Pearson, Paul (2024) *'What are we going to do': Biographical disruption after brain injury and the role of human rights as a catalyst for change.* PhD thesis.

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‘What are we going to do’: Biographical disruption after brain injury and the role of human rights as a catalyst for change

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MA Hons, MRes.

Submitted in fulfilment of the requirements of the Degree of Doctor of Philosophy

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September 2024

Word count: 116 852

Abstract

People living with a brain injury face a range of negative outcomes and societal barriers that impact on their ability to participate in society. Whilst the medical and neuroscience literature on brain injury is vast and growing, understanding of how people navigate society and different life phases following injury remains limited. The thesis addresses this major gap in the literature as it foregrounds the experiences and perspectives of people with brain injury which have been hidden historically, and in doing so reimagines an oppressed group as dignified, rights holders. The use of the dual lens of biographical disruption and a human rights-based approach is a further theoretical contribution. Both position the participant as agentic, as capable, and as deserving of an improving life. Furthermore, this research adds to the understanding of the role of brain injury support groups, which whilst long-established, lack understanding from the perspectives of the people that they aim to serve.

The thesis ethnographically explores the experiences of people who have a brain injury and involved a participant observation of a brain injury support group, in addition to biographical interviews with members of the group. By using the dual lens of biographical disruption and human rights-based approach, an innovative qualitative approach was created that foregrounded participants experience and revealed both their attempts to navigate society and the barriers to being and doing that they faced. These barriers began at the point of admission but were revealed to be multi-faceted and enduring long after the traditional ‘treatment’ phase ended. Participation in society was compromised, accountability largely absent, discrimination repeated, and processes were undermined by a lack of empowerment. The injury, whilst medical in its initial phase, was revealed to be an inherently social process, and one that was characterised by imbalances of power and a lack of rights-realisation. The narratives within highlight that in the absence of rights, resilience, and resistance, rather than rights-realisation, were the tools participants had at their disposal.

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Acknowledgements

I would like to begin by saying thanks again to the people who took part in this research. The trust you placed in me sharing your experience, and the welcome and support at the group was instrumental to this PhD. I am eternally grateful. I wouldn't have been able to carry out this research without the funding I received, and so massive thanks are due to the Scottish Graduate School of Social Science and Headway Glasgow who co-funded and enabled this research.

Huge thanks to my supervisors, Professor Jo Ferrie and Dr Chris Bunn. I first met Jo when I enrolled on the University of Glasgow Access course over a decade ago, and it was her inspirational teaching on sociology and disability that encouraged me down this path. I worked out what a PhD was as I wanted to one day do similar research, and so this dream was born. She has been the biggest influence on my development as a researcher and has continuously went above and beyond. It is an honour to have her as both a colleague and a friend.

Chris has been a dream supervisor and has taught me to trust in myself and the project. He has continued to support me despite his own work taking him to Malawi. His support and input to this research is much appreciated. Also, thanks to Professor Sally Wyke, who was originally part of the supervisor team and helped a lot to get this project going.

Thanks are due to Dr Alison Eldridge, for her teaching and support which has shaped the sociologist I have become. Also, thanks to Kate Jenkins, a wonderful teacher who offered words of support and encouragement to me on the day I left school. I clung to those words and her encouragement helped me to take what were for me, the daunting first steps years later into higher education.

My friends and family deserve a huge thanks for supporting me and believing in me during the PhD and before. My Mum inspired me to go into higher education, having herself graduated long after raising myself and my siblings. My father Gerry Pearson has been a hero. He has proofread everything, usually with no prior notice and a deadline of ‘now’ and never once complained. His insights were really valuable. Cheers Dad. Also, thanks to my

nephew Luke for the scones. The most eternal of thanks to my wonderful partner Anna for everything you have done and put up with. I wouldn’t have been able to do it without you.

Massive thanks and gratitude to Dr Simon Glen, who was a great support after my brain injury and who did so much to get the project funded and off the ground. Also, to Graeme Cumming, Gwen Naughton, and Naomi Baldini who all supported and encouraged me in different ways following my own injury. Last, but not least from the Headway Glasgow family, thanks to the wonderful Amy Prance-Smith for all the craic, support, advice and believing in me.

Huge thanks are due to Colin Robertson for his support with my work, and for all the work he has done and continues to do for people in Scotland affected by brain injury. Colin’s commitment and activism is a testament to the decent and empathetic person he is. Further thanks to Barry Black who provided much needed support, advice and friendship.

Further thanks are also due to my wider colleagues and friends who I have had the pleasure to work and learn alongside during this thesis, and who have supported me during hard times. The list is longer but special thanks to Sekou Ouattara, Fiona McHardy, Lydia Murphy, Juliet Enoch, Mohammad ‘Professor’ Alkhatib, Ishmail Yambasu, and Laura Robertson.

This work is dedicated to the memory of my Gran, Nan McGloan, and my great friend Henry Archer. My Gran was the strongest person I have ever met whose voice was always in my head during the PhD when things got tough. My great friend Henry passed away recently, and so this is one way I can thank him for everything he did for me and for being such a wonderful friend. I hope you are both somewhere beautiful, and that I did you both proud. I love and miss you both.

Declaration of originality

I declare that, except where explicit reference is made to the contribution of others, that this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Printed Name: Paul Pearson

Signature:

Glossary of key terms

Acquired brain injury	“Acquired brain injury covers all situations in which brain injury has occurred since birth, and includes traumatic brain injury as well as tumour, stroke, brain haemorrhage and encephalitis, to name a few. The effects are often very similar to those of traumatic brain injury, but there are key differences that make treating and coping with acquired brain injury quite different” (Headway UK, 2023)
Biographical disruption	“Disruption of taken-for-granted assumptions and behaviours” (Bury, 1982: 169)
Human rights-based approach	A conceptual framework based on human rights standards that empowers people to name and claim their rights. This approach increases duty-bearers and wider organisations ability to fulfil their human rights obligations. It creates accountability structures that enable people to seek remedies when their rights are not realised
Member	A person who attends the support group

Mild head injury	Loss of consciousness of less than 30 minutes (or no loss of consciousness), or post-traumatic amnesia (PTA) of less than 24 hours after injury
PANEL Principles	The PANEL principles are one way of breaking down what a human rights-based approach means in practice. PANEL stands for Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality. (Scottish Human Rights Commission, no date)
Traumatic brain injury	Traumatic brain injury (TBI) is an injury to the brain caused by a trauma to the head (head injury) (Headway UK, 2023)

Abbreviations used

ABI	Acquired Brain Injury
ASR	Asylum seekers and refugees
CAB	Citizens Advice Bureau
CCEW	Charity Commission of England and Wales
COS	Charity Organisation Society
COVID-19	Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2)
CRPD	United Nations Convention on the Rights of Persons with Disabilities
CT	Computerised topography scan
DLA	Disability Living Allowance
DNR	‘Do not resuscitate’ order
EHRC	Equality and Human Rights Commission
ESCR	Economic, Social and Cultural Rights
FEDACE	Spanish Federation of Acquired Brain Damage
FRE	Flesch Reading Index
GBIRG	The Glasgow Brain Injury Research Group
GCS	Glasgow Coma Scale
GOSE	Glasgow Outcome Scale-Extended

GP	General Practitioner
HIV	Human immunodeficiency virus
HRBA	Human rights-based approach
ICD	International Statistical Classification of Diseases Codes
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICP	Intracranial pressure
ICU	Intensive Care Unit
IPA	Interpretive phenomenological analysis
IPV	Intimate partner violence
ITU	Intensive Treatment Unit
JRF	Joseph Rowntree Foundation
MDD	Major depressive disorder
MHI	Mild head injury
MND	Motor Neurone Disease
MP	Member of UK Parliament
MRI	Magnetic resonance imaging
NHS	National Health Service
NSPCC	National Society for the Prevention of Cruelty to Children

OSCR	The Scottish Charity Regulator
OT	Occupational therapist
PANEL	The ‘PANEL Principles’: Participation, Accountability, Non-discrimination, Empowerment, Legality
PD	Parkinson’s disease
PIP	Personal Independence Payment
PPR	Participation and the Practice of Rights
PTA	Post-traumatic amnesia
RNIB	Royal National Institute for the Blind
RTW	Return to work
SCI	Spinal cord injury
SDS	Self-directed Support
SHRC	Scottish Human Rights Council
SIGN	The Scottish Intercollegiate Guidelines Network
SMOG	Simplified Measure of Gobbledygook
SQOL	Subjective quality of life
SSM	Supported self-management intervention
TBI	Traumatic brain injury

UC	Universal Credit
UK	United Kingdom
UN	United Nations

Chapter 1 Introduction

1.1 An introduction to the origins of the thesis

The path towards this research began in August 2000 when my brother sustained a severe brain injury. I had grown up sharing a bedroom with him and have subsequently witnessed both his recovery and the barriers he has faced. On the 29th of April 2011 I fell down a flight of stairs whilst leaving my home, causing a bleed in the right frontal lobe of my brain. I was admitted to hospital and transferred to a specialist neurology ward. Following some time, which is largely a blur, I returned home, and minus a short time in a rehabilitation unit, I began what was to be a lengthy period of disruption and repair, one which continues to this day.

Around eight months after, I began to attend a brain injury support group as a member, and in time, began to take on different volunteer roles within the organisation. Alongside this I studied sociology and began to carry out my own research (dissertations) in the field of brain injury. These collected experiences prior to the beginning of my PhD provided me with what is an uncommon, and perhaps unique, insight into the experience of brain injury; one informed both by my own and other people's experience. I became interested in the theory of biographical disruption whilst studying as an undergraduate. It provided an insight into a part of the experience of recovery that was not explained by any diagnosis or prognosis but was a process that I witnessed in myself and others around me. My interest in human rights came much later. I had always passively understood human rights as an important but still abstract concept present more in places such as the International Court at the Hague, than in the daily lives of myself and the people around me. Seeing its application in projects such as the Housing Rights in Practice project (Scottish Human Rights Commission, 2020), and in the work of groups such as Making Rights Real, and Participation and the Practice of Rights (PPR), demonstrated its transformative potential for people whom society has placed furthest from rights realisation.

1.2 Research background

1.2.1 Background of issue

1.2.1.1 Brain injury: a major public health issue

Brain injury is a major public health issue globally (Shivaji et al 2014, Kline, 2016). In the UK, it is estimated that each year "there are 900,000 accident and emergency attendances with head injury with 160,000 people admitted to hospital each year" (Medical Research Council, 2022: 1). It is also estimated that "there are approximately 1.3 million people living with disabilities resulting from these injuries" (ibid). The impact of an injury is specific but can include a range of potentially life-altering cognitive and physical impairments (Cole et al, 2015; Gardner et al., 2014; 2015; 2018). Whilst the fields of neuroscience and medicine have made significant progress in growing our understanding of the brain and the complex processes and impacts of injury, there remains a lack of research into how people navigate the life phases following brain injury (Muenchberger et al, 2008). This is despite the wealth of research that shows repeated poor outcomes in central areas such as health, employment, family life, and general life satisfaction. These outcomes speak to an experience that is further underpinned by higher risks of mortality and morbidity, secondary conditions such as epilepsy, and indeed the potential for further neurodegeneration (Cole et al, 2015; Gardner et al., 2014; 2015; 2018). It is an injury whose full consequences may not be realised for a number of years, and whose recovery itself may never bring the 'full' recovery that people desire (Teasdale and Engberg, 2001). It is within these contexts that people experience biographical disruption and attempt repair, a process that is precarious and ongoing. It is a process carried out in societies and social spaces that are often hostile, discriminatory and lacking in rights-realisation. It is this environment, and the hidden voices within, that this thesis explores.

1.2.1.2 Biographical disruption

The main sociological theory employed in this research is Bury's (1982) seminal theory of biographical disruption. This theory describes a point of disruption in the lives of people where "the structures of everyday life and the forms on knowledge which underpin them are disrupted" (Bury, 1982: 169). This can lead to a new-found "attention to bodily states not usually brought into consciousness" (ibid: 169), where people attempt to "establish points of reference between body, self, and society and to reconstruct a sense of order from the fragmentation produced by chronic illness" (Williams, 1984: 177). The theory has been applied to understand the experience of illness far beyond the focus on rheumatoid arthritis featured in Bury's (1982) original study, including in the field of brain injury research (Muenchberger et al, 2008). The biographical disruption experienced with sudden brain injury is, however, unique in comparison to many other illnesses, as it often does not involve the 'insidious onset' described in Bury's (1982) original research due to its usually sudden emergence.

This thesis uses the thematic lens of the PANEL principles, developed as a method to apply and understand what a human rights-based approach means in practice (SHRC, no date), to build on the existing knowledge of how people with brain injury navigate life following injury, and also how such approaches could benefit biographical repair. In doing so, barriers to participation following injury are revealed. This approach has particular relevance at this time given the Scottish Government's commitment to the incorporation of the following four UN human rights treaties into Scots Law which should strengthen the human right to health among other associated rights:

- The International Covenant on Economic, Social and Cultural Rights (ICESCR),
- The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW),
- The Convention on the Elimination of All Forms of Racial Discrimination (CERD),
- The Convention on the Rights of Persons with Disabilities (CRPD).

The research sought to provide a significant contribution to knowledge concerning the negative outcomes that people face following a brain injury. It sought to address gaps in the understanding of how such approaches could improve experiences of key sites of disruption such as diagnosis, primary and secondary care, employment, and the navigation of the wider social world.

1.3 Research aim, objectives and design overview

The aim of this research was to contribute to the understanding of how people navigate life and recovery following a brain injury, and to explore the extent to which support groups contributed to the moving out of a disruptive phase.

To achieve this, two main research questions were set:

1. To what extent is the concept of biographical disruption useful in understanding the recovery after a brain injury?
2. To what extent do face-to-face support groups contribute to adults moving out of a disruptive phase?

The first question aimed to understand how people with a brain injury reconstructed their lives following injury, to uncover how people carried out repair, and to uncover the socially enforced barriers that blocked repair and encouraged disruption. The second question sought to explore the role that is played by support groups - often the only source of long-term support and information for people and their families living with brain injury - in promoting repair.

