudson and Ozanne (1988) as ‘interpretivist’ – prior knowledge held by the researcher, an emergent and collaborative approach to knowledge generation and the recognition that ‘knowledge’ is time and context bound.

4.3.2 The importance and challenge of seeking multiple perspectives

This study sought to capture the experiences and perceptions of all contributing to the triad relation existing in neurological rehabilitation – between patient, family and health care staff. This triad grouping is based upon my experience as a health care professional and relates to those most visibly present around the bedside and those involved in decisions about care. Incorporating accounts of both the carer and the cared for in singular studies is noted as largely devoid from health care research (Henderson and Forbat 2002) and medical sociology. However, the concurrent gathering of multiple perspectives in the study of care relationships provide an important means of triangulation and hold the potential to provide a strong theoretical contribution within qualitative work, for example between patients, carers, and professionals (Henderson and Forbat 2002).

To explore the environments within which brain injury rehabilitation is taking place, the interactions that occur during the rehabilitative process and the practices which make it up, a range of qualitative methods were required. The inclusion of diverse groups of people required an approach which offered significant flexibility. The methodological approach suitable and flexible enough to address these aims is ethnographic.
4.3.3 What is ethnography and how has it been used in the study of health, illness and medicine, and in the study of time?

Ethnography can be defined as ‘participating, overtly or covertly, in people’s daily lives for an extended period of time, watching what happens, listening to what is said, asking questions — in fact, collecting whatever data are available to throw light on the issues that are the focus of the research’ (Hammersley and Atkinson, 1995, p. 1). Although this definition highlights the scope and potential of ethnography in terms of its breadth, what ethnography also offers is the opportunity for gaining deep and nuanced understanding of a phenomenon. This occurs because ethnography offers the opportunity for the researcher to observe the cultural understudy over time and within its immediate context. It is this that underpins the choice to use ethnography in this study.

Ethnography is a core research approach and methodology within the disciplines of anthropology and sociology, with an extensive history in the exploration of the social make-up of medical institutions and individual medical and allied health professions and their work. For example, Goffman (1961) conducted an ethnographic study of a psychiatric hospital which illuminated the regulatory behaviours and formation of social roles of patients and staff and made a significant contribution to the eventual ‘de-institutionalisation’ of psychiatric care. Similarly, Roth (1963) utilised ethnographic methods in his study of tuberculosis hospitals. A tuberculosis patient himself, he diarised his experiences. Once recovered, he conducted participant observations working as an employee and later carried out overt observations at two further tuberculosis hospitals. Roth’s (1963) publication from his study focuses on the routinisation of this environment and how ‘time’ and timing organises the keeping and discharging of patients.

In the exploration of the construction of medical work, Atkinson’s (1995) ethnography explored, among other things, the ‘medical talk’ of haematologists, highlighting how the interaction between doctors constructs medical knowledge. Ethnography is also an extensively used methodology within the study of the work of
nurses. For example, Lawler (1997) conducted an ethnography of palliative care nursing. Her work focusses on describing the ‘dirty work’ undertaken by these nurses, exploring the hidden nature of managing leaking bodies. Latimer’s (2000) ethnographic study of the ‘conduct of care’ on an acute elderly medical ward demonstrates how nurses organise ward life, and the role ‘technologies’ play in organisation.

Ethnography has also been used to study the construction of illness and the impact of ill health upon ‘self’. For example, Mol (2002) conducted an extensive ethnography in hospitals in the Netherlands. Instead of sitting by the bedside or following specific professional types, Mol observed diverse fields where the condition of atherosclerosis manifests – as symptoms for the patient, as medical work for doctors, as the focus of diagnostic and radiographic investigations. In doing so she was able to explain how the condition of atherosclerosis is constructed through multiple means and different sites. Bury (1982) used ethnography, spending time with rheumatoid arthritis sufferers, to illuminate the impact of ill health upon narratives of self. His concept of ‘biographical disruption’ as defined in chapter two, experienced by those whose illness alters their perceptions of self has made a significant contribution to the understanding of patient experience.

Ethnography’s role within health care based research has been described as being able ‘to illuminate, understand and ultimately interpret and present a range of perspectives – patients’, carers’, practitioners’ and commissioners’’ (Sharkey and Larsen 2005, p.186). Ethnography has therefore also been selected as this research aims, in part to do exactly that – to explore the experiences of patients with brain injuries, their relatives and healthcare professionals. Aiken (2010, p.96) argues that it is crucial that methodologies chosen to research relationships ‘reflect and refract the nuances of people’s shared lives and their complexly negotiated stories.’ Ethnography is described as having ‘powerful potential for uncovering the dynamics of relationships and behaviours in social settings’ (Sharkey and Larson 2005, p. 186) and therefore fits with another key element of the research – seeking to understand the relationships between the three groups. Alongside highlighting nuances in
relationships, ethnography is described as being able to identify what goes unspoken, tacit understandings and make visible unspoken rules, values of social interaction and organisation (Watts 2010). Illuminating the ‘unspoken’ and the tacit is critical in the context of rehabilitation where multiple knowledge types are at play through the crafts of multiple professions i.e. nursing and physiotherapy which sit alongside medicine and the understandings and practices of those who ‘care’ but have no named ‘profession’.

Despite the popularity of ethnographic studies in the 21st century study of the health care arena, demonstrated by the development of multiple hybrid journals such as Qualitative Health Research which boast multiple ethnographic studies of health care (e.g. Smith and Gallo 2007, McGibbon et al. 2010, Rosigno and Swanson 2011), many of which are conducted by practitioners, or those with healthcare backgrounds, the use of ethnography to examine rehabilitation is limited.

4.3.4 Time and ethnography

The use of ethnographic methods to explore ‘time’, the social construction of it and lived experience of temporality is much more extensive than the limitations of its use within rehabilitation., as highlighted in chapter 2. For example ethnographic studies with temporality at their core, have been used to explore energy biographies (Groves et al. 2016), the politics of urban design and promise of ‘regeneration’ (Davis 2011;2014;2016), environmental policy and sustainability and experience of winter flooding (Butler 2008), alongside experiences of health and illness such as cancer (Adam 1998, Harris 2015), nursing organisation (Waterworth 2003), the effects of time based therapies, such as reminiscence therapy (Okumuru et al. 2008; Baillon et al. 2004; Blake 2013) and effects of shared reading in eliciting reminiscence and allowing people with dementia who are often ‘stuck in the past’ be present and in the present (Billington 2012). The use of the interview in this work is dominant, although extensively adapted, and the use of observation far less prominent. The work of Allen (2014) and Kaufman (2006) however, is of note as both utilise observation extensively and over time to illuminate the centrality of time and
temporality in organisation of care work and hospital organisation. However, the use of observation to illuminate temporal issues within healthcare is underexplored.

4.3.5 Methods of data collection used in ethnography

As highlighted by Hammersely and Atkinson (1995), ethnography enables the collection of wide ranging and multiple types of data. This in turn means that the conducting of ethnography can also encompass multiple methods of data collection. Traditionally however those using an ethnographical approach have utilised two main methods – observation and interview. These two core ethnographic methods are continued to be used in their traditional sense, but have also been developed and modified extensively over the last 40 years. Charting these changes is beyond the scope of this thesis but, to provide brief examples, observational work has been developed to include observation and analysis in the digital arena, probing into online worlds (Dicks et al. 2005;2006), and has evolved to utilise the whole sensory experience of the ethnographer and participants under study. The work of social anthropologist Sarah Pink is of note, making extensive contributions to the development of visual and sensory ethnography (Pink 2001;2009), which considers how data is and can be collected by the ethnographer through the full range of senses available – i.e. smell, touch, taste as well as vision and audio and encourages ethnographic researchers to pay attention to the ‘sensorality’ of the social world.

Similarly, the development and modification of ‘the interview’ in ethnographic research has been extensive. The development of elicitation techniques within interviews is of particular note. For example, the work of researchers using ‘photo’ elicitation (e.g. Wells et al. 2013; Justesen et al. 2014), and the introduction of other techniques such as word sorting, button arranging, and other creative activities have been used to elicit participant response and work with particular groups of people, including those often considered ‘hard to reach’ or ‘marginal’ (e.g. Pélicand et al. 2006; Gillies and Robinson 2012; Kramer-Roy 2015; Mooney-Somers et al. 2016).
The ethnographic methods selected for data collection for this thesis were largely traditional in that they consisted of participant observations and semi-structured interviews. These methods are a staple for the social science researcher and as demonstrated earlier, have a long history of use within institutional settings. These methods also stand the test of time because of their flexibility to meet the needs of researchers seeking to explore an ever-changing social world.

4.3.5.1 Semi-structured interviews

Alongside non-participatory observations, semi-structured interviews were employed. Semi-structured interviews are a type of interview where the interviewer asks a small number of open questions, encouraging a narrative response from the participant. Interviews, as discussed above hold the ability to be flexible, this was critical for both the involvement of people with severe brain injuries and also enabled interview schedules to be developed and connected to the observations of the setting. For example, interviews could be modified and reference made to specific happenings in the setting already observed and to site specific context that was meaningful to participants. Semi-structured interviews thus enabled further exploration of and offered the potential for deepening and broadening understanding of what had and was being observed.

The combination of non-participant observations and semi-structured interviews was chosen both for the suitability in studying interactions, every day practices and multiple perspectives (experience, practice and action), but also for the maximisation of the inclusion of people with severe brain injuries. In this doctoral study methods were not adapted to meet the needs of the study or for ‘methodological development’, but to meet the needs of those being studied. The involvement of patients in this research, the approach taken and how methods were adapted is returned to later and discussed in detail in section 5.5.3.
4.4 Locating and differentiating the study methodologically

4.4.1. Brain injury, rehabilitation and ethnography

Qualitative research which examines brain injury rehabilitation tends to be either interview based, for example Jumisko et al. (2007b) who explore the experiences of brain injured people and their relatives by those outside of health care services. Research examining perceptions of rehabilitation, rehabilitative processes, clinical or therapeutic interventions is also predominantly interview based. Clinician views, family involvement in and the effectiveness of goal setting has also been thoroughly examined through interview (Levack et al. 2006; Levack et al. 2009; Alve et al. 2013) as has patient understanding of rehabilitation (Gill et al. 2012; Cott 2004). These studies focus on the care and rehabilitation of people with mild-moderate brain injuries, or at least those who are able to converse. The traditional social science ‘interview’ however quickly becomes inappropriate and unusable for people with severe brain injury. Those who may struggle to concentrate, be unable to verbalise, those who may use gestures or communication aids to ‘speak’ or those who are unable to ‘communicate’ consistently in any way are excluded from study where methods rely on ‘speech.’ To enable the inclusion of severely brain injured people requires a different approach.

There are a small number of brain injury rehabilitative studies which utilise observation – work which tends to focus purely on the recording and examination of health care professional team meetings (e.g. Barnard et al. 2010; Ferguson et al. 2009) or is focus group based, with this method being utilised to explore the experience of impairment, therapy or care again with those brain injured patients who are able to converse (e.g. Cott 2004). There are a range of ethnographic studies internationally which explore long-term care facilities caring for people with physical and cognitive disabilities, notably Morrisey (2012) and Muenchberger et al. (2012). Both these authors argue the importance of the inclusion of residents in research about them, yet still rely on semi-structured interviews. These studies also focus on the care and experience of people with intellectual disabilities, those who were born
with development disabilities, or for those who sustained hypoxic brain injury during birth and not those who sustained brain injuries as adults - who form the focus of study here.

Similarly, there is a vast literature base which examines the care, business, resident and family experience of those in residential and nursing aged care around the world using ethnographic methods (interview and/or observation) (e.g. Friedmann et al. 1997; Hertzberg et al. 2001; McGilton 2002; Hubbard et al. 2003; Galvin and De Roiste 2005; Lagacé et al., 2012). However, in contrast, there are only a small selection of ethnographic studies exploring adult brain injury rehabilitation and an even smaller set of those which include observation as part of its methodology. Banks’s (2016) ethnographic doctoral study explores the reconstruction of ‘self’ in brain injury rehabilitation. However, his study is limited to the observation of and illumination of experience of those with mild-moderate brain injuries. Banks’s ethnography is also centred on rehabilitation in the NHS, whereas the location of study here, is independent sector rehabilitative care settings.

Further work exploring brain injury rehabilitation and care includes ‘prospective observational studies’ which examine goal attainment for example, such as Bouwens et al. (2009), but such studies do not include ‘real time’ observation and focus primarily on documentary analysis of patient clinical and care records and the recalling of interaction and clinical judgements from treating clinicians. Furthermore, internationally there are population studies which examine the demographics of people aged between 16-65 living in either aged facilities of other types of long-term care institution (Buchanan et al. 2003; Colantonio et al. 2010) or their care needs (Cameron et al. 2001).

Banks (2016) notes the paucity of ethnographic research in brain injury rehabilitation as he locates his own study of moderately brain injured people in NHS rehabilitative settings, and Twigg (2011) notes a lack of observational work in relation to ‘body work’ which gets behind doors or curtains and is privy to ‘dirty work’. This
ethnography examines much behind the curtain care, behind door happenings and much of the life that is marginal in independent neurological care settings.

4.4.2 Families of brain injured people and ethnography

Similarly, in the investigation of the experiences of family members of those with a brain injured relative, the interview (Jumisko et al. 2007a; Kitzinger and Kitzinger 2012; 2014a; 2014b; 2015), questionnaire (Marsh et al. 1998; Chiambretto et al. 2001; 2010) or examination of psychological objective measures (e.g. Rivera et al. 2007; Leonardi et al. 2012) have to date largely been the methods of choice, with the occasional study utilising focus groups (Latchem and Kitzinger 2012). Several of these authors however highlight the need for ethnographic exploration (with a focus of ‘observation’) to further illuminate caring relations in brain injury rehabilitation (Kitzinger and Kitzinger 2012) or long-term care environments (Latchem and Kitzinger 2012), or medical, social and legal issues surrounding the care of those brain injured (Kitzinger and Kitzinger 2016).

The use of observation in this study therefore makes a strong contribution to the gap of observational ethnographic work in brain injury rehabilitation. It specifically makes a contribution to brain injury rehabilitation within the independent sector, issues of time, temporality and care, the observation of body work and happenings at the margins of institutional care settings.

4.5 Data collection

4.5.1 Participant or non-participant observer?

Ethnographic observations are categorised in the literature in terms of degrees of participation, as participant or non-participant (Cooper, Lewis and Urquhart 2004), complete member researcher, active member researcher and peripheral member researcher (Adler and Adler (1994). These categories refer to the extent the researcher is actively participating in or even working within the social world they are researching (Savage 2000). Tomkin (1984) would argue however that all observations are ‘participant’ as the presence of the researcher, irrespective of any
purposeful involvement within any social situation, impacts and contributes to the social milieu under observation. In the current study, observations were non-participatory, in that the presence of the researcher in the settings was solely for research purposes, and no clinical ‘hands on’ work was undertaken. This meant that the researcher had insight but was not known to the people in the setting prior to starting the research.

As a neurological physiotherapist by background and given my clinical skills, there was scope in theory, to participate in a setting and conduct ‘participant observations’ simultaneously. However, non-participant observations were selected here because I was concerned about my ability to keep an objective watchful and critical eye, while holding the many and continuous responsibilities to patients in my care. There are however many successful ethnographies such as Johnson (2015) who conducted a covert ethnography of the care of older people while simultaneously working as a care assistant. There are also ethnographic studies conducted where the researcher has done a little of both – participating in the running of facilities, for example washing up, supporting resident activities, but who report spending more time observing than participating (see Owen 2007; Morrisey 2012). For me, holding any pre-negotiated participatory role would have required a much longer period of time to collect data and would have risked compromising the depth and detail of the data collected. Being able to be present, in terms of being in the moment, focused purely on data collection and building field relations, without holding the responsibility of ‘professional’ in the setting enabled me to both capture the world under study in detail and also, enabled me to ask questions that would have been deemed inappropriate if I had held a professional role. For example, asking questions that a health care professional should know the answer to would have restricted the opportunity for me to challenge the knowable and illuminate the mundane (see chapter six).
4.5.2 The ethnographic sites – ‘the field’

This doctoral study was conducted at two independent sector neurological rehabilitation and long-term care settings in England that I have called ‘Bracken Lodge’ and ‘Goodleigh Hall’. These two sites were selected because they differ from one another but at the same time are representative of these types of care facilities in a number of ways. First, the type of corporate ownership differed between the sites. Neurological care centres within the United Kingdom are predominantly owned by either 1) lone entrepreneurs who own 1-2 care centres, 2) medium size companies who own a series of care centres which provide a range of rehabilitative and long-term care services only for people with neurological conditions, or 3) large corporations who may also own other types of health care settings other than neurological centres, such as Independent hospitals. One of the data collection sites was originally developed and owned by entrepreneurs but at the time of data collection had just been taken over by a medium sized healthcare company which owns and runs multiple neurological care centres in the UK. The other site is owned and run by a small corporation who have several neurological care centres and are planning further growth in the sector.

Second, the patient type was both similar, different and representative of the types of neurological patients cared for in neurological care settings in the independent sector. The type of neurological long-term care and rehabilitation settings care for people with a range of different neurological conditions but often with brain injured

---

21 Neither data collection site were known to me through my previous clinical work and employment in the independent sector. Initially I selected two potential sites, ‘Bracken Lodge’ and one other which would be possible to commute to from either my own or my parental home. I made contact with the managers of the centres initially via email. Access negotiations progressed well with Bracken Lodge and with the other site where an access agreement was written and agreed by the Medical Director. However, a few weeks before the commencement of data collection I was informed that the Director who had initially agreed my access had left the company. His replacement challenged the validity of the Social Care Research Ethics committee, who had granted ethical approval for this study as he was unfamiliar with its equal standing to NHS ethics committee. Although ethics concerns were resolved, email communication from the new director was tense, as was access visits to the site. Considering the eventual aim of this doctoral thesis is to improve caring relations, I did not want to contribute to tensions in relationships in these settings and suggested that it was neither in the sites best interests, nor mine for me to conduct data collection there. I then contacted Goodleigh Hall, explained the situation and was granted access thereby company directors following support from the site’s clinical services manager.
individuals making up the largest patient population within a setting. These places of care tend to differ in that they have some form of ‘specialism’ and admission criteria however, with a focus of the level of or type of impairments patients have. Both Bracken Lodge and Goodleigh Hall care are similar in that they care for people with brain injuries and other neurological conditions. They differ in that Bracken Lodge specialises in the rehabilitation of people with challenging behaviour following brain injury and has a smaller number of patients with severe physical impairments and in contrast, Goodleigh Hall specialises in caring for people with profound and multiple physical impairments, including those in disorders of consciousness, while also caring for a smaller number of patients with challenging behaviour, progressive neurological disorders and mental health problems.

Third, the size of the setting differed. Neurological care settings in the UK vary dramatically in size, from small units caring for 10-15 patients, to centres with up to 120 patients. Bracken Lodge cares for around 30 patients and Goodleigh Hall cares for around 70 patients. Finally, the location of the centres differed. The location of neurological care centres in the UK vary dramatically. Some sit next to private hospitals owned and run by the same company, others are in housing estates/residential areas of towns or cities, in the centre of towns, on estates on the fringes of towns or in the countryside. Bracken lodge is situated in a residential area in a suburb of a large English city and Goodleigh Hall sits just outside of an English town.

Although a singular in-depth case study of one site could have been selected for this study, the decision to conduct the ethnography across two sites was taken primarily to aid the preservation of participants’ confidentiality and anonymity. These types of care facility are, in comparison to other types of care facility (such as hospitals or care homes for the elderly) relatively small in number and there is therefore greater opportunity for identification of both place and people. The selection of two sites, but no more than two was taken because it takes significant time to establish relationships within the field and these places of care are significant in size and inhabited by many people. Researching any more than two sites would have
impacted upon both the depth and the quality of data collected. Quality may have been impacted because less time in each place would have reduced the type of access gained. For example, gaining the trust of staff to facilitate the observation of personal care took months of researcher presence and rapport building to achieve.

4.5.3 Sampling

As highlighted, this study sought to include multiple perspectives and three key groups – patients with severe brain injuries, their families and HCPs. Therefore, the initial aim for recruitment was ‘to observe and interview 10 patients and interview 10 relatives and 10 health care professionals at each research site - totalling a sample size of approximately 20 people with brain injury, 20 family members and 20 health care professionals.’ (social care research ethics submission). This number was calculated based on achieving the collection of breadth of experience of different types of staff, family and brain injured person and a number large enough to improve confidentiality. For example, in terms of staff, there are many different types of professional working in these settings – i.e. physiotherapists, occupational therapists, speech and language therapists, nurses, nursing and therapy assistants, managers etc., all of whom I hoped to include and capture their experience.

Similarly, while this PhD is focussed on people with severe brain injury, already a subset of the brain injured population, there is much variety in this ‘severe’ sub-section. I wanted to ensure breadth of experience and the variety of lives within this ‘severe’ category was captured. This has proved critical as during the analysis of key future issues and the writing of the findings chapters – a key futures issue is raised by and through the experience and lives of each type of severely brain injured person. In terms of family, the planned recruitment number was calculated based on a will to ensure inclusion of the range of family members and friends involved in lives – wives, husbands and partners, mothers and fathers, sisters and brothers, children, grandparents, aunts, cousins etc.
However, despite these plans, eight residents were included, four of which were interviewed and four of which were observed only as they were unable to be interviewed. Nine family members were interviewed and forty-nine staff. The reasons for the discrepancy in planned participation numbers and actual final numbers is discussed in section 5.5.3.

4.5.4 Recruitment of residents

Respecting and safeguarding individuals, especially those deemed ‘vulnerable’, is essential to research ethics and integrity (Daley 2015), yet there have long been concerns about the lack of involvement of people with disabilities, and the subsequent silencing of their voices, in social science research (Barnes 1996; Nind and Searle 2009; Nind 2011). Such concerns centre on those who have cognitive or speech impairments and those with profound impairments and multiple needs (Nind 2011) because of the concerns about participation and informed consent raised previously. Methodology has been one major barrier to involvement for people with cognitive and speech impairments as they can be excluded, seen as ‘difficult’ or even ‘impossible’ to interview (Hutchinson et al. 1994). Reducing methodological barriers to inclusion in social research has been extensively addressed over the past twenty years through the development of new emancipatory approaches and participatory, visual and creative methods and more recent recognition of the applicability of traditional methodologies (such as ethnomethodologies) for the purposes of enabling involvement (e.g. Boahen 2015; Jepson 2015). However, the inclusion of people with profound and multiple needs is not challenged by methodology alone; another key challenge is ‘consent’, how it is gained and handled by researchers and ethics committees (Lloyd 2013).

Many people with profound and multiple needs – including those with learning disabilities acquired brain injuries, dementia or other progressive neurological diseases lack the capacity to consent to involvement in research on their own behalf and key legislation is in place to both protect and enable these people (Parker et al. 2010). The Mental Capacity Act 2005 (MCA) in the UK has established a legal
framework for assessing cognitive capacity, a process for making decisions on behalf of incapacitated adults and conditions under which these adults can be lawfully included in research (see sections 30-34).

The use of research interviews and observation (all ethnographic and participatory methodologies) with people who lack capacity to consent on their own behalf, is included in that which is considered as ‘intrusive’ under section 30 of the MCA (Johns 2007; Jepson 2015). Under the requirements of the MCA (2005) researchers wanting to involve people who lack capacity to consent must obtain approval from an ‘approved research ethics committee’ and demonstrate that the research relates to the ‘impairing condition’ that causes the lack of capacity and/or that the research will increase knowledge of the care or treatment of people with that condition. They must also have an understanding of the Act’s principles and its Code of Practice and be able to demonstrate this through the design and proposed conduct of their research. A significant safeguard relating to the recruitment of individuals who lack capacity is that the researcher must seek a suitable ‘consultee’ to both ‘consult as far as possible’ with the individual, and taking into consideration any prior expressed values and beliefs, advise the researcher whether or not the person would or would not be content to take part in the research (MCA 2005).

Throughout the MCA (2005) there is therefore an emphasis on protection of the person who lacks capacity, and this is given priority ahead of aiding and maximising participation. The focus on protection in research governance is noted within ethical guidelines guarding the involvement of other groups deemed to be vulnerable in research, such as children (see Daley 2015). Subsequently, protection is foregrounded within research practice, especially with those who lack capacity and research is conducted through and with multiple safeguards in place. However, there are challenges in practice to conducting research under such requirements.22

---

22 For a detailed discussion about the recruitment of people with severe brain injuries in this research see Latchem (2016).
In line with these considerations and concerns, the recruitment of people with severe brain injury in this study was multi-layered, in that there were multiple protective steps of recruitment build into the design of this research. The recruitment of residents for both interview and/or close observation followed a four-stage process depending on whether or not they had the capacity to consent on their own behalf. Irrespective of capacity however, the process for recruiting residents began in the same manner each time.

Step 1: Following a period of initial broad observation (which allowed me to begin to get to ‘know’ residents and at the least learn names) I held a conversation with a pre-decided clinical gatekeeper\(^\text{23}\) at each site where we discussed potential recruitment of individual residents. This initial conversation enabled two main sets of information to be shared, first any advice regarding communication with the resident could be offered or any potential risk to the resident or to myself be discussed. Second, the mental capacity of the resident to make decisions for themselves regarding the research.

Step 2: Once potential residents had been identified, the clinical gatekeeper initially spoke with the resident, telling them briefly about the research and asked them if they would be happy to be approached by me to further discuss the research and their potential participation.

Step 3: For those who gave their permission to be approached (all asked did), I then approached them myself, introducing myself, explaining the research and working through the research information detailed on the research information sheet.

\(^{23}\) The clinical gatekeeper at both sites was the most senior clinical manager. Someone who had both clinical practice knowledge and operational responsibilities within the setting. This person was also the most senior person in the settings on a day-to-day basis and was the person with who access negotiations were made.
Step 4: Residents were then left with the information sheet and given a few days to think about their involvement before I approached them again to confirm whether or not they were willing to participate in the study.

A different process was used with recruitment of staff and family members. This is outlined in section 4.5.3.

In practice this process was followed each time, but with minor variations where the research was explained multiple times over for those who could remember who I was and what I was there to do and that they were to be interviewed, but could not always hold on to the details of the aims of the research. These participants had the capacity to make a decision on their own behalf because they could hold on to the information long enough to make a judgement in the moment, however they needed support to re-remember some aspects of the research during the data collection period.

The recruitment process for those who lacked the capacity to consent on their own behalf differed significantly to the process above.

Step 1: Should a potential resident be identified for participation but the gatekeeper either know that they lacked the capacity to consent on their own behalf (i.e. in situations where the resident was in a vegetative state) or there be concern that the person may lack the capacity to make a decision about their involvement in the research due to the complexity of the question posed and the information required to make it, the clinical gatekeeper would either inform me immediately whether or not the person had the capacity to consent, or carry out an assessment of their capacity based on their involvement in the research and then inform me.

Step 2: For those who were deemed to lack capacity, the gatekeeper would assist me in either identifying an appropriate personal consultee, for those residents who had close relatives who visited regularly and/or knew them well and were in regular
contact or, where this was not the case, consider who might be a suitable nominated consultee e.g. a member of the clinical staff.

Step 3: Having identified a suitable consultee, I wrote or spoke to the potential consultee explaining the research to them and asking if they would be willing to act as a consultee for the resident in this situation. All asked to act as a consultee did so.

Step 4: Consultees then consulted with the resident directly and as far as possible as per the mental capacity act and returned to me with their advice regarding whether or not the person would want to be involved should they have been able to make this decision for themselves. In all cases consultees advised that the resident would want to be involved and each explained the reasons behind their advice – all of which were steeped in the person's prior expressed values and beliefs and character prior to injury.

Once the consultation process was complete, data collection was organised. I discussed with the consultee when data collection would occur, to provide them with the opportunity to be present. No consultee felt they needed to be present at all times during data collection but each were present at least once during the data collection period for those residents who were involved in in-depth observations.
### 4.5.3 Sample demographics

#### Table 1: Recruitment breakdown and participant demographics

<table>
<thead>
<tr>
<th>Total Number*</th>
<th>Patients</th>
<th>Family Members</th>
<th>Staff Members</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>8</td>
<td>9</td>
<td>49</td>
</tr>
<tr>
<td>Male</td>
<td>6</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
<td>8</td>
<td>37</td>
</tr>
<tr>
<td>Under 25</td>
<td>3</td>
<td>0</td>
<td>15</td>
</tr>
<tr>
<td>26-35</td>
<td>2</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>36-45</td>
<td>1</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>46-60</td>
<td>1</td>
<td>7</td>
<td>20</td>
</tr>
<tr>
<td>60+</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>White British</td>
<td>7</td>
<td>9</td>
<td>35</td>
</tr>
<tr>
<td>White (other)</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Asian</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Asian British</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Black (African or Caribbean)</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Black British</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Mixed ethnic group</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Other ethnic group (i.e. Arab)</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>

* 66 people were interviewed, the other 4 ‘participants’ could not be interviewed due to their levels of impairment but were ‘participants’ in the sense that consent was gained for close observation (Many more people were, of course, observed as part of the ethnography but are not classified as ‘participants’
Table 2: Health care professional sample demographics

<table>
<thead>
<tr>
<th>Staff role</th>
<th>Number Interviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manager</td>
<td>4</td>
</tr>
<tr>
<td>Nurse Manager</td>
<td>3</td>
</tr>
<tr>
<td>Nurse</td>
<td>5</td>
</tr>
<tr>
<td>Health Care Assistant</td>
<td>12</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>4</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>3</td>
</tr>
<tr>
<td>Speech and Language Therapist</td>
<td>2</td>
</tr>
<tr>
<td>Therapy Assistant</td>
<td>7</td>
</tr>
<tr>
<td>Catering</td>
<td>3</td>
</tr>
<tr>
<td>Domestic</td>
<td>2</td>
</tr>
<tr>
<td>Administration</td>
<td>2</td>
</tr>
<tr>
<td>Maintenance</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
</tr>
</tbody>
</table>

As can be seen in the table, although the final sample closely matches the overall number of participants planned to recruit, its distribution does differ to the original plan – there are far more, and a greater range of staff than originally planned, and fewer family members and patients than originally intended. The reasons for, and implications of this shift between the planned interview sample and the actual interview sample is discussed below.

I interviewed more than double the number of staff originally planned. This is because there was significant interest and engagement with the research from staff at both sites, many of which wanted to be interviewed – including staff beyond those I had originally intended to include. First, I had planned to focus on HCPs, but through observations I noted the regular and consistent presence of both non-qualified care staff and non-clinical staff (i.e. domestic, catering, administration and maintenance staff) in the care of patients. It became clear that their involvement required study and subsequently I invited this type of staff to interview also. Second, I noticed that as I began to interview staff, those without qualified status boasted about being interviewed to others and reported how being interviewed gave them a sense of
importance and value. At the same time, some staff who had not realised involvement was voluntary and had not been approached by me directly, expressed that they thought that meant those who had been interviewed must therefore be more important than them. Who I interviewed therefore took on a moral status and therefore required me to take an approach of equality in terms of the types of staff I approached to be interviewed. It was important for relations in the field that I ensured there was no professional hierarchy or favouritism evident in who I approached for interview.

The recruitment of a much broader set of staff type for interview however also fits with my observations in terms of those with proximity to and interaction with the patient, so the inclusion of this broader set of staff served both the relational need and provided interesting data in and of itself and matched the observational data. The inclusion of non-qualified health care professional staff and those who provided non-clinical care became instrumental in the key findings of this thesis.

There are lower numbers of family members than originally anticipated. This is mainly because there was a striking absence of relatives who regularly visited residents within the setting (especially at Bracken Lodge). While that is not to say that there were not families who did, many families visited their relative regularly (daily or weekly), but also, there were many residents who did have family but did not have family who visited regularly. This meant that I had a lower number of people from which to recruit than anticipated. Those who were present in the setting regularly however did agree to be involved in the research in the main. Each site had a core community of families of whom were approached either in person if I saw them, or written to following advice from the clinical gatekeeper. Such advice was required because it was often difficult to ‘catch’ families. I would often miss their visit and not see them coming in and out, only to look at the visitor book and realise I had been observing elsewhere for example a therapy session while they had been visiting. Writing to families via the gatekeeper, either to their home addresses or left for them in their relatives room became in some instances, the only way of
introducing myself and inviting their participation. I recruited 5 of the 9 family members who participated in the research in this way.

Finally, there were fewer residents recruited than initially planned. This was due to the time needed to build relationships with brain injured residents and become known to them before beginning any approach for potential participation. Although I attended the centres for many hours at a time (details provided in section 4.5) and met people regularly, recruitment could not be rushed. This relational aspect is discussed further in recruitment section that follows. However, many residents (approximately 30) were included in broad observations - these were not interviewed but they contributed significantly to the findings of this thesis.

Consequently, the findings of this thesis are weighted towards the experiences and discourses of staff members. The first findings chapter (chapter five) draws predominantly on qualified clinical staff’s talk about residents and their work with them. The second findings chapter (chapter six) relates to the work and presence of non-qualified health care staff and hotel service staff, not originally anticipated to be participants within the study and the third findings chapter (chapter seven) then draws the varied perspectives collected together – that of residents, families and health care staff.

4.5.5 Ethics - Informed Consent and confidentiality

As highlighted in the recruitment section above, the potential inclusion of residents was initially discussed with the clinical gatekeeper who then made the initial approach to discuss the research with residents. All participants (residents, families and staff) were given an information sheet (or given it and talked through it, in cases where patients could not hold the sheets, or read for example) detailing the purpose of the research, what they are being asked to do, their right to withdraw, what will happen to their data and the intended impact of the research. Information sheets were given and consent sought for participation in interviews and/or individual observations. All participants were given a minimum of 24 hours to decide if they
wished to take part. Examples of the information sheets and consent forms used in this research can be found in appendix 3.1 and 3.2.

Before broad observations begin, the clinical gatekeeper informed staff and residents about the research and were asked to write to relatives to also inform them. When I arrived however, there were only a few groups of staff who had any recollection of being told that I was coming. While at both sites there was some disconcertion regarding who I was, in the main, the intrigue of both residents and staff enabled me early opportunities to discuss the research and begin data collection. I met with as many staff members as I could to explain the research and provide the opportunity for questions. Posters about the research were initially planned to be displayed in the settings to not only ask for participant volunteers but to ensure that people within or entering the research setting were aware that the research was being conducted and that they could ‘opt out’. The Social Care REC who reviewed the ethics application for this research requested that posters were used and approved a poster I had made. However, although these posters were used a little at Goodleigh Hall, they were not welcomed at ‘Bracken Lodge’ as ‘posters’ being put up was not consistent with something that was done in a person’s ‘home’, and the care institution that was Bracken Lodge was conceptualised by the company who ran it, as residents’ home. I was therefore not allowed to put up posters and a single small poster and sign was instead made for me by the gatekeeper and placed in the reception area.

Initially observation of the day-to-day activities of the setting were made in order for this research to give a full account of the brain injury rehabilitation healthcare setting in general. Observations were centred on general and repetitive events in the setting, formal and informal. Activities such as staff meetings, activity sessions and therapy groups, meal times and goal planning meetings were observed. At this point, no one person was the object of the observations, with the broader organisation and day-to-day occurrences of the setting the focus of observations.
Following broad observations, a series of more in-depth observations of individual patients’ rehabilitation were carried out. In those situations, individual consent to observe was sought as discussed in detail in the recruitment section. Finally, a series of interviews with patients, families and HCPs were conducted. Again, individual consent from each participant was sought as discussed above.

As highlighted earlier, conducting data collection in two neurological rehabilitation settings was selected, mainly to increase anonymity of individual participants and participating centres. This is because, even if the locations of data collection are for any reason identified, by having two centres involved patients, families and staff can be hidden in one another. Practical steps to ensure confidentiality were taken during data collection including the assurance that what was said in interview would not be shared with other participants and that all participants would be anonymised in any research outputs by the provision of a pseudonym and the removal of any identifiable features. To achieve this, each name attributed to a participant written in this thesis is a pseudonym and at times gender, professional type or familial relationship has been changed to enhance anonymity or quotes/observation data left unattributed.

4.5.6 Designing through Ethics

Ethics is a concern for all researchers; it pervades every aspect of the research process from conception and design through to research practice, and continues to require consideration during dissemination of the results. In healthcare settings, one of the first formal ethical hurdles is attaining ethical committee approval from either the NHS or social care research ethics committee (now the Health Research Authority). Therefore, at the outset of a research project, considerable attention is focused on anticipating and addressing ethical issues (Dingwall 1980; Goodwin et al. 2003).
In the case where the inclusion of people with both profound impairment and those who lack capacity to consent on their own behalf is critical to and at the centre of the research aims, extra and multiple layers of ethical considerations are required and at play. The extra attention required is made evident through the procedural requirements a researcher must work through in order to obtain ethical approval for this ‘vulnerable group’. In research in social care, independent sector settings, the ethical requirements to include those who can consent on their own behalf sits with and stops with the university. To study patients who have the capacity to consent on their own behalf, families and staff in social care settings requires university level ethics approval and clinical governance approval from the setting to be studied. In contrast, to study and include those in independent care facility settings who lack capacity to consent on their own behalf, the level of ethical scrutiny is significantly higher. An ethics application in these circumstances must be made to the Social Care Research Ethics Committee (now Health Research Authority), which includes gaining the sponsorship of the university, the completion of a 60-80 page ethical form, the production of all research materials, the booking of an application review with the Social Care REC, and the appearance in front of a panel of up to twenty ethical committee members. In the case of this PhD, I was required to make minor amendments to my original application including the addition of the creation of posters to alert people I was conducting observational research, but ethical approval was gained for this study immediately following minor changes requested by the panel.

Goodwin et al. (2003) rightly notes the immediate focus of ethics required in research projects, especially within healthcare. The immediacy of ethics within the research process is, in part, pragmatic. This is due to the length of time in practice it takes for any researcher to think through and pre-empt the ethical issues their research raises, the very early production of participant information sheets, consent forms, the completion of multiple and extensive ethical forms, the securing of university sponsorship, the booking in of the application for review by the research ethics committee and any post review modifications required by the panel. In a context of
a doctoral study or any study which is bound by time, securing ethical approval quickly is imperative to completing a study on time.

Such a foregrounding of ethics however is not benign upon the research process and does not merely effect the ethical ‘conduct’ of the research. Due to the immediacy of the researcher to pay attention to ethics, ethical consideration and research design are not distinct processes but work in tandem (see Franklin et al. 2012 for further discussion on ‘research-as-process’). In the case of this doctoral research study where involving those who lack capacity to consent is at its core, this study was therefore designed through ethics – both in thought and in process.

4.6 Doing data collection - Observation and interviewing

Data collection was conducted over three months at one site, first in Autumn 2014 and over two months at the other in Spring 2015. Thirty-six separate fieldwork visits were made to Bracken Lodge which averaged three days a week. Site visits and data collection varied between 5 and 8 hours each visit, limited at times due to the length of the researcher’s commute to access the site. In total 203 hours was spent onsite at Bracken Lodge (discounting access negotiation visits).

Twenty-eight separate fieldwork visits were made to Goodleigh Hall which averaged three days a week. The length of time spent on site varied between 4.5 and 12 hours each visit and the time of day and days of the week also varied – to include early mornings, day time and early to mid-evening. The length of time spent onsite at Goodleigh Hall at each visit was often longer than at Bracken Lodge, for three main reasons, first, because I had local accommodation when I went to Goodleigh Hall and did not have a daily commute. Second, I could only afford accommodation for two months of data collection at Goodleigh Hall and wanted to maximise data collection opportunities at each visit. Finally, I had built an ‘ethnographic tolerance’ by the time I reached the second data collection site. I experienced extreme fatigue through the ethnographic practice of continually noticing, making note and then later the highly cognitive practice of re-remembering as I wrote up my notes and added yet further
detail. Turning myself and being turned into a data recorder, while needing to act as responsible and sensitive observer and being participant within the community I was studying, was initially very tiring while studying Bracken Lodge. However, during my time at Bracken Lodge I honed my ethnographic field note recording skills and had practice at interviewing. As a result, this meant that I was less fatigued when in the field at Goodleigh Hall and I could work and record over much longer periods of time. In total 201 hours were spent onsite at Goodleigh Hall (discounting access negotiation visits). Data was collected on different days of the week (i.e. both in the week and at the weekends) and at different times of day in order to get as broad an understanding of happenings within the settings as possible, to aid the broadest access to and involvement of patients, visiting families and staff working different shift patterns.

Data collection was continuous in that data was collected from the moment I entered the sites until the moment I left and on my approach and exit to the sites. I often met patients accompanied by health care assistants or therapists walking to and from the site, I saw staff getting off the bus or being dropped off or collected, and witnessed groups of staff smoking as I pulled into the car park.