The research methods employed - biographical interviews and immersive participant observation - were selected to provide a platform to foreground the voices and experiences of people with a brain injury.

As the thesis developed, a decision was made to apply a human rights-based lens to analyse the social barriers erected by the State and other duty-bearers, and in doing so understand how this approach can begin to rebalance the dominant power dynamics that were disempowering, repeated, and obstructive to biographical repair. This led to the development of a third research question: How does a human rights-based approach enable biographical repair?

1.4 A note on terminology

The term ‘brain injury’ has been used throughout this thesis as a catch-all term. There are a range of umbrella terms such as ABI (Acquired Brain Injury: which refers to injuries sustained after birth), TBI (Traumatic Brain Injury: an injury caused by receiving a trauma to the head), and head injury. These terms encapsulate a wider range of injuries, conditions and commonly known causes such as stroke, which itself has different types such as subarachnoid haemorrhage. My own injury could be termed an ABI, a TBI, a parenchymal haematoma, a bleed to the brain, or simply a head injury for example. I settled on brain injury as it was the term most commonly used in my experience, and it hopefully makes for a more consistent read for people who do not have expertise or experience in the area. The exceptions to this are in the literature review, where specific reference is made to the terminology used in the original research, and times when a participant refereed to a specific term.

1.5 Structure of the thesis

The thesis loosely follows the traditional thesis structure. **Chapter 1,** which is the current introduction chapter, begins by discussing the why and how I undertook this research. It discusses the research background, context, situates the gap in the literature and the original contribution of the thesis.

The first literature chapter, **Chapter 2** ‘The medical perspective of brain injury’, focuses on the vast literature relating to brain injury. It begins with a case study of possibly the most infamous case of brain injury in history, that of Phineas Gage. This exploration frames the thesis and serves as both a cautionary tale, and as a reference point of comparison to the contemporary experience. This chapter begins by unpacking the effects of brain injury from a medical perspective, providing insight to the wide range of impairment that can be caused by, and is covered under, the umbrella term of brain injury. The process of diagnosis, a vital reference point for the individual in regard to biographical disruption, is then discussed, alongside treatment. Advancements in the understanding of neurodegeneration are covered due to their potential implications for people with existing injuries, and indeed people who may not currently be aware they have a brain injury or sit comfortably within existing models of understanding and support. A major section of this chapter relates to longitudinal studies on the impact of brain injury on people long after the injury has occurred, revealing insight into the chronic nature of the injury and the barriers faced by participants in this study and people with brain injury more widely. Patterns of brain injury in respect to changes in the causes and groups who are likely to sustain a brain injury are considered, alongside the links between oppressed groups and high rates of brain injury. This contributes to a widening of our understanding of hidden voices likely to be furthest from rights realisation.

In **Chapter 3**, ‘The sociology of brain injury’, the focus of the literature is on the sociological contribution to the understanding of brain injury. This chapter delves into the foundational theory that guides this research - Bury’s (1982) theory of biographical disruption. It traces the widening of the theory and concept, and its application to understand the experiences of people experiencing a range of illnesses, including brain injury. This chapter encapsulates critiques of the theory, and considerations of its applicability in understanding the experiences of people with a brain injury. The chapter then begins to draw on the literature relating to areas of the social navigation of life after injury. Within this are considerations of navigation of the medical world and the accessing of resources, highlighted as key in Bury's (1982) original study. The spaces that are occupied following injury, and the insight into disruption and repair, are explored, before attention turns to key markers of identity and recovery of employment. The chapter concludes with a consideration of a social security system that is barrier-strewn and looks towards the media for clues as to the negative discourses of disabled people and the societal oppression that this contributes to.

The final literature chapter, **Chapter 4** 'Charity, philanthropy, and the potential of human rights', charts the origins and development of the charitable sector in Britain, developments which inform societal understanding and discourse to the present day. The chapter explores how charities are regulated and governed, providing an important backdrop and understanding of the frameworks under which charities, and the host support group for this study, operate. As peer support is a central feature of this thesis, the role of peer support and community forms of self-management is addressed to provide crucial context and understanding. The chapter concludes with an exploration of human rights, their potential to increase participation in spaces where people are furthest from rights, and their potential as a framework that delivers humanising experiences in health and social care and other areas of social life. It further unpacks areas of policy relating to people's lives in which a HRBA appears, and an unpacks an example of the use of a HRBA to successfully empower people to name and claim their rights.

Chapter 5 'Research methodology'**,** outlines the research methodology and the methods of data collection and analysis that the study employed in this thesis. It begins by outlining the theoretical and ontological basis of the research, and the underpinning philosophy and epistemology, including the researcher position, and the role of ethnography and autoethnography which influenced the approach and development of the thesis. A central tenant of the research, how rigour and integrity was established, is covered in sections relating to reflexivity, confirmation bias, integrity and the insider perspective. The chapter then details and discusses the two-phase qualitative research approach of participant observation and biographical interviews. Finally, the negotiating of the ethics process and the subsequent turn from phenomenology to the use of the PANEL principles is followed by an in-depth description of the fieldwork process.

Chapter 6 'Participation – personal perspective', explores the concept of participation with a focus on the private self. The chapter examines to what extent people felt able to contribute to their own narrative of, and experience of, care. Beginning at the point of injury, the chapter captures the suspension of participation that effectively leads to a denial of rights. The evidence presented shows that at a time where participants were unable to express their need for and right to dignity, and exercise choice and access information about their own health, medical professionals appeared unable or unwilling to bridge the gap and deliver a human rights-based approach. Participants were unable to claim their rights due to extended periods of unconsciousness (which can be understood as having a bio-medical cause) and due to the inconsistency of, and limited access to, information relating to diagnosis (which can be understood as having a socio-structural cause). This took place in healthcare settings marked by declining investment in healthcare services and overworked healthcare professionals. The evidence presented found that following the trauma, healthcare settings were places where meaningful participation was largely absent despite its centrality to a person's human rights. If dignity were informing healthcare as it should, then participation should be the normative experience of participants in this research. This lack of participation began at the point of diagnosis, and continued through initial care, rehabilitation, and once an individual was back home. The subsequent difficulty in accessing information relating to the individual's injury and diagnosis illustrated a power dynamic between the healthcare professional and the person. The injury solidified a black hole in both memory and self-narrative that undermined attempts at repair. There was no recognition of this, or support to re-establish a biographical narrative from healthcare providers. This was symptomatic of experiences of healthcare which lacked dignity, had long-term negative impacts, and suggested a need for formally established thresholds for participation.

The analysis regarding participation began to unpack the interconnectedness of rights and the experience of brain injury as a social phenomenon where power and participation fluctuate. The participants' experience also showed that in stark contrast to the disempowering medical field, the participants in some areas resisted the homogenous and disempowering label of a passive entity. The lens of participation consequently enabled an understanding of the social processes that people navigate post injury, and how these are damaging, promote disruption, and undermine repair. Supporting post-trauma patients to make sense of their biography, ensuring they are as informed as is necessary to begin participating in their own care and health experience, and creating spaces where problems are shared and solutions co-produced by patients and healthcare providers, would improve the experience of people with a brain injury. This highlights the potential that a human rights-based approach could have in the rebalancing of power and in the realisation of rights, a potential that would improve the lives of people with brain injury.

Chapter 7 ‘Participation – public perspective’, focuses on participation in a more public sense, as participants navigated wider society and sites of repair, and disruption continued to emerge. This section highlights the need for a person's biography to be encapsulated in their care and support, and the potential for rights-based approaches to support holistic, rather than medical-focused rehabilitation and recovery focused solely on impairment. Where participation was present, co-creation took place, which helped to humanise participants and promote repair. However, when medical approaches were impairment-focused, solutions were not co-produced, underlining that the new self was not equivalent in rights to the old.

A dominant theme continued to emerge in this analysis, that highlighted the management of the injury, not as the ‘management of symptoms’, but of hostile and oppressive social environments, structures, and norms. This oppression was acquired and emergent following injury, and suggestive that a person with a brain injury is required to survive both the injury and a hostile society. Themes of passivity and dependency were reinforced by employers and by non-trauma health and social care providers. Had biographical recovery started in hospital, and had participants had explicit opportunities to participate and co-deliver a dignified experience of healthcare, they may have been more able to cope and challenge other social barriers to being and doing.

The possibility of human rights-based approaches to promote repair was a prominent finding throughout. Participation, and by extension, rights-realisation, was inconsistently experienced. This ensured that any biographical work carried out was at constant risk of being undermined. Narratives highlighted a post-injury environment where driving licences are revoked, and bus passes issued, which required further navigation of spaces that are inaccessible and often hostile. This finding is key because it suggests that attempting to reintegrate the acquired self into society will lead to more biographical disruption and undermine attempts at repair.

The third analysis chapter - **Chapter 8** 'Accountability' - focuses on the principle of accountability, which was a concept that remained largely hidden and unrealised for participants. This lack of accountability was explained as 'falling through the net'. This conceptualisation is a key finding, as whilst there was a strong awareness of the failure of the system, it demonstrates that participants did not view themselves as empowered rights holders. This offers insight into the processes of disruption, as a lack of accountability negatively impacts on the individual navigating the system and removes elements of their dignity. The reality that all participants had in some way 'fallen through the net' raises the question: does the net even exist? If not in practice, the net exists conceptually as people imagine that their falling through is an exception to the norm. As a result, when they fall through the net, and they all did, they viewed it as a personal trouble (Mills, 1959), as an individual issue, as 'bad luck' rather than the failure of the duty-bearers. In turn a human rights-based approach allows us to consider duty-bearers as being at fault, again as a conceptual argument which can be helpful. It is helpful for us first to consider that 'this is not the way it should be' and that 'someone ought to do something'. In first naming this 'someone' as a duty-bearer allows us to get it clear, hermeneutically, that someone other than an individual patient is responsible for dignity within health, social care and beyond. This needs to be established for people to then collectivise to determine what change is needed and examine who the duty bearer is.

Further to this was evidence which highlighted the interconnectedness of rights, and how failures in one can lead to impacts and negative outcomes elsewhere. Whilst the interconnectedness of rights is familiar, the tracing of the impact is less so. This chapter suggested the need for a rethinking of what redress means, and of the complexity of this, which may require a widening of responsibility on the part of the duty-bearer. These findings contribute to a call for maximalist incorporation of human rights law.

The fourth chapter of analysis, **Chapter 9** 'Non-discrimination', focuses on the experiences of non-discrimination. It draws strongly on participants' experience of attempting to return to work. The labour market was experienced by participants as discriminatory and hostile in ways which they had not experienced pre-injury. Given the central role of work and employment to understandings of identity, this represented a crucial area of disruption to individuals' biography. The social barriers imposed contributed to people being unable to continue in employment. This removed the stable role and status previously experienced, and denied a form of narrative continuation that may have aided repair to occur and stabilised people after injury. This chapter highlights employment as a key site of disruption that requires management regardless of whether a person returns to work. Inadequate legislation was key here, as social security - another safety net - was inadequate. Participants often found that their ability to access ‘reasonable adjustments’ to their work was barrier-strewn and ultimately, unrealised. The failure of the social contract again led to an internalising of societal oppression, that caused furthered disruption, but longitudinally led to a form of biographical confirmation. The social barriers were experienced bureaucratically and reproduced by colleagues who engaged in processes of ‘othering’ in a system where repetition of rights violation occurred. This encouraged a process of partial, and damaging repair, where participants had limited options, to resist by removing themselves from the labour market or to be resilient to right reductions and strive to be simply ‘normal’ or average.

The final analysis chapter - **Chapter 10** ‘Empowerment’ - focuses on the principle of empowerment, and how this is experienced in the context of the brain injury support group. Attending support groups was found to enable people to carry out biographical repair by resuming tasks that had been previously important to them and tasks that promoted independence. Within the data, this presents as a precursor to participation (which is in itself problematic as support groups may never be accessed or may be accessed years after diagnosis). The support group enabled biographical repair as it was a space where people were able to practice disrupted social customs such as reciprocity, establish new relationships, provide and receive forms of care, and engage in activities that were new and provided evidence of growth. Empowerment was, however, undermined when the group engaged with wider society. Public buildings were disempowering despite meeting legislation standards for accessibility, and spaces where access required a public reveal of personal information about their health condition, required resilience. This highlighted the need for conceptualisations of biographical disruption to encapsulate the meanings and experiences people derive from the societal fields they navigate (Meijering et al, 2019).

Chapter 11 – ‘Discussion and conclusions’ - provides a discussion of the themes and of the extent to which the data analysis contributed to aims and study research questions. The chapter also explores the limitations of the study, possible areas for future research that have emerged from the undertaking of this research, and recommendations relating to the barriers that were highlighted in narratives and the subsequent analysis.

Chapter 12 – ‘The Wounded Storyteller in the Field: An Autoethnographic Chaos Narrative,’ is an autoethnographic account that begins by providing context as to the intersubjective origins of the insider status of the author. The chapter applies Frank’s (1995) illness narrative as an analytical tool to engage with the fieldnotes of the researcher in the field. In doing so, a chaos narrative is revealed, which offers insight into the lived experience of brain injury, and questions the structures under which the knowledge production of this took place.

Chapter 2 The medical perspective of brain injury

2.1 Introduction

The medical literature on brain injury is vast. The field of neuroscience, neurology, and the treatment of neurological disorders is an area of rapidly growing research and knowledge. There is increasing understanding of brain function, and how injury can impact this. Although this thesis is a sociological contribution, much of what we know and understand in relation to brain injury what is known of the reality of brain injury, has emerged from other disciplines. The following chapter will begin by discussing the story of Phineas Gage, a landmark case of brain injury and misrepresentation, whose story is still used in contemporary academic teaching materials within the psychological and medical sciences to this day. The chapter will then proceed to unpack what a brain injury is, and how it can affect someone. How the medical world diagnoses injury and predicts recovery, and the complex nature of treatment will be addressed. This chapter shall also encompass literature on longer-term outcomes and the changing pattern of brain injury epidemiology. Consideration will also be given to whether the population has been fully identified. Finally, emerging research on neurodegeneration, and what this could entail for people with brain injury will be discussed.

2.2 The famous case of Phineas Gage

Extreme cases of survival following brain injury have long been a source of wonder and intrigue to the medical community and wider society. The story of Phineas Gage is a landmark case in the history of brain injury. It is, however, a landmark case for the wrong reasons. His story is one of incredible survival and great biographical recovery, but a story dominated and clouded by poor ethical practice and medicalisation.

In 1848, Phineas Gage suffered a brain injury following an accident, whilst working as the foreman of a railway construction gang. Whilst laying gunpowder, an accidental explosion forced a tampering iron to pass through his face and his left frontal lobe, before finally exiting through his skull (Harlow, 1993). The accident that Phineas Gage suffered would have ensured that he was living with a significant facial injury (Kotowicz, 2007). In this respect, he was required to navigate life with what would appear to be significant, life-altering, invisible and visible injuries.

Despite the gravity of his injuries, Phineas Gage survived and was able to live a remarkable life. Much of the learning from this case is derived from the accounts of John Martyn Harlow, the doctor who attended Gage, and provided a subsequent history of Phineas Gage's life in the years following his accident, up to his death in 1860 (Macmillan, 2000). His account provides a description of Phineas Gage's personality and capabilities prior to the accident, and the apparent catastrophic impact following the accident of the injury itself. Harlow described him as a as a man who possessed both "an iron will as well as an iron frame" (Harlow, 1993: 275), and provided his own description of Phineas Gage before the injury, and the change in personality apparently observed by some of the people who knew him:

> "Previous to his injury, though untrained in the schools, he possessed a well-balanced mind, and was looked upon by those who knew him as a shrewd, smart business man, very energetic and persistent in executing all his plans of operation. In this regard his mind was radically changed, so decidedly that his friends and acquaintances said he was 'no longer Gage'" (Harlow, 1993: 277).

The generally accepted view, informed by Harlow's reports, is that the change in personality experienced by Phineas Gage following the accident was drastic and permanent (Macmillan and Lena, 2010). This is despite criticisms more recently that Harlow's account is in fact 'vague' and based on what "Harlow *thinks* Gage was like" (Kotowicz, 2007: 123). Indeed, it has been argued that much of the 'learning' that was derived from this case "implies that whenever people suffer serious injury to the frontal lobes something essentially human can vanish" (Kean, 2014: n.p.).

Evaluating any change in personality following a brain injury remains challenging and problematic. It is a process that is often reliant on descriptions supplied friends and family. This approach does bear fruit however in providing signs of neurological recovery. The account provided by Phineas Gage's mother in the period following the accident suggests that the "description of Gage as being 'fitful' and 'irreverent', indulging in the grossest profanities, pertains only to the period immediately after the accident, probably for a period of some months" (Kotowicz, 2007: 118). This suggests that conclusions drawn as to the impact of severe damage to the left-frontal lobe from the initial assessment of Phineas Gage are not reliable.

This account also appears to be based on a belief that it was the neurological impact of the injury that caused these changes. How Phineas Gage felt about the cause of his injury for example, which amounts to a serious failure of health and safety on the part of his employer, remains unclear. An acceptance of Harlow's conclusions is problematic as whilst there is a general acceptance that brain injury can cause changes in a person's personality, it is less clear in when this is the cause of the injury, or when this is the person's response to the injury (Rieger, 2015). Kotowicz (2007) speculates as to the impact of returning to the workplace disfigured, that the description of being 'no longer Gage' may be down to society's failure to adjust to him following his accident. It is this description of social detachment in Phineas Gage that is perhaps most relevant, and one that appears routinely in accounts of people who experience and live with a brain injury. A social world that can be hypothesised to have been difficult and unforgiving then for someone to navigate and remains so today.

As highlighted by Harlow (1993), Phineas Gage went on to work in a range of new jobs which included a period of just under eight years (the majority of his post-injury life) spent working as a stagecoach driver in Chile. Macmillan and Lena (2010) describe how a stagecoach driver at that time, covering the route that it is thought that Phineas Gage did, was a highly demanding, and multi-faceted role. Prior to beginning the actual journey there would have been a requirement to load passengers' luggage, possibly handling considerable amounts of money all whilst interacting with the passengers. The driving itself required a high level of ability (each of the six horses were controlled separately) over what was thought to be around a one-hundred-mile trip taking something in the region of twelve to thirteen hours (excluding any prior preparation). This also required considerable planning and the ability to react quickly to the physical conditions encountered on the route in the form of often dangerous layout and topography, and indeed other stagecoaches; all this in a job, and land, that was unknown to Phineas Gage prior to his brain injury. Clearly, this suggests that there was a process of neurological recovery/adaptation, and that the impact of the injury is deserving of far more unpacking than one of great personality change. It is also evidence of great biographical reconstruction and repair. It is this underacknowledged aspect of his story that perhaps offers most insight and value to the understanding of brain injury both then and today.

How this learning has been applied in academia is concerning. Previous studies have found that this case unsurprisingly appears routinely in introductory psychology books (Macmillan, 2000). What gives rise to concern is that the accepted learning is questionable, and that the areas of most relevance to the understanding of the impact of the accident itself are the areas which suffer greatest from inaccuracy.

> "Remembering that the general level of accuracy is low, the elements that seem to be most accurately reported are the dimensions of the tamping iron, the fact of the explosion, the length and difficulties of the treatment (if reported at all), and the fact that Gage's behaviour had changed. The most inaccurate components are those about his work before the accident, the details of the changes in his behaviour, and his subsequent history" (Macmillan, 2000: 48).

That such inaccuracy pervades foundational knowledge of this most famous of cases suggests a need to re-examine the foundations. In this respect, this case has the potential to be damaging to the understanding and treatment of people today with brain injury.

In what was one final indignity, Phineas Gage's body was exhumed with what appears to be the consent of his family in 1867. His skull was removed and delivered to John Harlow (Macmillan, 2000). This completes a grim story of the medicalisation and final ownership of Phineas Gage, whose own account and perspective was never recorded, by the doctor that initially treated him.

It is clear that the story of Phineas Gage is a landmark case in the history of brain injury. It would appear necessary however that the retelling of this case continues. A retelling that focuses on the ethical issues and poor scientific foundations that much of the 'learning' is based on. His story is of value to the brain injury community because it is a great tale of biographical reconstruction. His case stands as an example of recovery, but one that, without the testimony of the man himself, is destined to only ever be partially understood.

2.3 The effects of a brain injury

There are several serious, life-threatening and potentially life-altering effects which can stem from a brain injury. Most are understood medically, rather than socially. Primary effects include focal injuries such as skull fractures, cortical contusions, intraparenchymal haemorrhages and subdural haematomas. These primary injuries can lead to secondary effects such as neuroinflammation, vascular and hypoxic-ischemic injury (Gardner and Zafonte, 2016). Neuroinflammation or swelling in the brain causes an increase in intracranial pressure (ICP), which can impact on brain structure, effect blood flow in the brain and lead to cerebral ischemia and oxygen deprivation (Maas et al, 2017). Medical interventions can include surgery and medication. The full consequences of the injury may not be realised for a significant period of time following the injury itself (Teasdale and Engberg, 2001), despite this, medical guidelines place focus on the early part of recovery (McMillan et al, 2014).

Headway UK (2017), in an attempt to make knowledge accessible to non-medics, break these effects down into three main areas; physical, cognitive, and emotional and behavioural. Physical effects may include a range of issues such as fatigue, mobility, epilepsy, weakness or paralysis, difficulties with speech and hormonal imbalances. Cognitive effects that are common after an ABI include impairments in memory function, concentration span, information processing, problem solving, aphasia, and visual-perceptual skills. Cognitive effects can also include impaired reasoning, affecting how a person comprehends rules and follows discussion with others. Cognitive impairment can also make repetition an issue in respect to a person sometimes having difficulty moving on from a topic of conversation or continually returning to the same point. Issues with insight and empathy are also common. Emotional and behavioural effects include mood swings, loss of confidence, depression and a sense of loss, anxiety, disinhibition, impulsiveness, and obsessive behaviour. Personality changes can also be experienced following a brain injury:

> “these can range from subtle changes in some areas to dramatic transformations. This can be particularly difficult for family members and friends to deal with as they find themselves dealing with a totally different person” (Headway UK, 2017).

Physical and mental fatigue are common issues following a brain injury. Beaulieu-Bonneau and Ouellet (2017) investigated how this developed over the course of the first year following a traumatic brain injury (TBI). A second aim of this study was to assess corelates of fatigue at the same intervals. The study involved adults who spent time in a hospital following a TBI. Participants were grouped according to the severity of injury, measured using clinical guidelines by the medical team when hospitalised. Willing participants then received a questionnaire by post at 4, 8, and 12-months post injury. The results of the study suggest that fatigue is complex, has a relation to severity of injury, and is a significant issue for people with a TBI. Cognitive impairments, sleep issues, and self-reported depressive symptoms were highlighted as problems linked to fatigue separate to the time post-injury. The relationship between pain and fatigue had closer links in the early post-injury period. The study concludes that fatigue appears to be not singular in cause following a TBI, but a collection of factors working in combination. As every brain injury is in a sense unique; this suggests each person's experience of fatigue may be similarly so.

The study makes no mention as to whether participants considered a questionnaire sent by the post to be the most appropriate method of inquiry. This can be viewed as an exclusion criterion. Participants may have had impairments that made filling in the questionnaire difficult or may not have had access to the relevant support required. Furthermore, the exclusion criteria included people unable "to provide informed consent or understand written or oral information due to cognitive or behavioural impairments" (Beaulieu-Bonneau and Ouellet, 2017: 986). It is unclear where the line is drawn in respect to informed consent.

2.4 Diagnosis / prognosis

The Glasgow Coma Scale (GCS) is a primary method of neurological assessment used and recognised worldwide to assess neurological function. In a paper reflecting on the history and development of the GCS, the authors (including Graham Teasdale who developed the GCS in conjunction with Brian Jenner) describe the method of brain injury assessment used previously, stating that "It is now difficult to envisage the chaos that characterised the assessment of patients with a head injury or other acute brain insult before the mid-1970s" (Teasdale et al, 2014: 844). The development of this scale has provided medical staff with a crucial, consistent, time-critical diagnostic tool. Diagnosis can now be aided by imaging machines such as magnetic resonance imaging (MRI) and computerised topography (CT) scans, and by further tests to assess intercranial pressure. Rosenfield and colleagues (2012) remarked that "the outcome of severe traumatic brain injury is dependent on delivery of high-quality care by a well-integrated multidisciplinary team of health professionals" (Rosenfield et al, 2012: 1095). This access is not universal and is often reliant on economic resources at a personal and national level, as well as on geographic location.

Prognosis remains difficult. However, prognostic research has increased. Indeed, prognosis models are now available that are the result of research using large datasets, encouraging a shift away from prognosis based on the individual experience of a doctor or department, towards one based more on scientific rigour and research (Maas et al, 2017). Whether these datasets cover all the issues that someone may face in the social world, or are developed through a purely medical lens in the social world is less clear. Improvements in areas such as MRI scanning, blood biomarkers, and increased ability to combine data from a number of sources offers the possibility to better understand the injury itself, and also to chart the evolution of a particular injury (ibid). This demonstrates that while advancements are being made that are welcome, a need to take a holistic view of recovery, one that includes the perspectives of people with brain injury, remains needed.

How neurological injuries are classified presents a barrier to understanding the scale of incidence. Chen and Collantino (2011) assessed international definitions of both traumatic brain injury (TBI) and spinal cord injuries. Their assessment found a wide range of definitions of TBI internationally, yet no clear, internationally accepted set of codes and definition for TBI. Use of standardised procedures would be of significant benefit to research on brain injury (Quaglio et al, 2017). Furthermore, the importance of these developments is highlighted by researchers that argue greater precision in the classification of injuries will lead to better eventual outcomes (Rosenfeld et al, 2012). Maas et al (2017) state that:

> “We also need to enable better characterisation of outcome after TBI: mortality is an inappropriate metric for a disease that can result in considerable disability in survivors, and current outcome assessment tools are limited by their unidimensional approaches” (Maas et al, 2017: 1032).

This suggests that there is a need to continue to extend research beyond the traditional climes of patient data, neurological scans, and neuropsychological testing. These approaches are an important part of our understanding of brain injury, but as Maas et al (2017) suggest, they offer little in terms of understanding the lives, and the disablement often experienced. These approaches also require people to have been in contact with some form of healthcare institution. Methods that engage people who face barriers to accessing these spaces (such as marginalised groups), must be embraced if we are to increase our understanding of the full experience and implications of having a brain injury. It suggests a clear space for sociological enquiry - an enquiry that positions the experience of the people who live with a brain injury at the forefront.

2.5 Neurodegeneration following a brain injury

Whilst the immediate impact of an injury to the brain can be unclear, the picture is arguably more unclear for the long-term impact. The field of neuroscience has however begun to investigate and better understand the concept of neurodegeneration. Cole et al (2015) investigated ‘brain age’ following TBI. Using neuroimaging, this research aimed to investigate differences in chronological and structural ‘brain age’, employing a predictive model that the authors developed. Amongst its participants, the study found that on average, the model (which was highly accurate when applied to participants without a TBI), predicted ‘brain age’ to be on average four years more than chronological age in those with a TBI. A pattern emerged that the further from someone’s injury, the greater the atrophy. This raises the possibility that the injury triggers a ‘progressive neurodegenerative process’ (Cole et al, 2015: 578), although, whether this is a new process or one that is interrelated to ageing, is unclear. These effects were observed in those with mild-severe injury, and not amongst those with minor injuries.

This suggests a need to further assess people who have had a mild to severe TBI in further intervals, should they wish, in the years following their injury. Neurodegeneration may be more manageable with strategies and techniques which are often relatively straight forward. Also, new technology, such as smartphones, may also provide greater support as new technologies become available. Various estimates are given in terms of how long a person can expect to recover following a brain injury. This research, however, suggests that a degenerative process may begin and run in parallel with, and beyond, the time of recovery. This also highlights the value of an interdisciplinary approach to the understanding of brain injury.