4.6.1 Broad observations and day-to-day ‘access’

An initial period of non-participant observations was conducted for three-four weeks of data collection at each site. At this stage I located myself in communal areas such as dining rooms, staff rooms, receptions, in-between spaces such as corridors and stairwells or shared ward spaces, in offices such as nurses’ stations, therapy offices or managerial and administration offices. I attended meetings with managerial staff, therapists and nurses, some of which I was invited to, some I stumbled across or learned about as part of being, listening and seeing in the setting. These meetings consisted of multidisciplinary team meetings, patient review or discharge meetings, morning or afternoon handovers or project meetings.
At each site, I was enabled and allowed to freely roam. Following an initial ‘tour’ of the building and a discussion with my ‘gatekeeper’ at each site, I was left to move around the buildings as I wished, without evident restriction. I was able to come and go as I pleased. I was not asked to ‘report’ on when I would be in the building or where I would be, other than to sign in and out as I entered and exited the buildings. At Bracken Lodge, my gatekeeper requested that I place a sign which read ‘Researcher in the House’ (which had been made for me by my gatekeeper) on a board in reception when I arrived, so that any visitors would know I was on-site and could avoid me or find me as they wished.

At Goodleigh Hall, the doors both to enter, exit and to move within required the use of an electronic fob which had to be tapped onto a panel by the door to release it. Each ‘fob’ was individually programmed to allow the entrance to certain areas of the building. I was provided with a fob on my first day as soon as I arrived, which enabled me access to almost every area of the building. My access included management offices but excluded any areas where financial or human resource information was stored/conducted. I kept this fob throughout the length of my data collection period and in-between visits.

At Bracken Lodge entrance and exit doors and internal doors near stairwells and separate patient/staff areas required the punching in of a code to unlock the door. On my first day, I was taken on a tour of the building and given the codes to all the internal doors and the door between units. I was not given the code to the front door but the entry of all through the front door was managed by a receptionist who let people in by the pressing of a panel by her desk.

As I got to know people within the settings and they began to recognise and interact with me, as I sat observing, staff at Goodleigh Hall especially would regularly come and sit alongside me and begin a conversation with me. These conversations often began with a question for me, and developed into deeply reflective conversations around their work, the happenings of that particular day and how they felt about what was going on around them and what they were a part of. It was during these
conversations where staff members would reflect specifically on the highs on lows of their jobs and express how seeing successful rehabilitation processes made them feel.

As I began to get to know people at Goodleigh Hall and Bracken Lodge and they became used to seeing me - I slowly negotiated access into different spaces such as laundries and kitchens, therapy gyms and relaxation groups. The building of relationships with a wider range of staff types and this broadening of access to ‘non-clinical’ operational areas of the building proved critical in understanding how patient futures are shaped. [See findings chapter 6]

At the outset, the research had been designed with a view of conducting broad observations, close observations and then interviews in order to allow a sequential and deeper understanding of individuals before interview. However, interviews were conducted within a few weeks and were run alongside observations. This happened for a number of reasons. First, some staff participants who were part of an allied health professional group (and therefore small in number within the setting) were either leaving their jobs or going on holiday. This meant therefore that for them to be involved in the research they had to be interviewed earlier than the research design originally planned.

This however did not seem to be a problem for participants as in practice it seemed that an interview is far less intrusive than observations. While an interview requires trust, interview volunteering was fed by participant intrigue and gave a sense of importance (interview invites therefore had to broaden to all). To watch however required a much greater relationship to be built, and to be built slowly and over time.

Close observations (especially those of a particularly intimate nature such as personal care or therapy sessions) therefore were often conducted towards the end of the data collection period in both settings as were interviews with patients. In practice, a great deal of trust from patients had to be built to interview them and an even greater trust required with patients and with staff, to access and get behind bedroom
doors to witness personal care. While staff and family interviews could be conducted at a much earlier stage than imagined, close observations took time and the privilege of their viewing an outcome of relational success.

I was warmly welcomed at both sites and interacted with frequently, so much so, writing up notes was often challenging as I would be talked to, questioned, involved almost everywhere I inhabited. It is however the highly interactive and friendly environment which encapsulates these places of care and captivated me both during data collection and during my own clinical career where I worked in such a place myself. My fondness of these environments and my will to understand them better has driven this PhD. Inhabiting these places and being taken in and ‘owned’ as ‘our Julie’ mirrored my own experience of working in such places as a clinician and later therapy team lead and eventually ‘matron’. While this PhD largely focuses on the troubling reality of the now extraordinary lives of those with severe brain injury and the subsequent constraining of lives, these places are full of warmth, dynamism and care between staff, families and residents.

4.6.2 Interviewing

In the original study design, interviews were scheduled to be undertaken after observations had been conducted. However, due to key participants going on holiday, taking another job and the general volume of participants wanting to be included in the research, interviews were conducted throughout the data collection period.

Initial interview topic guides were developed prior to data collection, utilising key questions trialled in a previous study with patients with neurological patients and their families about their care experiences in long-term neurological care settings (see Latchem and Kitzinger 2012) and questions used with health care professional consultees who took part in the pre-study consultation.

However, due to observations and interviewing occurring concurrently, topic guides could be personalised and learning from observations embedded within the
interview questions. As data collection developed, interview topic guides were developed with ever tailored and more sophisticated questions. Key questions about work background, positives and negatives of their work, experiences of working with patients with severe brain injury, experiences of positive and negative relationships with family members and how they foresaw the futures of the patients they worked with however remained constant. Critically direct questions about patient futures was always left to the end of each interview so that comparisons between spontaneous ‘future talk’ and that purposely asked about could be made. See appendix 3.3 for example staff and family topic guides and section 4.6.4 for further details about patient interviews.

4.6.3 Researcher identity, implications and management

As highlighted above and discussed extensively in Chapter 1, my background as a physiotherapist and experiences as Therapy Lead and Matron of a neurological rehabilitation setting has influenced the undertaking and location of this study and the questions it addresses. It is important however to also consider the impact of my professional status on my identity as a researcher, how I managed this within the setting and how my experience and identity impacted upon the data collected.

I informed my gatekeepers and all participants that I was a neurological physiotherapist by background. I intentionally made this overt self-identification as a clinician to help establish a relationship of trust with my gatekeepers. This was critical in a context where I was to be observing and interviewing patients with complex neurological impairments and where my access to these people was partially based on my clinical experience in doing so. However, while this identity was critical in relation to working with patients, I sought not to hold onto it too firmly while collecting data. Instead I presented myself in the setting, not as the practicing therapist, but as a researcher, a person who was present and engaging but not taking part in clinical activities. I managed my identity by wearing casual, non-clinical clothes. I also chose to wear long sleeves to further denote that I was not engaged in clinical work.
This masking of identity seemed effective in my communications with patients, staff and family members who got used to my presence as the researcher and accepted this identity. Despite my telling them about my background if they asked, the information I gave them seemed to be quickly forgotten and did not evidently carry over into the way I was spoken or responded to.

However, for the therapy staff present at both sites, my background as a physiotherapist was remembered and I was taken into these groups – to such an extent that at one site I was positioned within the therapy team, given space within the therapy office and considered ‘part of the team’. Being considered as ‘part of the team’ gave me immediate access to the practices, organisation and communication of the team and a position within the space. Because I was seen as ‘one of the team’, while participants were interested in the research and keen to know how I was ‘getting on’, they seemed to be largely unperturbed by my presence. Only at one site was one physiotherapist continually conscious of my presence and would make my presence overt by making statements about my watchfulness. In time however and once I had had the opportunity to spend one to one time with her, she too came to be unperturbed by my presence.

During the research design process I considered whether or not to conduct an ethnography while practising as a physiotherapist and thought about my responsibilities as a qualified healthcare professional during data collection. Following an experience of returning to the NHS after my position and Matron and recognising my inability to remain impartial for more than several weeks, I chose to conduct non-participant observations. Also, concerned about the responsibilities held whilst working in a clinical role and the challenge to balancing these with research, I chose to conduct research in places I had not worked and to assume no clinical responsibilities. I however, informed the ethics committee as part of my application that I would follow appropriate reporting guidelines should I witness poor care or unsafe practice.
4.6.4 Data collection with residents – a case by case approach

This research aimed to include people with neurological impairments as a result of brain injury, including those with more severe disabilities as they are often excluded from participating in research. How best to include people with severe brain injury who may have profound and multiple disabilities however is not only a moral and ethical issue but has practical implications.

Semi-structured interviews were selected as part of the data collection for this research. However, this type of 'textbook' social research method, while accessible to some participants with brain injury who are able to share their experiences in this way, for others, this method would not be appropriate.

People with brain injuries can experience an array of neurological symptoms and impairments which may inhibit their ability to participate in research interviews. Neurological impairments, although following some patterns, are unique to the individual. Asking patients with severe impairments to participate in a semi-structured interview would potentially create a barrier to their inclusion, and in essence act as a type of enforced selection process. Therefore, rather than participants having to fit with an exact preselected method, the method should be selected to meet the needs of the individual participant.

Data collection with patient participants therefore took a 'case by case' approach (Goodley and Moore 2000), where the best method and/or approach to data collection to fit the needs and abilities of the patient participant was selected in situations where participants are unable to participate in a semi-structured interview. This approach was chosen to enable a larger number of patients with brain injury and those with higher levels of disability to participate in the research, should they wish to. Such a multi-method approach is advocated by other researchers working with people from vulnerable groups (Booth 1996, Aldridge 2007;2014; Etherington 2000) and seeks to promote inclusion, recognises and values the voices of individuals in social research (Aldridge 2014).
The interview was the method of choice for part of the ethnography and in the main, the aim was to select either a different type of interview (i.e. a structured interview) or a particular interview elicitation technique. Although neurological impairments are specific to the individual, there are impairments that are frequently seen and known to me as a neurological physiotherapist by background and so I could, to a point, anticipate and prepare for supporting the involvement of people with severe brain injuries in the research. For example, I thought of those with intelligible but slurred speech who quickly fatigue, and prepared to conduct a more closed interview, to potentially be carried out over multiple sessions as an option. This was in practice, an approach that was used with one of the young men who participated in the research.

I thought of those with aphasia and agraphia or those with limited upper limb dexterity, a structured interview with closed questions may be possible. Yes/no and/or short responses through gestures, blinking or the use of a communication aid with eye gaze software would enable communication and participation in this instance. In practice, this approach proved vital as it enabled the participation of two residents, neither who could speak or had upper limb dexterity or movement to enable writing or pointing, but both were able to communicate consistently using facial gestures or a communication aid. In these cases, the interview was adapted in two ways. First all questions were closed – to enable a yes/no answer. However, yes, no answers alone are both time consuming and difficult to get any sense of depth of feeling or specifics. Therefore, I included sorting tasks within the interview to enable ranking of feelings and experience. This was achieved through printing cards with words and feelings or activities and sorting through these cards with the resident and creating a visual map of experience, of priority and strength of feeling over issues to enable both broader and deeper understanding of the residents’ experience. This approach also enabled the asking of more sensitive questions, in less direct ways, as is done in any other interview.
I thought of those participants with cognitive impairment and how the answering of multiple interview questions may be too difficult and to enable their participation more creative data collection methods may be required to enable them to express their experiences of rehabilitation. In practice, those who were recruited for this study required the two approaches detailed above and no further creative methods were required.

Alongside the actual method of data collection, the approach to data collection and how it was collected was also important. For example, people post brain injury can experience severe neurological fatigue. This means that they can tire extremely easily. Some patients can have difficulties with memory or problems with divided attention, meaning they are easily distracted and struggle to concentrate. In these circumstances, conducting the interview in a quiet place was required and breaks for a rest, or conducting the interview in several sessions, offered. In practice, finding a quiet space was at times challenging and the bedroom spaces (the only private space residents had) often felt an inappropriate place to conduct an interview. Interviews were then often conducted in quieter areas of communal spaces or places chosen by the residents themselves. Despite the lack of environmental control possible during the interview and despite their various impairments (i.e. speech, physical and some cognitive impairment), they all focussed on the interview and were able to work with me expressing their views for around an hour – an hour and a half – much longer than as a clinician, I would ever advise in theory or have anticipated. This experience however is frequently reported in the research involving people with multiple impairment (see Latchem and Kitzinger 2012).

Data collection was prepared for by a period of time with the resident getting used to my presence, a couple of introductions and conversations as part of the consent process as discussed earlier, and observation of how staff communicated with them. Discussion with the clinical gatekeeper regarding the best method of communication was discussed to check that my observations and own ‘assessment’ of what worked best was accurate and practical. Here, my background as a neurological physiotherapist was invaluable as I was able to use my assessment skills to both
notice and establish communication with patients who were severely brain injured, and to build rapport and conduct interviews successful with people with multiple impairments.

4.6.5 Data collection with staff and families

As highlighted above, interviews were conducted at a much earlier stage in the data collection period than expected, however, they were also conducted throughout my time at each site, in some instances, on my last day and at the last minute. As explained earlier, initially observations were focussed on patients, families and health care professional (or auxiliary staff) and ‘participants’ seen as these three groups - but the presence of ‘hotel service’ staff specifically and their involvement with patients was so evident that these ‘other’ staff were also invited to interview. As participants spoke to each other about their involvement some began to question why they hadn’t been asked for interview. Involvement in the research than began to take on a status symbol – although un intentioned. The voluntary nature and intention of the data collection was often missed by participants and to combat feelings of being excluded, multiple, frequent and broad ‘invites’ to interview were made. All interviews were conducted within the setting, although the offer to conduct them off site if families or staff preferred was offered. This offer however was not made to patients in order that I could ensure that their medical needs could always be met and their safety maintained.

Interviews were conducted mainly in rooms within the setting that were designated for meetings, in free office spaces or communal areas that were quiet. Interviews ranged in length from half an hour to 4 hours. At the end of each interview, participants were invited to anonymously write a key message on a postcard to patient, families, healthcare professionals, health providers, commissioners or policy makers. These postcard messages were considered ‘data’ and have been both analysed and used in the sharing of findings to assist the display of key issues identified through the research in an exhibition (see Appendix 4). For further details regarding how ethnographic notes were made see Appendix 3.6.
4.7 Data analysis

As highlighted at the opening of this chapter, an interpretivist approach to this PhD was selected, accepting the existence of multiple realities. To take this further, this study takes a socially constructionistic (Berger and Luckman 1966) view of ABI, in that ABI is a socially constructed phenomenon. It is a named category, ‘constructed’ as both an injury and resultant ‘abnormality’ and ‘impairment’ by society. Social constructionism in its simplest form assumes that the only realities that are possible are those we construct. Construction happens through shared language through which meanings and symbols are devised, negotiated and established (Clarke 2011). However, social constructionism is not purely concerned with the abstract or symbolic making of meaning. It is also recognises that the material world is also constructed, that we give and make meaning through interaction with embodied parts of the material world and our connection to non-human things (Mead 1934).

As Mead (1932) wrote ‘situations defined as real are real in their consequences’. The approach taken by this study therefore is best described by Clarke (2011, p.7) as ‘materialist social constructionism’. Clarke (2011, p.2) develops situational analysis in response to a need for methods that are ‘simultaneously epistemologically/ontologically based in the soil that nurtured pragmatism, symbolic interactionism, and grounded theory, and that also address demands for empirical understanding of the heterogeneous worlds emerging from this “fractured, multi-centered discursive system” of new world orderings.’ This speaks to my own concerns in the context of studying the world of brain injury rehabilitation – to tread a line which both recognises the socially constructed nature

24 We also form a material part of the environment ourselves, that both shapes and is shaped by and through discourse.
25 Arguably, a purely structuralist approach could have been taken to examine the research questions posed here. However, the methods employed and the access I had and to whom during the study meant I did not have the organisational vision through which to establish structural layers and factors and any interactions between them. Furthermore, detailed demographic information was often not available about patients who could not tell me themselves. Adopting a structuralist approach would also have required a much longer data collection period and undertaking a structuralist based analysis on the data collected would have led to an unsatisfactory partial analysis.
of medical categorisation and the organisation of work and interaction, but at the same time, acknowledges and holds central the reality status of living with and loving those with severe impairment. Therefore, ‘situational analysis’ as described by Clarke (2011) was chosen and applied to the data.

4.7.1 Situational analysis

Situational analysis is rooted in grounded theory. Labelled by Clarke (2011) as a ‘new methodological approach to grounded theory’ she draws on the social interactionalist history of the Chicago School of Sociology and the analytical framework of grounded theory, departing from its traditional conceptualisation of Glaser and Strauss and following Strauss’s attempts to capture the interactive nature of structure/process, practice/negotiation, all —conditional elements in situations (Clarke 2011, p. 38). Clarke (2011) sets up situational analysis, initially through the recognition of ‘social worlds/discourses’ and the situated nature of the construction of society. She proffers that situational analysis shifts away from a purely grounded theory approach which centres on analyses of social processes/action alone. In contrast, situational analysis is a material-discursive approach which moves beyond social process to multi-layered situational understanding of the social world under examination and how it is constructed.

The social worlds/arenas/discourses framework is reliant upon Mead's (1932) key concepts of ‘perspective’ and ‘commitment’ which purport that all actors have their own perspectives and commitments in relation to the situation/social world they are part of. Such an approach assumes the collective multiplicity of actors – that people do things together. It assumes that their involvement focusses on matters about which everyone in a particular social world cares enough about to act and be part of the creation of discourses which shape the social world or situation they are in (Clarke 2011).

---

26 Social worlds are made up of the collective actors in any given situation and the repetitive discourses in which these actors are committed to and heavily engaged within (Clarke 2011)
This approach to ‘social worlds’ is derived from the tradition of the Chicago School of Sociology, at the point in its history when sociologists argued that the social world could not be explained purely by segmenting any given geographical area for investigation and extracting it to be representative of a whole. A focus on seeing social worlds as ‘social wholes’ - formed of experience and action, made up of those acting in the same social role but in geographically diverse areas followed and ‘[g]eographic boundaries were dropped as necessarily salient and replaced by shared discourse as boundary making and marking’ Clarke (2011). Therefore, it is argued that social worlds, formed of, for example, occupations or recreation groups, create shared views from which the basis for collective action is formed (Shibutani 1955:1962:1986). Both individual and collective identities are therefore constituted through the commitment to and participation in various social worlds. Recognising that individual actors operate in and hold shared commitments in and across multiple social worlds, Clarke (2011) states ‘Insofar as it meaningfully exists, society as a whole, then, can be conceptualised as consisting of layered mosaics of social worlds and arenas.’ It is this conceptualisation of society as ‘layer mosaics of social worlds’ which underpins this PhD.

4.7.2 Social worlds

Strauss argued (1978, p122) that each social world has the three following characteristics - at least i) one main activity, ii) particular place(s) in which these activities were conducted and iii) particular means through which the activity is conducted.27 He asserted that once the main activity was underway, formal organisations formed to either develop the main activity or diversify and extend the activities of the social world. Similarly, Hughes (1971, p.54) explained the formation and activity of social worlds to focus on and organise around a ‘going concern’ ‘in which certain assumptions about what activities are important and what will be done can be taken for granted.’ He argues that individual actors typically participate in

---

27 Alongside Strauss et al. (1964), Clarke (1986,1991) and Star (1989) to name a few, have written about the study of social worlds using grounded theory methods.
multiple social worlds simultaneously, and that participation is fluid and in a constant state of flux. Drawing on Becker (1963), Hughes (1971 p54) continues, that at the core of each social world are ‘entrepreneurs’ - deeply committed and active individuals who cluster around the core of the world and mobilize those around them. In contrast, alongside ‘entrepreneurs’ Clarke and Montini (1993, p.45) posit that there can also be ‘implicated actors’ in a social world and/or arena – actors who are silenced or only discursively present—constructed by others for their own purposes. Such a concept highlights the importance of considering power within the construction of actors and analysing the place and role of less powerful actors and the consequences of others’ actions for them. This is of particular relevance in the context of this PhD, which focuses on some social actors who cannot engage actively or meaningfully in social worlds due to their impairments but are still ‘present’ in social spaces.

The description Clarke (2011) offers, drawing on symbolic interactionalists and ethnomethodologists of a social world of ‘going concerns’, ‘entrepreneurs’ and ‘implicated actors’ resonates with the formation of the world of brain injury rehabilitation. Brain injury rehabilitation in the independent sector is organised around a series of what Clarke (2011) refers to as key ‘going concerns’ from which action is organised and importance of task, action and interaction are formed. There is a presence of a set of key people (entrepreneurs) around which social action is organised in these places. Entrepreneurs in independent neurological rehabilitation settings however don’t just fit a cultural hierarchy of power, but are diffuse through the organisation with differing motivations.

The concept of ‘implicated actors’ is particularly powerful in situations where the human actor is no longer the ‘competent’ self-governing autonomous sovereign subject as impairments following brain injury prevent cognitive competence, self-control and autonomous decision making, but yet, the brain injured patient continues to be an actor and act upon the social world – an arena in which exists, at least in name for them. The constructed nature of those bodies with the most severe brain injury who cannot speak and are spoken for – existing in body and in and
through the discourse which surround them gives, keeps and shapes identity, is deeply poignant within the context of this PhD. The recognition of both action for others and the consequences of taking action following the construction of a less powerful actor through discourse therefore resonates strongly within social worlds which both constructs and revolves around the care of not non-human actors but non-competent human actors. The interaction and experience of health care staff and the actions they take in response to the construction of brain injured people and how that affects the lives and futures of the less powerful actor – in this case, the brain injured person is precisely what this PhD seeks to uncover and explain. Taking an approach which explicitly enables the identification of those silenced and marginal has proven to be key to the findings in this study.

4.7.3 Doing situational analysis

Discussing how neither grounded theory nor discourse analysis entirely recognises nor enables analysis of specific, situated social worlds, Clarke (2011) highlights that a situated approach is necessary which take elements of both of these approaches. She proposes three ‘analytical exercises’, systems of map drawing to help the researcher move around and through the data and to be used alongside making memos – a key precept of basic grounded theory.

The first of Clarke’s (2011) three mapping propositions ‘situational maps’ matches most closely to the way in which I organised my data. Unlike Clarke (2011) however I do not organise my data through the drawing of maps in the form that she outlines but utilise analytical questions she poses and work through the data using 'memos' as she describes, as a way of coding which initially asks questions rather than uses data to provide answers, notes themes, ideas, reoccurring discourses of which can be 'held' to then later either be discarded or 'feed' into more focussed analysis.

Clarke (2011) provides an opening caveat that situational analysis can be conducted on uncoded data and foregrounds the importance of the familiarity of the researcher with their data. It is due to my prior familiarity with the type of setting and prior
experience of the connectivity of the work and relations between professional groups which renders the situational and social worlds mapping drawing tasks for this purpose suggested by Clarke (2011) partially redundant in this context. However, data was grouped in profession and each professional set analysed together before looking across the data set which partially follows the situational and social worlds mapping analytical exercises described by Clarke (2011) and the theoretical view which underpins situational analysis.

Interview data was grouped into site, professional status, professional group or participant type. Instead of drawing maps I coded the data in the margins, beginning with open codes and initially using the social world groupings that Clarke (2011) highlights.

From this position of fragmentation, I then began to look across the data. I looked for repeated practices, happenings or discourses, for reoccurrence or absence across groups and sites. I explicitly looked closely at critical occurrences or key meetings where decisions may be taken or have to be made. Interestingly, this yielded limited future related knowledge. I examined moments where the future was spontaneously talked about and times when I had explicitly asked participants about it, in relation to themselves and others.

I was often gifted key areas of insight by participants making key statements in their own attempts to make sense of the world they worked in or inhabited. For example, see Clara’s ‘Poster boy Goodleigh’ in Chapter 5 and Elaine’s ‘There’s no future talking here’ in Chapter 7. Once strong areas of future making, imagining or constraining were apparent I focussed in depth on these areas and all related data. I explored data around these areas to ensure I had captured context, breadth and depth relating to each emerging story. In doing so, key occurrences with important future elements were held up and formed the three key findings chapters. Each chapter pulls together either a single ‘big story’ or a series of smaller stories which highlight a key element of future making in brain injury rehabilitation.
In the doing of my analysis in this way, I re-join Clarke (2011) as she describes a process following initial situational mapping of ‘relational analysis’. A process where, from a position of moving through and between the data, relations between elements, their nature, strength or weakness is drawn, in order to ‘help the analyst to decide which stories—which relations—to pursue’ (Clarke 2011, p.102). It is this relational analysis which drew out and foregrounded the three ‘big news’, key stories told in the PhD.

Data of observational nature and discussion in and through action and interaction was analysed in this grounded manner, but I also payed attention to discourses and dealt with data collected during interview more discursively. Although social worlds are considered as ‘universes of discourse’ (Strauss 1978) and as constituted through discourse, interview data was coded with open codes28, mirroring Clarke’s situational mapping conceptual categories – but considering experience, motive and relational context. Clarke (2011, p. 108) encourages those undertaking situational analysis to pay attention to what she calls ‘sites of silence’ – asking the question – ‘What seems present but unarticulated?’ This question, alongside her reflection on the importance of the presence of ‘implicated actors’ in any social world enabled the paying of attention to power relations and marginalisation, but without foregrounding power relations as the application of Foucault’s discourse analysis for example, might, but allowing them to emerge from the data. Such an approach brought to the fore the role of staff who are not constructed as ‘professional’ carers or people who ‘care’ at all; those who sit at the margins of neurological care home life, and the interplay between the imagined futures of brain injured patients who follow a rehabilitative trajectory and those who are unable – notably, those in a disorder of consciousness.

28 Open coding refers to the initial phase of the coding process in the grounded theory approach to qualitative research (The Sage Encyclopedia of Qualitative Research Methods, 2008).
Conclusion

This thesis adopts the materialist social constructionism epistemological position as laid out by Clarke (2011) and benefits from the sociological tradition of symbolic interactionalism in conceptualising the social world as ‘social wholes’ and ‘social worlds’. It employs ethnographic methods, observation and semi-structured interviews to explore and capture the everyday happenings surrounding the care and rehabilitation of people with severe brain injuries in neurological rehabilitation and long-term care settings in the independent sector.

The use of Clarke’s (2011) situational analysis and the questions each analytical mapping exercise asks allows the researcher to work towards developing a micro, meso and macro understanding of this world. While the analysis here utilises elements of each of her analytical exercises and pays attention to each level of analysis, particular attention is paid to and reports upon micro relations and meso level structuring of the social worlds that come together in the formation of brain injured patients’ futures during their rehabilitation. Such micro and meso foci comes from the absence of macro level influence over the happenings witnessed and experienced, evident in the data.

The following three chapters report my findings. Chapter five examines the role of those residents who successfully rehabilitate and highlights how even the brightest futures in this context are often negated and compressed. Chapter six explores the role of the ‘hotel service staff’ (cleaners, cooks, maintenance and administrative staff) - in the making of futures of brain injured residents. Chapter seven explores the role of the temporal in the relationship between residents, families and staff and explains how temporal mismatches and discrepancies in future imaginings cause tensions and are the source of conflict.
Chapter 5 – Findings 1: ‘Poster boys’ and the rehabilitative dream

5.0 Chapter Overview

The focus on ‘restoration’ and ‘return to’ is pervasive in the neurological rehabilitative literature, in professional discourse and clinical teaching, as discussed in chapter 3. In this chapter, using concepts of ‘imaginary’ and temporality, I explore how such a focus plays out in everyday talk within rehabilitation settings. This chapter explores how successful rehabilitation as an imagined ideal shapes the futures of both those who can fulfil it and those who cannot and demonstrates how rehabilitation becomes redefined in long-term care rehabilitative settings.

In this chapter I argue that successful rehabilitation as constructed by HCPs is a type of imaginary and explore how rehabilitation-as-imaginary is enacted through the distinguishing of and between resident types – those who are ‘rehabable’ and those who are not. I demonstrate the prevalence of the rehabilitative dream in staff talk about their work with residents and explore what this rehabilitative imaginary does for rehabilitation as both process and (material) practice. I argue that those who successfully rehabilitate boost staff morale and engender dedication to the specialism of neurological rehabilitation. I demonstrate how these residents reinforce rehabilitation as process and act as ‘poster boys’, providing a positive advertisement for the organisation and those working within it.

---

29 The ‘imaginary’ or ‘social imaginary’ refers to the set of understandings, practices, and common expectations that characterize the community (Anderson 1983), “the ways people imagine their social existence, how they fit together with others, how things go on between them and their fellows, the expectations that are normally met, and the deeper normative notions and images that underlie these expectations.” (Taylor 2004, p. 23)

30 The word ‘rehabable’ is not a word used in the literature but a term used in the speech of health care professionals. It refers to the judgement healthcare professionals make about whether or not a patient has the potential to make rehabilitative gains – to make improvements through the rehabilitation process and its interventions.

31 The term ‘residents’ is used here and throughout the rest of the thesis instead of ‘patients’. This is because in rehabilitative centres organisations frame their places of care as ‘homes’ not ‘hospitals’ and therefore the people they care for reside there. Although terms such as ‘clients’ are also used, ‘residents’ is most often used in neurological rehabilitative and long-term care settings and is used here to reflect their language.
Temporality plays a significant role in how rehabilitation is both constructed, but also challenged and contested. In this chapter, temporal elements of staff’s talk about rehabilitation is highlighted throughout. In doing so, I show how rehabilitation becomes redefined in long-term care settings, beyond the confines of the definitions presented within the medical rehabilitative and health care literature (see chapter three). I conclude the chapter by arguing that the pervasiveness of the rehabilitative imaginary shapes the futures of those who fulfil it but also brackets out the futures of those who do not.

5.1 What is ‘rehab’ as defined by those working within it?

5.1.1 Rehabilitation as restoration

Rehabilitation can be a place, a period, process and service. However, rehabilitation as a process and practice is dominant in the way in which staff talk about and define rehabilitation (see chapter 6). When asking staff what rehabilitation, and rehabilitative potential means to them, most give the definition closely linked to the Oxford dictionary definition given in chapter 3 - a definition which includes restoration of and ‘return to’ a ‘pre-morbid’ or ‘former’ self. For example, one physiotherapist said:

[rehabilitation is] getting them back to their premorbid state, so what they were like before they had their accident [...] it’s getting them back to a life where they are [pause] normal. (Harriet, Physiotherapist)

Although such focus of ‘return to’ is repeated in both formal rehabilitation definitions and staff talk, ‘return to’ a former self is impossible. This follows from Adam (1995) who explains that return to anything is impossible because although life and time can be experienced in a cyclical pattern, for example, the turning of the seasons - while spring follows winter and returns each year, it never returns in quite the same way, nothing is ever repeated exactly, nothing can be the same. Change is therefore synonymous with the passing of time and ‘return to’ is not possible. The focus of rehabilitation then is not and cannot be to turn back the clock or to restore a person to their literal past self, despite a strong discourse to this effect. Instead rehabilitation aims to help the injured regain a level of function that mirrors abilities
they held before their injury to be utilised in a better future life in contrast to their present injured state. Despite the focus of the past in rehabilitative definitions, it is, in temporal terms, a future-present concept.

5.1.2 Rehabilitation as time, in time and with time

Despite its pervasiveness in the literature, rehabilitation is not confined to the notion of formal goal-setting (of the type discussed in chapter three). Instead rehabilitation is seen in a wide range of different ways by diverse staff, including as something integrated into everyday care, interaction and ‘being with’ the residents. However, despite the focus on and range of rehabilitative definitions what also emerges from interviews with staff, in particular nursing and health care assistants, is that rehabilitation comes second to the delivery of routinized care regimes. Staff highlight that organisational and time pressures come into their interactions with residents and therefore prevent them from ‘doing rehab’, or at least rehabilitation as defined by them.

Rehabilitation is defined by some nursing and care staff as a time intensive process. Nurse manager Janice explains that doing rehabilitation takes more staff time and effort to achieve over the delivery of impersonalised routinized physical care such as washing and dressing. She says ‘[s]ometimes they don’t sit out in the wheelchairs because it is time consuming so their whole rehabilitation process is stopped.’ Rehabilitation is also resource intensive, in terms of the number of staff required to deliver it. Bianca a health care assistant explains:

_We have to keep her [a resident] in bed until she gets up because once she gets up she is a one-to-one. A lot of the time we are keeping her in bed because there is no one to sit with her. I think that is just getting in the way because you are not really doing the rehab thing and things get missed._

(Bianca, Health care assistant)

Through Bianca’s talk about what she is restricted in doing with patients, what rehabilitation _is_ becomes clear. Bianca talks about (and in doing so defines) rehabilitation as a process of individualised, concentrated care and attention, afforded to residents by health care workers. For her, the critical element of
rehabilitation is enabling patients to do things for themselves in order for them to re-establish their independence, in terms of being able to carry out tasks such as washing and dressing for themselves. She says:

_I just take my time now, why should I rush, they are not here to be rushed. If someone can do something and we are doing it for them that is not what we are here for. I think they forget that a person needs to be doing their own wash as much as they can. It will take half an hour longer than it would for me to do it. I could be with Daniel for over an hour, he can do it all himself, the majority himself and I think that just gets forgotten._ (Bianca, Health care assistant)

Bianca describes how time pressures on her work as a rehabilitation assistant, and a lack of staff who perform her role, could prevent all interactions with residents being rehabilitative – and she resists this.

_Researcher: Because of staffing pressures you have to do more for them, effectively to speed it up?_  
_Bianca: Yes. I don’t do it any more though, I have stopped doing it. I am not here to rush people I am here for them._

Rehabilitation - the enabling and facilitating of residents to do things for themselves takes time. Critically it takes _more_ time than if personal care is done to a person. Bianca concludes and demonstrates her resistance to the time pressures upon her and states her refusal to do to people and instead takes her time with residents – to facilitate them to do things for themselves, to ‘do’ rehabilitation and ‘be’ rehabilitated. Conversely however, for therapists, who compare their work within the NHS and their work in the independent sector, they talk about having more time to ‘do’ rehabilitation and that this allows for a greater range and type of times spent with residents. One physiotherapist reflects:

_It’s much more relaxed here with regards to community visits which I like. Next week me and Jack are going to go for a run in the park [laughs]. You wouldn’t be able to do that in the NHS, no time to do that and they’re clearly too high level so you would have to discharge them, but it’s quality of life. You don’t think about quality of life in the NHS unless they’re dying [laughs] whereas here, you tend to think about it more because you’ve got more time._ (Harriet, Physiotherapist)
Here Harriet highlights that rehabilitation is more, and applies to more people than is considered and included within definitions largely given in the clinical and health service literature. This is expressed as part of a broader rehabilitative definition by staff in two main ways – both as a process which involved the skills of many people, in professional terms – a multidisciplinary team, and a process which involves a rolling and integrated way of carrying out both focussed therapeutic clinical activities and the doing of the everyday. Rehabilitation as a process and a practice and the multidisciplinary component of rehabilitation is reflected within the healthcare literature definitions but not explicated in this way (see chapter three).

Discussing the multidisciplinary nature of rehabilitation an Occupational Therapist reflects:

*What I can consider is very helpful is a multi-disciplinary approach to their recovery pathway, where you have input from everybody. Synchronize that together and implement it, it works very well. With the clients we have here we have a multi-disciplinary meeting every two weeks for every client and when the needs are high we may be discussing the same plan week in week out; trying to find out the input that everybody else is bringing in.* (Kerem, Occupational Therapist)

Here Kerem highlights another temporal component of rehabilitation – timing. For Kerem, timing is an important part of achieving successful rehabilitation. He explains that multi-disciplinary involvement cannot just be present but must be synchronised. For rehabilitation to be successful, residents require input from different multidisciplinary members and their input needs to be at the same time. However, not any time will do. Synchronicity indicates a requirement for order, for purposeful co-ordination. To achieve the appropriate timing and synchronicity, input from each of the professions must be communicated.

Alongside synchronicity, effective collaboration requires recognition from all members of the team that all members have valuable input to offer. Ara, a Psychology assistant said: ‘If they have an appreciation for all the other professions you’re going to have a more worthwhile rehab process.’ Recognition that
rehabilitation requires co-ordinated collaboration was also reiterated by a Nurse manager who like Kerem extends ‘the team’ to include residents’ family, saying:

*It is really important that it is a collaborative process and by that I mean all of the therapy staff, all of the nursing staff and the resident if they are able to be but most importantly the family. I think it is important for all of us to get together and make sure that they have got a consistent approach and they know where we are headed or not headed. I think that is our greatest challenge trying to provide that consistency.* (Janice, Nurse Manager)

Here Janice identifies yet another temporal component to rehabilitation. Extending Kerem’s idea of synchrony she adds the need for consistency. Here consistency means both how rehabilitation is delivered and communicated by HCPs and shared aims and goals for any individual. She highlights the importance that all of the team hold the same imagined future so that residents “know where we are headed or not headed.” As well as rehabilitation as a multi-disciplinary process or taking a multidisciplinary approach, it is also defined as being a ‘holistic’\(^{32}\) process. One nurse manager defines holism as:

*looking at the person as a whole. You have to think about the social aspects, the cultural, the beliefs and values people have and psychological aspect of them. Looking at a person from all these angles make us think we can provide a very formidable level of care for these people.* (Arif, Nurse)

The place of holism within and as part of rehabilitation expressed here fits closely with the idealistic rehabilitative definition both as outcome and as process given in the medical and health care literature (see chapter three). A holistic approach of the process kind is seen as critical by nurse Arif – with clinical interventions and the ‘doing of the everyday’ as self-sustaining and reciprocal in achieving rehabilitative outcomes. An Occupational Therapist explains this further saying:

\(^{32}\)Holistic here is defined as ‘characterized by the treatment of the whole person, taking into account mental and social factors, rather than just the symptoms of a disease’. (The Oxford English Dictionary)
... find the occupation, find the activity that will engage them and will give them a satisfaction and quality of life and then just kind of throw in a few goals. (Maddie, Occupational Therapist)

The importance of finding ‘occupation’, or having something to do was echoed by Dean, a nurse manager who stated what he thought residents, and everyone needed – ‘somewhere to live, something to do and someone to love.’ Here Dean identifies a need for time to be filled and to be so in a meaningful way; albeit one that resonates with postmodern societal values of individuals leading productive meaningful lives. He suggests that the filling of time can be achieved in doing – both with vocational based activities and through care for and from others’ loving. He links a need for place, in which time can then be filled.

Dean’s talk (as is evident in the interviews of all staff) is interwoven with perceptions and judgements about what is the essence of a fulfilling life. Defining what rehabilitation is, reflects perceptions of what a good life and what a life of good quality is, but quality of life is a fluid concept which changes dependent upon which individual is being discussed. What counts as ‘quality of life’ for residents is distinctly different from what quality of life means for staff’s own lives, although there are also some shared values. I begin to identify these similarities and discrepancies later in this chapter and interrogate this further in chapter seven. How the futures of people with brain injuries are imagined is connected to the way in which ‘life’ and a ‘good life’ or ‘quality of life’ is considered, or at least, is considered by some, for others.

Although rehabilitation is deemed and seen by many as focussed and restorative, in practice successful rehabilitation is not possible for many people with severe brain injuries. Those professionals who are senior in terms of their experience within nursing and rehabilitative therapeutic roles frequently problematize the restorative rehabilitative definition and verbalise what rehabilitation is not, as much as what it is. Daphne a senior therapist reflects on her own professional role saying:

---

33 This resonates with the ‘affective turn’ within sociology which addresses the embodied aspects of meaning and experience, and particularly their felt or affective dimensions (Cromby 2012).
Here, things feel much more long-term and ‘open ended’ because people are much further down the line or they have, such significant problems that I’m not sure what my role is in rehab. I don’t know whether I’d call it rehab or therapy.

Here Daphne questions if rehabilitation is happening at all within her work place and critiques what her own role is within a framework of care that may not be rehabilitative, especially in the care of those with severe impairments. She continues:

There are some people here that are true rehab and then there are a whole bunch of people who are moving from that rehab bit onto maintenance. I think sometimes it’s unclear in my mind why someone’s here. (Daphne, Therapist)

Here Daphne draws a distinction between ‘true rehab’ (referred to at times by other staff as ‘real rehab’) and the type of service provision, care and therapeutic process delivered to some residents who were at Bracken Lodge and Goodleigh Hall. By ‘true rehab’ Daphne is referring to the illusory of successful rehabilitation - rehabilitation as a seamless process which ends in significant restoration of a person’s functional abilities. Daphne’s identification of ‘true rehab’ raises the possibility that rehabilitation may occur in various ways, but also that it may be said to be in action but is not happening in practice. What rehabilitation is and is not therefore is contested by those who work within it.

‘True rehab’ is defined by Daphne as only occurring at a certain time, place and point in the patient rehabilitative process or ‘pathway’. In indicating that there are residents at the neurological centre who experienced their brain injury many years ago and using that temporality to problematize and question if rehabilitation is both possible and present in the current setting, Daphne alludes then to true rehabilitation

34 ‘Maintenance’ refers to therapeutic intervention which does not aim to rehabilitate or promote resident improvement in their functional abilities but seeks to maintain their present state and attempt to prevent deterioration.