A study into the risk of dementia after TBI found evidence of its increased risk in people living with a TBI over the age of 55 (Gardner et al., 2014). The study found that 66.4% of the study participants, all of whom were aged 55 and over, received their TBI as a result of a fall. This again suggests that there is a public health issue within a public health issue that requires greater attention. It is also of particular interest to societies with an ageing population as without attention the number of people impacted would be expected to increase in time. Growing rates of brain injuries among the elderly would likely lead to an increased burden in terms of care and economic impact, in addition to the human cost. There could therefore be a tendency to view dementia and similar illnesses as something of a ‘ticking timebomb for those with a brain injury. Moretti and colleagues (2012) remind us however that,

> “TBI is neither necessary nor sufficient for the development of dementia. Patients with dementia usually do not have a history of TBI, and people who have survived a TBI do not invariably acquire dementia later in life” (Moretti et al, 2012: 1105).

Gardner et al (2015) studied the relationship between traumatic brain injury (TBI) and Parkinson's disease (PD). Their study used patient data from hospitals in California in 2005-2006. The study involved people who had a TBI aged 55 and over whose patient data was then tracked for 5-7 years. The study reported a 44% increased risk of developing Parkinson's disease for those middle-aged and older. The study was not able to discern if Parkinson's disease had developed as a result of a unique neuropathology due to the TBI, or due to a standard or partially influenced Parkinson's disease neuropathology. The study again noted the need for fall prevention, as this was the main cause of injury in the middle-aged and older group.

A further study by Gardner et al (2018) investigated the link between specifically mild TBI and the risk of developing Parkinson's disease. This study used medical records of American military veterans for the participant pool. This yielded data on a total of 162,935 people with a diagnosis of TBI with an average participant age of 47.9 with an average follow-up of 4.6 years. This study found an increased risk of 54% for people with mild TBI. These statistics continue the trend observed in previous research with a younger cohort. It is also noteworthy that this figure refers to mild-TBI. This increased awareness of neurodegeneration could have implications for clinical guidelines for people with brain injury who present with symptoms resembling the early stages of these diseases. GPs, and those who are likely to have first contact with the patient, would benefit from awareness on this issue; particularly as some of the early symptoms of dementia or Parkinson's disease may be easily confused for impairments linked to brain injury.

Advancement in areas such as stem-cell treatments may offer potential additional areas of improvement of outcomes in the future (Rosenfeld et al, 2012). However, Maas and colleagues (2017) caution that "most multicentre clinical trials of medical and surgical interventions have failed to show efficacy, despite promising preclinical results" (Maas et al., 2017: 987).

Existing links between concussions, or mild brain injuries, and morbidity have also been highlighted as a consequence following a brain injury, including an increased risk of suicide (Teasdale and Engberg, 2001) (unpacked further in section 3.4). Research is beginning to emerge that is exploring links between repeated concussion and chronic traumatic encephalopathy, although it is in its infancy due in part to a lack of longitudinal studies (McCrory et al, 2013; McAllister and McCrea, 2017). These studies highlight that there are groups of people in society who would appear to have had brain injuries and are living with the effects but may be unaware. The more the risks and impacts of a brain injury are understood by the public, the greater the demand will be on services that treat or support brain injury. It is vital that public bodies such as the Scottish and UK Governments are aware of this and act upon it, as it suggests that an already under-funded area can expect to undergo additional demand and strain in years to come.

2.6 Longitudinal studies

The long-term outcomes for people with brain injury are an area of great concern. Ponsford and colleagues (2014) carried out a longitudinal study which examined function at three specific time periods (2, 5, and 10- years post-injury) following a TBI. The participants of this study had received comprehensive inpatient rehabilitation. Two classifications were used to measure the severity of the injury: pastime of post-traumatic amnesia (PTA) and the Glasgow Coma Scale (GCS). The majority of participants (77.1%) were classed as having a 'severe' injury. This group was compared to another group with TBI, similar in terms of gender, education level, and years of education, though younger and with higher GCS scores. The participants were all asked to fill out 'The Structured Outcome Questionnaire' at each follow-up point. The questionnaire aimed to assess areas of functioning that are thought to be impacted on following a TBI. Alongside this, participants were scored using the Glasgow Outcome Scale-Extended (GOSE) at the 10-year follow-up. The results reported a wide range of biological, psychological, and social issues including neurological complaints, issues with relationships, and challenges returning to work. Issues with balance and fatigue, whilst being the most reported neurological issue, tended to improve slightly with time. There was a high reporting of changes in cognition in participants, and these did not decrease over time. Participants increasingly reported changes in executive and behavioural functioning, and in problems with relationships and social isolation. The authors proposed this suggested a growing level of awareness on the part of those affected as time passed.

Major depressive disorder (MDD) has also been found to be prevalent in people who have experiences a traumatic brain injury (TBI) (Bomabardier et al, 2010). Its rates, predictors and outcomes following a TBI have been investigated as part of a wider study into the use of sertraline to treat MDD following a TBI. Amongst the 559 people that took part in the study, 53.1% (n=297) were found to have met the criteria of MDD at least once. Of this group only 44% received counselling or a form of medication. It should, however, be noted that a high proportion of participants were in receipt of Medicaid, the national public health insurance for people with limited income and resources, which may have resulted in limited access to support. Another possible limitation of the study is its use of telephone interviews to assess at various monthly intervals, those taking part. The sole use of telephone interviews would appear to limit participation to only those who were able to successfully engage with this method of communication. It would, therefore, be of interest to see how people with impairments which restrict their communication would have responded over their first year following a traumatic brain injury. The authors conclude that "because MDD after TBI is an invisible disorder within an often-invisible injury, aggressive efforts are needed to educate clinicians about the importance of MDD in this population" (Bomabardier et al, 2010: 1944). It would also appear critical to educate people with a brain injury and their loved ones close about MDD and offer access to treatment and support.

Research on the long-term outcomes of brain injury in regard to mortality and morbidity is scarce, despite the contention that "identifying factors beyond age that predispose these patients to premature mortality remains a pressing public health concern" (Corrigan et al, 2014: E7). Corrigan and colleagues (2014) investigated health and social outcomes among people with a traumatic brain injury five years post rehabilitation. Using data from the TBI Model Systems National Database (TBIMS-NDB) between 2001 and 2007, this study found that deterioration in global outcomes was equally distributed across different age groups. This contrasted with a previous study by Kolakowsky et al (2012), that suggested age as leading to a greater level of deterioration. Corrigan and colleagues (2014) did not compare the mortality rates with a 'healthy' control group, but the findings "suggest significant mortality and morbidity occur by 5 years post-TBI in patients who have received rehabilitation" (Corrigan et al, 2014: E8). This exemplifies the potential of a brain injury to develop into a chronic condition where deterioration, as opposed to stabilisation or improvement, is a real possibility. This presents a challenge to the neat view of the chronology of injury, rehabilitation and recovery then leading to stabilisation. The experience and outcomes of those who have a brain injury but do not have access to, or do not receive rehabilitation is less clear. In countries where healthcare is particularly limited, or access controlled, post-brain injury outcomes could be particularly stark. Such outcomes could also be envisioned in countries where the overall care is better, but where access to it is limited due to social or geographical barriers. Further, this study found that life dissatisfaction peaked at 49% for the 40-49 age group, dropping with increasing age down to 8% for the 80+ category (Corrigan et al, 2014). These figures suggest that the priorities of rehabilitation are different for different age groups and should be tailored consequently.

McMillan et al (2014) carried out research that aimed to examine the mortality rate of a group of people diagnosed as having a ‘mild head injury’ (MHI), how this compared with a control group, what the factors involved were that caused death or survival, and to investigate the cause of death of those with a mild head injury. The diagnosis of MHI was made in conjunction with the Glasgow Coma Score GCS score at the time of initial hospital admission. The data was taken from information held by the National Health Service (NHS) for Scotland. The data related to people who had been admitted to hospital in Glasgow between February 1995 and February 1996 (n=2510). Two control groups were then created: one ‘community control’ (CC) group, which matched case-by-case by age, social deprivation (derived from postcode) and their gender. The second case control group, called ‘other injury control’ (OIC), related to people who had been admitted to Glasgow hospitals for other injuries, but again matched on a case-by-case basis to age, social deprivation (matching quintile of the Scottish Index of Multiple Deprivation), and the duration of their admission. The duration of admission was included in an effort to find a similar match for the severity of the condition, or reason someone was admitted. The study found that the people who were admitted to hospital with a mild head injury faced an increased risk of death. In comparison with the CC group, the rate was almost double. The study was not able to determine whether the increase in mortality rates “reflect[s] general health and lifestyle factors only, the development of long-term neuropathology associated with head injury, or both” (McMillan et al, 2014: 1218). The authors suggest the possibility that both are at play. This suggests a need for research into brain injury to continue down two parallel paths: one that is medical, growing our understanding of the functioning of the brain and the changes caused by injury to it, and the second examining how the social world impacts on a person following injury. Greater understanding in both areas would appear to offer great potential to highlight who is at increased risk, why, and how positive interventions can occur. This has the potential to both improve quality of life but also reduce the number of people with brain injury who die following their injury for reasons that remain shrouded by our lack of understanding. The study also revealed that the risk of having a subsequent brain injury was 18.72 times higher for those who had a mild head injury to those in the CC group. This is an alarming rate and one that should be considered as part of discharge guidelines and information provided by both hospitals and subsequent support groups. The causes of this risk of having another brain injury are likely to be both neurological and social, and again highlight the need for approaches that recognise both. Providing information, and further research into this massive increase of risk, would be an important step.

With that said, there are some potential methodological limitations to the study. Duration of admission as a match for severity is difficult as the length of a stay may not necessarily be linked to the severity. If a family is able to take care of someone, they may be released from a hospital sooner. Similarly, someone admitted to hospital due to a relatively minor injury may spend a longer time in hospital if they have no support from family or close friends. This can also be reliant on adequate social work representation that may or may not have been the case during the time period studied. This also offers clues into destinations of people with brain injury following discharge. People may leave earlier due to perceived family support; however, whether the family is prepared for what can be a long-term and complex rehabilitation period, or have access to support through this, is unclear.

McMillan and colleagues (2014) conclude that there is a real need for support in lifestyle choices following brain injury. This is of particular interest given the indication that a person's lifestyle after a brain injury appears to in part influence the increased mortality rate (Wilson et al, 2017).

2.7 Changing patterns of brain injury

Brazinova and colleagues (2021) carried out a systematic review of the literature relating to the epidemiology of traumatic brain injury (TBI) in Europe. Their study followed on from a similar review carried out by Tagliaferri and colleagues (2006). The studies' findings appear to show that the most common cause of TBI are falls and traffic accidents, with the latter increasing. Males, in every study included in the review were found to have higher rates of TBI. Comparison of the data was found to be difficult in part due to varying definitions of TBI. The review suggests that the overall causes of injury are changing. Public health campaigns and measures in relation to road traffic accidents, and their subsequent reduction over time, were contrasted to the increase in the numbers of falls, particularly by the elderly as an area that would benefit from greater policy intervention.

Peeters and colleagues (2017) aimed to investigate a growing assumption that epidemiological patterns of brain injury cause in high-income countries had begun to change.

This large sample study analysed data from people admitted to hospitals across Belgium between 2003 and 2012. Within this period there was a decrease in hospital admissions, although there was a sharp increase observed within the elderly population. This study supported previous data that pointed to the impact of measures to improve road traffic safety. There was a decrease in diffuse axonal injuries, which typically occur in car crashes, and an increase in contusions, which are common in falls. The authors remarked that "in [their] experience, loneliness, depression and subsequent alcohol use are factors that often contribute to an increased risk of falls causing TBI in the elderly" (Peeters et al, 2017: 68). This suggests that a system of structural neglect is bearing toxic fruit. The rise in brain injuries among the elderly observed in this study was, however, not explained by the increase of elderly people in the population, suggesting that some within this group are at greater risk than others.

Shivaji and colleagues (2014) analysed the epidemiology of hospital treated TBI in Scotland over a similar period, between 1998 and 2009. Falls were found to be the main recorded cause of admission. This was particularly prevalent amongst those aged 0-14, and especially in those in the 65+ category. As shown in the Belgian study by Peeters et al (2014), this is a rate that is continuing to rise without clear explanation. In the 15-34 age group, assault (40%) accounted for more than double the admissions than a fall and was the main cause of admission (Shivaji et al 2014). It must be noted that the data only refers to people who were seen in a hospital. It would be expected that the true figure would be far greater. The authors of this study suggest that geographical patterning is a logical step to identify where this violence takes place and then to initiate prevention measures.

Hamill et al (2015) investigated the gap in knowledge in relation to patterns of mortality relating to brain injury over the previous four decades in Scotland. Their quantitative study used data from the National Records of Scotland. This research found that there has been a substantial reduction in 'head injury' (authors term), although the vast majority of this occurred between 1974 and 1993. The number of deaths from head injury declined for most age groups. Contrary to this decline was the rise in deaths of those over the age of 79 who have experienced a brain injury. This increase was not explained by the increase of people living longer. The most noted decrease in cause of death was seen in brain injuries resulting from road traffic accidents, explained in part at least by the period studied coinciding with various pieces of legislation and public campaigns aimed at improving road safety. The other causes of death from head injury were not found to have changed significantly over this period, and the study again suggests that measures should be taken to address the concerning increase in brain injuries among the elderly. Hamill and colleagues (2015) also highlight an issue regarding the lack of a standardised International Statistical Classification of Diseases Codes (ICD) for head injury. This suggests that the full understanding of the global picture may be difficult to achieve without a greater level of standardised classification. Admission notes may also not reflect a brain injury as it may not be initially apparent. This may be due to a focus on what may be a more immediately serious issue such as a crush injury following a car accident necessitating more immediate focus and treatment.

Nguyen et al (2016) carried out a systematic review and meta-analysis that focused on the international incidence of TBI. This review found great variance in rates of TBI between different countries and age groups. The review concluded that “despite being an important medical, economic, and social problem, the epidemiology of brain injury is not well-characterized in the current literature, and capturing the incidence of brain injury remains a challenge, particularly with mild TBI” (Nguyen et al, 2016: 782).

2.8 The marginalised groups prone to a brain injury

As discussed, brain injury affects people from all areas of society globally. It affects people of all social strata, yet its particular impact on marginalised groups is an emerging area of research. Doherty et al.’s (2016) study aimed to shed light on the under-researched area of brain injury in asylum seekers and refugees (ASR). The authors contend that in order for this group to receive the clinical and humanitarian support they need, a better understanding of brain injury within this group is needed. The study focused on adults who had been referred to an NHS psychological trauma service in Glasgow. The study required participants (n=103) to fill out a specially designed questionnaire. A brain injury that included a loss of consciousness was reported by 51% (n= 53) of recipients. In 64% of cases the clinicians involved in treatment were unaware of their patient’s previous brain injury. This group, having already accessed a specific service, may not be representative of the general ASR population, who face barriers to accessing healthcare. Despite this, the number of respondents who reported a brain injury is startling. This study promoted the need for screening in the ASR population, and the requirement for greater links between brain injury and mental health services. The study also raises questions of the lack of knowledge that the medical professionals have regarding the groups of people they are treating. The authors highlighted that cognitive impairments resultant of a brain injury could be considered to have a negative impact on the ability of a person to successfully navigate the asylum process, which can lead to dire consequences for those affected.

There appears to be further links between marginalised groups and rates of brain injury. Several studies for example have shown high rates of brain injury in people experiencing homelessness (Hwang et al, 2008; Oddy et al 2012; Topolovec-Vranic et al, 2014). Gauld and colleagues (2011) carried out research into community-based brain injury rehabilitation in the Aboriginal community of Australia. This research highlighted issues surrounding access to treatment due to geographical distance as well as social barriers. This included a reluctance to access services that were provided by individuals who were perceived to lack cultural sensitivity. Further studies have identified high rates of brain injury amongst the prison population (Shiroma et al, 2010, Durand et al, 2017). O'Rourke and colleagues (2018) carried out a small-scale study into TBI and the female prison population. This study found the rate of TBI to be double that of the control group and equivalent to the male population. As it is thought that men have a general increased risk of brain injury, this is particularly revealing and concerning, and suggests a further marginalised group at high risk. These studies suggest that the needs of marginalised groups are not being met by services linked to head injury. The medicalised approach to brain injury therefore appears in need of a greater sociological understanding of brain injury.

2.9 Treatment

Despite attempts to develop universal indicators that establish a brain injury has occurred, homogenizing the experience of injury is problematic. Discussing traumatic brain injury (TBI), Gardner and Zafonte (2016) highlighted that the unique nature of each brain injury makes therapeutic intervention difficult. Whilst this is in reference to what may be considered to be medical treatments, it raises issues to be considered in all areas of brain injury, including brain injury support groups. It suggests that approaches by groups that have a 'one-size-fits-all' approach may risk effectiveness. Maas and colleagues (2017) concluded that "at the bedside, treatment strategies are generally based on guidelines that promote a one-size-fits-all approach and are insufficiently targeted to the needs of individual patients" (2017: 987), which suggests that the pattern of a monolithic approach to brain injury that endures is established at this point.

Despite the advancements made in the last 20 years in treating a TBI, Levin and Diaz-Arrastia (2015) highlighted variance in the clinical guidelines used to implement these advancements between different areas and medical facilities. Interestingly, they also noted an inconsistency in and interchangeable use of the term's 'concussion' and 'mild brain injury'. Whilst a medical professional should be aware of the definition of both terms, it would be revealing to see what difference, if any, it makes to a person if they were told they had received a 'mild brain injury' as opposed to a concussion. This change may help also in areas such as sport or the workplace. If the term 'concussion-management' was changed to 'mild brain injury management' people may regard protocols as being more important to observe.

This is informative to the current research as it would be of interest to see if any appeal for participants for the peer-support group was widened to people who had suffered a concussion and felt they may still be experiencing issues as a result. People who had suffered a concussion appear to be an at-risk group as demonstrated in the literature. It is also a group that may be in some regards unaware. In this respect they may represent another 'hidden' group within the ABI community, who similarly to other groups do not receive adequate support.

2.10 Chapter summary

The medical research illustrates that brain injury is not a static or simplistic entity but one that is dynamic and complex. The initial injury can be devastating and fatal. However, high mortality and morbidity rates continue long beyond the initial injury for reasons not entirely understood. In this respect there is a gap in research and literature. A lack of longitudinal studies has contributed to this gap. Furthermore, issues with the classification and recording of injuries has made this task more difficult. Research into neurotrauma has seen significant increases in funding but is still dwarfed by funding for research for other neurological conditions such as Alzheimer's disease and dementia (Quaglio et al, 2017).

This chapter also raises issues with the language used in the medical literature. Terminology such as 'mortality' rate appear commonly. This scientific and clinical language whose home is found in medical journals, and much of the academy, is perhaps complicit in softening the reality of what the term 'mortality' actually entails. Mortality rates are more sobering when read as 'death rates' (which is used in McMillan et al 2014). Furthermore, the language used to communicate scientific research is a barrier in itself. This makes the take up of scientific research by policymakers more difficult, also partly due to a tendency by scientists to aim to answer a research question as opposed to a specific problem (Quaglio et al, 2015). This indicates that a social science approach that places the experiences of the people living with a brain injury at its core, has the potential to impact policy in a way that neuroscience may be currently struggling.

Exclusion criteria, formal or informal, that dismisses those with more severe levels of injury, or impairments that make data collection more difficult to collect, is present. Whilst on a case by case basis this may be understandable, it represents the potential silencing of many of those affected. This suggests a need to address this lack of input and a need for more participant involvement. At the minimum, this should lead to increased consideration in the methodologies employed in the clinical research of brain injury.

For other chronic conditions such as diabetes, those affected will often maintain regular contact with the health service, which may not be the case for people with brain injury, especially further down the road of recovery. If neurodegeneration is a significant issue, then periodic screening to those who wish to access it would appear to be a logical step. In addition to the treatment and support for the individual, periodic screening could also provide a vital research data set to map brain injury and its evolution over a sustained period of time.

Brain injury should not be viewed as a singularly medical issue. If it is, then measures taken to improve outcomes will be expected to have limited success as soon as a person stops attending hospitals or rehabilitation services. There is clear evidence that a significant reduction in rates of brain injury is possible, and that outcomes, if someone does suffer a brain injury, can be improved. The medical literature, and the knowledge it has historically produced, is vital. However, it is lacking in its understanding of the psychological and social impact of brain injury, and consequently in much of the lived experience of brain injury.

Chapter 3 The sociology of brain injury

3.1 Introduction

Sociology, its methods, and the knowledge it generates, has significant potential to improve the understanding and consequently the lives of people affected by brain injury. This chapter will begin by discussing Bury's (1982) main contribution to the sociological understanding of chronic illness, namely the concept of biographical disruption. As noted by Malcolm and Pullen (2020), "the foundational significance of the concept is illustrated by the assemblage of derivative terms" (2020: 369). Accordingly, the widening of this concept to include biographical repair, abruption (Locock et al, 2009) and flow will also be considered. How this sociological lens can be applied to the understanding of brain injury will also be discussed. The effect of brain injury on mental health, and the societal scale of the increased risk of suicide will also be explored. The role of the family will be addressed, and by doing so the wider impact of a brain injury on the person with the injury, and on those nearby. The potential for a process of ambiguous loss, often poorly managed in society, will also be unpacked to consider if such processes occur. If so, their mismanagement represents a failure from society to fully comprehend the impact of brain injury. The role of gender on the lived experience of brain injury will be illustrated in the cases. Consideration will also be given to areas such as employment after brain injury, structural oppression, and the government's role in this in the form of social security. Finally, this chapter will begin to consider the role of wider societal influences, such as the media, in placing further strain on the lives of disabled people.

3.2 Biographical disruption

Bury (1982) contends that chronic illness is a significant disruptive event. Bury (1982) conceptualises chronic illness as an experience where "the structures of everyday life and the forms of knowledge which underpin them are disrupted" (Bury, 1982: 169). Bury identifies three key aspects of disruption in relation to chronic illness:

> "First, there is the disruption of taken-for-granted assumptions and behaviours; the breaching of common-sense boundaries… Second, there are more profound disruptions in explanatory systems normally used by people, such that a fundamental re-thinking of the person's biography and self-concept is involved. Third, there is the response to disruption involving the mobilisation of resources, in facing an altered situation" (Bury, 1982: 169-170).

Bury (1982) also discusses the impact of timing of the onset of illness. In the case of his study, participants had been diagnosed with arthritis, a condition seen generally as the preserve of the people older than the participants of the study. With brain injury, cognitive impairment (experienced with aging as cognitive decline), and physical impairment can be understood to share these characteristics. Such impairments suddenly experienced perhaps do not represent a "disruption of taken-for-granted assumptions and behaviours" (Bury, 1982: 169), more a shattering of them. It would appear that the further you are from either the age where these impairments are common, or a life where impairment appeared likely, the greater the potential for biographical disruption. Williams (2000) cautions against the assumption of chronic illness equalling biographical disruption by definition, and the failure "to account for a range of other possibilities in which illness may already be a central part of one's biography, either from birth, early childhood or in later life" (Williams, 2000: 60).

Biographical disruption has been found to have a significant, detrimental impact on people with sport-related injury, injuries that in comparison may seem trivial (Malcolm and Pullen, 2020). This is a useful insight to the current study as it suggests that severity of injury is not necessarily a useful indicator as to the biographical impact.

The concept of biographical disruption, and its development can be enhanced by further focus on "the timing, context and circumstances within which illnesses are 'normalised' or problematised' and the manner in which identities are threatened or affirmed" (Williams, 2000: 62). This widening of the lens to include context, and circumstances, allows a more individualised understanding of how a person experiences their chronic illness. Indeed, the concept has been criticised for failing to provide a space for the understanding of the individuality inherent to the experience and treatment of chronic illness (Reeve et al, 2010). This is particularly relevant to the understanding of brain injury given the wide range of impairment encompassed within the term, and the uncertain prognoses which can lead to a situation where the true impact can take time to become apparent. This also suggests that biographical methods are appropriate due to the fact that by enabling the person with the illness to dictate their life story, we are able to analyse how, where, and to what extent the illness features. This should offer glimpses into how chronic illness is normalised and problematised.

Following the initial diagnosis of a brain injury, a secondary diagnosis such as epilepsy may follow. Coupled with an increased risk of poor mental health, and possible links with neurodegenerative conditions, a brain injury may be the catalyst for a series of diagnosis and disruptions. This is an important detail to be considered when carrying out research that involves biographical disruption and repair in people with brain injury. Bury (1982) discussed how a critical feature of chronic illness is the sinister nature of its onset and how “non-communicable diseases do not ‘break out’ they ‘creep-up’” (Bury, 1982: 170). In the case of brain injury, this generally will not be the case. Usually onset is sudden, and diagnosis follows closely after.

The comprehension of the processes and turning points relating to identity change following brain injury was the focus of Muenchberger and colleagues’ (2008) study. This interpretive phenomenological study interviewed six people at six different post-injury time periods from 1-2 years to 25+ years. This study observed an acute process of identity disruption following the injury itself. Identity re-development was found to take place, but this involved processes of contraction and expansion that appeared continuous and where “no final point of resolution was gained, only a sense of tentative equilibrium” (Muenchberger et al, 2008: 988). The authors highlighted that each of the participants had met the majority of the traditional indicators of good outcome such as building relationships and owning their own home; but cautioned that these forms of measurement of outcome and adjustment required careful appraisal.

This suggests that whilst research suggests that many people with brain injury are likely to experience what would be considered poor outcomes, those whose recoveries appear more ‘successful’, may still be negotiating a complex and challenging experience. It again highlights brain injury as being a lifelong, complex, and poorly understood experience. The subjective and highly individualised nature of the injury, and the understanding of personhood would therefore appear to require rehabilitative responses that are flexible and there as required, well beyond the initial period of recovery.

The understanding and experiencing of a diagnosis are complex and socially influenced process. Harris (2009) studied the impact of hepatitis C diagnosis, and the consequent variation in how people understood and experienced their diagnosis. This qualitative study involved a total of 40 people. The single criterion for participation was that a person had received a diagnosis of hepatitis C. The data collection involved in-depth semi-structured interviews. These interviews began with asking about how the person received their diagnosis. This produced a theme of impact, which in turn contained two vastly different responses; ‘devastating’ and ‘no big deal’ (Harris, 2009: 1030). The study considered the relational context of some participants being overall relieved due to the fact that whilst they received a positive hepatitis C diagnosis, they often received a negative HIV (human immunodeficiency viruses) diagnosis at the same time. Among participants who had been diagnosed with both hepatitis C and HIV, a divide was observed. For Marcus, who identified as heterosexual, narrative was dominated by his HIV diagnosis which he previously hadn’t considered a threat to himself given its historic public perception as synonymous with gay, rather than heterosexual, men. On the hand, Luke, who identified as a gay man, framed his HIV diagnosis more positively, in part due to experience of seeing many people live full lives following diagnosis.

This study critiqued the application of Bury’s (1982) concept of biographical disruption on a number of a points. In the Harris (2009) study, the possibilities of pain, suffering and death were not radical departures from the norm but were in fact possibilities many participants already lived with. How community normalisation impacted on biographical disruption and flow (as illustrated in the case of Marcus) further underlines the importance of understanding context; a focus on context that the author suggests is lacking in Bury’s (1982) original study. Bury (1991) does, however, later discuss the importance of context, stating that “experiences are not only influenced by the social context in which the person lives, but by the nature of the symptoms, and their perception by self and others” (Bury, 1991: 454). This suggests that experience of an illness, particularly seeing people’s ability to live with illness in a more positive or successful way, enables biographical reconstruction and flow. It also, however, raises the question of the impact of seeing people who have not, or do not appear to be, adjusted or coping well with their illness. It suggests that those who run support groups for people who have received difficult diagnosis have an onus to explore and encourage biographical reconstruction. Participants also reported a lack of information relating to their diagnosis from medical professionals.