35 The ‘patient pathway’ is an NHS health care conceptualisation defined as ‘the route that a patient will take from their first contact with an NHS member of staff (usually their GP), through referral, to the completion of their treatment. It also covers the period from entry into a hospital or a Treatment Centre, until the patient leaves’ (DoH 2007) The term ‘patient pathway’ was heard within the narratives of staff interviewed here, who had previously worked within the NHS.
being a post-acute not long-term stage or state following illness or injury only. Rehabilitation then as Daphne defines it, is both place and time dependent. It is timed in that the post-acute stage after brain injury is roughly seen as the period of time immediately after a patient has recovered from, and no longer needs intense medical care and extends up until approximately 1-2 years following injury. True rehabilitation then is dependent upon place as patients with severe brain injury at this stage post injury remain, in the main, in NHS care settings. It is only after the post-acute rehabilitative phase in an NHS hospital or other care setting that patients are transferred to settings such as Goodleigh Hall and Bracken Lodge. As highlighted in chapter one, interestingly such patients are referred from NHS rehabilitative settings to independent sector rehabilitative settings for ‘slow-stream’ rehabilitation and/or ‘long-term’ care.

As can be seen in Daphne’s reflections, the slowing down and extended rehabilitative timespan changes the way in which she sees rehabilitation to such an extent that she re-evaluates and questions whether or not she is providing rehabilitation as she works with residents in these settings. She queries whether rehabilitation is happening there at all. However, conversely, the slowing down and elongation of rehabilitation as process is built in to a rehabilitation definition in the case of one nurse manager, Janice, who says ‘I perceive rehabilitation being quite a long process that has to be observed really quite closely.’ Questioning whether or not rehabilitation is happening within independent health care sector neurological care settings is not however limited to Daphne. A nurse manager raises the same question, however her questioning comes, not from the provision of therapies, the timing of delivery, the point in the patient pathway or the place, but instead focusses on the model and approach to rehabilitation taken and the facilities provided. She reflects:

I don’t think we are a rehab unit in the sense of the word rehab. I don’t think the facilities we have here allow us to have to have the rehab title. It is not because the nurses, therapists, the carers are not doing it I just think our model at the moment doesn’t give us the environment – doesn’t give us the rehab. To me rehab is having a proper rehab kitchen, not therapy assistant’s cooking it and bringing it out to you.... (Beatrice, Nurse manager)
Here Beatrice highlights that to deliver true rehabilitation, certain key facilities are needed for the promotion of independence. For Beatrice, as with other staff members, while expressed differently, ‘true rehabilitation’ is about restoring independence — and therefore strongly reflects the rehab-as-restoration definition within the medical literature. True rehabilitation then, requires the delivery of multidisciplinary therapies, at a certain time, for the right length of time and with the right facilities, which enables the supporting of residents to do things for themselves. Time and timing plays a critical role in both the defining of what rehabilitation is and forms a central operational role. Time and timing, is an important ingredient to producing true rehabilitation and ultimately, favourable restorative outcomes. Time then, is essential to the rehabilitative imaginary.

Aside from qualified therapists and nurse management, health care assistants also demonstrate uncertainty about what rehabilitation is and question whether or not they are providing it. Such uncertainty is demonstrated in an interview with Phillipa, a health care assistant who says: ‘I don’t class our unit as rehab but I suppose it is in a way because you are actually getting them to a point where they can be rehabilitated even more.’ Here Phillipa is talking about a ward which cares for people with the most severe brain injuries, those who are in prolonged disorders of consciousness. Here Phillipa both questions whether rehabilitation is being done on this ward with these residents and equally expresses a belief that rehabilitation encompasses more than the visibility of functional improvement. This idea of a stage before rehabilitation, and of making someone rehab-able is discussed in chapter 6.

Interviewees thus often question the meaning or enacting of ‘rehab’; however, later in their interviews these professionals answer their own questions, scope out their roles and highlight what rehabilitation means within these contexts. Through their talk of successful rehabilitation, they problematize their own questions and considerations that rehabilitation was not happening or may not be happening within their settings. For example, Daphne, a therapist, talks of a resident who she feels has rehabilitative potential years after her injury and after a prolonged period of being
at Goodleigh Hall, despite having questioned the presence and actuality of rehabilitation earlier in her interview. She says:

_Daphne:_ The very fact that they’re here means that they’re complex so they’re not going to be your really easy to engage ‘ahh there’s a speech therapist yeah! I love doing my speech therapy’ cause that’s not going to happen, so 28 days\(^3\) is too early. It might stay in, that funding might stay in or it might go out at that point and then there’s a lot of people here who have been here a while and they haven’t got it [therapy] in their [care] package. Trying to go back and ask for money is quite difficult. [Resident] had identified speech and therapy language therapy time when she actually was here for active rehab and had potential to change

_JL:_ Uh, you said had potential to change

_Daphne:_ Well has potential to change

_JL:_ She still does?

_Daphne:_ She still does. I think even in the beginning, had she had speech and language therapy we might have been able to shift her into a place where emotionally she could deal with therapy a bit better. And it’s taken her a huge amount of time to adjust to being here and to adjust to her new situation really. She might not be kind of psychologically and emotionally in the right place to accept the rehab and to work with you on it, it’s taken over a year to get her to that point.

Through thinking about specific residents and providing evidence of the successful rehabilitation of residents within the settings, these professionals highlight that rehabilitative progress can be made by those who sit outside of the true rehabilitative format they themselves define. In doing so they inadvertently undo the tight frame they themselves placed around the definition of what rehabilitation is and instead, temporally open it up.

\(^3\) Within independent sector facilities, NHS commissioners often ‘fund’ for an initial 28 days. Within this time staff within the independent facility are tasked with further assessing and establishing the needs of the individual resident and evidencing their needs for continual funding for rehabilitation and/or for specialised neurological input. If they fail to do this adequately, the commissioner may not extend the funding for the resident to stay longer and will transfer them to a long-term care facility which has a cheaper weekly care charge.
Managers, therapists and care staff deny and question the delivery of rehabilitation as process within their settings. They consider the rehabilitation they provide as different to rehabilitation delivered in other places and at other times within patient pathways. Yet, through reflection of individual residents they recognise rehabilitation as present and re-defined it beyond the formulised definition within the academic rehabilitation literature. In doing so, they extend rehabilitation temporally, highlighting it to be ongoing, with the potential to extend significantly beyond the confines of the construction of ‘true rehab’ conceived of as a process within the post-acute stage of care. In doing so, rehabilitation is opened up as process and practice and identified as a much larger reaching, longer process, steeped in individuality, with personhood at the core of its definition for those who work within it and delivering it.

5.1.3 The pervasiveness of the rehabilitative dream/imaginary

As identified above, on the one hand staff express concern and question if rehabilitation is being done in these settings, but on the other, discuss at length the recovery and progression of some of the residents they are working with. For therapists and other staff the being part of a successful rehabilitation process conceptualised as ‘restoration and return’, provides a great sense of satisfaction, achievement and motivation. Staff express the way they feel about working within rehabilitation as a process of restoration spontaneously during interviews and in reflective conversation with me. Staff speak directly about how the work of rehabilitation and the involvement in successful rehabilitative outcomes gives them a great sense of job satisfaction and had brought them to and kept them working within the area of neurological rehabilitation. As one Occupational Therapist explains:

As an OT that is how I get my satisfaction when I see recovery. That is how I chose also the neuro area because I feel this is an area where I have got hope for somebody getting back to life that is what satisfies me seeing someone recover and you know leading a normal like again as independent as possible. Some may never be 100% independent but you want to be as independent as
Possible some key activities of day-to-day which has actually motivated me.
(Kerem, Occupational Therapy)

Different types of health care professional, therapists, nursing and assistant staff all talk about the joy and pride they feel in being part of the successful rehabilitation process. One therapy assistant, talking about a resident’s rehabilitation states: ‘It is a case I feel so happy about and proud of.’ And a nurse reflects:

when I see somebody I assessed in the hospital, and to see him after five months that he can walk again, I think that was like ‘oh my God, I contributed to that’, you know. (Isaac, Nurse)

For some staff, especially therapists, satisfaction comes from an identification that it is them and the interventions they employ that lead to an individual’s restoration and recovery. A therapist reflects:

It was just so satisfying to see somebody go from nothing to that and it wasn’t just spontaneous recovery; for one of the very first times I think I can be very sure it wasn’t just spontaneous recovery because he is out of that period and this was proper rehab. We know how much work we have put in with [him] and how much we have turned his life around. We have done it for him and his family.

Here the therapist distinguishes between recovery that just happened, that which was spontaneous, and that which was achieved from rehabilitative work and slowly gained progression through a rehabilitation process. Here, temporality plays the central role in both defining rehabilitation and distinguishing between ‘proper rehab’ (or true rehab) and other forms or care or recovery process.

While the quote may seem egocentric, it is expressed more as a) a reflection upon and given as proof that they, an individual therapist, are able to and have the skills to be a good and effective therapist, b) as a demonstration of, a reification of the profession to which they belong, to evidence the effectiveness of the therapies and practices which are attributed to that profession and c) the collective working of a multidisciplinary team.
Satisfaction and achievement is discussed largely in terms of coming from and through a combined effort between resident and staff member, achieved through a process which includes the work of staff, their intervention or approach with a resident and the resident’s own efforts. For example, Maddie talks about a small gain she made with a resident through this rehabilitative relationship:

> [G]etting her to try this commode, she gave it a fair shot to be fair and then [she] did come down with me to gardening group. It is a tiny little thing, but it felt like a big achievement I think especially given her psychological state at the moment. (Maddie, Occupational Therapist)

Such emphasis on what is sometimes in the rehabilitation context regarded as a co-productive process between patient and therapist (because the goal and aim are realised together) is a contemporary approach in neurological rehabilitation. This approach involves working towards adapting to a life with disabilities (Gilbertson and Aldridge, 2008). However, this emphasis on adaptation was far less evident than the focus of rehabilitation as restoration within the talk of staff at Goodleigh Hall and Bracken Lodge as I will discuss next.

### 5.1.4 Small gains and big moments

The notion of small gains and examples of minute progressions are talked about in terms of residents who are not showing signs of improving quickly and are considered as being particularly complex in their clinical and/or social presentation. As soon as a resident is considered complex, the expectation of quick and great rehabilitative improvements is replaced by ways of doing and seeing which are small but considered significant in the context of the rehabilitation of that individual. However small the progress or gain however, such progress is talked about primarily as restoration. Critically, adaptation does not feature largely in the discourse of staff surrounding resident rehabilitation in these places, despite its identification as a key rehabilitative approach within the literature (see chapter three).
Alongside a discourse of the importance of small gains in the rehabilitative process, staff repeatedly speak of being present at or contributing to ‘big moments’ which mark the making of critical progressions within the rehabilitation process. Staff expressed happiness when witnessing or being part of milestones of rehabilitation, such as a person’s first stand(s) post injury, taking steps or beginning to regain speech. This is reflected by a therapy assistant Lucy who says: ‘I have been there for a couple of big moments, it has just been the best thing to see the look on his face, it is great.’ Similarly, a health care assistant, on being asked about the positive experiences she had had working at Bracken Lodge highlighted a ‘big moment’ saying:

*The best moment so far was seeing George walk the other day, I was just in awe. I couldn’t believe it because we hoist him every day. I have seen a change, like, he sits himself up a lot more, but to see him stand on his own two feet and really work at his walking was just mad, I thought that was wicked.*

(Crysta, health care assistant)

The triumph staff express at witnessing key rehabilitative progression was only surpassed by the fulfilment of the ultimate rehabilitative outcome – a resident going home. This achievement is described with excitement by a health care assistant:

*It is such a lovely heartfelt feeling that you just want to burst out and shout to everybody “they are going home, [Resident] is going home – he has done all this and he is going home after what he has done and what he has been through ... It is what it is all about, it is just marvellous.*

The discharge of residents to their home is considered a hugely positive outcome, and in many cases is the ultimate goal for both residents and those working with them. This focus on the ultimate positive outcome as “going home” however is so pervasive that it can negate the imagining of alternative futures – both for those for whom home is not the only horizon that they hoped for their future and for others for whom going home is not possible. This point is unpacked in chapter seven which explores how futures are imagined for residents and the discrepancy between such imaginings between residents, families and staff.
5.2 Successful rehabilitative stories

This rehabilitative dream, and the telling of ‘successful’ rehabilitation, leading to restoration via small and steady gains or big moments of functional return, is pervasive across observation and interview. Below are three examples from three different types of staff (a Speech and Language Therapist, a therapy assistant and an Occupational Therapist), talking about three different residents they have worked with who have successfully rehabilitated in one way or another.

If you look at Donovan after his brain injury he had two and bit years when he didn’t eat anything, he was fully peg fed, he was so unsafe orally and within six weeks he was starting something and that was a new thing for me. I have never been involved with so intensively with somebody with such a severe brain injury and so low level. You have a few patients who stick in your mind and that is one of them, on a good day he can eat a full pureed meal with a dessert can have fluids, his family didn’t think he would even be able to eat anything ever again. (Orazia, Speech and Language Therapist)

I think someone that comes to mind is Seb. When he came in here he had no use of his right arm and his right leg was really weak he couldn’t bear any weight there, he was in a chair. His behaviour was quite erratic and then we worked with him with speech and language therapy, he is not going to probably be able to talk but we have worked with him with communication aids and also with hand signals and gestures. He has become a lot more patient as a person as he has become more settled. Now he is walking around with a knee brace and he can move his hand more, he can get it from his side up to his chin almost …. (Lucy, Therapy Assistant)

I do cooking sessions with him [Luke], I do shopping sessions with him, it is about the holistic approach the whole thing so that helps, the whole thing is getting better all the time when we do our assessment. It is very encouraging he is now walking, and doing exercises, the other day walking on his own without an aid which is brilliant, he is still walking like a baby starting to learn to walk but he is walking which has never happened for a long time and is huge progress. There are so many success stories in neuro rehab so many success stories. If I was to talk about them all we would spend all day talking about them. (Kerem, Occupational Therapist)
Stories like these are told and retold by staff within these units, not just in interviews, but were also observed to be regularly shared between staff – particularly with new staff and with visitors coming to see the unit.

Although Occupational Therapist Kerem alludes to having multiple stories to tell, the telling of such stories at each site centre only on a key set of residents. At Bracken Lodge, Luke, Donovan, Daniel and Ezra are the residents who staff mainly discuss, either in the spontaneous telling of successful rehabilitative stories or when asked to talk about someone who they have worked well with or who has done well. Similarly, at Goodleigh Hall, two residents are predominantly spoken about – Sebastian (Seb) and Matthew. This is significant because over 40 staff were interviewed and over 100 staff were interacted with during the ethnography. Goodleigh Hall and Bracken Lodge collectively cared for approximately one hundred residents and yet, no more than six to eight residents were repeatedly talked about in this way. What was it about these men, the foci of these successful rehabilitative stories and what did the telling and re-telling of these stories do?

The characteristics of all these men (and they were all men) are similar in that they have progressed significantly physically, cognitively, behaviourally and emotionally to such an extent that all but two are now able to communicate, walk, wash and dress themselves with minimal support and make some choices for themselves. They are all considered by staff to have a good sense of humour and were personable – for example they readily initiate and engage in banter and micky-taking with staff. At Goodleigh Hall therapy assistants, nursing staff and health care assistants repeatedly refer to how much Matthew and Seb make them laugh – sharing with one another what these residents had said to them or to others. For example, therapists and therapy assistants would frequently come into the therapy office space having been with Matthew or Seb and make announcements such as ‘Seb cracks me up, you’ll never believe what he said today’ and recall humorous exchanges between them and one of these men, or an exchange Seb and Matthew have had with one another, other members of staff or other residents.
Lucy, one therapy assistant, talking about Seb during an interview, says – ‘He has got a really good sense of humour so people know how to joke with him and dance with him and things like that’, and another, talking to me about Matthew recalls:

One particular day, me and a resident were in hysterics - the other two TAs\textsuperscript{37} were having a heated discussion about what colour the wall was, some of them were saying it was more burgundy, others were saying it was cranberry and me and this resident [Matthew] just kept looking at one another and it, by the end of it we were both crying with laughter because of the argument they were having about the wall colour and it was a long-standing joke for about a month and a half. (Betty, therapy assistant)

While these men have many shared characteristics, they differ in age, the severity of their injuries, the mechanisms which have caused their brain injuries and the level of their recovery to date. Donovan, Luke, Daniel and Ezra are aged between 20-30 and Seb and Matthew are aged between 40-50. Some of these men have experienced brain injuries due to assaults or road traffic accidents while others have had spontaneous bleeds of the brain (haemorrhages). Seb and Matthew, Luke and Ezra have rehabilitated to levels of either complete or near independence and have become able to fulfil most ‘activities of daily living’, to communicate and make (some) decisions for themselves. However, two of the residents frequently chosen as exemplars of successful rehabilitation residents, Donovan and Daniel have not reached the functional levels of recovery that the other four men have. These two men have been significantly more impaired following their initial injuries than the others. Donovan and Daniel had been minimally conscious following their brain injuries and arrived at Bracken Lodge without an established form of communication, limited movement and unable to conduct any functional every day task on their own. Both, despite the severity of their injuries however have progressed significantly, beyond expectations. Both are now fully conscious, able to communicate either through speech or other established gestures and are progressing well physically. Donovan for example is just beginning to be able to stand and take several steps with help and Daniel can partly wash and dress himself and is able to stand intermittently.

\textsuperscript{37} Therapy Assistants
For one therapy staff member, Clara, she recognises the characterisation of this group by herself and others and how they form a ‘type’ of resident. Talking about Matthew and the telling of his progression as a successful rehabilitation story, she says:

...everyone goes on about how he is almost a totally different person and his behaviour has changed so much. He has made so much improvement in terms of his mobility and bits of his communication is a bit more reliable. [H]e has done so much that there is not much more being here would do; so in that sense it is the right thing that his future is looking outside of Goodleigh [...] on the whole he can dress himself and go about. He doesn’t need a wheelchair anymore, he doesn’t need walking aids really, so on the whole pretty independent [...]. So a Goodleigh success story, like poster boy Goodleigh, which is good. (Clara, Therapy assistant)

Here, Clara picks up that those who rehabilitate successfully become a particular type of resident, and that their success is harnessed. The importance of this particular resident type, the ‘poster boys’ is explored in detail below.

### 5.2.1 Poster boys

This concept of a ‘poster boy’ is telling and central to explaining how and why these successful rehabilitative stories are told. A ‘poster boy’, ‘poster girl’ or ‘poster child (US)’ is defined in two main ways, first as a person who appears on a poster for advertising and marketing purposes and second, a person who typifies, epitomizes or represents a key characteristic, quality, movement, cause or ideal (Collins English Dictionary 1979). In this sense, the person appearing on the poster is labeled as an embodiment or archetype, and their identity is synonymous with the associated ideal or representative of its most or least favorable aspects.

In the United States of America however there is less emphasis on a definition surrounding poster girl or poster boy, but instead the ‘poster child.’ The term originally referred to a child afflicted by some disease or deformity whose picture is used on posters or other media as part of a campaign to raise money or enlist volunteers for a cause or organisation. Such campaigns may be part of an annual effort or event, and may include the name and age of a specific child along with other
personally identifiable attributes. Notably, this convention was used by the Muscular Dystrophy Association. Jolene Kay Worley, became the first National Muscular Dystrophy Poster Child in 1955.

The men talked about above, act as ‘poster boys’ in rehabilitation and the independent sector health and social care business in three main ways. First, they typify the ideal, successfully rehabilitated patient and therefore promote rehabilitation as a process (and the professionals who are delivering it). Second, they are an advert, a marketing tool for the promotion of the service, the company who is providing the rehabilitation. This is particularly evident in independent sector care settings where the poster boy or girl can be seen on marketing materials, on leaflets and brochures and most notably, on websites which promote rehabilitative services (for example see http://glensidecare.com/service-users/service-user-stories/) Faces of residents sit alongside ‘testimonials’ which make successful claims to their progress and recovery; statements made by either themselves or their families.

There is also a third element to being a poster boy in this context. Poster boys and girls can be used as examples which typify the characteristics of a disease or impairment which are used to raise awareness of or raise money for assisting those with an illness or impairment, or are held up and used as case studies to be medically examined. The holding up or putting up of these poster boys and girls is literal in some medical contexts, particularly evident in dysmorphia clinics where pictures of people with some genetically caused deformities are photographed and displayed on walls or in presentations for discussion and analysis by medical teams. This practice and what it accomplishes in terms of its role in the categorisation of conditions and diagnosis has been recently described and analysed by Latimer (2013).

The holding up of a ‘poster girl or boy’ is also the case in much medical teaching and practice where individuals with certain impairments are displayed as clear examples of a disease (see Habif et al. 2011). Their characteristics can then be learned and looked out for during clinical assessment. There can also be displays of before and after medical intervention images, used as examples of successful products of
medical interventions (see Yoon et al. 2008; Zimmerman et al. 2010; Wei et al. 2016) and reinforcing the effectiveness of treatments – in this case, the effectiveness of rehabilitation. Individuals however can also be poster boys/girls for the atypical. They can be held up and constructed as unique and not fitting the ‘normal’ pattern of disease and impairment. They are then medical curiosities and constructed as a problem which requires solving through either the requirement of a new disease category, a new treatment or combination of treatments (Latimer 2013). In these cases the faces of people as typical poster boy/girl images may not be used, but instead elements of their anatomy – external or internal. The face or a poster boy or girl may be replaced by images of their bodies produced following X-rays, MRI’s, CT scans, PET scans etc. (see Levitt 2010). There is then a cultural and historical context of holding up certain types of patients – of the poster boy or girl – both in the form of the medical case study and as advert. But what does it take to be a poster boy in a neurological rehabilitation setting and how are these stories told? Contained within the extracts of success stories above (and others like them) there are seven key tenets which make up a poster boy and the stories told about them.

5.2.1.1 Low expectation of further rehabilitative potential

The first characteristic of a poster boy success story is an initial low expectation of rehabilitative potential. Staff speak of residents being considered to have reached their ‘rehab potential’ or reached a point of ‘plateau’. This low expectation is not one made by staff at the centre itself but comes from HCPs who have met and worked with the resident prior to their admission to Goodleigh Hall or Bracken Lodge, and have already tried to rehabilitate the individual. For example, in an interview with a therapist who was talking about one of the poster boys at Bracken Lodge, she said:

I know it was lack of motivation because therapists up to that point had just done everything in bed with him, they had written him off, the doctors had written him off as well so he wasn’t going to have any more [rehabilitative input].

Clara, a Therapy assistant talked about the surprise generated by Mathew’s progress:
when he first came [...] the person who came from CHC [funder] he was blown away that it was the same person

Poster boys tend to be admitted along with a low expectation recorded in a report which considers them to have no or limited further potential for recovery or a prognosis given in discussions between members of the referring or current treatment team and those who assess residents for admission to Goodleigh Hall or Bracken Lodge. The occurrence of these discussions between teams is evident within multidisciplinary team meetings at the data collection sites where potential new admissions were discussed. These discussions include the reporting of discussions held between rehabilitation centre accessors and the current treating team in the NHS hospital.

A low expectation of rehabilitation potential can also be directly linked to and based on the severity of the initial brain injury and the diagnosis itself. In some cases, like in that of Donovan and Daniel, certain diagnoses, such as the minimally conscious state, carry a lower level of rehabilitation expectation in terms of the level of functional recovery expected in comparison to more minor brain injuries.

Although clinically, there is a lower expectation of recovery for those who sustain hypoxic injuries than those who sustain traumatic injuries and this rehabilitative prognosis is written about extensively in the medical literature, this clinical forecast does not appear within the talk of HCPs in these places. Staff do not overtly link and pair diagnosis to prognostic expectations and neither do they overtly distinguish between residents’ diagnoses as a way of explaining why some people rehabilitate better than others. Only qualified therapists make any reference to patient diagnosis and the nature of their original injury (e.g. hypoxic or traumatic) at all, but this only occurs to distinguish between those who are fully conscious and those who are in a prolonged disorder of consciousness.
5.2.1.2 The challenge and rejection of a negative prognosis

However, despite the low expectation of rehabilitative potential which accompanies poster boys into the setting, within staff narratives includes a questioning and testing of this minimal rehabilitative prognosis. The potential of and hope for progress is therefore not entirely closed and lost, but judgement is suspended, at least for a time. For example, Physiotherapist Abram said: ‘it was almost, Donovan had reached his rehab potential but then I just took my own assessment, what can I do, what can he do?’ Here, Abram rejects the prognosis given to Donovan as having ‘reached his potential’ and instead asks himself what he as a therapist can do for Donovan, and assesses what Donovan can do for himself. This assessment leads to the discovery that Donovan does have some movement. He recalls:

OK he has got a good range of movement in his leg except in his ankle, let’s start him off on the bike to see if there is any activity. So he had his activity and we built up a good rehab relationship and bond with him and then continued to progress where he was, standing and things. (Abram, Physiotherapist)

Through the rejection of the prognosis of which had been placed upon Donovan, Abram was able to identify that Donovan had some muscle activity. The discovery of this small initial ability was then built upon, with the eventual reward of the restoration of some functional return – here, the practice and process of rehabilitation-as-restoration can be seen.

5.2.1.3 Intensity of rehabilitative interventions

Another key part of the story that is told surrounding both the outcome of these successfully rehabilitated residents includes the describing of an intense and often lengthy period of rehabilitation. This intense period of rehabilitation is characterised by and emphasised as labour intensive for either everyone, or by a key set of individual staff members, working consistently with the resident. The success of the rehabilitation is repeatedly linked to this period of ‘hard work’, which is reflected as coming from both staff and the resident themselves. Betty, a therapy assistant at Goodleigh Hall talking of the rehabilitation of poster boy Seb stated: ‘we’ve worked so hard to get him to this point.’ The point of this telling reinforces the dedication,
the consistency, the hard work of both professional and resident in achieving this outcome. The desired outcome therefore is not constructed as easy, but as toil, as effort and is a story of defying the odds through hard work.

5.2.1.4 Persistence and ‘not giving up’

Alongside the intensity of rehabilitative work, constructed as toil, this intensive period of rehabilitation is coupled with pervasive talk of staff determination, commitment and perseverance in the delivery of their interventions and building relations with residents. A therapy assistant again talking of Seb’s rehabilitation reflects:

Phillipe [physiotherapist] just kept persisting and persisting. This bloke just wouldn’t do physio with him, would not do it but Phillipe just kept going and going and going because we could all see potential in him, we could see that we could get him at that point where he could live independently again. (Betty, Therapy assistant)

And an Occupational Therapist explained:

You have to be patient and persevering as well even if the client may not see what you are seeing because cognitively they may be affected to the point where they are saying what is he doing that for or do I really need this, I just want to sleep but we know sleep, passive activity, does not help much in recovery so we try to improve that activity and give them more practical things to do. (Kerem, Occupational Therapist)

Here, staff connect their perseverance with being able to foresee a positive future for these residents. For Seb, staff could imagine a future of him improving successfully enough to live a largely independent life. This imagining is critical to residents’ actual futures—as here, this positively imagined future drove them to work hard, to provide intense rehabilitation and to persevere with their rehabilitative practice with this resident. This point will be expanded upon later.
5.2.1.5 The demonstration from the patient of consistent progression and improvement in multiple domains

To be a poster boy, residents must display progress, but not any progress will do. The stories told of poster boys always include those residents who have made continuous and functional progress in multiple domains. For example, improving physically, cognitively, behaviourally. This is evident within the story of Seb as told by a therapy assistant who said:

*He came in in a wheelchair, on a one to one because he was aggressive and we’ve got him from not being in a wheelchair, going out in the community, communicating with people, now it’s not verbal communication but he can communicate and to walking.* (Betty, therapy assistant)

Here Betty highlights that Seb has made significant physical recovery, so much so that he can now walk. She explains that he has made significant improvement in terms of his behaviour – highlighting the significance of this change by explaining that he once needed to have a member of staff with him always ‘on a one to one’ due to his aggression, to now being able to go out into the community. She also highlights that he is now able to communicate, although not verbally. The establishment of a consistent form of communication is also highlighted as a key progression made by Seb by other staff members in their stories about him. This pattern of achievement across multiple domains is seen in each poster boy story, every time one is told.

5.2.1.6 Improvement that makes discharge home or into the community possible.

To be a poster boy requires not just improvement in multiple domains and recovering beyond prognostic expectation, it requires improvement to such a degree that going home, or being discharged to live in a ‘community’ setting becomes possible. All poster boys had the potential of being able to be discharged from Bracken Lodge or Goodleigh Hall, due to now being able to do much for themselves and/or no longer needing the level of care, rehabilitative input or specialised input provided at Bracken Lodge and Goodleigh Hall. At the time of data collection Seb was being actively

---

38 Staff refer to ‘the community’ as a non-institutional setting—such as the family home, a small group home, independent living with warden controlled support etc.
discharged and another poster boy, Ezra, had recently been discharged home. The legacy of the success of Ezra’s rehabilitation was evident throughout the three months I was present at Bracken Lodge, as staff repeatedly told me about him and relived both the process of his rehabilitative progress and the moment of his leaving. For example, the story of Ezra was told to me in an interview with an administrator who recalled:

_Ezra was wheeled in and day by day the physio he received it was phenomenal, you know, because he was in a chair. Just seeing him getting out of a chair and taking a couple of steps and then going from one end of the corridor to another and then going around the block, you know the building block, and it is amazing and he walked out, yes, no stick, it was lovely it was really, really nice; even his speech because that was quite affected as well but that improved and it was really lovely, really nice to see it. His wife came and got him and that was nice. I mean he was tearful, everybody was tearful but you know and that is the sort of thing that is nice._ (Maxine, Administrator)

This moment, as can be seen in the telling of it by Maxine above, is full of emotion by the teller. While the words within the quote above note the feeling of both the resident and staff, what is said does not portray the joy with which this is spoken. Strength of emotion felt by staff in both the participation of the resident rehabilitation journey and bearing witness to their discharge home is present across the data set in terms of both interview data and in ethnographic witness of staff reaction following or during the discharging of residents. I observed leaving parties held for residents and the reactions of staff returning to offices having just said goodbye to residents or on their return from accompanying residents to their new abode. Verbal expressions of joy, laughter and smiles are often accompanied by tears, shed as a display of a mix of emotion - in happiness for the resident, in sorrow to be saying goodbye and at times, in concern of letting go of the care given to the resident within the safety of the rehabilitation centre. The emotion shown in these situations and the legacies these successfully rehabilitated residents leave, reinforces the argument that poster boys provide a significant morale boost for staff, and on leaving become poster boys in the true sense that they advertise a process and service although being outside of it.
Even if discharge home or to a domestic environment was not currently in the planning, the likelihood or the expectation that home or living in the community would be the outcome for these residents is always muted. For example, Matthew has made vast improvements in multiple domains and is the resident that the name ‘poster boy’ is initially attributed. On asking the staff member who had so referred to him in this way, what she foresaw for his future, she describes foreseeing him living in a setting away from the neuro rehab centre, but not alone and requiring ongoing support and the opportunity for constant interaction with others.

Donovan too is not yet ready to be discharged and is still requiring both therapeutic and care support. However, Donovan going home is talked about readily by both staff and family informally and by staff in team meetings. In an interview with Donovan’s wife, she tells me ‘Our house is just finishing having work done so yes, then we can start the discharge process to get him home then.’ And therapy assistant Charlie, on asked what she foresaw for Donovan in the future says: ‘I do think he’s going to improve a lot more, he’s going home.’ Charlie’s belief that Donovan will go home is unfaltering and said here without hesitation and with conviction. However, of all the ‘poster boys’, Donovan is the most impaired and has the highest and most complex care needs – but yet his imagined future of home is spoken strongest by those around him. Why his future was consistently imagined and strongly spoken about will be returned to later.

5.2.1.7 The sustaining of rehabilitative progress

To be a poster boy it is not good enough to just improve and be restored. Restoration must be lasting. The sustaining of rehabilitative progress is critical. Many residents had progressed significantly since their admissions to Goodleigh Hall and Bracken Lodge but were not considered ‘poster boys’. Patients such as Eddie and Cynthia for example had made significant improvement during their time in the centres, but these residents had also experienced decline.
Eddie had been admitted to Bracken Lodge following hypoxic brain damage. In an interview with his wife, she describes to me his state on admission, his subsequent improvement and then his decline.

He was completely paranoid [while in an NHS hospital], it wasn’t a good time. The doctors were not really listening, not listening to him, not really listening to me but eventually they had him assessed and we came here. He settled like that, paranoia, the delusional stuff stopped almost from the first day to an extent. For me it was incredible because I had seen him before obviously they [the staff] hadn’t here but I had seen him before and it was quite incredible. [...] Unfortunately, after a while physios, [speech and] language [therapy] all of that had to stop. Eddie went without it for 2 months and in that time he virtually stopped walking and before that he wasn’t in pads he was in pants, he would take himself to the toilet someone would go with him as he was walking with a frame, that stopped virtually. After about a year, he was over there for about a year they decided he was probably could be moved up to [another ward] getting him ready to come home. He had only been up there 2 weeks and his mobility went really bad, he was losing his balance, really bad, so they had to move him down on to [another ward] because he needed to be hoisted which only lasted for a short time but he has been here ever since. (Myla, wife)

In interviews with therapists, therapy assistants and health care assistants they remark on Eddie’s initial improvement but quickly reflect on the challenges of and the uncertainty regarding the cause of the decline in his mobility. Similarly, Cynthia was admitted following hypoxic brain damage and progressed significantly. Staff members, especially those who have worked within the centre for several years remember how Cynthia had progressed and the level of functional return that had been reached. For example, Bianca, a health care assistant recalls:

When I started, she was walking, her mood was always hit and miss how it is now anyway, but she was walking. She was at the gym with the Physio at the time and she would be at the parallel bars and she would have the wheelchair behind her but she would have a little step and Cynthia would do up and down and she would do 70 at a time then have a rest then do it again. (Bianca, Health care assistant)
The way in which both these residents and others who had progressed functionally following admission but had then experienced decline in the centre, are talked about is not in poster boy terms.

Despite their initial rehabilitative success, their decline rules them out of qualifying as a poster boy. Ara, a therapy assistant reflects on the deterioration of Cynthia saying:

*since I started here she’s gone, completely deteriorated with her orientation. Her proprioception’s terrible. When I first started she was walking daily with the physio, she barely goes on the bike now. It is quite sad to see there is a massive change in a year; it is really sad.*

Despite their deterioration and the level of care these residents required, there are plans for these residents to go home. As a health care assistant Crysta remarks *‘I’m excited for Eddie, he’s going home with Myla [wife]. He’s going to be in the best care he can with Myla because she loves him and they’re going to have a nice little place together.’* In each of these cases however, home is only being made possible because of dedicated family members willing to provide significant levels of care for their family member. Being a poster boy requires not only both rehabilitative progress, of functional return but also the long-term maintenance of it.

There is a distinction made and drawn between patients who have ‘rehabilitative potential’ and those who don’t, those deemed ‘rehabable’ and those who are not. Determining both these types (and other types) of residents helps illuminate how their futures are then conceived (or not) and in discerning who has future and who does not.

---

39 a term used in common speech to mean a person who has the potential to go through a rehabilitation process with some level of functional recovery as a result. The term ‘rehabable’ and ‘unrehabable’ is recorded in use in the legal cases regarding the withdrawal of treatment of people in a prolonged disorder of consciousness—namely, the case of Terri Schiavo.
5.3 Poster boys’ futures

5.3.1 Imagined and constructed

Towards the end of each interview, staff members were asked to think about residents in their care, to select several and talk about what they thought their future looked like. Despite the potential selection of three broad categories of resident – 1) those who were rehabable, 2) those who were not rehabable and 3) those who were dying, as all interviewed cared for all resident types, those most readily selected for futures’ discussions were poster boys.

At Goodleigh Hall, the future of poster boy Seb was most frequently referred to and thought of first. A nurse manager said:

> one of the proudest things for me at the moment is seeing Seb going out to see his placements to go home. We have gone so far with him, we have done so well, we have got this man back walking, communicating. He could have a good quality of life. That’s what our jobs are about on [ward]. Getting people like Seb back into the community and getting him to move on. (Beatrice, Nurse manager)

Seb’s future is constructed as leaving the setting, going home or back into the community, and living independently. Similarly, Mercy (a Therapist) also speaks of Seb’s future in this way, saying ‘Ideally the future would be him moving on to some supported living environment.’ Seb’s future then is imagined as a point of discharge, but the details of a future beyond his new place and type of abode goes largely unspoken. This pattern of future as a point of discharge, as a place of living and the unimagining of anything broader can be seen through the talk of other staff who spoke of Seb and other poster boys. However, while talking about Seb’s future, one health care professional, Mercy, did imagine a future for Seb that went beyond the point and place of discharge saying:

> He would benefit from some community work, particularly community speech and language therapy, to work with him in a transition from here to wherever he is going to be long-term. A small community, it doesn’t need to be in a nursing home, he needs to be somewhere like a group home type of thing would be ideal for him I think. Some level of support, he is independent with his toileting, he needs prompting with his showering, but someone that could help him with his meals allowing him to be as independent as possible but supporting him. (Mercy, Therapist)
Here Mercy talks about Seb’s future in terms of a transition point between one service and another. She provides a more specific imaginary of the type of place in which Seb needed to live in, in the future. She speaks of a set of daily needs which require to be met in his future place of residence. She goes a little further saying:

we would go into his own community and work with him within his local community so, how far is it to the local shops to go and buy his cigarettes? and actually do that a few times with the staff that would be looking after him so that the local community would be able to assist with that transition.

(Mercy, Therapist)

Here Mercy begins to talk about a life outside of the potential new abode, Seb having a future where he can be supported to go to the shops to buy his own cigarettes and that this would best be achieved by both Seb’s current care team and any new team working together, with him. However, this future of having daily needs met and a trip to the local shops to buy cigarettes largely mirrors Seb’s present concerns. The way in which his future is discussed is not opened up – but extended to largely continue, to be the same as it is today. His future is discussed as being both positive and successful by staff but yet it is presented with minimal opportunity or imagination for further development or change.

Similarly to Mercy, other staff spoke of poster boys’ futures as extending outside of a point of discharge home or alternative location. For example, Kerem spoke of poster boy Luke saying:

He is going to be able to maybe change from being a motorcycle mechanic maybe to a motorcycle mechanic tutor. While he is improving physically he may not be able to spend more time sitting, standing, bending, kneeling, it will take a long time but knowing that he is that way can make him somebody who can sit there and say ‘no that is not right, try that’ so it is still within the motor link and its field but it is a different call, a step back and then can instruct others. This is what I envisage to be his future this is what I see but I don’t make him lose hope because I still tell him what we want you to do is make sure you may not do exactly what you want but you will do something as near to be comfortable about. (Kerem, Occupational Therapist)
Here Kerem imagines both future activities for Luke to work towards and a potential for future employment. However, he also explicitly states how his work with Luke is not necessarily about creating a future that Luke would ideally want, but trying to make a future that is as near as possible to the future Luke imagined for himself prior to his brain injury. Kerem works to achieve this by working through Luke’s interests to re-shape an alternative but linked future.

To summarise, the futures of poster boys are consistently described in terms of a) a point of discharge and the location of living away from the rehabilitation service, b) variable levels of day-to-day independence or support to enable the fulfilment of some community-based activities (i.e. shopping) and c) some potential vocation or return to time with or role holding within their family. Poster boy futures however were also discussed in terms of ongoing need and strategies regarding how support could be continued to be given for them to be able to live away from the rehabilitation centre. While any return either to ‘home’ or ‘into the community’ was seen as a successful and positive outcome there was a distinct lack of the future lives of poster boys being imagined as much more than day-to-day survival in another place. Rarely (other than in Kerems’ comments) were vocational or activity hopes or opportunities open to these men discussed. Their futures, while deemed successful were largely unimagined and where they were, imagined within a framework of extreme limitation.

5.3.2 Unimagined, hampered and constrained

The way in which the futures of poster boys were imagined has already been shown to be deeply limited and unimaginative. These futures as a point of discharge and a life away from the centres however are seen as both positive and also permanent. However, the futures of poster boys were not only stories of imagined linear onward and permanent living away from the centres but instead, were contested and discussed in terms of being limited, hampered and constrained.
For one of the key poster boys at Goodleigh Hall, Seb, while he had been extraordinarily successful in terms of his rehabilitation, his future was still not his own. The discharge process of Seb from Goodleigh Hall was in action towards the end of my observational time there. The staff had held multiple conversations with Seb regarding where he would like to go, where he would like to live. The team had established that Seb’s wishes were to live close to Goodleigh Hall, not in the county he had come from. Despite his request, Seb was placed in a residential setting within his home county. The removal of choice from Seb regarding a key aspect of his life was taken by social services and commissioners who were to finance Seb’s onward living arrangements. Their decision, which did not respect his choice, was received as deeply upsetting to staff at Goodleigh Hall who had worked closely with him. Perhaps precisely because these poster boys had progressed to such a degree in rehabilitative terms, having their future curbed by those outside of the organisation or through other means such as funding restrictions were met with anger and upset, so much so that several non-qualified staff who had worked closely with Seb during his time at Goodleigh Hall were reduced to tears.