Cases where a medical diagnosis comes long after the injury itself, or does not happen at all, could be a further area of research. The previous studies on marginalised groups (Section 2.8) who self-reported brain injury could be an example of this. It may also be that they undergo an unknown biographical disruption. It would be of interest to see how the process of disruption and possible repair took place in those with a late diagnosis, or no formal diagnosis at all.

Chronic illness in the form of HIV among mothers was also explored through the lens of biographical disruption (Wilson, 2007). This study found that the participants, influenced by their roles as mothers and primary caregivers, did not conceptualise their illness in an individualised manner. The women in the study, and the actions they took, could be considered to constitute and attempt to "limit the effects of their condition on their children, and to protect them from biographical disruption" (Wilson, 2007: 621). Here we see that the participants, despite facing uncertain futures, began to develop and implement strategies that aimed to protect their children from biographical disruption. Given that they are a group who historically have received inadequate support, this individual response may have come from a necessity resultant from society's failure. This is crucial to the current study as it suggests that people who experience chronic illness, particularly those who receive inadequate support, may independently develop strategies that can be shared and used to improve the outcomes of people who experience similar illness or conditions. If we accept that brain injury and the research around it is medicalised, then the utilising of these 'hidden voices' and their understanding and experience has the potential to provide significant 'data'. The context is again important to the understanding of biographical repair and flow. An HIV diagnosis, historically considered to be a death sentence, did not result in biographical abruption. It would appear that the need to care, in the case of the participants of Wilson' (2007) study, for their children, at least in part, enabled a biographical reformulation to occur.

How biographical disruption is experienced in the context of Motor Neurone Disease (MND) was explored in a study by Locock and colleagues (2009). This qualitative study carried out narrative interviews with people living with MND (n=35) and people who had experience of caring for a member of their family with MND (n=11). This study introduced the term 'biographical abruption'. This addition to the concept refers to a situation where the individual considers themselves to be facing a death sentence and a denial of the prospect of any future as they had imagined it. It is separate to biographical disruption due to the fact that,

> "… whereas 'disruption' implies disturbance and unwelcome change, 'abruption' is intended to convey a sudden ending, literally a 'breaking off'" (Locock et al., 2009: 1047).

Abruption was also experienced by the family members in the study as the end of a shared future. The study contained examples of biographical disruption and repair, and how there was in some accounts a to-and-fro between both. This suggests a fluidity to the experience of disruption, for just as people can exit the phase of disruption, it is also possible to re-enter it. This is particularly relevant to conditions that are progressive, but also in the case of conditions such as brain injury, where the effects of impairment may not be immediately apparent. In cases such as brain injury that are not terminal, it would be of interest to ascertain if accounts contain evidence of abruption. Of further interest is the possibility that the person experiencing the illness experiences abruption whilst a family member does not, and vice versa.

The authors also highlight that "we can never be sure how 'real' or enduring repair really is, despite its importance as a narrative strategy to help people with MND cope psychologically" (Locock et al, 2009: 1056). Whilst this is in reference to MND, it is a reminder that chronic illness, and the impact it has on people's lives, is subject to change, a change that continues beyond the initial period following the diagnosis or full realisation of the impact of the illness. This study also enabled people who could not speak to participate by adapting the main data collection method of a traditional spoken interview using a variety of means. This is an example of how research approaches must be flexible and inclusive in order to capture as wide a range of lived experiences as possible.

In cases of stroke, prior knowledge of the injury has been theorised to reduce the impact of the disruption caused (Nasr et al, 2016). The prevalence of brain injury amongst the general population would suggest that people who have a brain injury will often have some degree of experience of it. However, the many terms applied to refer to a brain injury may mean that this is often not apparent. If experience of the condition, particularly positive ones, support a lesser disruption, then it stands to reason that negative experiences may worsen it. Given the often severe outcomes in terms of fatality and impairment resultant from brain injury, the possibility is raised that prior knowledge may also contribute to a worsening of the disruption experienced. This also suggests an issue with the umbrella term of 'acquired brain injury'.

3.3 Life satisfaction

It would appear logical to suggest that the more severe a brain injury, the greater the negative impact on a person's life satisfaction. However, Jones and colleagues (2011) found evidence that contradicted this viewpoint. Respondents answered questions relating to personal identity, changes in social networks and support, life satisfaction and the severity of their injury. The results of this study suggest that the more severe the injury, the higher the levels of life satisfaction. The authors found that

> "… the relationship between injury severity and life satisfaction could be explained by the fact that more severe injuries tended to be associated with the strengthening of both personal identities and social networks post-injury. This suggests that individuals with more severe injuries were more likely than those with less severe injuries to do significant 'identity work' and this accounted for the positive relationship between injury severity and well-being" (Jones et al., 2011: 364).

The more severe the brain injury, the study found, the more likely people were to access resources such as social networks. Such resources, such as group membership are seen as critical in the building of positive identities. This suggests that those with less severe injuries may be at risk of more complex biographical disruption than would appear immediately apparent. Their quantitative study involved 630 participants who were contacted via Headway UK. Respondents had an average age of 45 (M = 44.89), with a range of ages between 9 and 81 years of age. In terms of gender, 61% of participants were male, 38% female, and 1% did not state a gender.

An increase in recent studies on mild brain injury has shown people within this group to be particularly difficult to assess in terms of prognosis and outcome and are considered to be a group that "pose unique challenges, in that the survivor may superficially present as unimpaired, yet experience greater emotional consequences" (Kreutzer et al, 2016: 387). Strategies that engage people with apparently less severe injuries in processes that deal with the negative impacts of brain injury in terms of the impact to self and personal identity appear crucial. It also offers insight as to the poor outcomes faced across the spectrum of severity of injury for people with brain injury.

3.4 Brain injury and the impact on mental health

A person's mental health can represent a secondary area of impact following a brain injury. This area again highlights the possible merging of both neurological and psycho-social elements of the lived experience of brain injury. Teasdale and Engberg (2001) carried out a population study to ascertain the rates of suicide amongst people with a brain injury. This study utilised admissions records from the Danish National Bureau of Health register of hospitalisations, focusing on the period between 1979 and 1993. Data collection involved searching the database for both main and secondary diagnosis of brain injury. This is important as it is an injury which may not be initially apparent, or considered primary, particularly in cases such as road traffic accidents where a crush injury may be the most immediate threat to life. It would be of interest to consider how people who had received their diagnosis of brain injury in this secondary nature, subsequently experienced it, and how this compares to people primarily diagnosed.

The study split its participants into three different groups: *concussion* (n=126,114), *fracture* (n=7560), which referred to a cranial fracture, and *lesion* (n=11,766), which encompasses cerebral contusion and intercranial haemorrhage. The standardised mortality ratios were stratified by sex and age. For the concussion group there was an increase of 3.0 times the general population, for the fracture group an increase of 2.1 the general population, and for the lesion group an increase of 4.1 times the general population. This represents a collective increase in the rate of suicide across the collective group. There is a significant increase for the lesion group in comparison with the concussion and fracture group. This is of particular interest as it demonstrates a difference within the collective group. This suggests that the grouping together of people under the grouped terms, such as ‘acquired brain injury’, may in this respect not be useful. The risk generally was seen to increase with the severity of injury. The research did not identify specific risk periods, instead a constant level of risk was observed over the study period. The authors also highlighted that their findings revealed an increased rate of suicide amongst people who had been diagnosed with concussion, which in general would lead to one day’s hospitalisation for observation. The study concluded that “awareness of a suicide risk should be present in the assessment of any traumatic brain injury” (Teasdale and Engberg, 2001: 440). Given the length, and lack of decrease in the level of risk, there is a clear argument for a continuing awareness of this risk in assessments, and critically, support, for periods that far exceed the traditional periods of consistent interaction a person with a brain injury will typically have with healthcare professionals. This long-term awareness should also apply to support groups.

Is the severity of injury a factor in this relationship? Mainio et al (2007) examined the prevalence of brain injury and explored the relationship between severity of injury, suicide and psychiatric illness. The study was carried out in the Oulu province of Finland between 1998-2004. It used data from the National Hospital Discharge Registers and official death certificates. The study grouped those who had committed suicide after having a brain injury into two categories: concussion and lesion (cerebral contusion and intercranial haemorrhage). The study found that those who had been pre-diagnosed with a psychiatric illness before having a brain injury were at a greater risk of committing suicide. This may be as expected; however, it is a valuable insight. This represents a high-risk group within a high-risk group and treatment and support should consequently reflect this.

The study further showed that people with brain injury were vulnerable to issues with alcohol. In the concussion group, 71% of those who had committed suicide had been ‘diagnosed’ post-brain injury with an ‘alcohol disorder’. In the lesion group, 62% were similarly diagnosed post-injury. The study recommended that psychiatric consultation be built into rehabilitation, and follow-up care for those who present with history of mental illness and issues with alcohol. The study suggests a need to consider both if and why people are drinking following injury, and the need for prevention strategies and support for those affected that are specialised for people with brain injury. It also suggests that the medicalisation of brain injury, with its focus on early recovery neglects this issue.

In terms of ‘significant ongoing emotional problems’, Ponsford and colleagues (2014) found that for people with moderate to severe injuries, in both the younger and older age groups, these problems did not reduce, and that “by and large, problems that were present at two years post-injury were still present at 10 years post-injury” (Ponsford et al., 2014: 75). This suggests a failure in respect to the treating of these significant issues. These ‘problems’ can clearly be disabling in themselves, and the lack of improvement suggests both a neurological role and a lack or failure of support and suitable interventions. This failure amounts to the erecting of a further barrier that makes participation in society more difficult, and carries a potentially serious, and long-lasting cost to people with a brain injury.

3.5 Medical staff’s knowledge of brain injury

As part of a process of improving the knowledge and education of nurses in relation to brain injury, Oyesanya and colleagues (2018) investigated the concerns that nurses held regarding caring for people with moderate to severe brain injury. This study involved a total of 692 nurses and entailed respondents replying to the question “what are your primary concerns about providing care to patients with moderate-to-severe traumatic brain injury?”. Nurses reported a range of concerns that were centred around the care of those in-patients with acute injury. The management of brain injury long-term, and the comorbidities associated, received little attention. This lack of responses in relation to the care of patients dealing with the long-term impact of brain injury, i.e. chronic as opposed to acute,

> "… might imply nurses: (i) are not aware of important areas to take into consideration; (ii) may be aware of important areas to take into consideration but lack knowledge on how to modify the plan of care appropriately; or (iii) may be focused on issues unrelated to the patient's chronic cognitive impairments" (Oyesanya et al., 2018: 1416).

The lack of response relating to the chronic phase of brain injury, the authors propose, is related to the absence of clinical guidelines relating to the management of patients who are not in the acute phase. Whilst a focus on the treatment of those in the acute, and often life-threatening, phase of brain injury is understandable, a failure to consider the long-term impact in acute care is neglectful and adds further evidence when considering the difficulties that people face subsequently. This indicates a need for better management of brain injury as a chronic condition, beginning when in the acute phase, for all concerned to improve outcomes.

Communication difficulties are common following a brain injury. Consequently, the traditional doctor-patient relationship can be understood to be potentially more complex. Improved communication generally between doctors and patients can improve "better health outcomes, higher compliance to therapeutic regimens in patients, higher patient and clinician satisfaction, and a decrease in malpractice risk" (Shukla et al, 2010). This suggests improvements in this area could have a real impact in the treatment of people with brain injury. Furthermore, by increasing collaboration amongst different clinicians involved in a person's care, and training on the impact of brain injury, "the physical, psychological, financial, legal, and social devastation experienced by individuals and families could be greatly minimised" (Landau and Hissett, 2008: 83).

3.6 Information at discharge

Information at the point of discharge is a potentially crucial resource for people with brain injury and their loved ones. The early period following a brain injury is often a traumatic and uncertain time for both the person who has the injury and their immediate support network. The information provided to them at discharge can, therefore, be seen as critical. This provides an early opportunity to both support and educate people at the beginning of what may be a lengthy and inexact rehabilitation process. MacDonald and colleagues (2014) examined the readability of leaflets relating to 'head injury', a regular method of providing information, in Scottish hospital emergency departments. Forty-five leaflets from a total of 30 hospital sites were analysed using the Flesch Reading Index (FRE), a widely used measure of readability, and the Simplified Measure of Gobbledygook (SMOG), a measure selected due to its capability for measuring reading-level accuracy previously employed in the field of medicine. Leaflets were also assessed using the Royal National Institute for the Blind (RNIB) 'Clear Print Guidelines'. FRE scores estimated that 30% of the population were likely to be able to understand over 90% of the leaflets measured. The SMOG measures were above the recommended levels for health literature in all the leaflets measured. In terms of the RNIB guidelines, the compliance rate was 78%. Furthermore, leaflets were assessed for compliance to The Scottish Intercollegiate Guidelines Network (SIGN 46) guidelines on the early management of a person 'head' injury'. Twenty-four of the 45 leaflets scored below 50% compliance with none measuring in the 90-100% range. These leaflets were produced at a level above the general education level of those expected to access them. This represents a site of failure at a crucial time when most people's recovery is beginning, and cognition may be impaired. It is also of note that the authors, discussing how patient information leaflets are written 'to' those with a university level education, underlining that "those for head injury in Scotland are no exception" (MacDonald et al., 2010: 281).

Production and reproduction dates are often not found on leaflets, which makes it unclear whether information contained is current or out of date (Kempe et al 2014; MacDonald et al., 2010). This could have potentially serious consequences if out of date information is followed. One example being that of the assessment of brain injury and subsequent action taken in sports, otherwise known as concussion protocols. The variation in the standard of written health information given to people with a brain injury at the time of discharge indicates the need for standardised measures to which publications adhere (Kempe et al, 2014).