Alongside such constraint, future imagining surrounding the lives of poster boys were full of worry. Staff often spoke of the potential of an alternative future for poster boys, a future where they may return to a life prior to injury, a life and lifestyle which in some cases led them to injury in the first place. For example, staff expressed concerns regarding the potential that Seb could return to a certain type of lifestyle which could threaten his safety directly and/or lead to the improvements he had made through rehabilitation being lost. Beatrice reflects:

_We have got to get this man out I don’t want him to go backwards. We have got this man back walking, communicating. As long as he doesn’t go back out into the community and go back to the old ways with bad people he could have a good quality of life._ (Beatrice, Nurse manager)

Francis also expresses her concerns about the possibility of negative alternative future for Seb saying:
we’re a bit concerned, apparently he went to, [visit supported living accommodation]. When he came back, his behaviour is gone down. He stayed in his room, he banged the door, he was a bit tearful and I’m concerned that when he goes, he might go back to how he was. (Francis, nurse)

This alternative future for poster boys as one, not of continued improvement and successful re-integration with and in the community but one of potentially going backwards or one of continual constraint is presented in fact by Carol, a therapy assistant who worked ‘in the community’ outside of the units in a connected service run by one of the sites. Carol talks about two brain injured men who had returned to the community following rehabilitation, one to their own home and one to housing where they are supported around the clock by carers.

Talking about what she foresaw for these two men who had been living the classic poster boy future as heralded and foreseen by staff, a life of permanent discharge, beyond the walls of the rehabilitative centre and in the community, Carol problematizes this future of linear progress. She says about one man:

_Potentially he might have to move out of his home, maybe back into a Care Home or carry on having support 24-7. He is quite happy because he is around his own people in his own home. I think he will go along with whatever is going to happen with him._ (Carol, therapy assistant)

Here Carol highlights that the futures for poster boys do not necessarily permanently pan out the way imagined by staff, in that they do not necessarily have a future where they retain the improvements made during rehabilitation, but have the potential of decline. She also presents a passive engagement with the future for this man who she considers will ‘go along with what whatever is going to happen to him.’ Carol continues, speaking about the future for another brain injured man who she supports, Miles:

_As far as Miles goes, oh my days, I would like to be able to say one day he would own his own property and he will be able to see his children whenever he likes. Up until the point where reality sinks in and you realise he has an awful long way to go because he is just not at that point where the professionals are happy enough with him for him to move on in that respect,_
so we deal with him day-to-day, with Miles we deal with him day-to-day. What the future holds is anybody’s guess. (Carol, therapy assistant)

Here Carol imagines a positive future for Miles which is different to his current situation. However, she instantly problematizes the potential future she has just imagined highlighting that this is not something which will come to fruition in the near future, but is instead, a distant future for Miles. Because the positive future for Miles is, in temporal terms, a long time away, Carol reinstates then that the way in which she and those who work with Miles ‘deal with him’ is ‘day-to-day.’ Here then because the future feels so far away the temporal approach to the care of and a subsequent existence for Miles reverts to being ‘day-to-day’ and yet again, the future is bracketed out.

Carol explains why Miles’s future is hampered and the positive future potential she imagines is so far away. She explains that his future is impacted by his brain injury because he continues to want to live the life fitting the age he was when he was injured. His brain injury prevents him living and developing as he biologically ages. She explains:

Although he is 30 years old I would say he is about 18. He is very much a lad, he is very much into females, into loud music and going out with the boys but he is quite strange because his friends without brain injury have moved on, they have got married and had children. He had children at a young age exactly the same but the difference having a brain injury, he is very stagnant where his friends have carried on. Acting, behaving, generalising everything about a 30 year old should be doing but his culture holds him back because he thinks he should be doing all these things. (Carol, therapy assistant)

For Miles, his brain injury prevents him doing more for himself, extending his horizons and is preventing him developing. Miles was brain injured when he was a much younger man – of around 18. He perpetually lives in this age and the mind set associated with that phase of life because unlike his friends he has not developed and changed in terms of life style, work and family. He has missed many rites of passage and is unable to engage with and go through those which are still appropriate to his age and open to him now – these are no longer open to him. However for Miles, his future and his potential for development is also hampered by
the social world in which he was brought up and the ‘culture’ of those around him. Carol, who has worked with Miles for over four years explains:

*He does still associate with friends he has made over a very long time since childhood which is good to a point. Some of his friends are very nice but drugs play a big part, weed plays a big part. No-one makes any money, their culture is a non-working culture, it is social services with the children, it is the job seekers every 2 weeks. The culture over where they live is very much the same, that will never change, they can have all the responsibilities in the world but that will never change. Although you can’t take the culture out of the person and you shouldn’t, for Miles it is his downfall.* (Carol, Therapy assistant)

Later in her interview (and at a meeting I observe where Miles’s progress is reviewed by a professional multidisciplinary team), the negative impact of Miles’s drug use is revealed. The drug use exacerbates symptoms such as aggression and further reduces his motivation, ability to concentrate and remember. These issues with cognition prevent Miles being able to develop, follow routines and make commitments. This in turn prevents his ability to work and sustain employment and to supervise his children.

These two men were ‘poster boys’ during their inpatient rehabilitation, their rehabilitative success would have been heralded, as they fulfilled the rehabilitative imaginary. However, the reality of home and their future is not glowing, but limited. The latent effects of brain injury show in their today and severely impede their imagined and actual tomorrow.

On asking staff to consider the futures of other residents, especially those who weren’t rehabable, staff often struggled to imagine a future or construct an alternative future for residents who had severe impairments, were not poster boys and those who were not showing significant rehabilitative progress. For example, on asking Maddie, an Occupational Therapist to think about what the future looked like for a non-poster boy type of resident she says: ‘*You sort of want to pick someone a bit more positive (laughs) you know, um, oh my gosh, it is so hard to try and imagine actually.*’ However, after long pauses in interviews and significant thought, staff could offer some thoughts about what life may look like for others they cared for.
5.4 The futures of non-poster boys

Aside from poster boys one female patient and a young male patient with more severe impairments were mentioned as having futures. These residents were not making consistent or rehabilitative improvement across multiple domains, but were making progress in some areas. These residents were able to demonstrate clear and consistent, albeit slow improvements in terms of returning awareness or function in these two cases.

One resident, Marta, was considered by a health care assistant Philippa to be ‘coming along leaps and bounds’ as she had recently been able to begin to manage a couple of mouthfuls of food, had started using a speaking valve and regained some small movements in her arms and legs. Staff imagined that the future for this resident would see her making slow but continual functional improvement which could lead to the removal of her tracheostomy, an ability to eat and drink some food and fluid and communicate verbally. Although spoken tentatively, a broader future was imagined for her by one therapist Mercy, who said: ‘if we can get her weaned off her trachy she is a possibility. I think there is a chance she could be supported in the community.’

The progressions made by Marta however were made towards the end of my time at Goodleigh Hall. At the beginning of data collection Marta was seen as deeply challenging for staff and often distressed and frustrated by the severity of her impairments. She experienced several episodes of illness and in rehabilitative terms she had made little progress. Through frustration and concern about the distress felt by Marta, staff would frequently sit with me and lament over her current state. They expressed frustration at feeling able to do so little for her and were unable to see a future of any type of improvement for Marta. If anything they were concerned that she may in fact deteriorate. However, because she had begun to make rehabilitative improvements the future for Marta could then be imagined.
Aside from Marta, an Occupational Therapist, Maddie, spoke of a male resident, Lee who is in a minimally conscious state. Reflecting on a recent assessment she had been involved in carrying out she said:

we are seeing there is some tracking, we’re seeing some good response to oratory stimuli; so I would be interested to know if we can harness some of that [...] when you are giving him things, he’s maybe not making the choices but he is aware that there are two things in front of him because he looks from one to the other but you have asked him to look at the ball, he hasn’t done that, he’s not following the command but he knows there are two things … For someone like him could I give him back some quality of life if he is able to look between two things and make him start selecting something so … can I hold up different pairs of trousers and would he choose… (Maddie, Occupational Therapist)

Here Maddie explains that following a sensory assessment, it has been established that Lee has some awareness of his environment. She explains that when two objects are placed in front of him he can look between them. Because Lee can do this, that opens up a further potential which enables Maddie to look onward, to think about and imagine the possibility of Lee being able to identify the objects and eventually, maybe make a choice between them. She explains that if he can make a choice and indicate his selection this may enable him to have some control over his environment. However, Maddie identifies that a future for Lee, and other residents like him, is so limited because:

no matter what you do or what change you see, it doesn’t change the care needs. There is the profound disability and impairment there and it will always be – can I say it will always be? Pretty much, you can pretty much say it will always be full hoist with assistance of two, full rolling, full bed bath with the assistance of two, wheelchair user, attendant propelled wheelchair user. That outcome doesn’t change and it is like yes but if you have gone to the effort to find out someone has got some awareness and some consciousness you should give them some sort of life associated with that; even if it is just a little preference around you know making some communication choice. So, I would like to give him a crack and see where we get with him, that would be my best hope to see if somehow I could give him a means of demonstrating preference. (Maddie, Occupational Therapist)
Here Maddie both opens the future for Lee and then immediately closes it down. She highlights how through his recently established awareness of two objects, this may lead to the opportunity for communicating choice in the future, however, at the same she explains that no matter how much he may progress in terms of communication and choice his life will remain largely the same, the level of impairment and his needs will remain.

Even if Lee is able to indicate a selection between two objects or areas – he is still only able to select between two options. He is limited to a choice of two things, neither of which he may want. In such a situation ‘choice’ then is illusionary. Being able to ‘chose’ between two things does not necessarily open up anything for him or improve the quality of his life. The pursuit of this therapeutic aim and its achievement does not necessarily contribute to an improved future for him – and in doing so offers a present action that falsely represents a possible ‘improvement’.

While the futures of poster boys look to independent living and being engaged in activity and vocations, Lee’s future, at best, is imagined as being able to make a single and everyday choice. The future for Lee is focussed on ‘quality of life’ within a care setting, not of home and work. His future is one of hoped for minute improvement to enable choice making to open up his utterly closed world just a little. His future is largely about physical maintenance and ensuring comfort of the everyday. The importance of the everyday and those who make and attend to the mundane, in this context of future making is discussed next in chapter 6.

The temporal reach of the futures imagined for these people by staff are short and conceived of more in terms of an extended present than future. As can be seen in Maddie’s and in Mercy’s interviews, for those with severe impairments but who are making slow, small and steady improvements, the future is imagined in a compressed manner, is broken down and focusses upon the next small step. This temporal condensing and shortening has been highlighted earlier in terms of the operationalising usage of ‘goals’ to manage time, and in discourses of health care. In
chapter seven I highlight where and how such temporal management can cause tension and be met with frustration by both residents and their families.

In contrast, for those who have severe impairments but rehabilitate successfully, although their future is also severely limited, there is some temporal expansion afforded to them. For those like Marta the extended present imposed on her and her care as she previously struggled, has now been opened as a broader possible and imagined future, given through her making slow but notable rehabilitative gains. The futures of people with severe brain injury then can be both closed down during periods of stasis, but opened up and their futures temporally extended from an extended present to future if they are able to demonstrate signs of progress.

How and whether a future is imagined for residents with severe brain injuries through the rehabilitative process largely follows the ups and downs of residents’ physical and cognitive rehabilitative progress. The imagining of lives beyond an extended present however is only afforded to those who make consistent progress. For those who are unable to recover in this way, the future for them goes unimagined by staff and their lives and the focus of the care surrounding them looks mainly to this afternoon, to tomorrow, to next week, but does not extend further.

While a future could be imagined for those who were either rehabilitating well (poster boys) or making consistent progress, the future for residents who were not making active rehabilitative process was never spontaneously spoken about. Only through direct probing in interview and asking staff to consider the futures of residents did any mention of the futures of those with severe impairments who were making little or no functional progress were discussed. In situations where residents were not rehabilitating staff told lamenting stories of how care and rehabilitative therapies had been tried, often over long periods of time but for a range of reasons – such as uncontrolled medical conditions or symptoms following brain injury such as seizures or recurrent infections some residents did not make progress in terms of functional gain. In these situations, the narrative staff gave about the lives to come
for these people focussed on achieving the best ‘quality of life’ and every day comfort possible for these people. Kerem, an Occupational Therapist tells one such story saying:

*when there is so many epileptic seizures one after the other, we found as far as her therapy is concerned all you can do is to do our best to make her life better but not to give any new skills. I was feeding that client and she just had seizures, 1, 2, 3 of them 4 and 5 that day, it was the worst day. She has been in and out of a hospital now and again ... now, being in a neuro rehab institution we look at it and say are we still giving you rehab? it is not rehab anymore so that client needs to go into care because our role at the moment has actually diminished to zero.* (Kerem, Occupational Therapist)

Here Kerem highlights that recovery is no longer possible for this person and rehabilitation is no longer being delivered. Because this resident is no longer deemed to have rehabilitative potential Kerem states that she should ‘go into care.’ Here he means that the resident should be transferred to a place of care which purely provides care and does not provide rehabilitative services. Many staff and families spoke about how residents who are either unable to rehabilitate or who are no longer rehabilitating should go to an alternative care setting. This is expressed by a therapy assistant Ara who reflects:

*...essentially rehab potential has been met and they need to go on to a long-term placement it’s just a bit sad because you think of all the other people out there who have brain injuries, these guys could be moved on to somewhere more suitable so they can have a more fulfilled life and then you could get people in to do rehab.* (Ara, Therapy assistant)

Here Ara suggests that for those unable to rehabilitate they both prevent the rehabilitation of others by remaining and would also have a better quality of life if they were cared for elsewhere. Similarly, family member Helene who stated strongly:

*I just think you need to recognise when enough is enough for a lot of people and as awful as it sounds the money that is spent on keeping those people alive needs to be spent on the ones that need the rehabilitation help. Let those that want to die and have no quality of life go and that money put in to helping those that have got the chance for rehabilitation.* (Helene, daughter)
The required movement out of the rehabilitation setting of those who are unable to rehabilitate further is presented in terms of these people without a rehabilitative future preventing or blocking the possible rehabilitative future of another, who may benefit more from the rehabilitative services on offer at Bracken Lodge or Goodleigh Hall. Here the acceptance of a curbed future for one resident was highlighted as a potential of preventing future for another should they remain.

The movement however of residents who do not rehabilitate or are not rehabable is minimal within the settings. In actuality, the majority of the beds at Goodleigh Hall and Bracken Lodge were taken by those who were not actively rehabilitating and fell into this category of those who had reached their rehabilitative potential and were in need of ‘care’ but not rehabilitative services. Why was this the case?

5.4.1 Cash cows

During observation and interview, the problems which prevented the discharge or transfer of residents from Bracken Lodge or Goodleigh Hall to another setting was discussed. In an environment where futures are imagined largely as a point of ‘discharge’ or transfer from one place to another, this is not surprising. For those who had reached their rehabilitative potential and were considered in need of care but not rehabilitative services, reasons given for why these people were unable to leave the rehabilitative setting and be cared for elsewhere fell into two themes – the complexity of their needs and finance.

5.4.2 Complexity of needs

All residents at Bracken Lodge or Goodleigh Hall were considered ‘complex’ in medical and care terms. Their initial admittance to these services already signify that they have significant and multiple needs and are complex in terms of their neurological and/or medical presentation. Those who are brain injured and not complex do not reach the care of specialist rehabilitation and long-term care services in the independent sector. This is explained in chapter 6. ‘Complexity’ is determined
by policy (The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care 2012) and related assessment documents which define complexity through the presence, severity and unpredictability of multiple problems across physical, psychological, behavioural and medical/nursing domains (see NHS 2012). In-particular ‘challenging behaviour’, mental health problems and neurological symptoms such as spasticity require specialised professionals and services to support people with these symptoms. Long-term care facilities outside of the specialist neurological rehabilitation and care settings like Bracken Lodge and Goodleigh Hall provide care for people who have some care needs but often do not provide care for those with these more ‘complex’ symptoms. This means that in many cases there is nowhere else for them to go to, nowhere else where they can be cared for.

At Bracken Lodge, while they had a high number of people who had reached their rehabilitative potential and some were considered in need of long-term care elsewhere, there were also many residents who had reached their rehabilitative potential but were not considered to be in need of care in a care home. These men and women were often able to walk, talk (or communicate through other means reliably), eat and carry out activities of everyday living with minimal physical support but had significant problems with their memory, their ability to understand and severe behavioural or psychological problems. They could for example display aggression or anxiety, be disinhibited and sexually inappropriate, experience severe depression or other mental health issues. For these men and women, the problems they had with memory and their behaviour and mental health meant that they were deemed ‘difficult to discharge’ because again, places of care or support teams in the community were often unable to meet the care needs of these brain injured individuals. The consequence of this was that residents who had reached their rehabilitative potential remained at Bracken Lodge and Goodleigh Hall for long periods of time, even in circumstances where it was recognised that they no longer needed to be there or would be ‘better off’ elsewhere.
5.4.3 Finance

Second, while Bracken Lodge and Goodleigh Hall primarily promote their rehabilitative services, they do also provide care in the longer-term, precisely because as described above, there are brain injured people who are unable to be cared for in other places. What is critical for these places of care and care businesses is that their beds are full. Those who are unable to be cared for elsewhere and remain at Bracken Lodge and Goodleigh Hall in practice provide a stable and constant cash flow for the business. While ‘poster boys’ promote the rehabilitative service providing in these settings and boost the morale of staff, those who do not rehabilitate as hoped, but have complex needs which require skilled personal care beyond that in standard nursing homes act as ‘cash cows’. The constancy of the finance provided by those who remain in beds for the long-terms enables both the survival of the service but also its rehabilitative services and any business growth. In this way, those who do not rehabilitate and remain in these places of care and of rehabilitation in fact enable the potential of a rehabilitative future for others who have brain injuries and need rehabilitative services. Contrary to them ‘blocking’ a bed that could be filled by someone who may rehabilitate – they enable a rehabilitation service to be provided, for some.

Poster boys and non-rehabilitating residents each play a critical role in enabling the survival of rehabilitation centres and the services they offer. Different resident types – those who rehabilitate, those who do not and those who die, support and serve the needs of one another. Each have a critical role in both the present of and future for one another.

Conclusion

This chapter has shown the pervasiveness of the rehabilitative dream in the talk of staff at Goodleigh Hall and Bracken Lodge. I have highlighted how one type of rehabilitating resident acts as ‘poster boys’ for the rehabilitative imaginary. These residents boost the morale of staff working with people with severe brain injuries, many of whom do not significantly recover post severe injury. Poster boys and their
'success stories' advertise the rehabilitative service provider but also promote rehabilitation as a process, the rehabilitative therapies and specialisms which make up rehabilitative care.

Residents who are able to show rehabilitative progress (regaining the functional abilities lost through brain injury) have a future, in that a future is imagined for them by staff who care for them. These residents fulfil the rehabilitative dream. This chapter however has highlighted that even the future imagined for a poster boy, is not an entirely open one of further progression and independent living, but is contested, and often heavily compressed and curbed. Even the futures imagined for these successfully rehabilitated individuals is unimaginative and constitutes mainly a place of discharge and a type of living arrangement. Little else is imagined for the future lives and what they will look like for these residents.

The futures of other residents, unable to rehabilitate in the same way as poster boys, were largely unimagined and considered very difficult for staff to imagine. The pervasiveness of the rehabilitative imaginary in these places of care affects the way in which futures for other residents, unable to rehabilitate are imagined, and if they are at all. The rehabilitative imaginary brackets out an imagined future for others and closes down the horizons for those who do not and cannot be poster boys or girls.

For those who are unable to progress and will not make any further recovery, futures are rarely imagined at all. When pushed in interview to think about the life of non-rehabilitating residents staff spoke of their lives as an extended present and explained how they focus on ‘quality of life’ for these residents in the now, tomorrow or next week. Lives for these people then are temporally restricted, being imagined in weeks and months only. How open or limited a resident’s future is imagined mirrors the ebb and flow of an individual’s rehabilitative progress. While the future can seem closed to residents unable to show progress, if they do show signs of recovery, a future can and is then reimagined for them. Future imagining therefore is not static but is in a constant state of flux. For residents who do not fit the
rehabilitative dream (and are not dying), the imagining and working towards a future
that is as open as the future of a poster boy can however be somewhat buoyed. A
future can be imagined and opened up if residents have the unfltering support of
their families. Families who are committed to providing practical and emotional
support can make it possible for those unable to be largely independent to be safely
cared for outside of Goodleigh Hall and Bracken Lodge. Through family support,
futures can be imagined for those who have severe impairments and are not making
rehabilitative progress.

Such residents who do not have families to help create a possible future of ‘home’
are deemed to be in the wrong place and worse, are deemed by both staff and some
families to be preventing the rehabilitative future of another person. These residents
are therefore reclassified from rehabilitative resident to one who requires ‘care’. Some
staff then make attempts to dispose of these types of residents to make way
for more potential ‘poster boys’ with whom they can conduct ‘true rehab’. In
practice however, those who require ‘care’ but are not rehabilitating are often not
‘moved on’ because they hold significant financial value to the health care company
and often have complex and multiple care needs. The skills required to care
appropriately for these types of residents are often absent in standard nursing homes
or community support teams and therefore those unable to rehabilitate further
remain within rehabilitative care centres and become ‘cash cows’ for the business
sustenance and development.

While the pervasiveness of the rehabilitative dream, which is the outcome for only a
fraction of those within the walls of Bracken Lodge and Goodleigh Hall, help to hold
up hope – and the morale of staff, I argue that this ideal is disproportionate to the
reality of rehabilitation in these places and acts to bracket out the imagining of the
futures of those who cannot fulfil the rehabilitative dream. Critically, these non-
rehabilitating people require an alternative future to be imagined for them and by
those who work with them. Those who attend to the everyday of residents’ lives,
those who pay greater attention to residents who do not rehabilitate, what they do
for them and others is the focus of the next chapter.
Chapter 6 – Futures in the making – being made ‘rehab-ready’ and rehab-able in and through the everyday

6.0 Chapter overview

Chapters three and five discussed how the focus on restoration and ‘return to’ is pervasive both in the neurological rehabilitative literature, ‘professional’ discourse and my ethnographic data. The rehabilitative dream/imaginary remains the overall treatment aim surrounding some residents in rehabilitation centres in the independent sector, and their care is steeped in this language and rehabilitative practices. Yet – as shown the previous chapter - it is absent from the care and treatment of others, who undergo ‘rehabilitation’, but for whom return to or restoration of prior selfhood is not possible. What then does ‘rehabilitation’ mean in such a context? The word ‘rehabilitation’ is derived from the latin ‘rehabilitare’, from ‘habilitare’, which means to ‘make able’. In the previous chapter, the focus was on the exceptional, the ‘poster boys’. However, this thesis largely tells a story not of rehabilitation as restoration or return to, but of (re)habilitation, as a process of re-living, to ‘make able’ to live and be in the world in a new way. This new way however is far from romantic. This chapter (and the one following) highlights the problematic reality of the futures of people who ‘rehabilitate’ but cannot be restored to their former self, for them, their families and the staff members caring for them. This chapter focuses on those who are not deemed rehabable, those who are not ‘poster boys’ (or girls) and asks who cares for them and are their futures as simple as just unimagined? It shows how the care of those deemed not rehabable falls largely to those who do not have rehabilitative credentials – those not recognised within the literature and in practice to be part of the multidisciplinary team. It is this group of non-specialised workers (care assistants, cleaners, cooks, maintenance personnel) who make able and enable these residents to be in the world.

As I’ve shown in chapter 5, only certain patients are deemed rehabilitative material, to be ‘rehabable’ – able and possible to be rehabilitated. But how do patients access rehabilitation? How do they get to be rehabable following catastrophic injuries to their brain and subsequent periods of critical illness? In this chapter I unpick and
critique medicalized conceptualisations of rehabilitation as process and future orientated by drawing out the discrepancy between how rehabilitation is formally presented as ‘organised’ and structured and how it is practically accomplished. Expanding on the temporal discourse surrounding rehabilitation, I draw on the concept of ‘lived futures’ and will highlight the non-linear way in which ‘time’ and temporality in care organizes or arranges the lived experiences of those receiving and giving care. In addition, I will highlight the critical place of the mundane and every day in brain injury rehabilitation in the shaping of the lives and futures of people with brain injuries. This chapter explores these ideas with the aid of two new concepts - ‘rehab-ready’ and ‘rehab-able’, which are derived from my close analysis of the participants’ talk, practices and actions.

6.1 Being ‘rehab ready’

Staff, particularly therapists, talk about how some patients that are in rehabilitation beds are not ‘ready’ for rehabilitation, meaning they are not yet ready for the formalised programme of rehabilitation as delivered by the core specialisms and its specialists. Maddie, an Occupational therapist, talking about her work in a previous rehabilitation setting that had a fixed time of 180 days that patients could stay for highlights this idea of patients not being ‘rehab ready’.

```
we just got the most complex and severe and as a result it just became more post-acute because patients that have that complexity of needs are usually [...] just emerging so all of a sudden we were going from the rehabby sort of people that were getting around, but needed a few months physio, speech or OT and you would probably get them home, but all the while probably a 1/3rd of the ward was always made up of minimally conscious patients [...] So you kind of got two ends of the spectrum [...] yeah OK they are complex but that is not necessarily meaning they are ready for rehab, but you’ve got this 180 days thing now [...] probably day 170 they are at a stage where I want to start doing rehab with them, and they are able to engage in rehab. (Maddie, Occupational Therapist)
```

Here Maddie highlights that some of the patients who had been transferred from the acute service to a rehabilitation bed were still medically unwell and therefore not able to engage with the demands of rehabilitative therapeutic input. There is a specific ‘problem’ of not being rehab-ready, specifically for patients who have
already been in rehabilitation beds but not been rehab ready. Maddie, the same Occupational therapist explains:

Woo hoo finally we have weaned them off the oxygen and the difficulty was, there wasn’t really anywhere to send them to because [...] they should step down to a rehab facility and we had been that, so by becoming a level 1 unit we then shot ourselves in the foot in my opinion of having then nowhere to send them on to. So, it is a bit dissatisfaction. The intensity of care had gone up but the benefit of therapy wasn’t necessarily there, and then as you did see them starting to progress, you’re like great, OK, they have to leave us as they are not a level 1 patient anymore, but I really want to send them somewhere for rehab, but “oh look we don’t have anywhere”; I kind of a struggled with that. (Maddie, Occupational Therapist)

Here, Maddie is explaining that if patients are not rehab-ready while they are in a ‘Level 1’ rehabilitation bed, they cannot stay longer until they are ready for rehabilitation. They have therefore potentially missed their opportunity to receive rehabilitative input because they were not ready for rehab while in a ‘rehabilitation bed’ and there may not be a ‘level 2’ rehabilitation unit (another place where rehabilitation is delivered) available to them now that they are ready.

Kay, another Occupational therapist further highlights this problem of a fixed time in an NHS rehabilitation bed. She discusses the problem of patients being in rehabilitation settings too soon, when they are not rehab-ready and the problem of the ‘disposal’ of these ‘not-ready-for-rehab’ patients.

Kay: I don’t agree with a 60 day length of stay on a neuro unit, I just think it is ridiculous, and the pressures from all that, it is just a horrible, horrible place to work.

JL: What happens to patients at 60 days then?

Kay: On discharge they become bed blockers and then there is all the associated issues around bed blockers where they try to push them here, there and everywhere. Um, most of them do stay longer than 60 days and I know that is and has been under discussion with the whole kind of major trauma pathways and all that; they are getting people who are more acutely unwell so you can’t impose 60 day stay on somebody you can’t actually rehab because they still got every limb in plaster, so I just – it just didn’t sit comfortably with me.
These ‘not-ready-for-rehab’ or ‘not ready for rehab quick enough’ patients are now out of time and unable to remain in the rehabilitation bed. They get re-categorised, discharged and transferred elsewhere. These patients are in many instances transferred to receive slow-stream rehabilitation. The temporal and the tempo (speed, pace and intensity in this instance) is central to and underlies this movement in, out and within rehabilitation, its places and services. This becomes overt in the renaming of the stage and process of which these not ready-for-rehab patients will now enter. It is these not-ready-for-rehab ‘type’ of patients that formed a large subset of those with brain injuries at Goodleigh Hall and Bracken Lodge – places that provide slow-stream rehabilitation and long-term care.

The concern about what happens to or could happen to ‘not-ready-for-rehab’ patients who are in rehabilitation beds however is so significant that there are attempts to ‘hold on’ and ‘keep’ such patients or reclassify them as ‘rehab-ready’ through the technical work of setting goals. Maddie explains:

*There was always still the few that kind of snuck through [that] you managed to keep on grounds of having loads of goals set for them so (laugh).* (Maddie, Occupational Therapist)

With the transfer out of the NHS rehabilitation bed comes a change in service provision, place and a perception that the intensity of rehabilitative input (the amount and time patients receive therapy for each week) is reduced. This perception is expressed by both clinicians and families. While the ‘intensity’ of formalised rehabilitation in the independent sector is explicitly discussed as being different to that provided in level one NHS rehabilitation units – this is done so precisely because patients are not ready or able to benefit from or respond to such input. The benefits of this slowing of pace and its use to differentiate between services and define this stage of rehabilitation is highlighted by Kay talking here about the service at Bracken Lodge:

*I think the discharge planning is another thing that I think we do very well here because NHS discharge can be so rushed; you have to get them out get ‘em home. Yes we do still have pressures on us to get them out from funders,*
sometimes they say we want them out, OK fine but actually if we sit there in our meeting and say we think they need da, da, da this is what they are here for, this is our graded discharge programme. We have done that and we have done some very prolonged graded discharge programmes that I don’t think I have ever seen anywhere else. (Kay, Occupational therapist).

On asked to give an example of such a discharge process, Kay describes two lengthy processes which led to the discharges of two brain injured men home or back to their home area living independently in new accommodation. Below is one of the descriptions she gave.

There was another guy who had been here for 2 or 3 years. He would shout and throw himself on the floor and hit out at you if you tried to get him to leave the building. Eventually we got him to the shops, started going to the pub and he was to be discharged back to [home town]. From here to [home town] is not an easy journey so before we could take him there we had to find out whether he could manage that length in the car. We literally went out for a drive and we drove around for an hour and went somewhere for lunch. Eventually he started going to visit the Headway Service [in home town] and his community therapist was coming in to see him. They would meet him here, take him to Headway [town], spend a few hours there and then bring him back. They got him a bungalow and he started visiting that and he was eventually discharged [back to his home town] with a community package. I can’t imagine doing that back in the NHS because we are talking months here. (Kay, Occupational Therapist)

Here Kay’s description highlights the length of time the rehabilitation process for some residents takes – in this case at least 4-5 years and how through the extended time they have to rehabilitate residents, discharge and semi-independent living was made possible for this man.

6.1 Preventing rehab readiness

Maddie and Kay noted above that patients arrive in to ‘rehabilitation beds’ acutely unwell and because of the level of their medical needs at that time, are not (yet) ‘rehab-ready’. Reflecting on this, throughout the data both staff and families comment on an array of occurrences and factors which render patients not-ready-for-rehab, or not able to be rehabilitated – not only in the post-acute stage following their injury, but at different times during their rehabilitative path. For example,
families report that transfers from one rehabilitation setting to the other, clinical interventions and operations to manage secondary complications following brain injury all prevent patients being ‘rehab-ready’ for sometimes prolonged periods of time. For example, Emily, the wife of Donovan, a severely brain injured man reported:

*When Donovan first came here he had only been here two weeks and he was going in for quite a big operation to have shunts so that he could have more of the fluid drained off. When he had that done we don’t know if the operation knocked him back quite a bit and he had just moved as well... After that Donovan went really low and he wasn’t doing any writing any more he would just sit and he was very sleepy. I don’t think he sat in his wheelchair very much as much as he was before but I think it would have been about 4-6 months after that when he started to pick up again.* [Emily, wife]

6.1.2 What happens to those who are not rehab ready?

Patients who are not rehab-ready and have been unable to be rehabbed during their time in a level one unit or other acute hospital setting within the NHS, are in many circumstances transferred to places like Goodleigh Hall and Bracken Lodge to continue their rehabilitation over a longer period of time. While the core set of professionals named and discussed earlier in chapter 3 work within these places of care and treat these patients over long periods of time, there are also many others who work in these places and provide forms of care and services for these severely brain injured people. These include non-qualified care workers – such as health care assistants, therapy assistants and another group - cleaners, cooks, maintenance personnel and administrative staff - a group of people I collectively call ‘hotel service staff’.

As the ethnographic observations were conducted often in communal areas or at the bed side, the presence of non-qualified care workers and hotel service staff, and the absence of the members of the multidisciplinary team quickly became apparent. It is the work and the interactions they have with residents and the role I found them to be playing in the rehabilitation of people with severe brain injuries that I focus on
now. Their work, the way they work and the contribution they make to the care and residing of patients with brain injuries, their lives in the now and their futures is distinctly different from ‘qualified’ therapy staff.

The reduction in ‘intensity’ of contact with therapists and nurses enables and allows for time for ‘other’ interactions to take place. The care of these people who are not ‘rehab-ready’ falls to non-qualified care and non-clinical workers. The change of intensity and pace and the longevity of patient length of stay in these places is mirrored in the change of name that ‘patients’ are given. They shift from being ‘patient’ to ‘resident’. This change in label is demonstrative of the way in which both service and living occurs. ‘Patients’ are treated, ‘residents’ are helped to dwell and live. This emphasis on living is critical as through interactions and care of non-qualified carers, therapy workers and hotel service staff, residents’ rehabilitation does not stop, instead they are made ‘rehab-able’ through the conduct(ing) of the everyday. I will expand on this point below.

The next part of this findings section explores how the work of non-qualified care and therapy workers, through their care and interaction with residents, makes them rehab-able – focusing on two key domains, humour and atmosphere/environment. The following part demonstrates how the work of hotel service staff and their interactions with residents fit five key formal rehabilitative domains as defined and delivered by qualified rehabilitative professionals: cognition, physical function, occupation, communication, behavior/sociability - and highlights how rehabilitation in these places is the work of a much broader team than is conceptualized in the neurological rehabilitation clinical literature. This section highlights how these staff, through the conduct of the everyday make them rehab-able. The third and final section explores the experiences of these workers in conducting this interactive, informal rehabilitative work and what they face in the work of making others able.
6.2 Non-qualified care and therapy workers

Non-qualified care and therapy staff made up a significant part of the workforce of Bracken Lodge and Goodleigh Hall. Named ‘health care assistants’ (HCAs), ‘rehabilitation assistants’ (RAs) or ‘therapy assistants’ (TAs), these people are employed to predominantly deliver ‘personal care’ and directed, repeatable elements of technical therapy – as closely advised and directed by qualified therapists. In one setting, these roles were distinct, with the delivery of personal care the main role of the health care assistant and the delivery of ‘therapy’ the role of the therapy assistant, while at the other site, there was an attempt to combine these roles. This attempt however was experienced by those employed, in title only and not in actuality, as personal care and therapy in practice remained two distinctive roles, with the blurring of ‘activity’ delivery only, but not ‘therapy’. Care workers whose role meant they delivered personal care only repeatedly spoke of their wish to learn more formulated therapy and to have the time away from the pressures and requirements of delivering routinized personal care. They proposed this move would enable them to interact in a more therapeutic manner with residents, to conduct therapeutic activities with them and spend more time doing social based activities such as shopping and visiting places of interest.

This quote from Bianca is indicative of that expressed by nearly every HCA and RA spoken to.

*Just so we could actually do rehab as well as just washing. We have been trying to get activities done now in the morning and of an evening. The evenings have not been as easy to do but like between half eleven and quarter to one we have been trying to do, even if it is just one to one person, because that is what we signed up to do. To go out more, more outings.* (Bianca, Health care assistant)

TAs however, who were delivering ‘therapy’ tended to talk about how they wanted to develop their therapeutic skills and wished that there was more scope and support from within the organisation to get residents out of the institution and ‘into the community’. On asking HCAs what they felt helped patients and what they
themselves did to help patients, they would readily highlight the role within rehabilitation (and the effectiveness of) formal therapies. They would then remark that they themselves did not get much chance to see or be involved in the delivery of these therapies. One HCA remarked:

_We’re not really present, we obviously have to assist them into chairs and stuff ready for whatever, but we don’t participate. We see maybe a few stretches or something but, obviously in certain circumstances the stretches and that we can see some benefits of, because if they’re less stiff then obviously, we would notice that when we do care._ (Cassidy, Health care assistant)

However, HCAs would consider themselves able to observe, generate responses and be responsible for the care and caring of other areas of residents’ lives and the place within which they resided, such as ‘atmosphere’. The occurrence of the work and interactions about which HCAs talk about can be evidenced by extensive observational examples of them doing and achieving all they say. The following section utilises both interview and observational data to discuss and demonstrate how non-qualified care staff contribute to the rehabilitation of patients with brain injuries.

### 6.2.1 Generating ‘response’ through humour

In the care of people in PDoC, people whose level of awareness is often difficult to ascertain (and diagnosis contentious), rehabilitative care and therapy is geared towards the continual assessment, observation and attempt to generate and detect evidence of awareness, of consciousness. The assessment of these residents’ level of awareness is largely conducted in a highly objective way by specialised therapists. However, in practice and in the day-to-day, the observation and interaction with these patients with the aim of trying to both generate and ‘see’ responses, is the work of all staff and residents’ family. Conducting ‘observation’, assessing ‘awareness’ and generating responses is rehabilitative work conducted not by specialists alone, but by everyone. This work both in conduct and the interpreting of response is complex both in clinical and relational terms.
HCAs often identified themselves and their work as contributing to generating responses in these PDoC residents. They highlight how their work differs from that of therapists and other clinical staff in that they generate response through very different means; the use of ‘banter’ and humour being one such approach. Cassidy, a HCA, talks about how a resident responds to the use of banter around him. She said:

*I think we notice more things relating to atmosphere more so, like you’ve seen the banter this morning with Lee and you could see that he was reacting somewhat to it, you know it was noisy, it was chaotic, we were having a bit of a laugh, nothing inappropriate was said, nothing derogatory towards him was said, it was just pure old banter and having a laugh. And you could see he was trying to raise his head and follow what was going on in the room, you know. So you see sort more that kind of thing that goes on.* (Cassidy, Health care assistant)

The moments of care of which Cassidy speaks and the use of banter in these interactions was witnessed and captured during observations. The use of humour and banter however was not limited to interactions with those in a disorder of consciousness. Humour formed a significant part of the relationship between non-clinical workers and other brain injured rehabilitating patients who were fully conscious. The purpose of using humour according to staff is to improve resident compliance with personal care tasks, especially in situations where residents displayed ‘challenging behaviour’, improve resident motivation to participate in group activities and to lift their mood. One health care assistant describes one such scene.

**Cassidy:** *I mean I try to make everything a joke, especially with Archie because I find that I get more out of him. If you could have seen the day that he said moo, because obviously we went from the God thing to the and then Maria called me cow and I said “I don’t think he’ll say ‘cow’, that’s nearly as hard as God” and we carried on and we just heard ‘moo’ really loud*

**JL:** *Wow! [JL laughs]*

**Cassidy:** *Just really loud and really clear and we both stopped for a split second, I swear I was dying, I was hanging on to the bed, I couldn’t stop crying with laughter [JL laughs] It was so funny [JL laughs] it was quite comedy gold, you couldn’t have timed it better.*

**JL:** *Do you think he surprised himself as well?*
**Cassidy:** He did, he really genuinely did and after that moment we’ve been slowly trying to work on it [...] we try and talk every day, even five, ten minutes, see how he’s going. It’s what he wants to do. He’s asked to try some more words with me, in terms of speaking, but he doesn’t want it put in a health action plan, because he doesn’t want to be told that at, let’s say ten o’clock every morning he is going to talk. That’s not what he wants, he wants it informal, he wants it, if he feels like it and I’m available he wants to try a few words, and he wants to keep it simple.

Through humour, Archie, a resident with extreme disability and complex impairment, unable to move and unable to speak, is enabled to say a word. He is made rehab-able through every-day banter. From this one moment, an informal set of rehabilitation plans were made – to attempt to practice speech. For this resident, he had become very frustrated with formulised speech and language therapy. Through these social means and through his relationship with this carer however he began to attempt to speak. In this instance, laughter, humour did something else asides the generation of sound and speech. It also generated movement. The following extract is taken from an interview where myself and the carer recount this moment.

**Cassidy:** we spend probably twenty minutes longer with Archie in the morning because we spend so much time laughing.

**JL:** It was amazing, when I was with you and Maria showed him the moo socks, remember that day?

**Cassidy:** Yep!

**JL:** The laugh rippled through his body and it’s amazing isn’t it, it was like it exploded in this physical way, and of course he can’t move can he, but the laugh moved his entire body, it was remarkable

**Cassidy:** It was

**JL:** So much so that Patsy put her hand on his chest to stop him [falling off of the bed]

Archie could not move any part of his body other than his head yet laughter produced movement, when he laughed, his body moved, he generated movement through laughter, movement which could not be generated in any other way. Through laughter, Archie is able to generate abdominal pressure and activate his diaphragm to support the generation of sound. Laughter also enables him to activate some abdominal activity which initiates chest movement. Archie is unable to do this with conscious effort and for him, laughter
importance of humour, and how it supports rehabilitation is also noted by family members. Emily, the wife of a severely brain injured man Donovan explains how her husband both favours working with people who have a good sense of humour and who give ‘banter’ and how that boosts his mood.

*It is just the way they are, they have a joke and a laugh, they took the time to understand the type of person he is by looking at his pictures and asking us about him. We would tell them about his personality and I think they knew by looking at Donovan he is a bit of a lad, likes a bit of a laugh, so they all have a joke with him and it really perks him up, you can see he enjoys that. I think Donovan works better when somebody is outgoing with him and just chat away to him and get to know him because it takes him a bit longer if there is somebody new and a bit quiet and shy, I think he finds that hard and don’t know quite what to do. (Emily, Wife)*

For Donovan, staff and family recognised that the use of banter and humour enhanced his ability to ‘work’ at his rehabilitation. Staff recalled a therapy session where a group of Donovan’s friends visited him and joined the session. They provided him with encouragement while joking and teasing at the same time. Staff state that the effect was that Donovan worked to his maximum within the session and was able to begin to step. They relate this positive session to the banter delivered by his friends and his will to ‘show off’ in front of them. The use of humour then is linked by staff to playing a critical role in making residents able. Although not in the typical sense of action, humour generates responses and subsequent movement/action(s) which take them towards achieving some type of rehabilitative outcome.

### 6.2.2 Attending to atmosphere

Non-clinical staff contribute most significantly to the generation and monitoring of the atmosphere in the main areas in which residents dwell. Attention to atmosphere is given and modified in relation to resident needs. This is reflected by

is the only way he is able to activate some musculature in his body. I was able to identify this occurrence and make the point about the role of laughter due to my professional background as a physiotherapist. My clinical experiences and neurological analysis skills have influenced the way in which data here has been analysed.
one family member Myla, who talks about how a change in environment from a hospital to rehabilitation centre made a significant change to the behaviour, mental health and wellbeing of her husband following brain injury. She reflected:

**Myla:** When he first came here he was sort of, he could actually walk, they put onto the JBU but after the first night they realised he needed to be on OCU so they took him over there. He settled like that, paranoia, the delusional stuff stopped almost from the first day to an extent. For me it was incredible because I had seen him before obviously they hadn’t here but I had seen him before and it was quite incredible. They were very calm over there, everything was very quiet it was a very small place there wasn’t a lot of noise going on, things like that, so it was quite calming for Eddie.

**JL:** Do you think that calm environment was the key thing that made that change or was it something else that they had done?

**Myla:** I think it played a huge part towards this because obviously where he was before in a hospital it was very noisy, there are things going on all the time, lots of noise, lots of, you know, he was disturbed a lot of the time and, of course, when he came here that stopped; yes I think it played a lot towards calming him down.

Attending to the needs of residents included the personalisation of the environment they were in. For example, staff remember the individual likes of residents and applied their preferences to the creating of environments. For example, staff used the science fiction interests of one resident to select films and music and the femininity and popular culture of another resident to set the mood of her room – turning on pink fairy lights and selecting popular music for the radio. The efforts of staff and the importance of personalisation was noted by family members. For example, Elaine, the mother of Lee, noted how staff recalled his interest in cooking and their selection of cooking programmes through the television in his room.

Alongside personalisation of the immediate environment, staff also thought about the atmosphere on the whole ward and in communal spaces. They recognised the importance of its control for both clinical and rehabilitative purposes, and the problems an unmanaged environment caused. Speaking about a breakfast group Lucy, a therapy assistant said:
We have got TV up there so we put the radio on in the background or we give the residents a choice, sometimes they want to watch the news and that can be a talking point. We have to be careful not to really distract people from eating because that can cause coughing episodes that you don’t want but it is a lot of them out of the environment. When you have breakfast on the unit it is kind of staff shouting at each other ‘can you help me with somebody, can you do this, can you do that and the residents don’t have the independence to use the skills they have because it is the time and it is not the staff’s fault it is just obviously, they are quite stretched and have to get people up so when half are having breakfast and half are getting up it is quite a busy time. So I think we alleviate a little bit of pressure for the residents who want more time and really benefit from having more time as well. (Lucy, Therapy assistant)

Here Lucy identifies that both time and environmental control is critical to enabling and supporting residents to conduct and practice tasks, such as getting their own breakfast. Lucy also identified the ‘therapeutic’ nature of ‘doing’ the everyday.

For example, she talks about the impact of what sharing food in a ‘breakfast group’ did for residents.

Being able to be on a unit earlier and be involved with someone at the beginning of somebody’s day it is a different kind of relationship you get with them; I think it is really nice. Originally it was set out the idea of the breakfast group was an OT Group for instance with them we had potential for residents that needed behavioural management, people that weren’t getting up early but had wanted something to get up for and so it is nice to have that long 2 hour period where they don’t have to be rushed to get ready or do anything and it is just nice to sit and you can see people reacting much more positively because there is less noise and distraction. So like yesterday although Seb cannot communicate verbally, Matthew was looking out for the butter and he just passed it over and it was like “oh cheers mate” and I had never seen them talk before and it was something completely unsupported by any of us but it was an awareness of each other and about themselves.

From when it first started to now the speed of processing you can see the difference because people know what is next in the sequence and not looking at a teabag thinking where does this go; they are like yes teabag and having gestures for the water and the milk and the spoons; it is really nice because you can see those little changes. (Lucy, Therapy Assistant)
Although these care staff often questioned their role in true rehabilitation given their non-qualified status and whether what they did could be called ‘rehabilitation’ or not, there was a recognition from some that the work they did, did contribute to rehabilitation. Some staff recognised that their work with residents enabled residents to access rehabilitation delivered by professionals, that there was a need and a process of making certain residents ‘rehab-able’. As highlighted also in chapter 5 Philippa, a HCA expresses this succinctly during an interview saying:

*I don’t class our unit as rehab but I suppose it is in a way because you are actually getting them to a point where they can be rehabilitated even more.*

(Philippa, Health care assistant)

However, the conducting of therapy and care in and through the everyday is not limited to therapists, assistants and non-qualified staff in care job roles. Those who worked in administrative, catering, maintenance and cleaning roles, collectively referred to here as ‘hotel service staff’ also worked with and through the everyday with resident.

**6.3 Hotel service staff do this through the conducting of the everyday**

**6.3.1 Cognition**

The work of hotel service staff involves significant interaction with residents around complex social and functional processes. Through the conducting of the everyday, hotel service staff can assist residents whose abilities to communicate, interact and remember are impaired – helping them around issues such as memory, ‘orientation to time and place’ and planning. For example, a finance administrator at Bracken Lodge interacts with patients on a daily basis as they come to her office to either access or return money for safe keeping. The extract from field notes below charts one such scene.

[Luke, the resident, comes in to the office and Ben, a carer, appears at the office door. Maxine, the administrator is stood at her desk searching through wallets containing individual patient money and financial information].

**Maxine:** *Luke wants his card.* [addressing Ben]
[Luke nods. Maxine stands behind her desk and holds a credit/debit card and a piece of paper looking at Luke].

**Maxine:** *I’ll give you the piece of paper* [Looking at Ben] *Have you got a pen? Luke wants to change his pin to one he can remember.*

[Maxine informs Luke and Ben that Luke needs to take the piece of paper with the pin number on it so that he can remember it. Maxine mouths to Luke that his pin is ‘xxxx, his birthday’. She tells them that they need to write down a new pin once they’ve changed it so that Maxine can put it back with his card in the money wallet when they come back in case Luke forgets the new number].

**Luke:** *You’ve got enough money* [nods towards the money wallets on the table and the cash tin].

**Maxine:** *How much?*

**Luke:** *Three hundred.*

**Maxine:** *What for?*

**Luke:** *Going with mum.*

**Ben:** *He’s going to [town] with his mum to buy clothes.*

**Maxine:** *That’ll have to last you all month, ok?*

**Luke:** *Ohhhkaay.*

What Maxine has done here and does every day is aid patients in learning and understanding processes and rules – in this case, about money. She re-teaches a skill which is required in everyday life – how to use a banking system – the going to a place to both access and deposit money. As can be seen with her interaction with Luke, Maxine requests that patients account for their expenditure. The extract is just one illustration, Maxine also monitors residents’ understanding of the value of money and current prices when they request monies, asking them what they are going to use the money for and checking that they understand how much they cost. Brain injured residents can significantly under or over-estimate the cost of a train ticket, a meal out or a packet of cigarettes and when they do Maxine corrects them. She also has a protective, safeguarding, role: talking to them about the need to safeguard their own
money—showing how money is locked away, reminding them that excess monies must be returned to her and showing them how it goes back in to their individual money wallets—their own ‘account’.

Maxine’s technical work provides an informal banking system for residents but her interactional work with them enables an opportunity for the (re)learning of contextual processes which both mimic and feed into real life banking, accounting skills, an orientation check of their understanding of today’s contemporary finance, safeguarding monies and co-designing adaptive strategies to combat short-term memory issues. All of this ‘fits’ with cognitive rehabilitative techniques which a health care professional such as an occupational therapist would look at when assessing a patient’s cognition and communication during conducting a functional task such as banking.

6.3.2 Orientation

HCPs working in brain injury rehabilitation continually assess whether or not ‘the patient’ is orientated ‘to time and place’. In medical, nursing and therapeutic practices, this checking of orientation is often done as part of cognitive assessments but ‘orientating the patient’ is also done as a practice, as an intervention. At Bracken Lodge and Goodleigh Hall – ‘daily orientations’ were practiced as the one-off tasks of therapy assistants mainly or sometimes health care assistants.

For some residents, ‘orientation’ formed the start of the day as they are instructed to gather together in a morning meeting. In these situations, the extract below shows how ‘orientation as practice’ is done. Simon is a rehab assistant, Luke and Eddie are residents. Simon is stood by a whiteboard and asks:

Simon: *Can someone tell me the date?*
Simon: *What day is it?*
Luke: *Friday.*
Simon: *Where are we?*
Luke: Bracken Lodge
Simon: In?
Luke: [English city]
Simon: Yes. Let’s start with Mr Eddie. What you got?
Eddie: Morning meeting at ten. Late.

‘Orientation’ as it is meant and practiced here is in effect a repetitive series of questions. Question about calendar dates, days and clock time, about institution and geographical location and about a series of planned daily activities, which are scheduled at the beginning of the week and then recorded publicly each day at a group meeting. The activities recorded on a board are there for residents to refer to throughout the day. However, there is more to being orientated than ‘orientation as practice’ and to being orientated to any given moment: orientation includes orientation to an individual community, to spring to summer, to lunch-time, to match-time to Christmas-time.

In comparison to the more formalized therapeutic practice of orientation, hotel service staff provide orientation for residents in all sorts of ways and in ways more akin to a sense of local time. They do this through the routinisation of their work, so for example, the cleaning of communal areas and residents’ bedrooms remains the same each day. These repetitive working processes provide a sense of local time – local organisation entirely specific to the setting but which passes and indicates the time of day in this place.

Their presence alone can be telling; the arrival of catering staff on the wards announces that it is time for breakfast, lunch or dinner. For example, at Bracken Lodge, the anticipation of lunch is worked up throughout late morning as catering assistants walk around the building announcing what is on today’s menu. The clattering of pans and cooking smells, the intensification of chatter and singing in the kitchen and the movement of staff in and out the closer it gets to lunch time creates a buzz – a lunch time atmosphere, letting patients and everyone know that lunch is on its way. More directly, as catering assistants walk in and out, they are often asked ‘when is lunch?’ or told ‘I haven’t had any breakfast’ and they gently inform the
current time, the time that lunch will be and how long it is before it will be on its way - and they remind residents what they had for breakfast. In this way ‘orientation’ is not a singular therapeutic practice but an ongoing and continual one, contributed to by all.

6.3.3 Physical function

Hotel staff also aid residents with physical functioning. Brain injuries can cause significant motor disturbances – abilities to both activate and control muscles and movement, co-ordination and sensation can be severely damaged. Common in brain injury are problems with mobility (moving, walking), upper limb function (reaching, grasping) and ora-motor control (chewing and swallowing).

At Bracken Lodge and Goodleigh Hall catering services paid real attention to the production and presentation of meals for residents who have ‘modified diets’, so those requiring food of a certain consistency due to difficulties with swallowing or other ora-motor dysfunction – food that is either soft or entirely pureed. These modified diets are produced for all meals for residents’ safety but also, chefs and catering assistants produce foods of varying consistencies for speech and language therapists to ‘trial’ patients on. This enables speech and language therapists to see if residents can ‘cope’ with a new consistency – meaning, can they swallow the food or drink without ‘aspirating’ (inhaling food or fluid into the airways). The production of these modified meals is critical in both ensuring the safety and rehabilitation of residents’ swallows, but also critical to providing nutrition and energy.

In addition to the production of meals of different consistencies, catering staff think about and through food to enhance both resident mealtime experience and create rehabilitative opportunities. For example, catering assistant Allegra talks about how they use the colour of food to help residents who have pureed and fork mashable foods to be able to identify what they are eating:
So if we’re making a stew for example you’d whack everything in a pan. To a person on a normal diet you’d have a stew with mash and veg, but someone with a specific diet requirement like fork mash or puree, instead of putting the carrots in the stew, because when you blend it, the colour just looks a bit gooey, you cook it separately. So it’s just the lamb, with the carrots with gravy and some mash [all separated on the plate] so you can actually distinguish, see what’s what. It’s nice for them to identify what they’re having, and usually, the foods relate to colours and you know [what food is on the plate] so it helps. (Allegra – catering assistant)

Brain injured residents may also have both altered taste and visual deficits so identifying foods can become very difficult for them. Here Allegra recognizes not only the issue of the food losing its form, but also the type of impairments patients may have. By techniques such as using bright colours, shapes and space in plated purred meals, Allegra seeks to assist residents in identifying what they are eating.

In terms of mobility, during an interview with a housekeeper, Ally highlights how when she is cleaning on the units and a resident comes to the cleaning trolley she will walk with them.

*When I was on the unit working regular [...] I suppose we give them quite a bit of attention really, give them a walk if they come to the trolley.* (Ally – housekeeper)

While elements of the technical work hotel service staff do contribute to and enable the rehabilitative efforts of specialist staff (i.e. a speech and language therapist, dietician) the spontaneous interactive work of hotel service staff, such as housekeepers walking with residents, contributes to aiding physical functioning. Beyond this, some hotel service staff independently recognize residents’ physical impairments and seek to build these concerns into the technical work they do. The attentions of these staff to the challenges that neurological deficits cause for residents in the everyday make both a rehabilitative contribution but are also acts of care – enhancing residents’ quality of life.
6.3.4 Occupation

A wide range of activities for residents are organised and run by hotel service staff at Bracken Lodge and Goodleigh Hall. For example, at one of the sites a gardening group was planned, organised and run between a maintenance man, Geoff and therapy assistants. Geoff had met with the therapy assistants to organise what was needed and undertaken preparatory work for the group including clearing the greenhouse, buying compost, seeds, sorting pots etc.

In one gardening group the task for that week was planting seeds. A group of five residents, all with very different impairments attended. Residents welcomed each other as they came in and asked one another how they were – a level of engagement between them that wasn’t visible day-to-day. They filled pots with soil and planted seeds aided by therapy assistants and an Occupational Therapist. The occupation provided purposeful use of upper limb function and the meaningful practice of fine motor skills. Residents attended to the task while engaging in occasional banter with one another and the staff present. In addition, conversation about and through the task was generated - what seeds were being planted, how they had to be planted, how deep, etc. and how long they would take to grow was discussed. This provided some residents with the opportunity to share their gardening knowledge.

But at one of the sites, ‘occupation’ was taken much further. The two maintenance men at Bracken Lodge, Mick and Asher, engaged residents in maintenance work for the centre – including both residents currently rehabilitating and those who have left but were still requiring high levels of care in the community. Those still rehabilitating at the centre would work with Mick or Asher and be started with a few tasks such as painting rooms or some basic plumbing. Residents were instructed step by step in their work and for those who worked with Mick and Asher, some were then afforded a broader work experience by being invited to take a ‘break’ in the staff room. One man who was now living with 24-hour support in the community had been contracted to work back in the centre with the maintenance men three to four days a week. For this individual, not only did the work provide occupation and payment, but keeping
his job required following rules and fulfilling certain requirements – attending to personal hygiene, planning and organisation for example. The work also provided him with a routine, and occupation, aimed at reducing the risk of him returning to substance misuse.

6.3.5 Communication, behaviour and sociability

Hotel service staff were asked what they thought was good for or helpful to residents. They repeatedly reported that residents needed more stimulation than they received, staff that they trust and that know them and the appropriate therapies to help them rehabilitate. But while these service staff had a strong sense of what ‘good’ for residents they always missed the magnitude of what they themselves did.

Having asked Hilary, a receptionist, how she found interacting with residents she responded:

*I like speaking to them and I say morning to them, even, like Donovan, sometimes he’ll put his hand up and whatever he can manage but I always say hello or morning to them, I could never sit there and just ignore them*” (Hilary – administrator)

Donovan was profoundly impaired and his cognitive processing very slow, with a long delay between any command and action. Donovan being able to raise his hand in the moment – in direct relation to, in response to Hilary’s ‘Good morning Donovan, you alright love’ – was something only being generated by his social interaction with her.

Hotel service staff assist in the generation of appropriate responses and appear to positively affect residents’ mood and behaviour through the provision of occupational tasks, conversation and socialising opportunities. For example, at one site, an entire afternoon of entertainment was organised by one of the maintenance men, Asher. The party was arranged weeks in advance and everyone was invited. Asher cooked for all the residents, staff and visitors aided by the regular chef and the catering assistants. A band set up on the lawn and at mid-day everyone gathered
inside and out and were fed. Residents who often appeared depressed danced, men who frequently displayed aggression and fought with one another sat together joking and chatting.

Hotel service staff observe while they work and get to know residents so well in some instances they are able to identify behavioural patterns and attempt to correct behaviour deemed inappropriate or dangerous. They do this primarily by verbal prompts informing the resident that their behaviour is inappropriate i.e. “That’s not a very nice thing to say Mark”, or if they know the resident well, they give a short and single instruction requesting the resident cease their behaviour. Hotel service staff however recognise that single requests or statements are often ineffectual at changing behaviour and so prompts are often followed by an attempt to distract or re-direct. This is done by either attempting to engage the resident in conversation i.e. ‘I saw your mum came in to see you last night’ or an attempt to re-orientate with the reminder of a forthcoming event, i.e. ‘Come and sit down, dinner will be ready in a minute.’

At both sites food is at the centre of all celebrations. Catering staff create seasonal spreads, which include pureed, fork mashable and ‘normal diet’ options creatively presented as demonstrated in the Halloween feast prepared at Goodleigh Hall pictured in Figure 1.
Catering assistants spoke about how they made sure that at celebrations, everyone is enabled to be included and eat (or taste) the same food (if not entirely fed by percutaneous endoscopic gastrostomy) by it being carefully modified.

We got bonfire night coming up so we’ll do some research. Obviously, they’ll be the normal diet clients, the forkmashable ones, we’ll see what we can combine. We had the [themed] day, the normal [diets] had [flavoured] chicken, the fork mashables and the purees had the same thing but we just had to make sure there was no bone in the chicken, so, they’re enjoying the same foods, the same calories, same protein, same fun, same [flavoured] chicken but just different consistencies. It’s just not making that person feel left out. (Allegra – catering assistant)

Hotel Service staff think through food to keep patients safe, but also consider their needs to be able to enjoy food, and more than that – they use food to express and celebrate cultural diversity within the care setting and enable inclusion in the sharing food at social events and celebrations.
6.4 The experiences of hotel service staff

The first section of this chapter demonstrated that the way in which hotel service staff conduct their work and interact with residents constitutes a type of informal rehabilitative work, contributing to residents’ care and rehabilitation, but how do hotel service staff feel about what they do? What role do they think they play? And what does it do for them? This final section attends to illuminating the experiences of hotel service staff.

Hotel service staff were asked to talk about their experiences of starting work at Bracken Lodge and Goodleigh Hall. Many reported that they were alarmed by what they saw when they first arrived - to such a degree that they weren’t sure if they’d be able to cope with working at these places. The experience of Minnie, a housekeeper, is echoed in the accounts of many hotel service staff:

> Oh I was shocked, so shocked, I thought ‘oh God’, I couldn’t believe it, you know, the sort of people you come across and how they are and what’s happened. It’s just, I found it quite upsetting at first, yeah, I thought ‘I don’t know how long I can stick this for’. (Minnie – housekeeper)

Their ‘shock’ came as a result of seeing patients’ impairments and disfigurement and the mechanisms of their injuries. One administrator talks about the first time she saw a resident who had had a craniotomy.

> I think it was the first time I saw her without her hat it was like it took my breath away it was OMG and it is that initial shock isn’t it? Like with the carers they all knew about it and it that different level and again because I haven’t worked in this industry it was like ‘Ooh’ and I go goosey all over. (Administrator)

Some talked about being nervous of the machines (suction equipment, nebulizers, ventilators). Several explained how they felt worried when they are with these patients on their own. One explained how she used to worry when patients in disorders of consciousness would cough and appear to ‘stop breathing’ and that she would call for help in a panic.
They were also shocked by the behaviours of those with brain injuries and affected by the sounds some residents made such as moans and grunts: ‘it sounds awful.’ They also recounted being yelled, screamed and sworn at, having things thrown at them and even being attacked by residents. Some like Minnie, a housekeeper, talk about these experiences in a matter of fact way:

*It’s quite a difficult unit on there, one of the more difficult ones I think because it’s loud, you’ve got wanderers, you have got some that can be violent as well.* (Minnie – housekeeper)

Others discuss the fear they can feel when around patients with challenging and aggressive behaviours, one housekeeper recalled how she and another domestic used to shut themselves in an office to protect themselves from an aggressive patient on one of the wards who used to ‘go for them’. But despite the dangers of the work, hotel service staff spoke about how these experiences were ‘just part of it’ and that they had just ‘got used to it.’ To ‘get used to it’ they seem to enlist strategies of knowing and getting to know residents. As Maxine says:

*With regards to clients I felt scared because I didn’t know how to interact but obviously that just came with getting to know people on the floor, getting to know the staff, realising what individual clients could and couldn’t cope with and understand and all that sort of thing.* (Maxine – administrator)

And in other cases, they simply learn through experience, how to look out for signs of potential aggression and develop quick reflexes.

*There’s been several that they’ve tried to take a punch at my face and luckily I’ve ducked out the way […] I’m always careful, if I know what they’re like, if they’re not in a very good mood, you can [laugh] get a punch in the face but I’m always wary of that to be honest. Once you get to know, the people that do that, I’m sort of, I’m quite quick to move away!* (Minnie – housekeeper)

Some are aware of the dangers and highlight their needs for information about patients:

*I think people forget we are part of the team. […] I’d have to ask but I wonder if we are allowed to read patient files, because we need to know quite a lot about these people. If you’re not a carer going in to do personal care, you’re*
often in twos aren’t you, but we’re alone in rooms …. If they’re aggressive then they’ll be a trigger, there’s always a trigger. I make a point now of asking about residents. (Ally – housekeeper)

Many hotel service staff felt that they themselves and their work went ‘unseen’ and wasn’t valued by others. They tended to underestimate the technicalities and accomplishments of their day-to-day work and spoke about how they didn’t always feel like part of the team. However, that was not always the case – some did have a sense that their work fed into something bigger, into caring for residents. Maxine, a finance administrator reflected:

I do enjoy it and it is nice to see the clients come in but then walk out, so it is very humbling, very humbling. […] you see the progression and the improvement that the clients are making, you know, you see them wheeled in in a chair and then they walk out and it is lump in throat time, yes. You feel like OK I haven’t physically helped but you somehow are one spoke in that wheel. (Maxine – administrator)

And Allegra and Clare, catering assistants, support this idea of everyone having a role in care, explaining how the maintenance man, Mick got, involved with requesting a cake to be made for a resident’s leaving party:

**JL:** So I noticed the other day when Daniel was leaving someone had made him a cake.

**Allegra:** Get me! Yeah

**JL:** Whose idea was it to make him a cake?

**Allegra:** It was both of our idea to be fair

**Clare:** I think more Mick though actually […] We had him coming in going ‘I wanna cake. A Manchester City one’ Ok!

**Allegra:** We found out that Daniel was leaving a week before we made the cake. We were like ‘Oh we should make him a cake’ and then Mick said ‘he loves [sports club]’. But this is the perfect example of the, how we work well as a team because Mick is a maintenance manager, he’s got naff all to do with care or cooking!
Some highlighted their own frustrations about not being allowed to meet the needs of residents when they either felt they could, or at times, even had the training and experience to help.

*If I see a patient with wet trousers, I tell someone [...] [but], why can’t we do it [help them change]?* (Ally – housekeeper)

One housekeeper talked about how historically domestic staff had assisted care staff at meal times, helping patients to eat their meals but that had been stopped and they were no longer allowed to do this.

The domestic and administrative staff talked about how the interactional work they did with patients gave them a feeling of worth and added value – something that they did not feel they attained through the technical work they were employed to do. Megan (a housekeeper whose main task is cleaning the units) on being asked how she felt about her work, and how she came to work there said:

*Megan: If I’d known what it’d involve I wouldn’t have gone for it, but it’s too late now, I’m here and I love it.*

*JL: Why do you love it?*

*Megan: The people, people are really nice here [pause] and I’ve gotta sing to Frankie.*

Frankie is a young man who is minimally conscious. Staff who work regularly with Frankie believe that he recognises voices (although this had not been formally assessed at the point of data collection). Every day Megan cleans his room and sings as she cleans and she notes her singing to Frankie as an important part of her daily work. And Ally, a housekeeper, highlighted that her job entails much more than what is in the title.

*We’re housekeeper, part carer. Everyone has the same role – we’re all responsible for the health and wellbeing of patients, in whatever way. [...] I like the interaction with residents. It gives you a bit of feeling of worth instead of mopping floors.* (Ally – housekeeper)

Interacting with residents transforms the mundane technical work they do into care
and rehabilitative work—giving these staff an added sense of value and increasing job satisfaction.

**Conclusion**

This chapter has highlighted how hotel service staff and other non-clinical workers contribute to both the care and the rehabilitation of residents with severe brain injury. They do this first, through the technical work they carry out which provides a service or fulfills a variety of day-to-day ‘needs’—such as the providing food, a clean environment, maintaining the working of everyday things—water, sewerage etc. Second, they carry out their work with the needs and impairments of residents in mind. In doing so they conduct their work in a way that acts as forms of rehabilitation. Food is not just prepared, it is specially adapted and presented to assist the meeting of nutritional needs alongside helping residents to overcome visual deficits, potentially enabling more self-feeding for example. Interactions about money are crafted into informal cognitive sessions assisting with processing skills, memory and orientation. Third, in addition to the technical work they are paid to carry out, hotel staff go above and beyond to interact purposely with residents in big and small ways, providing opportunities for socializing and providing appropriate stimulus such as singing to residents with profound impairments.

How hotel service staff conduct their technical job roles and what they do in addition, in their interactions with residents maps directly to the areas and key concerns of ‘rehabilitation’ conducted by qualified HCPs—thereby challenging and disrupting the notion of rehabilitation as reported in the medical literature as being something delivered by qualified professionals—and opens it up to be, in practice a process involving a much broader range of people and their work.

The work of these people, especially hotel service staff, focusses on keeping the present and maintaining the immediate environment which makes up a place of residing. Through keeping the present by the conduct(ing) of the everyday, and helping patients be in the world they in turn make (some of) them rehab-able—enabled to access the formalised therapeutic care offered by therapists—treatment
which may well improve their abilities to function and ‘restore’ elements of their pre-injury self. In this way then, they shift from present keepers to future makers.

In this chapter I have added to the literature in the following ways. Methodologically, I have highlighted the importance of ethnography in terms of being able to challenge ingrained ideals of clinical practice – i.e. ‘who’ does rehabilitation. Substantively I have contributed to the literature in recognising the role of non-clinical staff in rehabilitation. ‘Hotel service’ staff are rarely, if ever included within the healthcare literature or identified as ‘core’ to the care team, or even a part of it at all. While there is some social sciences research which explores the labour of these type of workers within other institutions/ settings (e.g. LaPointe 1992; Hviid et al. 2013), there is little research which explores the work and experiences of such staff working in places of care, and even less written about the contribution they make to the care. This chapter has both identified and addressed this gap. Theoretically, I have highlighting the centrality of the temporal in defining, categorising and ‘disposing’ of patients in and through rehabilitation both in process and place and have considered the role of keeping the present, doing the everyday, has in making futures.
Chapter 7 Future talk – relationships and the temporal in brain injury rehabilitation

7.0 Chapter Overview

In chapter 2 I referred to the work of Juhila et al. (2015) who explore how ‘time’ is talked about in rehabilitation. Picking up on their analysis of ‘future talk’ and ‘time talk’ and their identification of temporal clashes in patient/professional interaction, here I extend this work into the arena of brain injury rehabilitation. As highlighted in the methodology chapter what the future looks like for residents as imagined and contributed to by staff has formed the bulk of the findings thus far, explored extensively in chapters five and six. In this chapter, the voices of residents and families are foregrounded.

This chapter opens by illuminating how residents imagine their own futures and identifies how these imaginings differ from the way in which their future is anticipated by others. It is followed by an exploration of how families talk about residents’ futures and identifies how their imaginings are also distinct from that of residents and staff. This chapter concludes by returning to the experiences of staff and presents the way in which HCPs perceive the role of families in making or curtailing the futures of residents.

7.1 What future do residents imagine for themselves?

For many residents included in this study, communicating the basics of their everyday experiences/needs is a huge challenge, or not possible at all. Communicating hopes for and feelings about the future then is, in many cases, unattainable. However, within the sample of eight residents included in this study – the eight for whom consent was gained as the focus of close observation and interaction - four could tell me what they foresaw for their own future. In two cases, this telling was gathered through a spoken interview, adapted to meet the communicative needs of the interviewee (e.g. closed questions and taking breaks to deal with fatigue). In the other two cases, the residents communicated non-verbally, using gestures and
movements of their head and/or eyes. Interviewing these two residents took on a distinct form which included closed questions with ‘yes/no’ answers, asking questions with a series of ‘options’ to assist narrow down or guide me in ascertaining the most accurate response to any given question. For questions where the response could be broad or where a sense of priority, order or preference was wanted, a series of cards were produced before the interview with various potential answers detailed. Through ‘yes, no’ gestures the cards were then sorted and ordered to provide a sense of what was most important, from which more nuanced questions could then be asked. Unlike staff and family interviews where future talk could be both analysed as that which was ‘naturally occurring’ and that asked about directly, without an open and continuous narrative from residents, the future, in the main, could only be asked about and responded to directly.

All four residents could tell me about a future they imagined for themselves, in three cases in significant detail. These residents responded quickly and without hesitation – or, in the case of those unable to respond verbally, answered as quickly as any other question posed to them. This was in complete contrast to staff who, when asked to imagine a future for the residents they cared for, paused, often frowned and made exclamations about the difficulty of the question posed.

Residents described a future full of activity, purpose and/or returning to daily ‘normal’ routines of lives lived before injury. For one man, Eddie, his future mapped closely to the rehabilitative definition of ‘restore and return to’, in that he foresaw returning to his own home and the restoration of the daily routine he had established prior to his injury. This included making his meals in a certain way and visits to his local pub. Re-establishing his ‘normal’ routine sat alongside returning to plans he had made for himself prior to injury including holidays with close family. However,

---

41 The card sorting activities made during interviews with those unable to verbalise were photographed as part of the interview to act as data but they are so highly personalised and require extensive ‘blacking out’ to assure confidentiality that they cannot be usefully displayed here.

42 Although verbal communication was not possible with all residents and two of the four residents interviewed here being unable to speak, I use the term ‘speak’ or ‘spoke’ here to generically mean communicated and ‘voiced’ to mean expressed.
the notion of ‘return to’ was not evident in the imaginings of the other three residents: Luke, Archie and Serena. These individuals imagined a future that had some reference to past lives or routines but mostly, the future they imagined included new aspects and incorporated their selves as they were now, following injury.

Luke planned to move away and live in another country with family. Archie, foresaw a rich life being supported within the care setting, and the improvement of both basic and social needs being met within his current abode. For example, he foresaw (and was looking forward to) being able to have a bath, being supported to spend more time with his family within the care home setting and outside of it and enjoying complementary therapies. He envisaged a life of learning and potentially of supported employment or volunteering which utilised any new learning. For Serena, her future imaginings focussed on spending more time with her family outside of the care home, living in a place other than the current care setting, but not her previous home, and with the potential of living with others. Her imaginings were primarily social over occupational/vocationally focussed. For example, she envisaged spending more time with her son, making new friends and going to places of entertainment that she enjoys such as the cinema.

The distinction between the three residents who imagined a future which was not focussed on restoring a past life lived within their own home or community and the resident whose future imagined closely mirrored his life prior to injury, was their level of recovery post injury and remaining impairment(s). The three residents who imagined future lives that did not strongly reflect their day-to-day life prior to injury, all had severe and multiple impairments which would remain for the rest of their lives. In contrast the one resident whose future focussed on returning largely to his life prior to injury, his rehabilitation and recovery was extensive. He was fully mobile and almost entirely ‘self-caring’ - able to wash, dress and cook basic meals independently.
Distinctly, for Eddie (the resident who had achieved significant functional recovery) his future imagining focussed on ‘being free’. Freedom for him was a central part of ‘independence’. His will to return home was in part about enabling him to exercise his freedom to become fully independent again. While in rehabilitation the ability to demonstrate ‘independence’ is part of the rehabilitative process to enable discharge home. However, in this case Eddie felt he would only be able to exercise independence once he was back at home. He felt unable to be independent in the care home setting because he had to accommodate others. He explained:

> Well independence, it’s in the mind, it’s a freedom to do what you want, when you want and how you want um, I can’t describe it more. Switch on the TV to watch whatever programme you want. The only independence I’ve got is in my room and even that can be limited at times.

The tension around freedom and independence and their importance was expressed vividly by Eddie who, talking initially about being held hostage, said:

> I feel very much like I am a victim held for a much longer time, against my will, in that I want to get back home and start living a life. I feel I’m being prevented from doing that so, I feel there’s a slight relationship between hostage [laughs], hostage victims, I know it sounds ridiculous.

In a pause between recording Eddie talked further about his sense of restraint and capture but also the way in which he felt about staff, his ‘captors’. He spoke of the support he had received from staff who had helped him relearn skills of everyday life. Cooking was an example he provided, referring to his time with an Occupational Therapist as ‘critical’ for his recovery. He recognised his need for the help he had been given and his current reliance on such support, despite the extent of his rehabilitation. He expressed his fear about returning home and spoke of his affection for the staff who had helped him. Through telling the story of ‘Stockholm syndrome’ – a situation in which the captured develops an affinity or affection for their captor, Eddie highlighted the tension he felt between wanting his ‘freedom’ but needing and liking his ‘captors’. For Eddie, to have a future, the first step was to ‘return to’ a life at home. Returning home would enable him to be free, which in turn meant he could
be independent. From this point of independence, Eddie felt he could then, ‘start living a life.’

The future that residents with permanent impairments imagined for themselves was not reliant on ‘recovery’ like Eddie’s, but instead incorporated their impairments. They foresaw opportunities for living in different settings, education and activities. Without context, these imaginings may seem somewhat unrealistic. However, in the case of these individuals and their circumstances, what they imagined was practically possible. Their hopes for their own futures however relied upon relationships with and support from others, and it is this requirement for support from others which may have been unrealistic in terms of what could be offered by family members, staff or service provision in health, social care or education.

7.2 What is the future about for families?

The futures residents imagine for themselves are distinctly different from that which staff imagine for them. Discrepancies in future imaginings however don’t end here. The way in which families imagine residents’ futures are also distinct. In this section, the way in which some families speak about the future is presented.

7.2.1 Restoration and improvement

For some family members, the future they imagine for their relative focuses on restoration of consciousness or the functional abilities of their relative. In an interview with Emily, she focusses upon her husband’s rehabilitative progress to date, his further potential for recovery and her expectation that he will recover further. Her expectation that recovery will occur is present throughout Emily’s interview and underpins much of what she says. For example, she reflects:

*I think it helps for us to be able to record things but for when Donovan is better as well so he can read back and see exactly how far he has come. To come from being in a coma state to how he is now is just – it is still a short space of time for the type of brain injury he has had – I don’t think any of us imagined he would even be like he is now, it is amazing what he has been through, it really is.* (Emily, wife)
Emily repeatedly recalls how her husband has already progressed beyond the expectation of both HCPs and the family, and bases her current expectations of his continuous improvement on the extent of his recovery to date. She says:

*He has already shown that you can do anything you want to do, anything is possible with a brain injury. They didn’t even think that Donovan would wake up from his coma and since that happened he has arm wrestled people and shaken hands. You ask for a hug and he will give you a hug, you can sit and do things with him and you can see he is listening and thinking for himself.*

(Emily, wife)

Emily’s belief in her husband’s potential for further recovery is also linked to his prior health and strength, his determined nature and her notion of the brain’s capabilities. She said:

*I know anything is possible if you believe it enough and that person is determined enough and you give them the confidence, I think the brain can do all kinds of things. I think he will keep getting better.*

(Emily, wife)

For other family members from different families, however, they explicitly reject the idea that ‘recovery’ is linked to such strength or determination and spoke out about how, from their experience, this was not the case. Myla, talking about the partial recovery of her husband following a hypoxic brain injury and what she hopes for in the future reflected:

*I don’t think he will change a huge amount, no. The damage that has been done can’t be repaired completely. I know you have neuroplasticity, but that is only to a certain extent. [given who Eric was] if he could manifest it [neuroplasticity44] he would, but that is not how it works.*

(Myla, wife)

---

43 This idea of recovery being connected to determination and strength is also prevalent in interviews with other families of people whose relatives are (or were) in a prolonged disorder of consciousness. Within interviews with over 70 family members conducted by Professor Jenny Kitzinger and Professor Celia Kitzinger between 2010 and 2016 families frequently talk about how their relative ‘is a fighter’ and their expectations of their relatives recovering based on either their own strength of character, fortitude or physical strength. Examples of this can be found on their healthtalk.org resource.

44 Neuroplasticity is *‘the ability of the brain to develop new neurons and/or new synapses in response to stimulation and learning’* (Concise Medical Dictionary 2010).
Hope for further recovery however is not relied upon by Emily or Myla. Their plans for their husbands, themselves and the wider family incorporate the current abilities and impairments of their relative alongside hope, or in the case of Emily, belief in the ability of her husband to regain further functional abilities over time. Emily imagines a future for herself, her husband and family all living together again. The family home is not suitable in the context of her husband’s current care needs and so, with extensive support from social services, Emily, at the time of interview was in the process of ensuring that her future imagining came to fruition.

Emily: Our house is just finishing having work done so yes, then we can start the discharge process to get him home then. It is all exciting.

JL: Yes, I can see the big smile on your face.

Emily: It has been a bit too long.

JL: What changes have you had to have him at home?

Emily: We have had a wet room downstairs and the driveway put up to the front door so he can get in. We are moving from where I am at the moment because it is only a small 2 bed and has to have wide doorways, wider hallway. Our bedroom will be downstairs so we haven’t got to take him up or down the stairs, it is just that we will have more space for his equipment and the type of chair he has I wouldn’t get it through the front door where I am now. There has not been too many adaptions it is more about the space and the wet room downstairs. I think they are going to put a ceiling track so we can get him in and out of bed easily into his chair, so it is going to be worth the wait.

However, expression of expectation in or hope for continuous recovery is not prolific within many family interviews. Instead, the futures families most predominantly imagined for their relative focusses on practical changes and support to assist i) the restoration of family life, ii) enhancing the quality of their relative’s life, iii) discharge out of the care setting or, for some families, iv) their relative being allowed to die. The future related content of family narratives also includes the change to their own lives and futures, the struggle to return to everyday life and their own efforts to take control of the future for their relative and themselves.
7.2.2 Restoration of family life/family togetherness

In many cases, the hopes of family members are based on trying to restore or return to the past – and in this way fit with the rehabilitative definition of ‘return to’. In this way moving forward is, for some family members about trying to do or achieve things which enable or resemble something that was good, or cherished in the past. In some instances, the future was about creating opportunities for repairing and reconnecting relationships within the family – especially those that had been shattered because of their relative’s injury. Elaine and Joyce, for example talk about plans they have which would enable Elaine’s sons (one who is brain injured), to engage in a shared activity outside of the care home – in this case, fishing. She explained:

*Elaine:* We want to get Lee out, we want to get some vehicle or something, we want to get him out to where we live so he can fish and Addy [Lee’s brother] wants to fish with him. So we have got to have plans and we have got to have things to look forward to because I don’t want Lee here for the rest of his life. We have got to be doing something with him even if it is out just in the fresh air, just get him in that, you know, if we get a mini-bus thing and take him out.

*Joyce:* When I have the ramp done we can wheel him right around and he can actually fish from the decking and Addy has said he wants to come as well didn’t he?

*Elaine:* [...] He [Addy] is focusing on what he wants to do when he [Lee] gets home and come and see Lee, come and stay with us, so that was good.