It is unclear how accessible these leaflets are for the people who have had the injury itself. Whilst a 'one size fits all' approach to those with cognitive impairment would be inappropriate, efforts to make the information accessible to all is crucial. If information is held by family members and those providing care, access can be understood to be potentially restricted. This fits neatly within historic trends of restriction and inequality faced by disabled people. The potential contribution of this denial of knowledge, which is readily available in the medical and academic world, to the often-dire outcomes faced, represents a form of structural violence.

Choudhry and colleagues (2019) carried out a prospective observational study aimed at investigating the readability of hospital discharge summaries for patients with a brain injury, and whether this would decrease patient readmission and phone calls relating to the injury. This study involved 1072 patients, broadly similar in terms of demographic split pre-intervention (n=493, 46%) and post-intervention (n=579, 54%), at a trauma centre in Minnesota. Despite the post-intervention group having a higher proportion of severe brain injuries with longer hospital stays, there was a significant reduction in both readmission (within 30 days) and phone calls (within 30 days) relating to their injury. This decrease was connected to an increase in patient autonomy and improved care, linked to an increased understanding at the time of discharge of the medical information provided. In particular, the study evidenced a ‘remarkable’ reduction in calls relating to pain management, despite no change in prescription procedures or policy. The study suggests that this has particular implications beyond the primary benefit in countries such the United States that have issues with opioid over-prescription and addiction. It is critical that areas such as discharge are examined, as in many regards they represent critical early steps in the journey that people take post-brain injury. It may also represent one of the first steps where the process of recovery begins to falter or fail.

3.7 The experience of the family in the early stages

Family members are the group most likely to provide long-term care following a brain injury, and often adopt additional roles and responsibilities in the often-misplaced assumption that the situation will be resolved in the short-term (Kreutzer et al., 2016). Whiffin and colleagues (2017) aimed to investigate the effect of a brain injury on the family members in the first-year post-injury. The perception of how the person injured had changed, but also, how they themselves had changed, was investigated. This qualitative study involved nine people from three families who had all had a family member who had sustained a brain injury and been admitted to a neuro-intensive ward.

Each participant took part in three unstructured interviews at time periods of one, three, and six months. Narrative analysis identified four narrative structures used by the participants:

biographical attendance, biographical disruption, biographical continuity, and biographical reconstruction. Biographical attendance emerged in the early accounts and involved family members looking for hints or character traits, exemplified by the injured person displaying familiar physical or character traits. This enabled a connection between the past and present self or person to be made, and indicated the possibility of recovery, despite the early stage and unclear prognosis.

Biographical disruption was illustrated in how changes in self and the impact on family life and their social world had been affected. The perspectives of the families and the process of biographical disruption is particularly complex as the brain injury created “changes that were sometimes unquantifiable” (Whiffin et al, 2017). Biographical continuity was illustrated in the participants’ accounts, with a return to work being viewed as a particular milestone and barometer of recovery. It would have been of interest to see the accounts of those with the injury at this time in order to compare if that was their own perception, or if the families’ view was clouded by a desire for the ‘intact’ return of their loved one.

Biographical reconstruction was a process that involved both the injured person and participants’ sense of self. Reconstruction was complicated as participants continued to experience emotional distress and difficulty throughout the year. This would appear to suggest that reconstruction is a long process that may require repetitive renewal. Previous ambitions that were unlikely to be realised by the injured person, were shown to also have been part of the wider family identity. Shared experience and narrative were critical to family unity. On the contrary when families shared experiences and spaces, but had contrasting or plainly different interpretations of these, narrative misalignment, was shown to create feelings of isolation which “emphasised the division within families and illustrated how the family could be pulling apart” (Whiffin et al, 2017: 11).

Family members and loved ones will often be present when a person is receiving critical care following a brain injury. Kean (2010), using a constructivist grounded theory approach investigated the experience of having a family member in an Intensive Care Unit (ICU) following a brain injury, and found evidence of ambiguous loss. This involved focus groups with nine families, five of which had experienced ambiguous loss. At the time of the interview, the lengths of stay in ICU ranged between seven days to three weeks for the families that experienced ambiguous loss. This suggests that this loss can begin to be experienced, and consequently have an impact, in close proximity to the injury itself. Whilst the need for long-term support is apparent, this indicates that processes should be in place also in the short-term. The spectre of the loss of the ‘essence’ of the person was raised and “it is the ongoing nature of the loss and the uncertainty as to what has been lost of a person’s ‘essence’ that have an impact on families and individuals within families’ futures” (Kean, 2010: 72). The change in this ‘essence’, coupled with the ‘identity ambiguity’ that families perceived to have taken place was experienced as an ambiguous loss. Ambiguous loss, Kean (2010) contends, can be seen, therefore, to be contributing to a breakdown of relationships within the family and of the family itself. Whilst the family is presented as a unit, the different implications for each, depending on their position within the family, emerged. The possibility of becoming a carer appeared more likely for the mothers who took part in the study, which highlights again the social-gendered influence. This supports the use of sociological approaches with which to explore and understand this area.

The effects of a brain injury can be delayed and become more apparent over time (Rolland, 2017). This further complicates the role of family as their role as carers may become more complex, rather than less, as time goes on. The increased risk of neurological conditions such as dementia and Parkinson’s disease (Gardner et al 2014; Gardner et al, 2015) further raises prospect of a potentially uncertain, long-term aspect to the care required, of which those involved may be unaware of. This further underlines the need for long-term, accessible support, which gives consideration to both, and, indeed, the possible progressive, nature of brain injury.

3.8 The role of GPs

General Practitioners (GPs) have a central role to play in respect to the long-term support of people with a brain injury, and specifically in relation to suicide prevention (Simpson and Tate, 2007). This is reliant on a person accessing their GP, and also feeling comfortable discussing such an issue, and crucially that their GP is empathetic to their situation. The power dynamic of this relationship adds a further level of complication to this. A GP often acts as a gatekeeper to a wide-ranging number of services. They will often provide sick-lines that may be essential in an employment and financial respect. They may provide pain medication, decide who to refer to additional services such as counselling or psychiatry. Furthermore, they are perceived to hold a privileged position of authority and respect, which may prevent equal engagement on level terms. Finally, their knowledge of brain injury may be limited and out of date. Here again, the spectre of medicalisation looms large. It suggests that support is needed for all to navigate this area. Simpson and Tate (2007) suggest that a valuable contribution to suicide prevention can be made by GPs, families, and community brain injury services working together. This may require recognition of each stakeholder as an equal, as opposed to what is arguably a hierarchical and unequal current state of play.

3.9 Navigating rehabilitation

Given the often life-long impact of brain injury, and the possibility of sustained recovery and improvement, the navigation of rehabilitation services is an area of interest. Graff and colleagues (2018) investigated the navigation of rehabilitation in adults with brain injury from the point of discharge up to four years post-injury. This qualitative study, based in Denmark, utilised in-depth, semi-structured interviews with 20 participants who had sustained mild-severe brain injuries, focusing on the lived experience of the people who had sustained the injury. Three main themes emerged from the data: ‘a new life’, ‘family involvement’, and ‘rehabilitation involvement’. Evidenced under the theme of ‘a new life’ existed evidence of positive growth. Participants reported a new appreciation of family, and a new perspective to live life to the full. The injury had altered the normal trajectory or expected biographical path of the participants, and caused a biographical disruption, yet life goals were still being met and plans being revised from which new roles emerged. The burden of emotional support emerged as being a significant issue under the ‘family involvement’ theme. Participants further reported dependency on family members to be responsible to coordinate their care and contact with the healthcare and insurance organisations involved, though the role of family members was reported positively in this respect.

This reliance on family members does highlight serious issues in such a process. It creates a situation where the competency of the family members charged with navigating these often-complex systems will have a direct impact on the support a person receives, and theoretically also an impact on their recovery and future outcomes. The process may remove people from an active role in directing their own care and, critically, is one on which the goodwill of all parties is required. This final requirement suggests it is a process that is open to a lack of participation for the person who has sustained a brain injury.

The ‘rehabilitation impediments’ section of the study by Graff and colleagues (2018) highlighted the difficulty participants faced in navigating the rehabilitations by themselves.

Participants with a mild brain injury were particularly vulnerable in this regard as those with more severe injuries are likely to receive more intensive and long-term treatment. Once again this underlines the need for approaches that are specialised to the individual, and encompass the unique challenges faced by people with a mild brain injury. A lack of age-appropriate services in one case resulted in a young woman being placed in a nursing home. This resulted in a socially constructed barrier to her meeting people her own age and resulted in her living a life that bore no similarity to that of her peers.

Participants in the study reflected on the need for better coordination of services, specifically the need for the creation of a specific role to better achieve this, and to have someone assigned to it. A lack of clarity as to who was responsible for this coordination created a situation where,

> "The responsibility to initiate rehabilitation was unclear. In cases of uncertainty the family often took over, albeit they were unprepared for the task" (Graff et al, 2018: 931).

The study also discussed the role in the Danish system of General Practitioners (GPs) acting as gatekeepers for referral. If it has been established that the person has a brain injury, when possible, the option to self-refer to what the individual believes is required, seems logical. The impact of a brain injury can result in a loss of autonomy, and at times dignity, in all areas of a person's life. A move towards a model of greater autonomy for individuals to access care that they deem necessary, at the correct time, would appear appropriate and needed.

3.10 Impact on mental health of family/support network

The impact on family members' mental health is an area of concern. Calvete and de Arroyabe (2012) investigated associations between social support, coping response, depression, and grief amongst family members that cared for people with brain injury. This cross-sectional quantitative study based in Spain involved a total of 223 participants, 72.2% of whom were female and 26.9% male. Participants were members of the Spanish Federation of Acquired Brain Damage (FEDACE), a non-governmental organisation supporting people with brain injury and their families. The study found 28.5% of participants' responses indicated that they suffered from severe depression. Emotional support and instrumental support (support from family members that enabled them to meet their own needs, see friends, and have ‘breathing space’) were found to be associated with decreased rates of depression. Whilst this finding may seem unsurprising, it points to the need for formal structures of support. This is further supported by the positive association found in the data between involvement in caring for someone with a brain injury and depression and grief.

The high rate of female primary carers (72.2%) is consistent with the gendered nature of ‘caring’ and domestic labour in western societies coupled with the increased rates of men who sustain a brain injury (Calvete and de Arroyabe, 2012). It does, however, highlight that frameworks or support systems develop approaches that recognise how caring for someone, coupled with the intersectional discrimination faced by women in society, is experienced.

The possible negative psychological impact is also a potential issue for the medical staff who treat people with severe brain injury. Harvey and colleagues (2018) discussed the clinical management of ‘devastating’ brain injury. The concept refers to the situation where initial assessment at the time of admission reports a person as having an immediate threat to life. It can also refer to a situation where limited recovery is likely and where consideration is being given to limiting or withdrawing treatment. The authors suggested the possible need for psychological support for the staff who work in such environments. This may be of similar benefit to people working more widely in brain injury. The psychological toll of working in this field currently remains unclear.

3.11 Ambiguous Loss Theory

Ambiguous loss, and its impact on families, after brain injury has received relatively little academic attention; however, studies that have explored this area found evidence that indicates that ambiguous loss is experienced consistently by those who have the injury, and their families (Kreutzer et al, 2016: 388).

Ambiguous loss theory has two conceptual forms. The first where a person is physically missing but remains psychologically present. This could be for example a family member who has disappeared. Secondly it can be seen in cases such as brain injury where someone can be physically present but is psychologically ‘absent’, or in other neurological conditions such as Alzheimer’s (Kreutzer et al., 2016; Kean, 2016). It is this second type of loss which is relevant to the current study. The theory offers the possibility to better understand the family, which is in many respects the central field, and the area from which much of the accessing of resources will originate. Furthermore, the success of the family in holistic terms could be considered to be critical to the outcomes that people with brain injury face. The basis of ambiguous loss theory “is that uncertainty or a lack of information about the whereabouts or status of a loved one as absent or present, as dead or alive, is traumatizing for most individuals, couples, and families” (Boss, 2007: 105).

The absence of a complete picture ensures that the meaning attached to what has caused the feelings of ambiguous loss and grief are subject to change over time (Boss and Carnes, 2012). This suggests that the disruption that caused the ‘ambiguous loss’ requires management as opposed to a focus on a ‘cure’ or ultimate resolution. Ambiguous loss can develop more rapidly in those with more severe injuries, which suggests a need for individualised timing with regards to interventions designed to support people experiencing such ‘loss’ (Kreutzer et al., 2016). Strategies to live with loss are considered a more suitable therapeutic aim as opposed to attempts to ‘get over it’ (Boss and Carnes, 2012). Indeed, ambiguous loss rejects the possibility of closure but maintains the possibility of meaning being “found in situations that defy resolution by focusing on resilience, not just pathology” (Kreutzer et al., 2016: 390).

Four distinct categories of ambiguous loss have been identified specifically in relation to relationships following brain injury: ‘the loss of you, me, us’; ‘the loss of security’; ‘the loss of connectivity’; and ‘the loss of future’ (Godwin et al, 2014: 402). Within the ‘the loss of you, me, us’ category, issues around a loss of self, and an inability to label the subsequent grief, were prominent. A longing for the person that had been was complicated by the lack of validation “without a death certificate, divorce decree or the compassion usually provided by others in times of grief” (Godwin et al, 2014: 403). The influence of cultural and social norms and behaviours is evident. The support provided in terms of cultural processes, such as a funeral, are absent, and with it the compassion offered from others and the possibility of closure. The mention of death certificates and divorce decrees also indicate that within cold, bureaucratic processes, a comfort and closure can be achieved.

‘The loss of security’ category referred to the loss of the previously assumed benefit of security derived from being in a relationship. This referred to a wide range of areas from emotional stability to financial matters. A frequent feeling of being trapped and insecure simultaneously was evidenced. The loss of connectivity was identified as a particularly significant type of ambiguous loss. An inability to connect emotionally left partners vulnerable to feeling alone to face the future. The yearning to reconnect "dominated narratives, muddled by the confusion of being unable to mourn a lost relationship and the support that it provided" (Godwin et al, 2014: 404). This illustrates the complexity and difficulty entailed from grieving for someone that is still physically there, and a relationship that continues in a sense.