However, as can be seen here – the ‘return to’ element is about restoration of relation and togetherness. Within the future plans that Elaine and Joyce sketch out there is much that is new and different. Returning to what was cherished in the past is only part of the aim. Here, to achieve ‘return to’ requires many things that are new and future orientated. Surfaces around the home need to be altered, the location of the gathering and the fishing is familiar but different. Lee will be unable to fish with his brother like he once could. Restoration and return to is not possible, only the
striving for an exchange and activity which resembles something that was positive in the past. This again fits with the social theological understanding of time outlined by Adam (1995), discussed in chapter two and five, who highlights that while the experience of time is a circular and repeating one, in that the seasons return, the months of the year cycle round, they are never the same and we can never return to a previous time.

7.2.3 Quality of life

For some family members, whose relatives are (or were) in a permanent or minimally conscious state, the future hopes or aims they hold for their relative are not based on, nor hold expectations of ‘improvement’ or recovery, but instead focus on improving the quality of life of their relative. The will to improve or maximise quality of life is particularly present in the future talk of family members whose relative is in a minimally conscious state, or those who believe that their relative has some awareness. As one sister explained:

*Marty is still breathing, he does react, he has something behind his eyes so he deserves whatever else we can give that can improve his life. [...] I really believe that he is in there and while he may not be fully recovered and be a brain surgeon there is enough recognition for him to have a quality of life and understanding.*

For this relative, their aim and hope for the future is the settlement of a legal case from which the compensation received would enable the purchase of a wheelchair-accessible vehicle and the provision of complementary therapies.

For other family members, improving the quality of life for their loved one could mean attending more to everyday preferences that the person had prior to injury and things that they still seemed to get pleasure from post-injury. For example, Cora, talking about her daughter Charis said:

*Charis loved having baths so to be able to have a nice bath and shave her legs and all that. She would get out of the bath at the end of it and she would be just so petite and her little pink rosy face from soaking in the bath it would be*
lovely. Like a real glow she was really happy afterwards. I think it is little things like that you need not to lose sight of, she has got her normal preferences I think a lot of that is still there. She doesn’t show it as much but if you do something to her then you can see she is still there. (Cora, mother)

For all family members interviewed whose loved one is in a minimally conscious state, part of their plans for the improving quality of life focusses on their relative being outside or being able to ‘get out’ of the care home. For example, Elaine said:

we want to get like a vehicle so that we can take him out even just out to [nearby town] and the local park in the fresh air and things like that. (Elaine, mother)

The importance of ‘fresh air’ is linked by family members as being something important for the general health of relatives and related to providing essential stimulus and generating or improving their level of alertness. Hazel reflected this when she talked about what she wanted for her sister:

I am desperate to get the mini bus so I can stimulate her and take her out. So she has got something else to look forward to because when she is out she is awake. (Hazel, Sister)

Family members recognise the long-term nature of the impairments of their relatives and, in some cases, speak about how, while they ideally wished that their relative could return home or be at home with them, the care facility is where they will remain, ‘for the foreseeable future’. Achieving and improving ‘quality of life’ in this context then turns the focus back to the quality of care and service provision within the care home.

7.2.4 Discharge home or outside of the care setting

Five of the nine family members interviewed spoke about hopes for the future where their relatives would return home. What ‘return home’ meant however and how these future plans were being shaped is of relevance here. For family members Elaine, Joyce, Emily, Myla and Helene, the future they envisage and were taking action to bring to fruition included a move to an entirely new ‘home’. Returning to
the original ‘home’ that they had established as a family was no longer possible due to the needs of their relative following brain injury. However, although they are going to, or hoping to go to a new place, they repeatedly spoke about ‘getting him home’ ‘going home’, ‘returning home’. Home, for them therefore did not necessarily mean returning to a previous place but is instead, about restoring living together. Again, future hopes rest on a ‘return to’ togetherness which resembles a past situation but is not a return to the same.

For two families, future hopes of getting their loved one home not only means to a new place but also to an entirely new way of living together that is not the same as the situation was prior to their relative’s injury. Two families spoke about plans to live with their relative to meet their social needs. Helene for example talks about her hopes for herself and her son to live with her father in a new house.

\textit{The long-term outcome that I want is to have a house for Max [son] and I with an annexe for my Dad so he is right there with 24 hour care provided by [community based care staff connected to the care home] because they know him and I trust them; so that I can see him every day, so he can see Max every day because that is the two most important things to him.} (Helene, daughter)

And Elaine talks about her hopes for her son Lee to live with herself and her husband. She says:

\textit{I want to, when Lee’s court case goes through, I don’t want a lot – I want to get a house built, a bungalow built so he can come and live with me and my husband and have full time carers but I am not going to be his carer ever because he would hate that. I’ll just be there all the time but in the background.} (Elaine, Mother)

For all these family members, the new arrangements for both their own living and that of their relative are talked about as ‘ideal’, as positive or ‘exciting’. Myla for example said:

\textit{we have our own place but there is somebody there on site should we need them, so yes that is really the ideal, the ideal.} (Myla, wife)

Although such changes in accommodation and living arrangements are spoken about as ‘ideal’, they are only ideal within the new circumstances they find themselves in.
Family members’ talk does not reflect that what they had in the past was ‘ideal’ and that this new life is the best it can be in the circumstance. They speak not of loss nor make comparison to the past but instead talk exclusively of the new, future plans for living arrangements. Such future talk is much more prevalent within family narratives than it is in staff interviews. A point which will be returned to later.

Some families interviewed had already made a move to a new home, long before the opportunity or possibility of the returning home of their relative was clear in medical terms. This first move had been made by family members from the family home into different homes to be closer to the rehabilitation centre that their relative was being cared for or to be closer to other family from which support could be gained. The relocations that these families had made were extensive in geographical terms.

7.2.5 The future as the end of life

Although for many relatives, the future for them focusses on either continuous improvement of their relative and/or plans to live together in a new family home, not all future talk by families focusses on recovery or going home. For one family, the future holds the potential of confirming whether or not their daughter has some awareness through further assessment and ‘evidence’ of consciousness being ‘demonstrated’ through fMRI scanning. Rachel, a mother talks about her daughter saying:

I think Louisa has altered but I am not sure to what degree, but we are hoping that in the future she will go to Addenbrooks [UK hospital] to get the MRI scans. (Rachel, mother)

In this case however, the hope of the information to be provided by the scans is not in hope of confirming consciousness, but in the hope that it will not. The future ‘hope’ of this family for their daughter is that she will finally receive a PVS diagnosis and that such a diagnosis will then enable her to ‘have the right to die.’  Rachel reflects:

Rachel But all through – this is something else that we spoke about– we’ll just get to 6 months and then she is assessed and she will have the right to die.
That was mentioned lots and lots of times, and we were thinking we will get to 6 months and then she won’t have to live like this but then that never – it like just went out the window. If she was proven to be in a vegetative state then she would have the right to die but we would have to go to court for her.

JL And what do you feel about it?

Rachel We were all for it, we were all for it.

JL And now?

Rachel I am not sure, I am not sure.

In this particular case, Louisa’s injury was hypoxic and according to the Royal College of Physician’s (2013) clinical guidelines, for those with hypoxic brain injuries, a ‘permanent’ diagnosis can be given six months post injury. For this mother, the future they foresee for their daughter focusses on being able to obtain her ‘right to die’. However, this timed and knowable future path is now being challenged and Louisa’s future is being made uncertain again, as the possibility of her having some consciousness and therefore being ‘minimally conscious’, seems to close down (at the time of interview at least) the option of death following the withdrawal of artificial nutritional and hydration (‘the feeding tube’). For this mother, the possibility of her daughter having some consciousness, has also begun to shift her own feelings about the withdrawal of artificial nutrition and hydration.

7.2.6 The painful future of returning to everyday life for family members

When speaking of the future, Rachel, the mother of Louisa discussed above, speaks not only of a changing future for her daughter, but of the slow and painful struggle for herself to return to doing ‘normal’ things in her own life. For example, she spoke

---

45 Until 2015 only applications made to the Court of Protection for the lawful withdrawal of artificial nutrition and hydration for people with a PVS diagnosis had been successful. Those in a minimally conscious state had been previously rejected – such as the M v W case in 2005. However, the landmark case of Paul Briggs in 2016 ruled for the withdrawal of artificial nutritional and hydration from a person in a minimally conscious state: the decision made was based on arguments which combined consideration of diagnosis, prognosis, quality and sanctity of life with very strong weight being given to the prior expressed values of Paul Briggs and the discrepancy between his wishes and values and his current and likely future state.
of only recently being able to make choices when out shopping or decorating her own house, as such choices were always made with her daughter.

We started decorating our house last year and we couldn’t go and choose nothing because Louisa would always, but we have moved and we have bought stuff, but it is hard sometimes because she was always there and good at that sort of thing and having her opinion. We couldn’t go shopping [after Louisa injury], sometimes even when you are shopping now you think I have got to get home because, I don’t know what comes over you, you just think I can’t stand this no more, all these people around me. It’s like a slight panic attack. (Rachel, mother)

In contrast to the future hopes of ‘return to’ illuminated so far in family relatives where ‘return to’ means a restoration of something cherished but that was not the same, Rachel’s future talk here is distinct in that she speaks of returning to things that are much the same as they were for her prior to injury, without any notion of progress or moving forward. For Rachel, returning to ‘the everyday’ is a painful process because her every day was entwined with her daughter and so accentuates the loss of her daughter in her life.

7.2.7 Taking control of the future for their relatives and themselves

Most relatives speak about how they are attempting to take control of the future themselves by pushing for improvements in care standards, working with various health and social care agencies to ensure adaptations to or moves to new accommodation, or to bring court cases to fruition to release funds that can be used to improve the quality of life for their relative. The centrality of their role in making changes for themselves and their relatives was highlighted explicitly by Myla who says:

I have been without Eric now for 2½ years and I want him home. Apart from physio I don’t think they can do any more for him here. They have settled him with his medication, they have his meds right that’s all settled and really what else can they do? I don’t, really don’t, see why he is here now. I have spoken to them about that, they are aware of that and probably agree with me. So it is me that has instigated it, it is me that wants him home. (Myla, wife)
Here Myla considers that HCPs have done all they can to shape the future of her husband and now, it is up to her to make a new life for herself and her husband, within the context of his remaining impairments. Although Myla talks pragmatically about the plans she is making (and in many cases family members speak excitedly about plans and actions being taken which they feel will lead to a better future for them and their families), she also expresses concern of what the future will hold and the problems she will face.

How the future looks for me is I tend not to think too deeply on it, I know it is going to be hard work, I know it is going to be lonely because you do or can become very isolated; because of how Eric is I won’t be able to take him to visit people, because their homes aren’t wheelchair accessible, they don’t have disabled toilets. I know it is going to be hard work and I know it is going to be very frustrating because I have that now, you know having him at weekends, and I do have to apologise to him because I do lose my temper sometimes, I do get very frustrated and I say to him I will push you and he will say “but you need to”, so he does understand. I know to a certain extent what it will be like but not fully, to a certain extent I think I know what I have got coming. (Myla, wife)

7.2.8 On hold, stasis, limbo

Although some family members speak of a future for themselves that is full of upcoming changes and action, other family members describe the future for themselves as static or ‘on hold’. Hazel, whose sister is in a minimally conscious state, when asked what her own future looked like replied: ‘Um on hold. Compartmentalised that this is the way it is now, therefore, work with what you have got and I don’t make plans.’

Family members spoke a lot about ‘waiting.’ How waiting was experienced and how it impacted upon them however varied significantly and was dependent upon the length of time that had passed since their relative was injured, changes in the state of their relative to date and current circumstance. Hazel who spoke of her life and future as ‘on hold’ has a sister who was been brain injured over 10 years ago. While she feels her sister has made some progress in terms of level of awareness, there is still an ongoing negligence court case. Without the resolution of the case the
appropriate money is not being made available for the care of her sister which would enable the maximisation of her quality of life. To this end, Hazel feels that all her hopes for her sister’s future are on hold and in turn, this impacts upon her own future.

Conversely other family members, although the future they hope for (both for themselves and their brain injured relative) is not currently seemingly in motion, speak more happily about being in a phase of waiting. Elaine was able to state that for her family ‘there is a good future now’, even though she was awaiting outcomes of court cases and various clinical assessments and there was little that was tangible in terms of moving towards the future she hopes for. She was however able to imagine a positive future despite being in a phase of waiting because significant change had recently happened for her family, and she viewed her current situation, and that of her son as significantly better than it had been. Elaine and her family had moved closer together and closer to the care home where Elaine’s son Lee was being cared for. Lee was in a place of care that Elaine considered gave much higher quality of care than the care home he was in previously. She was hopeful that a pending court case would provide the funds needed for a new home where her son would be able to be with his family and appropriately cared for.

7.3 Temporal tensions in relationships

The potential that differences in understandings of, or constructions of time have in contributing to tensions in relationships between patients, family and staff has been muted throughout this thesis. In chapter one I highlighted literature which details that relationships between patients, families and staff can be tense due to differences in the expectations held by these different groups. In chapter two I pull out findings from a study which explicitly examines that the way in which patients and HCPs talk about time in goal setting and discharge planning meetings differs and contributes to conflict between them (see Juhila et al. 2015) and in chapters five and seven I detail the way in which residents, families and staff imagine resident futures. In the final section of this chapter I bring the perspectives of residents, families and
staff together, draw out the differences between them and argue that these temporal differences contribute to difficulties in the relationships between these three groups.

7.3.1 Future imagining mismatches: residents, families and staff

Residents imagined futures and lives that were much fuller than those indicated by staff or by families. While staff and families constructed resident futures largely as time ‘at home’ with family conducting, at best, a range of activities with family support, in contrast residents imagine a future for themselves which extends beyond time with family and being in the home.

There were two key mismatches in terms of imaginings held by residents and those held by staff. First, in terms of ‘poster boys’, staff limited their future life, largely to being at home. Although poster boys themselves did not have big ideas for their future, they did see it as including a life outside of their home (whether that be a return to the family home or a new home). The future for them included, being able to walk to the local pub, meet with friends, spend time with family (in particular being able to do things with their children) and travel.

Second, the future for residents who were not poster boys and were imagined by staff as having largely static futures, a life lived out within the current setting. In contrast, these residents spoke of a future which was much more active, and saw the care home setting as a launch pad from which to engage with the wider world – including accessing entertainment, vocational opportunities and/or learning.

Residents’ imaginings fit with the rehabilitative imaginary – of return to a life of meaning and engagement with the wider world, but in an adapted form. Residents did not unrealistically imagine themselves having restored ability to move or speak or ‘rehabilitate’ any further than they had currently, but instead saw themselves doing things which were possible within the realms of their disability, but just required adaptation and support from others.
All families interviewed were relatives of people with very severe brain injuries, most of whom were in a disorder of consciousness and who could not indicate in any way to me what they might imagine for their own future. In this case, there is no direct comparison available between the way in which families and residents imagined and foresaw their futures. It is however important to recognise that discrepancies between resident and family aims are recorded in the literature as sources for conflict within rehabilitative relationships (see chapter one). There are however discrepancies between the way in which staff and families imagine and construct the future for residents and the way in which families engage with and want to make plans for the future.

7.3.2 ‘There is no future talking’ - Temporal compression and mismatch of temporal frames for families and staff

Within interviews with families it was evident that the way in which relationships were formed with HCPs and the tensions in them were temporally connected. For residents who were not rehabable, families nonetheless saw a future for their loved one and they wanted to bring the future they envisaged closer – whatever that future may be. Staff however, while at times seeing this potential future, saw it as distant, and focussed on the many steps in between. They tended to chunk time into manageable sections – into an extended present rather than a far-reaching future. While this allows for both time to be managed, and for the management of family expectations – this prevents broadening horizons or extending possibilities for residents. It also contributes to tensions in relationships as families need to focus on and see a broader future for which they can strive.

The absence of talking about the future and staff’s acknowledgement of the hopes of families and residents was identified by both residents and families. This was stressed in an interview with a mother, Elaine, talking about the potential for recovery of her son Lee:
Yes, everybody I have spoken to in the past don’t know anything, they don’t say anything. I have never had anybody that says, you know, just for someone to say to me “well Lee has come this far um don’t give up”, like we don’t know what is ahead, we can’t say whether Lee is ever going to speak, whether Lee is ever going to eat but in the future he might speak, he might but there is no future talking of how or whether he is going to do anything. It is only us we just don’t ever give up and we, you know, we are always going to be thinking not of miracles, I don’t believe in miracles, but the hope of he could. (Elaine, mother)

Here Elaine highlights the key tension between herself and staff. She identifies the absence of discussion about the future potential of what her son may be able to achieve, however small. She explicitly notes the lacking temporal element to these conversations – the future. Families recognised that staff were not able to tell them anything that would unfairly raise their expectations but a lack of discussion about the future or the avoidance of discussion about small potential changes was experienced as frustrating. Elaine for example explained how she understood that her son would never recover function such as walking but she believed that he would make further changes. Elaine continues:

I do understand that people can’t say this because they are raising your hopes [but] everyone has got a story. It was only me reading something on the website saying about this guy had a brain injury similar to Lee’s and 5 years later he started to speak. I was told that once it is 2 years for Lee, how he is now is how he is going to be. I am not going to believe that. I don’t believe he is ever going to walk or talk but I am not going to believe that this is how he is always going to be because he has got different in the last few months. (Elaine, mother)

The changes Elaine foresaw her son making however are not physically based but cognitive. This is critical in the case of patients in a disorder of consciousness. ‘Change’ for families of this patient group can mean changes in overall appearance, awareness, responsiveness. Whether or not such changes lead to functional improvement or are measurable, is not of concern to Elaine here. The subtlety of what she means by change does not fit with health care definitions, distinctions and measurable notions of function.
Therapists and other staff members however frequently aired the concerns about raising family expectations through their own interactions with them. Staff repeatedly and spontaneously gave examples of situations where they felt families’ expectations were higher than their own predictions about recovery. They explained how families’ expectations could be raised when clinical milestones had been passed or they witnessed small improvements or signs of recovery in residents and this being extrapolated by families to mean that further recovery would therefore certainly come.

Maddie, an occupational therapist talking about her work with families of residents in disorders of consciousness, remarked:

...you are just the punching bag at times because they [some families] are still in the very acute distressed stage of this shouldn’t have happened to my daughter or this isn’t fair and they are still expecting them to get better and maybe people have said at the acute stage “oh they have survived surgery so it means the odds are good.” (Maddie, Occupational Therapist)

Conversely, other families who balanced both future hopes and present realities much more tightly were considered by staff to be much more ‘realistic’. For example, Cora and Ben were spoken about as parents who were ‘realistic’ in their understanding of the long-term nature of their daughter’s level of disability and the practical realities of her care. Ben reflected:

For the foreseeable future I think this is her home as much as we would like her home the costs and implications to get our house in to the state that is needed... (Ben, Father)

Cora and Ben however retained goals and hopes for good care and some possible change in the level of consciousness for their daughter – but already recognised that such changes would not alter her level of care needs. Cassidy, a HCA speaking about her own relationship with Cora and Ben, and small possible changes in the level of the awareness of their daughter that had been noticed by staff said:

They have noticed things too, but they are not the ones that are going to hold their breath, and expect it to happen. (Cassidy, Health Care Assistant)
On occasion staff spoke about the pragmatic nature of some family members who had full realisation of the situation they and their loved one were in and had begun to take action to safeguard their own future in light of the long-term nature of their relative’s condition. Maddie reflected on a conversation she had had with a relative:

I had one woman saying “sorry I have decided that I should write my husband out of my Will because let’s face it he is going to need a nursing home with full care and if I die before him the kids will get nothing ‘cause it will all go to him. He’s still my husband but I have written him out of the Will.” She had become so pragmatic about it and so they surprise you. (Maddie, Occupational Therapist)

Families who were ‘realistic’ were talked about positively and used as an example of having a ‘good’ relationship with staff. Staff also then spoke about families being realistic and having a good relationship with staff as beneficial for the resident. Interestingly, staff spoke more openly about the future for residents whose families had ‘realistic’ expectations.

Health care professionals’ concern not to raise the expectations of family members and the differing ideas of what ‘change’ means between these two groups compresses the temporal reach in which these relations operate. Condensing time and focussing on goals to manage the unknown negates discussion of non-functional, immeasurable ‘change’ that is, for many families, important.

### 7.3.2.1 Goal setting as device to compress time and manage expectations

Therapists spoke about the use of goal setting as a device through which to manage time, to temporally compress and remain focussed on only a few days or weeks ahead to ‘manage expectations’. The setting of goals could be used as a way of demonstrating the resident’s lack of progress. Their inability to reach goals acted as a way of inadvertently communicating staff’s expectations to family members of both the current and anticipated future state of the resident. Furthermore, the use of goals not reached could also be used as markers to support discussions about the need for change in service provision or even change in the type of care setting. Maddie explains:
goals are a great way of staying focused; whether it is because someone is deteriorating and you are monitoring where they are at. It usually involves setting your grading up and, you know, it doesn’t mean you can’t grade down as well. So, it just keeps the focus and yes it is a care facility and some residents will be here a long time and goals are just used as a way of kind of moving people on, you know, saying OK they have now established this level, they can cope with the next stage of care package at home or whatever. [Maddie, Occupational Therapist]

Staff however identified the problematic nature of goal setting, highlighting the potential discrepancy between what they were aiming for and what families and residents themselves hoped for and had hoped for themselves. Therapist Orazia spontaneous reflected:

As a therapist you get so bogged down in setting a goal and looking forward, we don’t look at the wider picture and Daniel’s family is a perfect example of that. What hopes did they have for Daniel, what hopes did Daniel have for his life? Nobody has looked at that and nobody cares and what psychology will say is “oh we have offered them a support session.” That is not what it is about, it is about keeping that - setting expectation from the start and saying [to] your family, “your relative has come here they have had a brain injury, we need to talk to you.” That needs to be fed back to the team, that will help goal setting, that will help therapy, that will help rapport, just one single thing at the start of admission that could help so much. That is not just basic case history taking: “this person was a builder, they used to work here and this is how old they are.” (Orazia, Therapist)

Here Orazia overtly recognises that the hopes, dreams and expectations of Daniel and his family about his life are entirely unknown by the clinical team. Orazia suggests that if the health care team were aware of the hopes that he and his family had held for his life prior to brain injury, this would help them make better rehabilitative plans and also reset expectations that his family now had for his life in the context of brain injury. Critically, Orazia highlights that this lack of future knowledge is a source of tension and is, in her opinion at the root cause of what became strained relations between this professional team and family.

However, despite the talk about goals within interviews and some observation of the recording of objective measures for a national database, I did not observe allied
health professionals set or review goals with residents in any treatment session. What had been achieved or not was however spoken about in review meetings, but in a generic rather than SMART goal specific way. Also, when asked about goal setting in interviews allied health professionals were often sceptical about the usefulness of them for residents and considered goals to be of more use for administrative purposes rather than as part of effective clinical practice.

Residents themselves also reported frustrations regarding the future and how this is talked about by staff.

Eddie: Um, more openness and explanation about people’s destinations, about where they’re going, um, in my case, hopefully it’s [another rehab setting] which is three miles from my house, and then home.

Frustrations expressed by residents focussed mainly on discharge time, or timing of a long awaited trip, visit or activity.

The future for families, or more specifically, the way in which families engage with the future on behalf of, or about their relative becomes a significant point of tension in the relationship between family members and staff. Families look to a future and work to ‘return to’ a situation which resembles the past, where possible. They temporally project into the future, and focus on what is to come. Conversely health care staff do not project into the future and instead tend to stay within the realm of an extended present. This is because an extended present, although not precisely knowable, is easier to predict, to manage and to fill, than the future which is a far too open and an unmanageable domain within which to operate. This temporal compression is enacted to increase staffs’ inability to control and accurately predict the future but is also born of the staff’s concern that inappropriate predictions of future outcomes, actions or abilities of the patient may ‘raise expectation’ of family members.
7.3.3 Families open futures and broaden patient horizons - Staff’s recognition of the role of families in brain injured futures

Despite the temporal clashes in the triad relations between staff, patients and family when future imaginings and direct discussion about the future seem to be largely at odds between these groups, equally – staff spoke at length, about the role families play in opening up and creating futures for residents.

In a time when the needs of the individual are not expected to be absorbed by families, and reducing pressure on families and anyone to care, the importance of what families can provide for patients was not discussed or aired in public. However, the difference in patient futures for those who had supportive and present families and those who did not was discussed spontaneously and at length by staff during interviews. Staff repeatedly reflected on the benefits and the critical importance of the support of some families – and overtly recognise that the future that was now laid out in front of some residents was there only because of the support, dedication or determination of their family. Lucy, a nurse, highlighted that one benefit for residents with supportive families was that they could help fast track rehabilitation, for example by facilitating leave back to the family home sooner.

*If you have a patient that has got a really proactive family their home leave is going to be started as soon as they can, but a patient who hasn’t got any family they don’t have any leave, so that makes a difference.* (Lydia, Nurse)

7.3.3.1 Families hamper and endanger futures

Conversely however, staff noted how the behaviour of some family members did exactly the opposite and could hamper or even endanger the future of some residents. Some families were considered, rather than as proactively involved in rehabilitation, to pose a potential risk to residents’ wellbeing and safety. Orazia, a therapist provides an example of this when she explained the actions of one family who brought food to a resident that he could not safely eat because he had an inefficient swallow reflex.
Orazia: [...] we then had some problems with his family and rather being direct with therapy with him I was very much involved with family because they were bringing in things he shouldn’t be having.

JL: As food?

Orazia: Yes. I had to do a lot of education with them. He was always going to be discharged, there was this talk about him having his house and all of the family were going to move in with him, there was obviously concerns about that because if they are coming here and giving him inappropriate food what are they going to do behind closed doors.

In this case, Daniel’s family were considered as posing a threat to his future by hampering a potential discharge into his own home. Through their actions of providing food considered ‘unsafe’, an unmonitored environment, such as a home of his own, was considered an unsafe option because of his parents’ actions, not his own abilities.

Alongside overt risk, family’s participation, or their lack of, in rehabilitation and their social lives were also discussed in terms of either contributing to or hampering resident rehabilitation.

Reports from rehabs [care assistants] say they never take Daniel out, they just visit once a week, I know they live in [English town] but they don’t take him out locally. There was never this ownership it was like: Daniel lives with you, he is your responsibility, we just come and visit as and when. He loved all visits by his family and you could tell as there was more negativity building up he was becoming more and more negative. They would take no responsibility in being part of his rehab. (Orazia, therapist)

Here, the lack of family participation and assistance in both the general mood and providing social opportunities for the resident was considered as hampering his rehabilitative progress – and therefore impacting his future. Such familial and social issues as the key hindrance to the rehabilitation process, successful rehabilitation and onward journeys was also reflected by a nurse, Lydia. Reflecting on the family-resident relationships within her own unit she commented:
I think social issues be it family, being a massive, massive thing, I think if family aren’t proactive and supportive it massively affects the patient on a few different levels. From my own experience, unfortunately, and it is not the way it should be, in services it is almost always the patients who have families that are proactive are the ones that have the better treatment and they are the ones you get complaints from family. Whereas patients who don’t have any family I think can affect the care if I am going to be completely honest. (Lydia, nurse)

Here Lydia alludes to the impact on staff’s own actions caused by the regular presence of family members. The presence and involvement of family motivates staff to ensure the quality of care standards to avoid, as Lydia suggests here, complaints. Furthermore, Lydia highlights the practical ways in which the absence of family support can affect the rehabilitation and future of residents:

I think it can affect discharge, things like home leave, discharge destination, things like that. Obviously contact with people that are exterior to staff, I think that makes a massive difference as well. I think they need to have their own social network who can remain in contact with the life and person they knew before. Obviously that is difficult because, you know, people may not remain in contact after somebody has had an injury. (Lydia, nurse)

Families, then, are seen to both assist to open up or fast track the future horizons for residents – through either aiding their rehabilitation through providing social and environmental support, or conversely, their presence ensures that the level of care and rehabilitation they receive is the best that health care professional involved in their care can provide.

7.3.3.2 Requirement for constant future reimagining and reorganisation

Staff also identified how, as discussed in chapter five – resident futures open up and close down in line with their rehabilitative progress or stasis. Staff discussed how difficult this must be for families who are faced with the constant flux of future frames and the resultant need to repeatedly reimagine the future. They identified that these moments and times of required reimagining were the root cause of times of tension between them and families. Mercy, an experienced physiotherapist discusses this:
A couple of people that I can remember that have had significant problems [their relative] had made a huge amount, of progress and they [the family] were very grateful at the time but then [...] when that progress stops that can be a point where there can be a lot of tension because you are saying actually they are not now going to get any better [and families think] “But that’s your fault because you have not given them enough physio or they need more psychology”. Those situations can often be a lot harder I think than those that have not been through a period of rehabilitation. You give somebody a bit of improvement and it is “right we want more and more and more.”  (Mercy, Physiotherapist)

Orazia passes similar comment, discussing a resident who had originally been admitted in a vegetative state and had emerged to full consciousness:

He made a great recovery and you know it was verging on miraculous. His parents were so pleased and then it wasn’t enough because “now we want him to walk and we want him to do this and why isn’t he not doing this?” Wow do you realise what he is doing? You know, this guy was doing nothing and now he is wheeling himself around in a wheelchair and he is talking and he is eating and he is playing card games; seriously be grateful for what you have got but because he had made this amazing recovery. That was really difficult because we are then, we are the horrible people, he is not going to get any better, he is not going to walk – “well that’s because you are not giving him enough physio”, no he is just not going to walk; so that is difficult. Whether that is (sighs) I don’t know, is it educating them about it, whether it is a denial thing, I can’t say.  (Orazia, Therapist)

Another occupational therapist, Kay, highlights the tensions in the relationship between therapy staff and a family member when initial ‘progress’ had been made but the resident was now no longer improving but in fact declining. The lack of progress meant that therapeutic interventions were not successful and therapeutic focus switched from striving towards recovery and positive change, to that of maintenance – maintaining the current state and trying to prevent further decline.

[resident] was rehab and then she became maintenance because she is not going to get any better. I think that is where a lot of the issues in the complaints in therapy cropped up although it had been explained that she is now on a maintenance programme. She has not got any active goals and we are not going to be doing as much therapy and even in that case we said at this point we would normally hand over all programmes to the rehab
assistants. We are not doing that in this case because she is so complex we are still maintaining some input. Obviously, all that went in one ear and out of the other and the complaint was that the therapy had been reduced with no say so whatsoever and why was she not getting any therapy? So, you have those arguments but actually we only stop the therapy once they stop getting any better. (Kay, Occupational Therapist)

Here, the switch in provision of therapy and the expectation of therapists was indicative of the future expectations of the resident – in this case, one of further decline. This switch in direction of change was considered by Kay, to be at the source of a particularly volatile relationship between staff and a spouse.

Conclusion

Temporal mismatches exist in multiple ways in relation to the way in which futures of residents are imagined by themselves, their families and staff members. The residents interviewed, despite severe and multiple impairments, imagine a positive future for themselves, one which includes enjoying social based activities, spending time with loved ones, accessing education, acquiring new skills and contributing to the world through work or volunteering. Conversely, the imaginings of staff focus on the place of living and conceive of residents’ futures to be largely within these places, not outside of them.

Irrespective of the severity of residents’ impairments, families hold some form of imaginary about the future and changes that they hope will occur. What ‘change’ however looks like is often conceptualised differently by families and staff. ‘Change’ for family members may mean minor unmeasurable changes in the level of awareness they perceive their relative has rather than functional, tangible and measurable changes staff and their professions seek to generate. In situations of significant uncertainty staff resist talking about the future out of concern that what they say may raise the expectations of family members about what can be achieved by the resident or what can be provided for them. In these situations, goals may be used, either to make the future more manageable by focussing on shorter time frames of days or weeks, or conversely be used as a device to demonstrate lack of
progress being made. However, for families, resistance to and the absence of talking about the future can be frustrating. Many do not want to be held in an extended present and need to look to the future in much broader temporal terms than health care staff are willing (and able) to engage with.
8.0 Conclusion

This thesis has sought to explicate how the futures of people with severe brain injuries are shaped during rehabilitation and the role that time plays in mediating relationships between patients, families and health care professionals.

In chapter one I introduced the key group of people this research is about, exploring what is known about them in demographic terms and how they are talked about within the clinical rehabilitative literature. I discussed the literature which identifies conflict and difficulties between the triad of patient, family and health care professional relationships in rehabilitation and reviewed work which offers temporal related reasons for these relational tensions.

In chapter two I discussed the theoretical foundations of this thesis, bringing together the vast bodies of literature which explore time. I reviewed the work of key social time theorists and drew out core concepts of time as social which underpin much of this work. I identified how social theories of time have been utilised within empirical research across multiple fields before focussing on the empirical temporal work within the fields of sociology of health and illness and health care sciences. In drawing across vast bodies of work I highlighted the diverse use of ‘time’ in social science and health care research but illuminated gaps in the application of a temporal lens in relation to brain injury rehabilitation.

In chapter three I explained the history of rehabilitation and explored how it is defined and what that tells us about the temporal orientation of rehabilitation – or at least what it is proffered to be. I described its core practices as defined by the clinical rehabilitative literature and examined, in detail, one central tenet of rehabilitation – goal setting. Through a detailed review of the goal setting literature I began to unsettle and critique the temporal orientation of rehabilitation and in doing so, began the temporal exploration of brain injury rehabilitation and the investigation of how the futures of people with severe brain injury are shaped during rehabilitation.
In chapter four I justified the ontological approach taken and described the study design, it’s methods and detail the conduct of the research. I discussed the core tasks undertaken in efforts to include those this research is about and detail the way in which participants were recruited. I explained how data was collected and discussed the realities of conducting an ethnography in rehabilitative institutional settings. Highlighting key challenges and opportunities which arose during data collection I highlighted the benefits of ethnographic research in these settings and troubled the dominance of researcher-led recruitment and interviewing. I concluded by explaining the analytical approach taken to data and the origins of this situated approach.

In the first findings chapter – chapter five, I showed how the futures of different types of resident are imagined (or not) by the staff that care for them. I illuminated how, even for those considered to epitomise the rehabilitative dream - ‘poster boys’, their futures are imagined in a contained, constrained way. The hope of staff for these residents rests mainly on discharge location and the type of living accommodation they can aspire to be supported within. The detail of what this life look likes within this new place of living, outside of the care home setting however is not expressed in staff narratives. Even when staff were directly asked to describe what life might be like for residents who have left the rehabilitative setting, and therefore what they were striving to help their patients achieve, little was offered in response. The lives projected to be lived out in settings other than the rehabilitative/care home environment go entirely unimagined by the staff even though (or especially because) ‘discharge’ to this outside environment is their main goal.

In the second findings chapter, chapter six, I focussed on the lives and futures of residents unable to fulfil ‘poster boy’ status, those whose futures are imagined as lives lived out largely within the confines of the rehabilitative and long-term care setting. I challenged the notion that the ‘multidisciplinary team’ and those who ‘do’ rehabilitation is only consultants, nurses, therapists, social workers and the family – but instead includes a wide range of non-qualified health care workers including
health care assistants, therapy assistants, housekeepers, catering, maintenance and administrative staff. I illuminated how these people take care of the everyday, and show how, through the conduct of everyday tasks with and around residents, they make those who are not yet ready for rehab, rehab-able. Furthermore, I argued that the way in which these non-qualified staff interact with residents and what they do with and for them maps directly onto the formalised rehabilitative domains through which qualified staff also work. Health care assistants and hotel service staff therefore, conduct informal rehabilitation through the doing of the everyday. In these ways, these keepers of the present, aid the opening up of resident futures.

In the final findings chapter of this thesis, chapter seven, drawing on previous research which identified the tensions that exist in rehabilitative relationships (e.g. Shaw and McMahon 1990; Gebhardt 2011), extending work which has explored variations in understandings of and approaches to time between patients and health care professionals (Juhila et al. 2015), and work which identifies variations in temporal positions taken up by family members of those with severe brain injuries (Latchem 2013), I identified that there are mismatches in the way in which the future is imagined by residents, families and staff – and that these temporal differences contribute to tensions in the relationships between them. I also discussed how future imaginings by health care professionals (in particular therapists) are mediated by their concerns about giving residents and families ‘false hope’ and highlight their own view that residents’ and family members’ hopes for the future can lack ‘realism’. As highlighted in chapter one this is echoed within the rehabilitative brain injury literature which focusses on the importance of health care staff ‘managing expectations’ of patients and families – yet in chapter seven, in contrast to the clinical rehabilitative literature, I highlight that in the case of residents interviewed here, what they imagined for their futures was largely realistic and almost everything they wished for seemed achievable or able to be supported.
8.1 Opening overview of the discussion

In this closing chapter I discuss the value and implications of the findings summarised above by drawing together the substantive, theoretical and methodological implications of this research. I outline the original contributions this thesis makes to the fields of sociology and health care sciences and to rehabilitative practice and highlight the implications this work holds for rehabilitative practice and policy. I conclude with considering the limitations of this study, unanswered questions and make suggestions for further work.

8.2 Original contributions: theoretical, substantive and methodological

8.2.1 Theoretical contributions

This research supports aspects of the theoretical work of Adam, Adam and Grove and Novotny. It does so by identifying that health care professional practises within rehabilitation act to compress time and bring the unknowable future closer to the present. In doing so I argue that rehabilitation is conducted within Novotny’s (1994) concept of an ‘extended present’ and have provided specific empirical evidence within the field of healthcare which identify efforts to ‘tame’ the future (Adam and Grove 2007). In doing so I have provided contemporary support to the existence of Adam and Groves (2007) conceptualisation of the future assumptions made by societies throughout time. However, in providing empirical support for the contemporary existence of the assumption of ‘future as fortune’ (the assumption underpinning the belief that the future can be tamed and is ours for the making and taking – see Introduction), I make an original theoretical contribution. I add to their work by highlighting that the assumption of ‘future as fortune’ has not been overtaken in contemporary society by the newer more modern assumptions of future as ‘fiction’ and ‘fact’ that they identify.
Also, while Adam (1995) and Adam and Groves (2007) usefully identify the multiplicity of times and the ability of society to hold multiple future assumptions at the same time, I extend this work by providing the beginning of empirical evidence that different future positions and understandings of time can be held by different groups of people, at the same time, in relation to the same issue/topic/experience. I therefore demonstrate that the ‘grand theory’ offered by these social theorists has some purchase in its application to nuanced empirical data.

8.2.1.1 Sociology of time

 Critically however, this thesis has demonstrated how, by the application of temporal theory to rehabilitation, rehabilitation as process and practice becomes redefined and can be reconceptualised. In one way, rehabilitation is a practice which negates its futures orientation by operating in an extended present, but at the same time, the temporal lens demonstrates how it is conceived of as a much longer process than the two-year frame proffered in the clinical neurological and rehabilitative literature. Furthermore, the temporal lens applied here has highlighted how rehabilitation is a practice which extends beyond its clinical confines and shifts towards being a more broadly social practice, reliant not on the technicalities and technologies devised by medicine and through the professionalisation of certain work, but on the doing of the everyday.

8.2.1.2 Sociology of health and illness

 This thesis has explored how rehabilitation is defined by those who practice it as both restorative and as maximisation and optimisation – but, despite the impairments of those in independent sector rehabilitative settings, rehabilitation as restoration and the rehabilitative dream is pervasive. This rehabilitative imaginary does much work – first in providing health care professionals and staff with both motivation and satisfaction. Second, it attracts professionals to the discipline and sustains them within the difficult nature of neurological care. Third, because of their motivation and belief in the rehabilitative format, it enables them to care and support those who
cannot rehabilitate in the same way as others. The rehabilitative imaginary and those who achieve it then carry the care of others with very severe and permanent impairments. Fourth, it reifies professional health care skills and supports and sustains the development of allied health professions and specialist rehabilitative nurses. The rehabilitative imaginary plays a large part then in the creating and shaping of resident futures and the sustaining of care quality for others. In this way, this thesis contributes to the broader sociology of health and illness literature which uses the concept of imaginary and adds to the small but growing sociological work which has begun to critique the way in which people with brain injuries are constructed in and through rehabilitation (such as Banks 2016).

The implications of explicating the role of the rehabilitative imaginary is that the findings here balance out and neutralise what could be seen as a problematic discourse. The rehabilitative imaginary can be framed as being problematic in that it has the potential to deliver false hope, but it is also powerful in the creation of ‘good care’, and is an important discourse which generates much positive action for all patient types within these settings. I highlight for example how rehabilitative successes boost staff morale and in turn provide them with the resilience to carefully attend to and care for those who do not improve or change. I argue that its dominance does more good than bad. However, an awareness of the prevalence of ‘restore and return to’ within staff discourse in comparison to other models of rehabilitative approach is important. Health care professionals who work in environments with multiple patient types and those on different trajectories should not stifle the rehabilitative imaginary, but must be cautious about the pervasive nature of rehabilitation as restoration. The careful but broader use of rehabilitation as optimization may be a more useful discourse for use with families of those in a disorder of consciousness for example – where the approach of optimization is most certainly practiced, but not so overtly spoken.
8.2.1.3 Health care sciences and rehabilitative literature

In this thesis, I showed the connected and interdependent nature of the sharing and shaping of futures by and for all those who inhabit neurological rehabilitation centres. In this way, I make an original theoretical contribution to the healthcare sciences and rehabilitation literature by arguing that each patient type supports the other in terms of holding and creating a present which acts as a platform from which those with rehabilitative needs in the long-term can be supported and those unable to rehabilitate are given specialised care.

I demonstrated by the data presented from interviews with staff and some families, that those who cannot rehabilitate can be framed as preventing or hindering the rehabilitation of potential poster boys. Through temporal examination however, I argued that each type of resident plays a role in sustaining either the financial status of the organisation or morale of staff and therefore suggest that the future taking discourse of one patient from the other is misguided. Conversely each resident type makes the future or the present of the other. Those who are unable to rehabilitate serve as ‘cash cows’ for the organisation and enable the rehabilitation of ‘cheaper’ poster boys by providing financial security. Poster boys, in return boost staff morale and sustain them through the provision of the detailed but more repetitive care of those who do neither rehabilitate, making rewarding rehabilitative gains, nor die to provide the professional reward of facilitating ‘a good death’.

8.2.2 Substantive contribution

Substantively this research has contributed to the literature in three main areas - sociology of time, the sociology of health and illness and health care sciences research on brain injury rehabilitation. Through applying a temporal lens to rehabilitative practice this thesis has illuminated rehabilitative practices and demonstrated a further use of the sociological analysis of ‘time’ in another area of empirical study – brain injury rehabilitation.
8.2.2.1 Contribution to the Sociology of health and illness

Broadly, this thesis has contributed to the sociology of health and illness literature in several ways. First, it has done so by reinforcing the identification by medical sociologists that the aims of much institutionalised health care work practice is shaped by patient discharge (or ‘disposal’), as identified by Latimer (2000). It adds to this body of sociological literature by demonstrating how the aims of discharge plays out in the specific practices of brain injury rehabilitation and shows how the pervasive aim of discharge impacts upon and severely confines health care professional imaginings of the future (see chapter five).

Chapter six contributes substantively to sociological research on work and the construction of healthcare specialisms and specialists. It does so by reinforcing how those considered to be specialist are reified in the literature and in practice as those ‘doing’ rehabilitation and in doing so negates or hides the work of others. In highlighting the experiences of these marginalised workers this thesis reinforces how societal framing of manual labour or domestic work as holding a low social status plays a part in the way in which these workers feel about their work. This thesis adds to this literature base by highlighting how ‘care’ holds a higher status in comparison to ‘domestic work’ alone and identifies how the caring acts these employees conduct during their work enables them to attribute value to the mundane work they are employed to do. Through interaction with residents the ‘mundane’ work of hotel service staff is turned into care and rehabilitative work, which enables staff to gain a sense of value from the low status attributed to their job title.

8.2.2.2 Contribution to the literature on the Sociology of time

This thesis has contributed substantively to sociological work on social time and particularly, the small body of research which examines how time is talked about in health care interactions and demonstrates the power of the lens of time in explicating health care practices, experience and care relations. This thesis has contributed to this body of work by explicating how time and temporality plays a role in the defining of residents in neurological rehabilitation and long-term care settings.
I have illuminated how within these places of care which are often considered to be the end of the ‘patient pathway’, that residents types are still distinguished between in terms of their ability to ‘change’ or not, just as in other care settings in acute care and NHS rehabilitative settings. I have also demonstrated, in detail that there is a discrepancy in temporal understandings, needs and imaginings between the three groups of patient, family and health care professional. Such identification has enabled the consideration of the role of time in these relationships, especially in terms of creating or contributing to tensions in these relationships.

8.2.2.3 Contribution to health care sciences and rehabilitative practice

This thesis has shown that time is central to rehabilitative definitions and practice(s) – but that there is a discrepancy between what rehabilitation is said to be and what it actually is. I began my original contribution to this in chapter three, through reviewing the literature, where I begin the temporal critique this thesis offers. I questioned the temporal orientation of rehabilitation and the practice of goal setting. I highlighted that despite the extent of the goal setting literature and its proffered centrality within rehabilitation, the evidence for its direct usefulness in relation to improving rehabilitative outcomes for patients with neurological conditions was weak. Instead I showed how the literature on goal settings focuses on its use for team working and organisational goals and suggested that goal setting could be a technology to condense time and manage expectations of patients and families, rather than act to contribute towards patients making rehabilitative progress.

Substantively this thesis made an original contribution to the health care sciences and rehabilitative literature through the key offerings in chapter 6. Through close observational work at the bedside this thesis has shown both the presence and work of non-qualified people – those of hotel service staff. I have identified how i) the work hotel service staff do – both their day to day work and the way they interact with residents constitutes ‘informal’ rehabilitative work, and ii) fits with the constructed notion of the professional multidisciplinary work and its therapeutic aims. While the clinical literature defines that those who ‘do’ rehabilitation are those within the grouping of specialist professionals within the multidisciplinary team, I
have highlighted that iii) the who of neurological rehabilitation is not these core professionals alone. These findings highlight how iv) the rehabilitative team, in practice is a much broader team – which includes all of the health care professional defined in the literature as the ‘multidisciplinary team’ but also includes hotel service staff. Please see appendix 4 for details about the initial impact made through sharing the findings from this thesis.

8.2.3 Methodological reflections and contributions

In this section I first reflect on the implications of conducting ethnographic methods, particularly, the impact of ‘non-participant’ observations and discuss four key contributions this thesis makes to the methodological literature.

The use of non-participant observations in this study provided three key opportunities. First, the act of sitting still and observing ‘at the bedside’ – quickly illuminating the presence, work and interaction that patients with severe brain injuries have with non-qualified staff – sets of observations which provided some of the most central findings of this thesis. Second, the freedom which conducting observation offers enables the research to explore places and spaces over and through time. Not being limited to pre-defined moments of the interview, observational freedom enables a more grounded and emergent way of researching, reducing the dominance of pre-formed ideas or experiences. Third, the use of non-participant observations enabled the inclusion of people with severe injuries. This was achieved in two ways, first, being able to observe and be with people with the most severe impairments enabled their involvement in research, when due to the severity of their impairments explicating their immediate world would not be possible in any other way. Second, being present in the setting near to people with severe brain injuries enabled them to get used to my presence and demonstrate over time either an acceptance of my presence or equally a rejection of it. The importance of this is discussed below. The conduct of both broad and in-depth observations enabled the diverse collection of data and gave room for ‘surprises’, but also offered the opportunity to focus on particular lives. In-depth observations allowed me to
check if and how what was seen broadly came together around a single resident and played out in their everyday life.

The use of semi-structured interviews and taking a case by case approach offered enough flexibility to suitably tailor to the needs of individual participants. This both enabled their participation in this research in the first instance, and then maximised the gathering of their experience and views. Semi-structured interviews offered an overall structure to interviewing but again provided the flexibility to work across and allow for differences and variation. Semi structured interviews could also be undertaken quickly in situations where staff were under time pressure, or could be easily broken up into sections to enable staff to be interviewed in blocks rather than needed to maintain a single narrative. The mix of observation and interviews afforded the opportunity for me to contextualise interview questions to the setting, and improve my ability to make the interview most relevant to the participant, and to better understand their experiences.

8.2.3.1 Four key contributions

Through the conduct of this research, four key methodological issues and/or contributions have been made. In the below section I explore what has been learned through the conduct of this research, what issues have been raised through it and how the way in which this research has been carried out has been successful.

8.2.3.2 Troubling researcher-led recruitment

In all cases in my research, potential participants who lacked capacity (and were conscious) but often severely impaired, with complex and multiple needs, actively demonstrated whether or not they were willing to be observed. The extreme example of Riya (see appendix 3.4) is but one. People with impairments ranging from mild to severe also chose whether or not to interact with me. Those who were mobile through any means and able to converse verbally, did so spontaneously, enquiring about me and engaging in conversation. Those who were unable to communicate verbally and whose close family had acted as personal consultees and advised their will for involvement, responded to my presence and to me through
gesture and behaviours. Their responses to me were then checked and interpreted by family and staff members who knew them well. Equally, several residents who lacked capacity to consent but whom I would have selected to explore the potential of their becoming ‘participant’, demonstrated to me that I was not welcome or wanted in their space. With scowls and physically turning away, they made it known that my presence and watchful eyes was considered intrusive to them. In those cases, I moved away and did not pursue their participation.

In practice then, many residents ‘self-selected’ by either coming towards me and interacting with me or de-selecting, by making it evident they did not want me around. While I do not wish to suggest that ‘interaction’ equals consent it does provide a key indicator of willingness to interact, or not. In research which utilises methods such as ethnography, where the presence of the researcher must be at the very least, well tolerated, the gathering of interactive potential and the tolerance of presence is critical for the appropriate participation of those who lack the capacity to consent on their own behalf. For further discussion on the implications of the MCA upon recruitment and the self-selection of participants see Latchem (2016). This thesis therefore contributes to the research ethics and emancipatory literature by highlighting the potential use of broad ethnographic observations as a tool to allow and enable residents’ self-selection in research.

8.2.3.3 Researcher-led interviews

As also highlighted in chapter 4, in practice, it was at times challenging to find quiet spaces to conduct interviews with residents. Despite often difficult environmental circumstances, residents managed to concentrate well during interview and in some circumstances, took control of the conduct of the interview and the immediate environment. For example, one resident, Eddie, began gatekeeping who came in and out of the space. My experience with Eddie (as reported in appendix 3.5) challenges the researcher-led research process highlighted and data collection which is foregrounded and assumed in research governance framing. Furthermore, Eddies’ actions highlight how the interview is not conducted in a social vacuum, but is part
of the social world. Eddie identified that his bedroom was an inappropriate place to be interviewed by a young woman. He therefore selected the best place to be interviewed within the space he had open and available to him. Eddie welcomed me into his place of living. Despite my presence in the setting for nearly three months at the point of interview, Eddie recognised and distinguished me from ‘staff’ and therefore saw and treated me as ‘guest’ or ‘visitor’. Eddie assumed the role and the responsibility of host. Ensuring that Eddie had complete control over the interview enabled him to exercise and reinstate appropriate social behaviours – interestingly, some of which he would have been ‘assessed’ to have been incapable of. The way in which Eddie controlled the interview also tells much about the setting and the way in which visitors are seen and treated by the men who ‘live’ there. The rich opportunity and the important paying attention to the surrounding actions during, pre and post any interview is conceptualised as ‘waiting fields’ by Mannay and Morgan and the rich source of data these situations provide discussed in their 2015 paper. This thesis therefore contributes to the qualitative health research and methodological literature through highlighting the ability of people with brain injuries to manage their own interviews and adds to the body of work on the importance and contribution noticing during ‘waiting fields’ offers.

8.2.3.4 Ethnographic methods and a case by case approach

This thesis utilised ethnographic methods in conjunction with a ‘case by case’ approach. The successful inclusion of people with severe and complex neurological impairments through these means offers support to and provides a useful demonstration of the use of this approach.

8.2.3.5 The value of hybrid researcher – skilled to interview, confident to include

Although my status as a healthcare professional has been briefly touched upon, I have not yet made any overt statement connecting my clinical skills and methodological conduct. Interviewing people with severe neurological impairment, being able to adapt interviews around multiple and complex communicative and cognitive impairments is outside of the abilities of many social science researchers
without some prior experience. I have been able to conduct this research and involve people with severe brain injuries in the way in which I have because I have ten years of clinical practise experience working with and treating people with neurological conditions. My physiotherapeutic assessment and communication skills were critical to the conduct of this research. This thesis therefore contributes a strong argument for the benefit of the hybrid healthcare-social science researcher in research which seeks to explicate the experiences of people with severe neurological impairments. Through the skills of the researcher, those normally considered ‘difficult’ or impossible to interview, are made possible.

This thesis therefore contributes to the methodological literature substantively through demonstrating the use of a case by case approach and presenting how stock and well-tried methods can be adapted suitably for the inclusion of people with severe brain injuries. It contributes by providing an explicit example where the hybrid clinician-social scientist, trained in social science methods and has clinical experience is useful in enhancing inclusion of vulnerable groups – in this case people with severe brain injuries. This thesis contributes to the research ethics literature by challenging ‘protective’ researcher-led recruitment and interviewing, and instead demonstrates the abilities of those who ‘lack capacity’ to contribute to research involvement of their own volition.

8.3 Implications for policy and practice

The findings of this thesis offer evidence of exciting practices ripe for celebration and utilisation, alongside areas for concern in urgent need of change. Beginning with areas of concern and finishing with points of celebration, this section summarises the key findings of this thesis and explains their direct relevance to practice and policy.

8.3.1 Extending time for rehabilitation and establishing new patient pathways

This thesis has identified how the practice of rehabilitation and the future making potential of this process extends far beyond the time limits its delivery is largely confined within. This has implications for funding frameworks and policy – in that
rehabilitative funding is often limited to a post-acute phase of months rather than years. This thesis highlights that there are patients who are not-ready-for-rehab but occupy rehabilitative beds and are unable to take advantage of the rehabilitative therapies they are offered at that time. Equally, these not-ready-for-rehab patients do not necessarily remain unable to engage with rehabilitation, as they can be made rehab-able through informal rehabilitative practices elsewhere. The findings of this thesis suggest therefore that instead of the linear ‘patient pathway’ of acute care to rehabilitation to slow-stream rehabilitation/long-term care, some patients with severe brain injuries may benefit from an inverted pathway. Instead of seeing patients move from acute care into NHS rehabilitation beds, this new pathway would see patients being transferred from acute care into slow-stream rehabilitation/long-term care settings in the independent sector. Here they would receive slow stream rehabilitation through largely informal rehabilitative practices to make them rehab-able, and then be transferred for more ‘intensive’ rehabilitation back into the NHS once rehab-ready.

8.3.2 The importance of imagination

This thesis has highlighted a discrepancy and an inequality in the way in which staff imagine the futures of the people they care for. The futures of those who do not demonstrate rehabilitative gains, is barely imagined at all. I suggest that this lack of imagination, has significant implications for rehabilitation practice in two ways. First, if we accept that all futures come following action taken in the now, a lack of future imagining, prevents rehabilitation being delivered to some patients at all. Second, a lack of future imagination for patient reduces the scope of rehabilitation and negatively impacts upon the lives of people with severe brain injury. If we do not imagine things for the future, we do not take action in the now.

The research has identified the pervasiveness and the role of the rehabilitative imaginary within the context of rehabilitation and long-term care settings. Although this discourse is problematic in that it is inaccurate for many, it serves multiple purposes which provides positive support for all resident types. However, for those residents and their families for whom any notion of restore or return to is not a
possible future, rehabilitation as maximisation could be more actively promoted as a discourse. For example, managers and those responsible for marketing could seek to promote ‘rehabilitation as maximisation/optimization’ alongside ‘rehabilitation as recovery’ on websites and on meeting news residents and their families to help balance the hopes and expectations, and reify the importance of the optimisation approach to rehabilitation. This may have implications is shifting funding priorities and in establishing different patient pathways.

Although I have highlighted above, and in the summarising section at the opening of this discussion, how the findings of this thesis relating to the mismatches in future imaginings between residents, families and health care professionals contribute substantively to the literature, what has not yet been considered are the implications of these findings for practice. Residents, families and staff imagine the future of residents differently. The differences and discrepancies in these imaginings provide insight into health care practices, professional framing, service provision and the triad of resident, staff and family relations. These mismatches provide a source of tension in the relationships between these three groups. In chapter seven I highlight how a lack of ‘future talking’ by health care professionals can be experienced as frustrating for family members - recognition then from health care staff that families at times need discussion which incorporates a much further reaching temporal frame than is commonly used may foster positive relations and communication between families and health care professionals.

8.3.3 Respecting present keepers and protecting informal rehabilitative practices

This research highlights that all employed within neurological rehabilitative and long-term care settings can play a critical role and contribute to the rehabilitation of people with severe brain injuries. Therefore, every role held in these places comes with a responsibility of care. This research highlights an opportunity for people in managerial positions of power or those with recognised therapeutic skills through professional titles, to recognise both the presence and the scope of the rehabilitative work of non-qualified workers and to consider how to harness this labour for the
benefit of residents’ future and flourishing. Furthermore, understanding how hotel service staff know how to do what they do – how they develop techniques, rehabilitative understanding and build rapport without the benefits of specialist training, or indeed any training – could be explored and utilised to train others both specialist and non-specialist.

8.4 Limitations of this study

Although the benefits and usefulness of the questions posed, methods selected and the contribution the findings from this study have made are discussed above, there are limitations inherent in any study and by any and every selection of methods.

The ethnographic methods selected here enabled in-depth and nuanced study of the everyday of neurological rehabilitation settings and individual lives. However, due to the broad range of observations conducted and, at times, the infrequent happenings of certain types of professional meeting, there were occurrences and happenings that were not captured in detail. To do so would have required significantly longer in the field. This therefore demonstrates that there is ‘missing data’ – and further data available for capture and consideration in reference to its role in shaping futures of people with brain injury rehabilitation.

Although this study included many people with severe brain injuries through a variety of methodological means, only four patients with brain injuries were able to be interviewed and eight observed in an in-depth manner. Interviewing a larger number of people with severe brain injuries would be useful to either support, refute or extend the findings presented here.

The temporal reach of this study was limited to the past, present and an extended present. The study followed individuals over a maximum three-month period. The study of brain injured futures could be approached differently. For example, some form of longitudinal investigation could have been considered, taking snapshots of lives over a longer period of time and examining differences in lives between one point in time and the other.
Finally, this study sought to explicate how the futures of patients with severe brain injuries are shaped in and through relationships with others and rehabilitative organisation process and practices – utilising social science methodologies and a temporal lens. Although this study has gone a substantial way to address this question, further questions have been generated through the course of this research, which must be considered and responded to, in order to deepen understanding of what, who and how the futures of people with severe brain injuries are shaped.

8.5 Unanswered questions and further work

One of the key findings, and troubling realities uncovered by this thesis is that even the futures of poster boys are imagined almost purely as a place of discharge and their lives beyond the walls of the institution or new place of living are not considered in any great detail. Although I have been able to identify that the pervasiveness and organisation orientation towards discharge may play a significant part, this thesis has not been able to entirely explicate why futures of the severely brain injured are imagined in such constrained ways by staff. This thesis therefore raises this as a further question for consideration.

A further key finding of this thesis includes the identification that each resident type supports the future of one another. Although I have begun to explicate the intricate interdependency of different types of residents in these places, what has been identified here, requires further exploration. This is an important area because if the future taking discourse identified in staff and family members (which suggests that those who do not show rehabilitative gains prevents the access to rehabilitation of another person) persists or becomes pervasive, it poses a threat to the very people their discourse seeks to protect.

Although questions relating to the temporal orientation of rehabilitation have been addressed throughout the findings chapters, while goal setting served a useful purpose in the positioning of this thesis and in presenting the inherent problem of
temporal confusion evident within the literature, the argument I began to build about goal setting being a technology to manage time and expectations has only partially been attended to. This is because goal setting practice was noticeable in its absence during my observations. Consequently, it did not feature strongly in the findings chapters of this thesis. However, in many of my interviews with healthcare professionals, I did explicitly ask (towards the end of the interview) what they thought about the goal setting process and what it offered both them and patients. Preliminary analysis suggests that staff give lip service to goal settings, conducting them for administrative purposes rather than as part of effective clinical practice. This area however needs much further exploration, separate, concentrated secondary analysis and further observational work to support or dismiss the questions raised in chapter three and seven.

The temporal confines that staff use initially when defining true rehab fit with those within rehabilitative policy and funding criteria. There is no place for a process of rehabilitation, extended temporally and outside of the confines of true rehabilitation in policy and funding frameworks. Through these documents, such extended rehabilitation occurring outside of true rehabilitation is not rehabilitation, it is care. The effect of such temporal bounding of rehabilitation within policy and funding frameworks requires exploration – and an analysis of temporal constructions of rehabilitation in policy and funding could be a useful addition and development of the work explored here. Furthermore, this thesis has focussed on practices of people within neurological rehabilitation settings. What it has not done however is to consider in detail whether or not health and social care policy affects actions and lives in these places. The role of policy more broadly in the shaping of patients’ futures could be an area for further study.
8.6 Closing summary

Through applying the lens of time, the intricacies of brain injury rehabilitative practice and relationships have been illuminated. This thesis has demonstrated how time as topic has unsettled rehabilitative definitions and aims, and shown how, in the case of rehabilitation, the temporal can be used as a guise to cover up motivations and actions. These findings demonstrate that the temporal aim of rehabilitation inherent within its definition of ‘restore and return to’ and its proffered orientation of ‘future’ are not matched in practice. Brain injury rehabilitation is not purely a process of restoration and return to but of adapt and make new. It is not one of future orientation but predominantly operates within the realm of an extended present. Brain injury rehabilitation is a constant process of bringing the future closer to the now; to tame the future, reduce uncertainty and make the unknowable, knowable. The application of the temporal lens uncovers the hidden and illuminates the effectiveness of non-professional people’s interactions in and through the conduct of the everyday. In this way time reconfigures rehabilitation, extends it beyond the confines of a ‘professional’ process and opens it up as a social practice of care and caring by everyone present in neurological rehabilitation and long-term care settings.
References


306


Hickman, L., Phillip, J., Newton, J., Halcomb, E., Al Abed, N. and Davidson, P. (2015). Multidisciplinary team interventions to optimise health outcomes for older people in


312


Latchem, J. and Kitzinger, J. 2012. What is important to residents with neurological conditions and their relatives in long-term care centres? [Online]. Available at: http://www.cardiff.ac.uk/jomec/resources/Long_Term_Care.pdf [Accessed 21 August 2013].


National Quality Board. (2013). *How to ensure the right people, with the right skills, are in the right place at the right time: a guide to nursing, midwifery and care staffing capacity and capability*. London: National Quality Board.


Ostermann, T., Bertram, M. and Bussing, A. (2010). A pilot study on the effects of a team building process on the perception of work environment in an integrative


Appendices

Appendix 1 – Prelude – Good morning Charis

This appendix offers a data-inspired prelude to the PhD to help readers who do not have experience of severe brain injury and neurological rehabilitative settings visualise the situation and people this PhD charts.

“Good morning Charis! Hello sweetheart it’s only Ally. I’m just gonna mop your floor and just dust off these bits alright.” Ally walks to the far end of the room and pushes open a pair of patio doors. “Phew, that’s better, let’s get a bit of fresh air in here a minute.” Ally works her way around a pile of discarded packets which once held some type of dressing or medical equipment on Charis’ bedside table. She lifts up a plastic jug and then a tray littered with little plastic pots and wipes underneath. Ally carefully lifts up pictures stood on the chest of drawers at the end of Charis’ bed, dusts them and puts them back. Holding up one she says “Your chap is a handsome fella isn’t he! Such a nice boy. But he’s got himself a catch hasn’t he Char!” Ally pauses and then says quietly to herself - You look like you were having a nice time there.

The room is decorated with battery powered pink fairy lights, carefully placed girly trinkets and a selection of pictures, some of Charis and her boyfriend, others of her friends, her parents and brother. Ally finishes dusting and walks into the middle of the room. She leans on the cotsides, hard white rails either side of Charis’s bed and gazes at Charis’s face. Gently and more quietly she says “You alright sweetheart?, you look a little flushed this morning.” Ally pauses for a moment looking at Charis and then takes her mop and wheelie bucket. “Right, just gonna do the floor now Char and I’ll be out your hair.” Ally mops the floor rapidly from the patio doors back towards the main bedroom door. As she reaches the door Betty comes in at speed nearly colliding with Ally and the bucket.

“Oh God! Sorry!” She says. “Morning!” Ally calls at her cheerfully, laughing, “steady the floor is wet.” “Morning. Oh right, Ok.” Betty calls across to Charis “Morning Charis, it’s Betty. I’m just gonna do your stretches.” Ally looks up at Betty as she finishes mopping. “She looks a bit sweaty this morning Bet.” “Right, Ok.” Bet replies. Ally backs out of the room pulling her cleaning trolley behind her. She pauses in-between Charis’s room and that of the next resident. She takes a deep breath. Such a beautiful girl, lovely family, it’s such a shame. Life’s cruel. She is broken from her thoughts by Minnie another housekeeper who walks past and raises her eye brows saying “need a new mop head”. They both laugh and Ally pushes her trolley into the next room.

Betty heads straight for Charis, leans on the cotsides and in close to Charis’s face. “Right then, hello you, let’s have a look at what these arms and legs are doing this morning.” Charis stares forward until Betty speaks. Her eyes flick towards Betty momentarily, the left side of her face twitches a little and her eyes then flick around for a few seconds as if she’s searching for Betty. “Sorry sweetie, I’m gonna have to

330
move ya, you look pretty comfy too!” Betty scans Charis face, looks down her body and then touches her forehead. *Hmm she is warm.* Betty presses a button on the bed and the cotside collapses down. She holds Charis’s head in her hands and gently pulls out the pillow and rests her head back down. “I’ll sort your head out in a minute. Don’t go to sleep on me though Charis!”

Betty picks up Charis’ arm, bends and straightens it a few times, slowly, and then lifts her arm up and to the side. “Well done Charis, normally you’re shouting at me by now, so you must be chilled today. We’re going to go in the opposite direction in a minute Charis Ok.” Charis makes a loud single snort. “You’re not meant to snore on me Charis! I’m going to stretch your fingers out now. Can we relax them? Well done. I’m just going to hold them in that position for a moment.”

Betty holds Charis’ hand flat on the bed. She mouths and sings quietly along to Heart Radio playing through Charis TV which is mounted on the wall. “Right, let’s get the splint ready then Charis.” Betty picks up an oddly shaped object led on a chair in the corner of the room. She lays Charis’ hand over it, pulls over a soften strap and secures it then picks up a Disney pillow and puts it under Charis’ arm. “I’m going to come round and do the other side now Charis alright.”

*I hate doing this, I know it has to be done but sometimes I worry that I’m hurting her. I get that I’m doing this so we can keep her clean. If her hands get so tight we can’t wash them, she’ll get infected and that’s horrible too so I have to do this.* Betty lifts the cotside back up and it clicks into place. She moves from the left side of Charis’ bed to the right and collapses the cotside again and repeats the stretching sequence. She moves from looking at her own hands to Charis’s face. There are a few seconds of quiet as Betty concentrates on her hands pregnant with chatter as Betty chats away to Charis like she’s her best friend. “Saw your lovely fiancé in here yesterday visiting you.”

In a moment of quiet as Betty concentrates on stretching Charis’ right hand Cassidy bursts through the door. “Hello Charis!” She calls. “Hiya” Betty replies quietly. Cassidy, seeing that stretches are in action quietens down and approaches Charis slowly. She goes around to the left side of Charis’s bed and leans over the cotside and whispers “Hello babes, is this one giving you trouble?! Is she messing you about after we got you so comfy? Shall I sort her out?”

Betty: “She’s a bit warm Cass.”

Cassidy: “I did shower her this morning.”

Cassidy touches Charis forehead. “She’s a bit sweaty too. Ok, I’ll do a set of obs.” Cass leaves the room and returns moments later wheeling a tall contraption. She whacks it into the door frame as she enters with a clatter. The contraption has a small screen on the top, a little basket on the side with a twisted mass of wires spiralling down a central pole. Cassidy untangles some of the wires and plugs the contraption in to a socket at the wall. She rips open a piece of material with a lead
coming from it and places it around Charis’s upper arm. “Just do your blood pressure
Char.” Cassidy presses a button on the screen and the machine buzzes and the cuff
on Charis’ arm puffs up. As the machine does its work Cassidy takes out a handheld
piece of equipment from the little basket. She pushes the tip of it into a set of white
cones and clicks one onto the end. She places the cone covered end into Charis’ ear
and presses a button. A few seconds later the machine beeps and Cassidy removes
it from Charis’s ear, discards of the cone and looks at a small screen on the device.
“38.1”. Cassidy and Betty look at one another. “I’ll tell Patsy”.

Betty: “Help me get her comfy again.”

Cassidy: “Oh that’s right, come in here, mess up my work and then get my help to
do it again, I don’t know!”

Cassidy and Betty shift pillows behind Charis, Cassidy reaches behind Charis’
shoulders and pulls her forward a little as Betty plumps and wriggles in the pillows
behind her.

Betty: “Right Charis, sorry for shifting you about darlin’. I’ll leave you with Cass for a
bit. Do you want me to say to Patsy or are you?”

Cassidy: “I’ll go now, she’s looking pale too isn’t she.”

Betty: “Yes she is”.

Betty goes in to a bathroom, set at an angle to Charis’ bedroom and washes her
hands. She looks back over her shoulder towards Charis, frowns and looks at Cassidy.
Cassidy is still stood leaning on the cotsides over Charis stroking her face and talking
softly to her. Cassidy looks at Betty worriedly. Betty dries her hands using paper
towels from a dispenser on the wall and heads for the door. She goes straight
towards a small office out on the main ward area, picks up a folder and sits on a
wheelie office chair by a desk. A gaggle of women occupy the office, some on the
phone, some stood talking, some pouring over a single sheet of paper. One prods
Betty, “Hey Betty, bad about Mikey in’t it. I only saw him last Wednesday up the
Football Club.” Betty places her hand on her folder, looks up and talks to the women.

Cassidy continues to gaze into Charis’ face. I can hope and pray all I want can’t I, but
you’re not going to change. This is what it is. I hope somehow that you know I’m
here, that you can somehow hear and understand me, that you get something from
me bounding in here every morning. I hope you like my jokes. We would love it if one
day you woke up and little by little you started coming back, it would be amazing, and
you could do physio and you could have all different sorts of rehabilitation stuff and
you can try and do three blinks for yes and two for no, and sometimes I think you can
do that but then I think, is it really fluke? Is it really happening? Are you really doing
that? And is it meaning that you’re getting better or does it just mean you could do it
all along and I didn’t notice?
I keep thinking, is it going to make it easier for your parents if one day we could say ‘yes, you know the difference between yes and no, so ask you a question, you’ll do three for yes and two for no’, does that, will that make it better? I think you turned a little and looked to the right yesterday when I came in, and normally you only ever turn a little to the left when I’m at that side, but we have to be careful that we don’t say things based on a few incidences, that you’re waking up or you’re more responsive. I know your mum and dad take it with a pinch of salt because that’s the way they are isn’t it, but you say that to someone else’s parents who’s aren’t like that and you’ll give them false hope, and that’s not fair. There’s so many territories I don’t want to and can’t step in.

Cassidy strokes her head and talks to her. “So you’ve had a lovely shower this morning, you’ve had your stretches, all is going well, now, shall I cut your hair short, Mohican style!” Cassidy laughs. “No! You not keen! Ok.” Cassidy is pulled from her thoughts as Patsy rushes in carrying a tray. “Morning Charis, It’s Patsy, I’m here to give you your medication.”

Cassidy: She’s a bit warm Patsy, I’ve done a set of obs. Her temperature is 38.1.

Patsy: Right, ok, let me just give her her meds and then I’ll take a look.

Patsy puts her tray down on Charis’ bedside table. She pours water into a couple of white paper pots, opens a syringe, picks up one of the pots and stirs the solution with the end of the syringe. She reaches under Charis’ covers and pulls out a short tube tucked just into her pjammas. “I’m just going to give you your medication Charis.”

Patsy unclips a white clip compressing the tube with a click. She unscrews a tiny cover at the end of the tube, holds the syringe up and squeezes it until a small amount of liquid comes out. She twists the syringe into the top of the tube before slowly plunging the liquid in. She is mainly silent as she swaps syringes, reloads with medication and water and slowly plunges them into the tube. Cassidy chats away quietly to Charis. With the last twist off of the syringe, Patsy reclips the clip, screws the cover back on and tucks the tube back into Charis’ pjammas. “All done Charis. Right, so what was her temp?” Cassidy looks up at Patsy, “38.1.”

Patsy: “Who washed her this morning?”

Cassidy: “I did”.

Patsy: “Had she passed urine? Was her skin all intact?”
Cassidy: “Her skin was fine. I’m sure her pad was wet yes, but let me just check.” Cassidy picks up a folder resting on a chair in the corner of the room and flicks through several pages. “Yes”.

Patsy: “Ok, well she’s just had some paracetamol, let’s put her on 2 hourly obs ok and we’ll just keep an eye.”
Patsy scoops up her tray and piles all the small empty pots onto it and rushes out the room. She walks to a trolley, unlocks a door and pulls the door down to make a table, uncovering a stock of medications inside. She peers at the fob watch on her chest. **10 o’clock already! By the time I finish this round I’ll be needing to start the next. You just can’t get anything done in this place!**

Throughout the morning Cassidy and another health care assistant check on Charis. She sickens, her temperature rising and even the slight responses she gives to the direction of voices fades. The GP is called and as his arrival is awaited Patsy calls Charis’ mother. Sat in the nurses station, Patsy pours over a white lever arch folder holding Charis’ medical records. She lifts up the phone receiver and pauses before she dials. *Oh, I have to tell her now, I’ve held off as long as I can. They were both here all day yesterday. I bet she’s at work today as well.* Patsy dials and the phone rings. Charis’ mother Cora answers the phone, “Hello”.

Patsy: “Cora, hello, it’s Patsy here from Goodleigh Hall.”

Cora: “Hello Patsy, how are you? Is everything ok?”

Patsy: “Hi, I don’t want to worry you but Charis has quite a temperature this morning. We’ve been watching her closely this morning, her oxygen saturations are all ok but her temperature is up and she’s tachycardic, uh, sorry, her heart rate is a little fast. We think she’s got another infection. I’ve called Dr Andrews and he’s coming out to see her.”

Cora: “Right, ok. Who is with her?”

Patsy: “Cassidy is with her.”

Cora: “Ok, that’s good. Ok, do you think she’ll need to go to hospital?”

Patsy: “I’m not sure at the moment, but she may need IV antibiotics again and if that’s the case, then yes she’ll need to go in.”

Cora sighs. “Ok, I’ll finish up here and I’ll be on my way.”

Patsy: “OK. See you shortly.”

Cora: “Thanks Patsy.”

Patsy puts the receiver down and sighs too. She quickly scribbles in the folder in front of her and then returns to her second drug round of the day.

Charis is seen by Dr Andrews, a local GP who after quizzing and listening to the accounts of Patsy and Cassidy and listening to Charis’s chest concludes that she most likely has another urine infection and will need a course of intravenous antibiotics. He however considers Charis to be stable and well enough for transport to hospital.
to be organised within the non-emergency four hour window. Just as Patsy is on the phone to ambulance transport services in the nurses station Cora walks on to the ward and into Charis room. Cassidy is by Charis side with her arms around her stroking her head.

Cassidy: “Ah look! It’s your lovely mum Char.”

Cora puts a couple of bags down and goes straight to her daughters’ bedside. She leans over the cotside and kisses her on the cheek and feels her head. “Hello chicken!”

Cassidy: “She has a temperature.”

Cora: “Are you hot stuff little Miss!” Cassidy and Cora laugh. Cora smooths Charis’ head and chats away to her quietly. “Are you feeling poorly my little chicken?” Cassidy carefully pulls her arm out from under Charis shoulders and pulls the wheelie contraption towards the bedside again. She looks at Charis who feels different to her, somewhat floppy. Sweat is pouring off her head. “Charis.” Cassidy calls her name and stares at her face searching for a sign of response. There is no twitch of her face or flicking of eyes. Cassidy teases, hoping to generate a response, “Charis, I’m going to get the scissors now and cut off all your hair off, you’re gonna have a nice Mohican!” Again she searches Charis face for a response but none is seen. “I better just take another set of these.”

Cora: “Has the GP been?”

Cassidy: “Yes you literally just missed him.”

Cora: “What did he say?”

Cassidy: “I don’t know, sorry, he went outside to speak to Patsy.”

Cora: “She is very sweaty, it’s pouring off of her.”

Cassidy takes another set of ‘observations’, Charis’ blood pressure, temperature and heart rate, and times her breathing rate. Cora moves around the room putting away clean clothes in Charis’ wardrobe and putting new bottles of shampoo in Charis top drawer. She begins to think through what she will need to do should Charis need to go to hospital. I’ll just wait to hear what the Dr had to say and then I better call Ben again. No point disturbing him until I know what the plan is. But she looks just like she did last time. How many times is she going to go through this, my beautiful girl. What can we do? I can go with her and Ben will have to leave a bit early to be back for when Simon gets in.

Cora looks across to Cassidy and smiles quietly. Cassidy smiles back. To see somebody who looks like your child who isn’t in fact any more, there’s no way you
can deal with that. I do not know how Cora and Ben deal with it. As Cassidy finishes the obs, Patsy hurries into the room. “Hello Cora, I’m sorry, I was on the phone.”

Cora: “What’s happening? Please don’t say she needs to go to hospital again. We hate it when we have to go to hospital. They don’t know her, they don’t understand her and they don’t care for her like you all do. We have to be there all the time, we can’t leave her for a minute.”

Patsy: “Dr Andrews has just seen her, he suspects she has another urine infection and will need IV antibiotics, so I’m so sorry but she is going to have to go in. He feels that she is well enough to go in non-emergency transport, he’s told us to keep monitoring her and I have put in a call to transport. They’ll be here any time within the next 4 hours.” Cora sighs, frowns and then quickly puts on a brave face: “I’ll pack a few things and call Ben.”

Patsy: “I’m just sorting notes to go with her.”

Cassidy, staring at the obs recording she has just made calls to Patsy. “Patsy, can you just come here a minute.” Patsy goes across to Cassidy and Cassidy points to the page. Patsy pulls her glasses off of her head to take a look. “Ok, so her temperature is still high, her respirations and her sats are still ok. Keep an eye on those and let me know if anything changes.”

Cassidy: “She’s definitely more sweaty. I haven’t been on break yet, is it alright if I nip out now?”

Patsy: “OK, I’ll give her some more fluid. Transport is on its way. She needs antibiotics. Yes, go and take a break a minute while I give her some more fluid.”

Cassidy puts her face close to Charis, “I’ve just gotta go nip have a quick drink Char alright, I’ll be back in a minute. Don’t cause any trouble when I’m not looking!” Cassidy squeezes Cora’s arm as she heads out of the room. “Do you want a coffee?” Cora pats Cassidy’s hand. “Thank you, but I’ll get one myself in a minute after I’ve called Ben.” Cassidy leaves Charis’ bedroom and grabs a packet of tobacco, a set of papers and her lighter out of her bag stuffed in a kitchenette cupboard. She calls across to another healthcare assistant as she disappears into a linen cupboard. You had a break yet? “No”, the voice replies, “I’m coming now, see you out there.”

Cora kisses Charis gently on the cheek, “I’m just going to call your Dad a minute chicken ok, tell him what we’re up to.” Cora leaves the bedroom and sits in an armchair out on the ward. She riffles in her handbag for her mobile phone and calls her husband. “Hello love, Charis is poorly again. Yes I’m here. I didn’t want to worry you until I knew what was going on. They’re not saying much but she’s clearly poorly, we can’t get much out of her. It’s a nasty infection, probably urine again. She’s going to need IV antibiotics so an ambulance will be here sometime in the next 4 hours. 4 hours, I know, it’s because it’s a non-emergency. I will love. Can you get out a bit early so you can be with Simon? Ok, good. I’ll call you later. I know, how much more
can she take? I know, feels like she’s going backwards again. I’ll speak to you later.” Cora takes a deep breath, makes herself a coffee in the kitchenette out on the ward and goes back in to sit with her daughter.

Cassidy walks slowly off the ward, up the stairs and out of the building. As she walks she thinks:

It’s bloody typical, it seems like she’s been more responsive recently, and they’re about to do some more tests to see if there is something there, but fucking Chrissy, I can’t believe she went and said Cora and Ben ‘oh I feel like she’s waking up, she’s getting so much better, she’s so much more responsive’ bla bla bla. I know she was trying to help but actually you’re not, because it’s not the case, it’s false hope. Luckily, they had noticed things too I suppose and luckily they are not ones that are going to hold their breath, and expect it to happen. But they are aware that there have been these little changes, which makes today even more devastating because they’re just nothing right now. Is this it now, has something changed now? Have we pushed to have you potentially reassessed and maybe there was a bit more of you coming out and now potentially this could be it? Please, don’t let it be like this now. Cassidy looks up to the sky. We won’t be greedy, we’ll just have what we had back, at least we can have a bit of interaction.

Cassidy rolls a cigarette and stands in the smokers’ area chatting, smoking and shivering.

.................................................................................................................................................................
Appendix 2 – Goal setting

2.1 Person centred care, service user involvement and participation in goal setting

The act of collaborative goal setting is repeatedly linked and considered to fit with ‘person centred care’ – a model or “a philosophy of care that encompasses the physical, emotional, social and spiritual needs of the patient and ideally includes mutual collaboration between the patient and the professional” (Cott 2004, p. 1412). Person-centred care places the person central in all decision making and treatment delivery (Hebblethwaite, 2013), “shifting the emphasis of services to [...] actively involving patients in the decision making process” (Dalton et al. 2011). However, it is important to note that multiple terminologies are used within the literature including ‘patient-centred care’ and ‘client-centred practice’ which are used interchangeably in the literature but can have different meanings (Cott 2004).

There has been a significant rise in service user involvement in health and social care policy both in the decision making within their own care and treatment over the past 30 years (Elwyn et al. 2007), but also more broadly in service provision and design - so much so that service user involvement in health and social care service review and research is now a requirement stipulated by almost all commissioning and funding bodies (Beresford 2002; Smith et al. 2008; Kvarnström et al. 2011). There is now also a significant body of research conducted with the specific aim of developing the process and evaluating the impact of service user involvement in research (e.g. Boote et al. 2006; Barber et al. 2007; Barber et al. 2011).

The rise of the lay voice, service user involvement in health and social care policy and its impact of decision making and care practice(s) has a complex history and is only discussed in part in this thesis. The conceptualisation of patients as ‘consumers’ beginning in the 1970’s and 1980s (Cott 2004) is considered key to have had played a significant role in achieving such a rise. Patients as consumers encompass the notion that individuals have a ‘duty’, in part to care for themselves as well as the responsibility that lies with the state to provide health care (Burr and Nicolson 2008). If patients are consumers however, this in turn gives them the right to be involved in making choices and decisions about their own health and the services they receive. ‘Consumerism’ has therefore “stimulated service-wide, strategies of participation and community involvement” (Smith et al. 2008, p. 303) and is considered responsible for the growing emphasis on individual rights and choice in health and social care (Beresford 2002). Not only has this driven the requirement for the increasing involvement of users in health and social care service review but also patient centred care and an understanding of the user/lay perspective.
The importance of patient and lay involvement however is not just a discourse coming from within health care and its professions (nor did it originate there) but from patients and families themselves with multiple reports that being involved in, and the active facilitation of patient and family involvement in decision making processes is valued and considered as critical for maximising person-centred care (Conneeley 2004). For example, in the case where people lack capacity (common in severe brain injuries), family involvement in care planning is critical so that the prior expressed values and beliefs of the patient are made known to the clinical team and subsequently and appropriately considered in ‘best interest’ decision making as required under the Mental Capacity Act (2005).
Appendix 3 - Methods

Individual consent forms and information sheets were produced for patients, family and staff participants and personal and nominated consultees. Here the patient information and consent forms are presented as an example.

3.1 Patient Consent form

Cardiff University School of Social Sciences
Glamorgan Building
King Edward VII Avenue
Cardiff
CF10 3WT

Telephone: 07772265786
Email: LatchemJM@cardiff.ac.uk

CONSENT FORM (patients): Version 1.4

Study title: Shaping, sharing and negotiating futures in brain injury rehabilitation

Name of researcher: Julie Latchem

Please read each statement carefully. If you agree with the statement, please tick the box.

1. I have been given information about taking part in the shaping and sharing brain injury rehabilitation study.

2. The information has been explained to me.

3. I have understood the information.

4. I understand that taking part is voluntary.

5. I understand that I can change my mind about being in the study and can stop taking part at any time.

Please tick the box if you agree
6. I understand that I can ask for my data not to be used up to 6 months after I’ve given it.

7. I give my permission to the researcher being present and to take notes during meetings, care and treatment I receive from health care professionals.

8. I understand that there may be times that I would not want the researcher to be present and I can ask them to leave.

9. I agree to participate in an interview.

10. I agree to my interview being audio-recorded.

11. I understand that it is ok if I don’t want to answer some of the questions.

12. If I lose the ability to make decisions for myself during the study, I want any information I have given before then to be used in the study.

13. I understand that my real name won’t be used.

14. The information I give can be shared with other people carrying out research studies.
15. I agree to the information I give being stored in the UK Data Archive. □

16. I agree to things I say being displayed in public, in publications and on the internet. □

17. I agree to my postcard messages being displayed in public, in publications and on the internet. □

18. I have been told I can ask for a summary of the study and its findings by completing the form below. □

I agree to take part in the above study.

……………………….      ………………       ………………….    

Name of Participant  Date        Signature

……………………….       ………………        ………………….

Witnessed by         Date         Signature

……………………….       ………………        ………………….

Witnessed by*        Date         Signature

(*Second witness signature required if consent can only be given verbally, through established gestures or through the use of a communication aid).

When completed: 1 for participant; 1 for researcher (original).
PARTICIPANT INFORMATION SHEET (patients):

Version 1.4

Study Title: Shaping, sharing and negotiating futures in brain injury rehabilitation.

This leaflet describes a research project that is being carried out at [rehabilitation setting] as part of a PhD.

The leaflet has been produced to help you decide whether you would like to be involved.

The aims of the study:

1. To find out what kind of things may have an effect on how well a person with brain injury recovers.

2. To better understand the relationships between people with brain injuries, their families and healthcare professionals in rehabilitation.
1. To find ways for helping people with brain injuries to provide information needed for research.

2. To find out ways to improve the rehabilitation experience for everyone involved.

Who is doing the study?

The study is being carried out by Julie Latchem [pictured below].

I am a doctoral student at Cardiff University.

The study is part of my PhD qualification in Sociology.

I am also a fully qualified physiotherapist and have treated many people with brain injury.
What and who does the study involve?

First, I will be observing what happens at [rehabilitation centre] to get an idea of what goes on there day to day.

I will be hanging around seeing meal times, activity sessions, multidisciplinary team meetings, nursing handovers etc.

I might see you but at this stage I’m not looking at any one person in particular.

If you do not want to be observed please let myself or [gatekeeper] know. My contact details can be found on page 1.

Details of when and where I will carrying out my observations will be displayed on posters in reception and on the wards.

I will then spend time with people with brain injury seeing what their rehabilitation involves.

I will also interview people with brain injuries living in [rehabilitation centre].

I will be interviewing family members and staff at [rehabilitation centre] too.

What will I be asked to do?

I will ask you if it is ok for me to spend some time with you seeing what your rehabilitation involves.

I would sit with you and go where you go. I would make notes about what goes on.

You can tell me if you don’t want me around at any time.
I’d also like to interview about your experiences of rehabilitation.

I am interested in:

- What happened to you
- Your views and experiences of rehabilitation
- How you feel about your relationships with the staff
- Any difficulties with other people you have come across
- What you think may have caused the difficulty
- What was done to try and put things right

The interview would be carried out at [rehabilitation centre] at a date and time to suit you.

You will set the pace. If you feel tired, we can take a break or finish the interview at another time.

The interview will be recorded on a voice recorder or in writing.

If you use any special equipment to communicate, I will make sure I find out how it works.

At the end of the interview I’ll ask you if you would like to write a message to other people with brain injury, their families, healthcare professionals, health providers or policy makers. You don’t need to put your name to it.

I’m asking everyone involved in the research to write a message.
I’d like to display the messages to help make other people aware of the key issues raised during the research.

**Why do you want me to take part in this research project?**

I want to collect the views and experiences of people with brain injury who are receiving rehabilitation.

**What are the benefits of me taking part?**

By sharing your experiences you’ll help other people understand what brain injury rehabilitation is like.

By participating you’ll help inform other researchers about how best to involve people with brain injuries in research.

The findings will be shared with healthcare professionals, care providers and policy makers.

The findings may make a difference to the way rehabilitation is managed and carried out in the future.

**What are the risks of taking part?**

It is possible that you might get upset if we talk about things that are difficult for you.

You don’t have to answer every question.

We can stop the interview at any time.
**Do I have to take part in this research?**

It is your choice.

If you do not want to take part, that is OK. It won’t affect the care or support you receive.

If you are interested in taking part I will talk to you about the study and give you the chance to ask me any questions.

If you decide to take part but then change your mind then that is fine. You can stop the observations or interview. You don’t have to give a reason.

If you take part and then change your mind, you can withdraw your data up to 6 months after you’ve taken part.

If you do withdraw it won’t affect the care or support you receive.

**Will my taking part in this study be kept confidential?**

The [gatekeeper] will know that you are taking part and any staff and family members that see me observe you will know too.

Reports written about the research will not name anyone who has taken part.

Every effort will be made to remove and change details that might risk someone identifying you.

Everything you say to me is confidential unless you tell me something that indicates that you or someone else is at risk of harm.

I would discuss this with you before telling anyone else.
What will happen to the information?

I will write a long research report (a thesis) using all the information given as part of my PhD.

I will write up the research findings to be published in medical and health journals.

I will write a short summary of the research findings which will be available to you on request.

You will be asked if the information you have given can be shared with other researchers to use for other research projects.

If you do not want me to share the information, it will be destroyed when this research project is finished in around 3 years time.

Who is paying for the study?

Money from the Economic and Research Council is paying for this research study.

Who has reviewed the study?

This study has been reviewed and was given a favourable opinion by the Social Care Research Ethics Committee on 21st May 2014.

The Social Care Research Ethics Committee is a group of independent people who review research to protect the dignity, rights, safety and wellbeing of participants and researchers.
If you have any concerns about the research please speak with the researcher, Julie Latchem or [gatekeeper] in the first instance.

If you wish to make a compliant regarding the research then please contact:

Helen Falconer  
Research Governance Officer  
Cardiff University Research, Innovation and Enterprise services,  
3036 Newport Rd  
Cardiff  
CF24 0DE

Email: falconerhe@cardiff.ac.uk

Telephone: 02920879130

Fax: 02920874189
What Happens Next?

If you feel you would like to take part in this research study, please let me or [gatekeeper] know.

You can speak to me when I am at [rehabilitation centre]. I'll be there on (days) between (months).

You can email me: LatchemJM@cardiff.ac.uk or you can fill in the slip below and leave it at reception and I'll come and see you next time at [rehabilitation centre].

Please feel free to ask any questions before you decide.

Thank you for taking the time to read this leaflet.

Julie Latchem
3.3 Interview schedule/Topic guide

This section provides the initial topic guides devised prior to data collection and submitted along with the ethics application.

**Interview schedule/ topic guides for study:**
‘Shaping, sharing and negotiating futures in brain injury rehabilitation’

The topic areas and questions presented here have been produced by the researcher, informed by consultations to date, previous research experience, the literature and clinical experience in the area of study. To ensure deeper contextualisation the Interview questions will also be informed by the broad observations and interactions in the field. This interview guide therefore is indicative.

**Interview schedule - Families**

Each section has several key open questions – asked with a view to eliciting a narrative response and to let participants tell their story in their own way. A series of more specific questions detailed below can be used for prompting and probing as required.

**Introduction**

1) Tell me a bit about X [relative] - (maybe prompt if appropriate what were they like? and how are they now?)

[Be sure to have collected basic information on individual’s relationship to and brief info on brain injured individual: year of injury, cause and nature of injury, original diagnosis/prognosis and diagnosis/prognosis now by end of interview (if not here).]

**Overall key open questions**

**Rehabilitation experiences**

2) Can you tell me about what care and treatment X received before they came to [current rehab centre].

   - What did you think and feel about [X treatment]?
   - What did you understand by…..?

3) Can you tell me about the care and treatment X is having at the moment?
What do you understand X treatment is doing/achieving?
What do you feel it is doing/achieving?
Can you tell me about what you feel has helped X? How do you feel this has helped?
Can you tell me about anything you feel has hindered X? How do you feel this has hindered?
Is X working towards any goals at the moment? What are they?
Can you tell me about goal setting for X? How were goals set? By whom?
Have you been involved in X’s goal setting?
Have there been any disagreements about these goals?

4) Can you tell me about your experiences of supporting X through his/her rehabilitation?

Tell me about what you have found helpful?
Tell me about what has been difficult?

Relationships

5) What do you think makes for good relationships between you and the health care professionals working with X?
6) How do you feel about your relationships with them?

Tell me more about any positive aspects of these relationships.
Have you experienced a good relationship? Can you describe that for me?
Have you experienced any difficulties? Can you give me an example?
What do you think has caused these issues?
Looking back, can you tell me about how you think any problems could be resolved/prevented/improved?
Can you tell me about anything that you think gets in the way of you having good relationships with the staff at [rehabilitation centre]?
What helps?
Can you give me an example?

7) Is there anything we have missed in our discussion about relationships with the staff?
Looking forward

8) Can you tell me what you think is ahead for X?
   - Can you tell me about what you envisage in the short term? (clarify with them what time period they are referring to following their response)
   - What do you envisage happening in the longer term? (clarify with them what time period they are referring to following their response)
   - If appropriate: Can you tell me more about the care and treatment needed to support X in the longer term?

9) What do you think is ahead for you?
10) Can you tell me about any improvements in the rehabilitation/care/treatment of X that you’d like to see?
11) Is there anything that could be changed/improved to help you?

Closing question

12) Is there anything you’d like to tell me about your experiences of the rehabilitation of X that I’ve not asked you about?

Postcards

If you could say anything to other families, healthcare professionals, people with brain injuries, health providers or policy makers, if you had a key message for them – what would it be?
Interview schedule - Health care professionals

Each section has several key open questions – asked with a view to eliciting a narrative response and to let participants tell their story in their own way. A series of more specific questions can be used for prompting and probing as required.

Introduction

1) Tell me a bit about how you got here

- How long have you worked as a X?
- How long have you been working with people with brain injuries?

Overall key open questions

Rehabilitation experiences

2) Tell me about a typical day for you.

- Can you tell me about a day that went really well? Why was it good?
- Can you tell me about a day that went really badly? Why was it bad?

3) Can you tell me about what it’s like to rehabilitate people with severe brain injuries?

4) What does it mean for you to work in this field?

- Can you tell me about the work that you do to help a patient fulfil their rehabilitative potential?
- What helps and hinders you to do that work?
- What does ‘fulfil a patients potential’ mean to you?
- As a physio/OT/SALT – what do you feel is your unique role, your mandate?
- Can you tell me about a patient that you feel you did really well with? What happened? What was good about it?
- Can you tell me about a patient that you feel went really badly? What happened? What was bad about it?

5) What do you think are the key things which help patients to fulfil their rehabilitative potential? Can you give me an example? What hinders them? Can you give me an example?
6) Can you tell me about goal setting in your work?

- Do you set goals with patients?
- How are goals set? By whom?
- How do you use goals with patients?
- Why do you use them?
- Are there disagreements over goals?
- Can you tell me about multidisciplinary goal setting?

Relationships

7) What do you think makes for good relationships between you and patients with severe brain injuries?
8) What do you think makes for good relationships with the families of patients with severe brain injuries?
9) How do you feel about your relationships with them?

- Tell me more about any positive aspects of these relationships.
- Have you experienced a good relationship with a patient and with a family? Can you describe that for me?
- Have you experienced any difficulties? Can you describe a relationship that didn’t go so well?
- What do you think has caused these issues?
- Looking back, can you tell me about how you think any problems could be resolved/prevented/improved?
- Can you tell me about anything that you think gets in the way of you having good relationships with patients and their families at [rehabilitation centre]?
- What helps?
- Can you give me an example?

10) Is there anything we have missed in our discussion about relationships with patients and families?

Looking forward

11) Can you tell me about what you think will happen to people with severe brain injuries in the future?

- Can you tell me about any forthcoming changes to neurological services you are aware of? What changes in neurological services do you anticipate in the future?
• Do you have any concerns about patients leaving [rehabilitation setting]? If so, can you tell me about them?

12) If you could change anything about the treatment and/or rehabilitation services that people with severe brain injuries receive, what would it be and why?

Closing question

13) Is there anything you’d like to tell me about the rehabilitation of people with severe brain injuries, your relationships with patients and families that I’ve not asked you about? Have we missed anything?

Postcards

If you could say anything to other healthcare professionals, patients, families, health providers or policy makers, if you had a key message for them – what would it be?

Interview schedule/topic guide - Patients

As highlighted in the main application, a case by case approach will be taken when working with people with severe brain injury. Due to the range and likely severity of their impairments the exact way in which questions are asked and phrased will vary.

Patient interviews will closely follow the topic areas as the family and health care professional interviews but, for those who are unable to provide narrative responses, their interviews and the way in which questions are asked will be developed individually, tailored to them and their needs.

In most cases, it is anticipated that patient interviews will be heavily informed by the observations of their rehabilitation carried out prior to their interview. However, it is possible that some participants will consent to an interview but not to observations.

Here, only broad questions and ideas for prompts have been produced.

Introduction

1) Can you tell me a little bit about yourself? Can you tell me about a typical day before your (accident/illness)

2) Can you tell me what happened to you?

[For those participants who have consented to be observed and have been observed prior to interview, checking an understanding of what has happened]
to the patient from what has been understood so far during observations and informal conversations will be more appropriate.]

**Overall key open questions**

**Rehabilitation experiences**

3) Can you tell me about the care and treatment you received before you came to [current rehab centre].

4) Can you tell me about the care and treatment you are having at the moment? Tell me about a typical day here, now?

- Are you having physiotherapy/OT/SALT etc?
- What do you do with………………………….…..
- Can you tell me about the things that have helped/is helping you?
- Can you tell me about the things that have hindered/is hindering you?
- Can you tell me about your goals? Are you working towards any particular goals at the moment?
- Can you tell me about formal goals set with your rehab team?
- Can you tell me what your goals are?
- How were these goals set? By whom?
- Have there been any disagreements about your goals?

[For those participants who have consented to be observed and have been observed prior to interview, using information and understanding of the rehabilitation received by the individual will inform questions in this section. Reflections such as 'in your physiotherapy session I watched last week you did x,y and z, how do you find [intervention]/ how do you feel about….?]

**Relationships**

5) What do you think makes for good relationships between you and the health care professionals treating you?

6) How do you feel about your relationships with them?

- Tell me more about any positive aspects of these relationships.
- Have you experienced a good relationship with member of staff? Can you tell me about them?
- Have you experienced any difficulties? Can you describe a relationship that didn’t go so well?
• What do you think has caused these issues?
• Looking back, can you tell me about how you think any problems could be resolved/prevented/improved?
• Can you tell me about anything that you think gets in the way of you having good relationships with patients and their families at [rehabilitation centre]?
• What helps?
• Can you give me an example?

7) Is there anything we have missed in our discussion about relationships with staff?

Looking forward

8) What is the next stage of your rehabilitation?

• What are your plans in the short-term?
• What are your plans in the longer-term?

9) What could be done/changed to improve your rehabilitation/treatment?

Closing question

10) Is there anything you’d like to tell me about your rehabilitation that I’ve not asked you about?

Postcards

If you could say anything to other families, healthcare professionals, people with brain injuries, health providers or policy makers, if you had a key message for them – what would it be?
3.4 Observing and being observed – capturing one another

This appendix provides a detailed account about observational experiences within the field sites.

During my time at Bracken Lodge, I would sit at the far end of the communal lounge and observe everyone that sat in and passed through that space for up to an hour at a time. Riya, a brain injured woman was one of six residents who was often sat there. Riya could speak at least two languages and would often speak in a mixture of them. English would break through when she was cross, felt ignored or made a demand. Riya could be fun-loving and seek to interact with those around her, but she was also easily angered and at times, would wail in distress. Her happiness, anger and distress was not evidently stirred by anything in particular and her emotions and ‘behaviours’ could change suddenly.

Riya was able to make some decisions for herself, for example deciding what to eat given two options to choose between. However, she lacked the ability to remember and assess information in order to make decisions about more complex issues. This applied to making a decision about her involvement in the research. Riya lacked the capacity to give informed consent to participate in my study.

Riya had one visitor, who visited infrequently, and I did not speak her language. No other family members or friends were in contact with her. This meant, that because I did not have funds for a translator, there was no personal consultee I could talk to regarding the potential of Riya’s participation in the research. Riya was not well known by staff, her history was unclear and no one could tell me much about her. No individual member of staff seemed to have a better rapport with her than others although many knew her well in terms of her behaviours and preferred care routines. In theory, a health care professional working with any such resident would often be fully appropriate to act as a nominated consultee, in the case of Riya, it seemed that no one knew her well enough.

---

Ethical approval for this doctoral study was gained from the Social Care Research ethics committee, who granted approval in the knowledge that the study would include only those who could communicate through the English language. The Health Care Authority does consider 'cost' as a 'fair' reason for the exclusion of those who may have 'difficulties in adequate understanding of English', particularly in student/educational research (see hra.nhs.uk). However, language as a barrier to consultation for the enablement of Riya’s participation does raise ethical issues. In theory it may have been possible to access local services, but in practice it is likely that such attempts would have outrun the data collection period. At one setting I observed long waits and high costs for translators required for patient communication directly relating to their care, let alone decision making or for research purposes.
Within the space of the lounge from one side of the room to the other, Riya attempted to interact with me on many occasions but, because of the distress that Riya displayed at times and because there was no ‘personal’ or no truly appropriate ‘nominated’ consultee her inclusion in my research was not taken further.

Even though I could not observe Riya closely, speak with her in terms of conducting any type of interview or learn her personal routines, she formed a critical part of the everyday within that place. She contributed to my understanding of the setting which I would later describe. Unable to involve her further I appropriately kept my distance, not to intrude upon Riya. However, towards the end of data collection at Bracken Lodge I was walking through the lounge one morning passing Riya who was seated in a wheelchair at the end of the room, and the following occurred.

Extract from field notes:

Riya stretched out her arms towards me, grabbed my hand and then arm and pulled me towards her. Her grip was strong and she took more and more of my arm to such an extent that I was held captive in her firm but friendly grasp. Bringing my face close to hers she began to chatter to me in a whisper, with all the expression and sound of divulging deepest secrets and imparting the latest gossip. Riya is brain injured and although she has speech it is a mix of jargon (of made up words) and the multiple languages and dialects she speaks that I do not. Riya holds me close and chatters away. I look at her and smile while she tells me all she wishes. Stood in an awkward and uncomfortable position pulled down and in by Riya I gently try and release myself from her grasp but every time I try she pulls me closer still. I nod towards the chair by her side and tell her I need to sit down. She releases her grasp just enough to let me move, hovering her hands over my arms as I move towards the chair, ready to pounce and grab me tight again if I attempt to move away. Once seated Riya grips me tight once more and pulls me in to her and returns to her whispers, apparently sharing her deepest thoughts, all the gossip, chatting and giggling with me. Jane, a health care assistant walks past us:

Jane: “She won’t let go of you now! Riya let go of her, you don’t even know her!”

Riya looks up at Jane, speaks to her in another language, sternly and with exclamation. She looks back at me and gently strokes my face and looks back up at Jane crossly, pulls me closer still and carries on talking to me.

I do not know what Riya has said to Jane, and Jane does not know either, but through the tone of her voice and the action of stroking my face, I interpret her to have told
Jane that of course she knows me, that I’ve been there for months, how can she say that she does not know me?

Following my purposeful and careful avoidance to remain at distance and not to ‘intrude’ on her, Riya ‘captured’ me herself. She brought me to her and held me in an interaction. While I was, at a distance, trying to ‘capture’ her world and unsure whether I should or could encroach into it any further, Riya answered that herself by bringing me to her. Riya chose to be participant. She saw me, not as a stranger, but as a familiar face and one with which she chose to interact.

The implications of this data collection experience has been considered and detailed in the context of how it troubles researcher-led recruitment practices constructed by and through the MCA (2005) legislation. See Latchem (2016) for a full discussion.

3.5 Resident-led interviews

Despite my clinical awareness of the issues faced by brain injured patients in relation to divided attention, fatigue etc. one interview was conducted in a space that was repeatedly interrupted by others. The space was chosen by a participant, Eddie, himself. Eddie is a gentleman who has problems with his memory, the occasional word finding difficulties, and displays moderate disinhibition. He repeatedly makes overt his heterosexuality and like of women, especially young women. However, despite this, and the only personal space Eddie had available to him being his bedroom, Eddie highlighted to me that his bedroom was an inappropriate place for the interview and instead invited me into a communal kitchen/dining area to interview him there.

During the interview Eddie would take 1-2 questions at a time, providing a response and then asking me to stop the audio recorder and taking a short break. He would then ask me to restart the audio recorder and invite my next question. During this process of Eddie’s choosing, the space was repeatedly interrupted, with other residents coming in and out to make drinks. These interruptions required the stopping and restarting of the interview each time.

Extraordinarily Eddie not only managed the interview, in terms of telling me when he was ready to take a question and when he needed a break, but choosing and controlling the space we were in, and conversing with others coming in and out of it. Each time someone came in to make a drink, Eddie patiently waited for them to do so and would then ask them to leave to enable us to continue with the interview. At one stage, one resident who was easily angered and was physically aggressive came in. Eddie patiently waited for him to make a drink and began to talk to him explaining we were in the middle of a meeting and carefully asked him to leave. The resident
began to become irritated by the request. Instead of Eddie reacting and rising to the response of the other patient, he calmly and carefully spoke to him and the man soon left. The continuous interruption was frustrating for me as an interviewer, but Eddie displayed remarkable self-control and was able to provide a reflective interview despite the environmental limitations.

3.6 The technicalities of data capture

The data collected consists of ethnographic field notes made during observations and interview transcripts. Field notes were written either in ‘real time’, in the moment, at times when I was sat in a lounge, an office or a meeting or retrospectively following adhoc conversations in corridors or when participants chose to engage directly with me. At times when participants came and sat with me and started conversation, stopped me in the corridor or approached me through curiosity or concern, these interactions required my absolute attention, in the moment and could not both happen and be recorded at the same time. Although, in the case of some ethnographies, retrospective notes are written hurriedly as researchers crouch in toilets or disappear into cupboards or hidden spaces to write (e.g. Latimer 2000), the overtness of my presence as researcher and the conduct of the ethnography meant that I simply sat and wrote notes as soon as possible and as soon as appropriate following any interaction.

In the early stages of data collection at Bracken Lodge – new to being the living breathing data recorder that is the ethnographer, I made attempt to move away to a quiet space to record events just past. A problem however quickly occurred where the writing up of notes of events which had just happened were in competition with the recording of new events that occurred around me despite all attempts to be on my own. This however formed an interesting observation. As I sought out quiet places and inhabited what I thought were largely vacant spaces within the building, I was almost always joined by someone. In response to this ethnographic challenge I learned to record quickly and to, at times, make a choice between what was more important – recording the event that had just occurred, or to attend to what was in front of me. My choice was based on recording either, the most unique happening or the most insightful or well-expressed conversation. Whatever choice I made, to record what had just gone before or to record what was happening now was in practice a pay-off of detail. Both happenings would be recorded, just those recorded in the moment or as close to their happening as possible were simply more detailed. However, as I practiced the skill of ethnography, both my recording accuracy, memory for verbatim speech and for actions and their order improved and in
situations where the recording of past events were overtaken by present occurrences, overall recording accuracy improved.

Observational notes included the recording of action and speech, of feeling, atmospheric and environmental factors and at time, stick(wo)man sketches. At the beginning of each observational session speech was recorded. Although I had the raw notes of my in the moment, or as close to, notes, they did not stay in this form alone. My handwritten fieldnotes were then typed up at the end of the day or the following day to enable ease in data analysis later on. However, this second recording took on three roles. First, the second recording added to and ‘improved’ on the initial record. As I typed up the fieldnotes to my surprise I added more detail. I often extended the notes as I was able to recall a feeling or an action. To make sure I could recognise where and when I had made these additions, I wrote them in red. Second, the typing up of notes in this way became an opportunity for very initial analysis, in two main ways – first in familiarising myself with my data and second in the very beginnings of noticing patterns, ways of doing and discourses. At this stage however this type of analysis was minimal as my mind was so full of and focussed on collecting and recording.

Third, this practice of writing up also contributed to data collection moving forward – illuminating what was missing or areas where data was thin or incomplete or where my understanding was lacking. Recognition of phrases used that I did not understand, the telling of stories that were or had been incomplete, the unknown outcome of a particular challenge that had faced staff that day, for example. The grounded way in which the data was collected was directed, in part through this note writing and reflexive process.
4.1 Sharing of findings and initial ‘impact’

The research ‘findings’ were shared with participants at both setting in a variety of ways in 2015-2016. As part of access negotiations and discussions with participants during the recruitment process and the ethnography itself, plans to share findings were repeatedly discussed – and called for by participants’ eager to know what had been found.

The findings reported in chapter 6 were the first set of findings to be shared. Formulated into a series of presentations to deliver to participants, health care professionals and academics, these findings were shared and discussed throughout 2015. Before any public presentation of these results were given I sent the presentation to participants and returned to my sites to share it with some of the key hotel service staff ‘actors’ directly.

I received unanimously positive responses from hotel service staff, health care professionals and families expressing their interest in, reflection on, and, at times jubilation of what the findings were saying. Participants expressed delight at the focus on their work and contribution and a willingness to ensure that their colleagues saw the findings. For example I received the following email from ‘Allegra’ a catering assistant:

Mate that presentation is awesome!!! [...] that was brilliant and so good to just know someone, (yourself), was talking about our work and positive input we, as the "hotel service staff", have towards the clients. I high fived myself when I recognised our conversations ha!

I’ve told [Mick] the maintenance manager about your presentation and read out a couple of things. He was genuinely chuffed about it. After I told him about your presentation his exact words were, "ah that’s wicked man good on her."

I’m meeting up with [catering assistant] today I will discuss the presentation with her and email you back with her feedback..

Health care professional participants also responded to the presentation and gave feedback both verbally and via email. Therapists in particular reflected upon and questioned how it was that hotel service staff were learning and able to interact so positively and successfully with residents and queried whether the way in which they learned could be understood and utilised to train other staff. This reflection was
also made by a physiotherapist who heard the presentation at a conference in April 2015 and tweeted about the talk. Family member participants also responded to the hotel service staff findings considering them to be ‘thought-provoking’.

I asked a key participant, Ally to sit with me when returning to one of the sites to discuss the findings. I explained to her that I wanted to share some of the study results with her, that I wanted to give a presentation about it at a series of conferences, to health care professionals and to sociologists and wanted to know what she thought of it before I gave it. We sat side by side on the ‘thinking sofa’ and I delivered the paper to her. I displayed the presentation on a tablet to show her the slides and flick through them as I talked. As Ally recognised herself in the data and heard the papers’ content a tear rolled down her cheek. She quickly wiped it away, leant across to me, kissed me on the cheek and said, ‘I love you’. I ask her if she is happy with the paper. She tells me that she is and that it means a great deal to her to have her work recognised.

‘Ally’ and I are in email communication afterwards discussing the findings. I asked her what is was that had made her cry. She replied in an email:

Well what can one say....I reckon Allegra says it all. Well done. I feel so rewarded that someone has recognised that housekeepers are not just toilet cleaners! Why did I cry when I started reading it? Perhaps it is years of being thought of as "only a cleaner" and being told to "be invisible" it is the way you begin to believe in the end. Thankyou.

Alongside the singular delivery of the findings in chapter 6, I organised a two-day event in 2015 entitled ‘Coma, consciousness and decision making: reflecting on care for vegetative and minimally conscious patients and their families’. This event showcased art works and theatre, inspired by research conducted with families by the Coma and Disorders of Consciousness Research Centre (CDoC), Universities of Cardiff and York and included the presentation of all the PhD initial findings via an exhibit that I called ‘PhD corner’.

The event was held in a neuro rehabilitation care setting and organised along with site staff. The two-day event was advertised both internally and externally. Internally individual letters of invitation were sent to families to whom the exhibition was most relevant, staff were informed of the event and plans made for the release of as many staff as possible from ‘the floor’ so they could attend. Externally, the event was advertised in the local press and direct invitations were sent to organisations and individual professionals through established professional networks held by the host settings professionals. The first day was focussed on internal staff and family members and the second day external health care professionals.

The aims of the event, from the sharing of the initial PhD findings were to:
1) Improve family-staff relations through awareness of one another’s experiences (and to recognise mutual understanding as well as potential for conflict).
2) Raise awareness of the contribution that ‘hotel service’ staff make to rehabilitation.
3) Bring together all layers of the organisation to engage in key issues within the care of people with severe brain injury.
4) Build capacity within the settings staff body by providing opportunities for innovative continuing professional development.

4.1.1 Audience and Attendance

Both days of the exhibition were well attended. The first day opened with around 40 people in attendance including members of the settings senior management, therapists, therapy assistants, nursing and care assistant staff and seven residents’ family members. Members of housekeeping staff also viewed the exhibition, attended some of the talks and the shadow puppet performance. All family members in attendance and many staff stayed for all the events that day (from 2-6pm).

The second day was also well attended by approximately 15 external professionals, a director and a selection of the settings’ nursing and care staff, some of whom had chosen to attend on their day off. External attendees included Physiotherapists, Nurse Managers, Consultants and CHC assessors.

Staff who had chosen to come to the exhibition on their day off reported that they had chosen to attend the event because they wanting to gain knowledge to empower them to do their jobs better and provide the best care for residents and families that they could. They spoke about being interested in and intrigued by the exhibition and wanting to attend to see what they could learn.
PHD CORNER:

Initial findings were displayed across a series of display boards around the room and in a seated area providing an opportunity for both interaction with and to add to the data.

PhD corner included the exploration of the work of ‘hotel service’ staff and their contribution to care and rehabilitation and the display of sketches, interview excerpts and postcard messages depicting both the conflicts and care in family-staff relations in these settings.

4.1.2 PhD corner: The work of hotel service staff

One key element of PhD corner was the display of the work of ‘hotel service staff’ – and the role they play in the rehabilitation of people with severe brain injuries (see chapter 6). The display about hotel service staff highlighted the role these workers play in the care of people with severe brain injuries and illuminated how the work they do maps to the work of qualified health care professionals and acts as informal rehabilitative work, and that this work and the way in which these staff interact with residents makes a significant contribution to their rehabilitation.
A selection of statements were printed in bold and added to the display to introduce theoretical elements of the thesis. These statements were used to highlight that the work of hotel service staff contributes not only to lives of people with severe brain injuries in the now, but also their futures.

One key futures related statement that was displayed can be seen below:

They enable the opening up of residents’ futures and are quiet but critical future makers.

Concerned about whether or not the theoretical frame of temporality would resonate with attendees, the presentation of the theoretical statements were carefully considered before the exhibition. This concern however was put aside when during the exhibition, a member of clinical management took my hand and led me across to PhD corner. Stopping by the hotel service staff board she pointed directly to the statement shown above and said: ‘That is it, and nobody sees it’

Following the event, a discussion held with a therapy assistant who had viewed the exhibition further highlighted the impact of this section of PhD corner, when she was able to verbalise that ‘everyone is a part of everything’ and told me how what housekeepers and maintenance personnel do a lot for residents.
Following the work presented in PhD corner about hotel service staff therapists within the setting reported that they are now talking about the work of these personnel and including their contribution to residents rehabilitation within the induction package that ‘new starters’ are given when they first start their jobs. All staff, of all job type attend these inductions.

4.1.3 Thematising PhD corner with flowers

Key themes and messages from the data collected during the PhD was mapped onto and displayed using five key flowers and their meanings – the forget-me-not, the bluebell, Iris, daffodil and snowdrop.

Data was displayed using the flowers and their meanings as headings to key sections. Within a section headed with the forget-me-not chosen because of its meaning of ‘love and memories’, how the rehabilitative stories of very particular patient types prevail in the narratives of staff when asked to think about residents’ futures and how the dominance of these stories masks, stunts and highlights how the futures of others go unimagined was presented.
Using the **bluebell**, with its meaning of humility and gratitude, how staff members and residents, families and staff talked about what they were grateful for (often the care and support of one another) was charted, and also highlighted how staff in-particular spoke with humility about their work despite the huge challenges they face day-to-day, which often included physical threat and injury to themselves.

The **daffodil**, with its meaning of forthrightness provided the opportunity for postcard messages collected from staff following interviews with them which identified key areas of concern that staff raised and key messages they wanted to send to commissioners and managers to create positive change in these environments.

The **iris**, through its meaning of hope and faith was used to explore the faith that staff and families have in the rehabilitation process, how assured they were about what was ‘good’ for residents, what they needed and what they hoped for in the development of their work and care of people with severe brain injuries.

The **snowdrop**, signifying newness and change charted what changes staff foresaw in their area of work, in their place of work, what changes they wanted and future they foresaw.

Alongside the meaning of each flower and the data presented to match, five key questions were asked of attendees.

1) Pick up a forget-me-not and tell me - What should be remembered about care and rehabilitation of people with severe brain injuries?

2) Pick up a bluebell and tell me – What are you grateful for in your work or the care of your relative?

3) Pick up an iris and tell me what you hope for in the future for your work, your place of work or the people cared for within it.

4) Pick up a daffodil and tell me what issues need to be tackled in the care and rehabilitation of people with severe brain injuries? What do we need to be forthright about?

5) Pick up a snowdrop and tell me what needs to be overcome to make positive change?
Attendees were invited to take a flower card, answer or comment on the corresponding question and then ‘plant’ their card in pots places around the exhibition space. Having written their flower card and ‘planting’ their ideas/thoughts, attendees were invited to take a small parcel of bulbs and plan those for real, in the hope that when the bulbs flowered in the spring they would be reminded of the exhibition, the thoughts and ideas they had from it.
Fourteen flower cards (five bluebells, four forget-me-nots, four iris and one daffodil) were written and ‘planted’ and over 30 parcels of bulbs were taken to be planted. A selection of the messages written of these cards are presented below.

I hope the future for my place of work continues to pull together the unity of all impacted by tragedy. I love where I work xxx

I am grateful to work in this environment because I have learnt what it is like to truly ‘care’ for somebody and not in just the sort of friendship – ‘care’ for somebody kind of care. I am grateful because it’s made me realise how precious life is and how we should not ever take anything for granted!

Remember that patients are people. Just because they can’t talk doesn’t mean they can’t understand. When professionals talk in front of patients as if they aren’t there, how ‘professional’ are they being?
I’m grateful to be able to care for the residents and watch their progress while the therapies are used. You notice different progresses in different strategies.

I am grateful for being part of the residents lives and being able to care for them.

I am grateful in my work that I can just be myself and able to make some of the residents laugh, it gives me a feeling that I’ve achieved something positive.

I wish people would remember that the residents are still human beings. A resident once said to me “Don’t define me by my illness”

There should be more charities helping people and families through this, especially children.

4.1.4 Family-staff relationships

Alongside the key PhD themes, the display included a series of other elements to the display to highlight further ‘findings’ of the research. This included messages from families to staff, from families to other families, from staff to families and from staff to other staff that had been written by participants at the end of interviews.

These ‘messages’ demonstrated a ‘mirroring’ of understanding and the existing and surprising appreciation of one another and the recognition of each groups’ experiences.
A selection of data charting the perilous work of care assistants - how they are frequently injured and recover, with humility and bravery having being attacked by residents with challenging behaviours was displayed. Despite these less obvious and more hidden elements of the PhD corner display, these were all looked at by attendees.

4.1.5 Engagement and interaction with PhD corner

Across the two days attendees viewed the exhibits in PhD corner and the related display boards around the yellow room. Staff and families stood and read the boards intently. Some people took pictures of the boards, or elements of it. Content filled the full lengths of the board and many attendees went to the effort of crouching to view the bottom sections. Attendees photographed elements of each section of PhD corner, especially those who were visiting from other organisations.

As highlighted above, the sections of data displayed which were linked to the meanings of flowers were dressed with baskets of bulbs. The board displaying the work of hotel service staff was dressed with objects to represent each of the key occupations – a mop and bucket and a washing line to indicate housekeeping, tools and wellington boots to represent maintenance work and a washing up bowl filled with crockery to highlight catering.
Housekeeping staff who viewed the exhibit touched the mop and joked that the mop on the display was better than the ones they used for their work. The washing line was decked with underwear – some of which was purposely scant to draw attention to and generate engagement with the exhibit. While the underwear drew some of the hoped for engagement through jokes, one clinician remarked that she was pleased to see the use of younger style and more ‘sexy’ selection underwear in connection with an event about people with neurological conditions. She remarked that people could forget or not see people with disabilities as being and wanting to wear that sort of underwear.

Within PhD corner sketches taken directly from ethnographic notes which portrayed moments of ‘care’ or problematic care scenes were both displayed within each section and a selection printed onto postcards. Attendees were invited to write their own messages on these postcards and ‘post’ them into a post box.

Nine postcards were filled out and ‘posted’, the majority choosing to use the card with the below image printed on it, selecting it because of the ‘heart’ radio image on the television, not because of the link to music but merely to the emotional meaning of ‘heart’ and it’s connection to care.
A selection of post card messages can be seen below:

“Never feel guilty for feeling sad, angry, annoyed, frustrated, tired, a little less caring today, we know love is always there, and while you are remembering this for yourself, remember this for others too.”

“I think it is worth knowing that what we do is always at the heart of residents’ best interest and what we think is positive, however I now, after the conference understand that the communication between us and families’ needs to be a lot stronger in order to understand what families would want or how they feel.”

4.2 Post event discussions with staff

Approximately one month after the event I returned to the location where the exhibition had taken place to speak with staff and family members about the event and to ask them for any further thoughts and feedback. Staff reflected that they felt the event had opened up and generated an interesting dialogue highlighting that “Therapists are people too, you brought out therapists as people.” Similarly housekeeping staff who had attended the exhibition reflected with me that the exhibition had raised awareness of their contribution, that they felt noticed by the work and that the exhibition had led them to reflect themselves more about the contribution they were making and what more they could do for residents.