The fourth category referred to 'the loss of future'. The conflict between the feeling that the planned or idealised future, previously assumed, had been lost, yet still existed. This left individuals "feeling as if they were standing on quicksand with only the certainty that future plans will not be the same" (Godwin et al., 2014: 404). This indicates that the biographical disruption that is experienced is one that can be particularly complex. Furthermore, the aspect of a shared future that is lost contains the possibility that the disruption may be shared, but also individualised depending on a range of factors such as the impact of the injury cognitively, physically, and mentally on both partners; the access to resources such as rehabilitation, support from social networks, and crucially economic resources. Medicalised approaches do not appear to offer holistic approaches to such issues.

In regard to the clinical treatment of ambiguous loss, Boss and Carnes (2012) discuss the aim of adopting a different narrative that is less focused on negative feelings such as "guilt, shame, remorse, or desire for retribution" (2012: 466). With brain injury, the environment where this adoption is desired is a complex and difficult one. Clinical approaches to ambiguous loss are complicated by the harsh reality that "paradoxically, what we hope for is motivation for personal change despite having a problem that resists change" (Ibid: 466).

The 'problem' in the case of brain injury, is one that is often poorly understood by all involved. Consequently, the theory of ambiguous loss can be understood as offering both a better understanding, and a possible tool with which to better support people with brain injury, and those around them, to process and manage the effects of the injury.

Kreutzer and colleagues (2016), drawing on extensive clinical experience and the results of a literature review, suggested the need for mental health services that engage people with brain injury to be aware of ambiguous loss theory. Furthermore, they stressed the principles of ambiguous loss theory are integrated into the assessment and treatment of families. One issue with this approach is that if it is accepted that many people 'fall into the cracks' of the system following a brain injury, such initiatives may fail to reach those that need them.

Especially if there is a time component to the full realisation of the issue, giving the tendency for people to no longer access medical services after an often-short period of time. This suggests a role for services that interact with people that are based within the community and are more likely to be consistently accessible.

How brain injury affects the relationships of those in a previously established relationship is another complex and emotive area of the lived experience. Godwin and colleagues (2014) applied a grounded theory approach to explore the impact on coupled relationships following a brain injury. This qualitative study involved a data set that included 29 blog entries, six previously published memoirs and five reported narratives. These combined accounts from the perspective of both the person with the injury and their partner/caregiver. In addition to this, five medically authored pieces (four written blogs and a transcribed video-blog) on subjects relating to brain injury and the impact on marriage and relationships were also included. The medically authored pieces were included due to a lack of empirical data on the subject, and also in an attempt to triangulate the data and to aid the substantiation of any theories that emerged. The study identified a new theory of ‘relational coring’. This theory identifies that brain injury:

> “deconstructs relationships through the intersection of ambiguous losses, identity reformations and tenuous stability and, for couples who remain together and engaged in their relationship with one another, these experiences are filtered through ‘Non Omnes Moriar’—the threads of retained couplehood which a couple are able to identify and hold on to” (Godwin et al, 2014: 410).

The themes of ambiguous loss, identity reformation and tenuous stability are the elements contained within the process of ‘coring’, which in turn removes much of the substance of the relationship, with ‘Non Omnes Moriar’ being the shell or exterior that, without attention and a process of reconstruction, are a reduction of what previously existed. The treatment or healing process that was identified in this study was termed ‘relational recycling’. This delicate process involved the creation of a reconstructed identity, ‘The new us’. This involved a ‘recycled’ mix of the broken pieces of the old relationship which were then reformed, with which to fill the gap or core created by the impact of the brain injury. By understanding these processes, the authors suggest an opening by which to understand what happens to couples following a brain injury which in turn can be applied to support relational healing. Again, it is unclear what support, if any, is offered to people with brain injury and their partners.

3.12 Gender

Gender is particularly relevant in the case of brain injury. It is in an injury that affects more men than women. This, in combination with the patriarchal nature of society, suggests that brain injury is an area where the voices of women are in danger of being minimised or silenced. Morris (1991) highlighted that within both political movements generally and the disability movement in Britain, positions of power in relation to theory and powerful positions within organisations have tended to be held by men. Methods that enable the voice of participants to come to the fore, and that aim to not direct the discussion, appear particularly relevant.

Such methods are evidenced in Ivany and colleagues' (2018) qualitative study which investigated how women that experience intimate partner violence (IPV) are affected by brain injury. Nineteen women aged between 18-44 were involved in the study, with a total of 41 interviews analysed. This study aimed to investigate how a brain injury experienced as a result of IPV impacted on the participants' lives and relationships. The participants in the study discussed experiencing what the authors highlighted as being examples of structural violence from health and legal services. This stemmed from a lack of trust owing at least in part to previous experiences. The impact of their experience of brain injury and IPV could be seen in how "they calculated their risk of death in daily interactions and disclosed facing mortality in a very concrete way" (Ivany et al, 2018: 175). How a person came to have a brain injury is clearly important when decisions as how to best treat and support them is decided. An approach that encompasses the social impact, as in these cases and many it is where the injury originates, appears crucial. Self-reporting of brain injury, as utilised in this study, appears to be a useful method of data collection, particularly in relation to vulnerable or minority groups.

The findings reported frustration around the lack of screening for brain injury at the point of admission to a women's shelter, and an overall lack of overlapping resources. Given the negative experiences and reported inadequate support from traditional agencies, it would seem that community support groups would be well placed to offer support to women affected and the groups who currently work in the field. This again underlines the central issue with a medicalised approach to brain injury: it does not encompass the complex nature of life following or leading to a brain injury. This approach also appears to fail particularly those who are not visible, or those that are vulnerable, marginalised and poorly served by society.

Much of the literature discusses the need for preventative measures to reduce rates of brain injury. In this case, the direct cause is male violence against women. This represents a group that would be expected to be grossly underrepresented in any official data. It also indicates a need to apply qualitative methods, particularly in cases where the voice or perspective has been hidden by structural forces and violence. In Scotland, violence was found to be the most common cause of admission to hospital with a brain injury for young adult men (Shivaji et al 2014), though the true figure of brain injury caused by violence amongst this group can be expected to be higher. The reasons behind someone committing an act of violence are multifaceted. However, the tendency for these acts to be committed by men suggests a need for preventative measures that target them specifically, and long before the ages that they start to commit them.

The lack of literature in relation specifically to how women experience brain injury was highlighted in a narrative literature review carried out by O'Reilly and colleagues (2018). This study reviewed 36 papers and highlighted five main themes: relationship and life satisfaction; perception of self and body image; meaningful occupation; sexuality and sexual health; and physical function. This review highlighted that despite a history of previous research in the social sciences that studied how women perceive themselves in the social worlds they inhabit, "how women perceive themselves following TBI and adjust to a new normal is insufficiently researched to adequately understand the lived experience of this population" (O'Reilly et al, 2018: 2340). Qualitative biographical methods may be well positioned to access and amplify the voices of this marginalised group to highlight and expand the issues they face, and consequently guide future research in the area. This is particularly the case in light of the lack of the adoption of people's narratives and their sense of self as therapeutic tools within healthcare responses to brain injury in the UK (Mäkelä, 2017).

3.13 The role of biography and space in disruption and repair

The spaces people occupy, and any changes following an event such as a brain injury, offer clues as to how people live their lives, and how such events may have changed them. Meijering and colleagues (2019) examined bio-geo-graphical disruption and flow after a brain injury. This study intended to comprehend how people with a brain injury “renegotiate their engagements with everyday places, in terms of bio-geo-graphical disruption and flow” (Meijering et al, 2019: 28). This study carried out interviews and a place-mapping exercise. This study involved 18 people (female=9, male=9) and their ‘significant others’. Participants were aged between 30 and 75 and lived in the Netherlands. The study found that accounts were not dominated by disruption or flow but evidenced a more nuanced and intertwined process. Access to previous spaces, and acceptance that some places were no longer reachable or easy to use, was crucial to their recovery or repair. The authors highlighted the interplay between places, and how they exemplified flow and disruption. They discussed one example of how a living room can represent an area to socialise, and how a smaller room elsewhere can represent a place to withdraw, if, for example, the person was to feel unwell. An understanding of place, and strategies that utilise them, are clearly of benefit to both the knowledge of how people with a brain injury live, and how this understanding can be applied to improve lives. This underlines how much of the experience of brain injury is reliant on access to resources; resources to access different spaces, resources in respect to rehabilitation, resources in respect to family or significant others, and, ever looming, resources in economic terms. The participants could not necessary do all the things they did pre-injury and faced choices such as whether a person wanted a good family life or a good working life. This weighing up, and restrictions imposed, can result in what has been described as situations where “the erstwhile taken-for-granted world of everyday life becomes a burden of conscious and deliberate action” (Bury, 1982: 176). The medicalisation of brain injury encourages a tendency for all involved to focus on the injury and the resultant impairment. The study by Meijering and colleagues (2019) encourages a rehabilitative approach that focuses more on meaningful places than the body itself, and also highlights where community (re)integration may be difficult. This focus on living environment is crucial in terms of disruption and repair as it is ultimately this environment that the people return and “it is to this living environment that ABI survivors need to feel physically, affectively, cognitively, and socially bonded again” (Meijering et al, 2019: 29).

Participants were interviewed alongside their ‘significant other’. Whilst this may be for support, it was unclear whether the option was there for people to take part in an interview without their ‘significant other’. If they are reliant on this other person, particularly in getting around, then it may have been difficult to express their feelings on the subject in the company of that person. It would have also been of interest to see points of divergence between two accounts that were gathered separately. This study also highlights the critical, and often forgotten role of those who support and help to care for people with a brain injury.

It would be of interest to apply a similar study to young people with a brain injury, as they are known to inhabit different spaces. It may also be that the spaces they occupy following injury are less accessible, functionally or psychologically, following their injury. If rehabilitation is directed by older people, there may be a tendency to underestimate the importance of these spaces in terms of biographical repair and the self and identity. This has clear potential to provide greater understanding of how people with a brain injury navigate their lives and participate, or are limited to participate, in society.

Physical activity levels following a brain injury are often low. Analytis and colleagues (2018) found that a person's level of physical activity and habits after having a brain injury were linked to their previous activity level. It also suggested that an individualised approach that considers lifelong habits, would be most successful. This is a reminder that brain injury does not create a person, and that the life someone lived before, and its understanding, is critical in their recovery. It also further reinforces the need for approaches that are individualised, not only because a brain injury is an injury that is very specific to the individual, but also because people's lives before and after can be understood as being so also. Access to physical activity in the form of gyms and sports clubs may also carry an economic cost, a factor worthy of further consideration, particularly in respect to individuals who are subject to structurally enforced economic hardship. This has public health and economic implications, as a physically healthier community could be expected to also be one with better mental health, and consequently require medical services less frequently overall.

3.14 Employment

Brain injury can have a significant impact on employment. The reasoning for stretches beyond the neurological impact of the injury itself and can be seen to be a complex interplay of both medical and sociological factors. Cuthbert and colleagues' (2015) study aimed to describe the employment patterns of people with moderate to severe brain injury over a 10-year period. This study focussed on people aged between 16 and 55 who had received inpatient rehabilitation between 1989 and 2009. The longitudinal study took place in the USA and involved a relatively large number of participants (n=3618), all of whom completed at least 3 follow-up interviews at intervals of 1, 2, 5, and 10 years post-injury. Factors such as pre-injury education level, age, and gender were found to be covariates of employment rate. The authors highlighted that in the years immediately following a brain injury, people appear to experience improvement in terms of their recovery and community reintegration. This is not a pattern that was necessarily seen to continue as the study found that:

> "this recovery appears to peak by 5 years postinjury, at which time these individuals appear to regress, and in some instance even experience worse outcomes than immediately after postinjury" (Cuthbert et al, 2015: 2134).

These findings were supported by a further study that specifically assessed mild brain injury and employment four years post-injury (Theadom et al, 2017). This study, based in New Zealand, found similar long-term issues in relation to unemployment, work limitations and productivity loss. This further adds to the evidence suggesting that brain injury, rather than being an injury that stabilises after a recovery period, displays elements of an evolving, chronic injury that develops long after the initial injury occurs. There are biological elements that may be resultant of this, such as neurodegeneration. There are psychological factors such as dealing with evolving feelings of loss of self and identity; also, social factors. People appear likely to experience a collection of these constituent parts. This provides further evidence of a need for sustained long-term support for people with a brain injury.

Previous studies have found patterns of moving in and out of employment following injury (Ponsford et al, 2014). How a culture of zero-hours contracts and precarious working conditions and the need for employee so-called 'flexibility' impacts on an individual with a brain injury, and whether it raises additional barriers to employment and participation in society, would be of interest. A return to employment is a significant step in terms of a measure of recovery. A greater understanding of people who have managed to return to employment following injury would be beneficial to understand the factors that contributed to this form of reintegration.

3.15 Return to work

The application of specific sociological lenses and insight is a valuable tool in the understanding of the lived experience of brain injury. Stergiou-Kita and colleagues (2017) explored gender influences on people returning to work after a brain injury. This small-scale study (n=12; females, n= 6, males, n=6) focussed on people whose injury had specifically occurred in the workplace. Amongst the participants, women were more likely to discuss work limitations faced after their brain injury with their employers and to seek support in terms of rehabilitation. Workplaces that were viewed as being 'nurturing' were seen as more supportive environments as opposed to the more unsupportive environment of "traditionally male-dominated, masculinized workplace cultures" (Stergiou-Kita et al., 2017: S44). Whilst this was a small-scale study, it is revealing of the possible negative effects of gender roles on recovery following a brain injury. This is also suggestive of economic environments presenting a further barrier to rehabilitation and reintegration following brain injury.

Research that focuses on the same area of interest, but comes from a different point of enquiry further reveals the societal impact on lived experience following brain injury. Arango-Lasprilla and colleagues (2009) carried out a study that investigated job stability following brain injury amongst ethnic minority groups in the USA. Data was drawn from 633 people with a moderate to severe brain injury who had received acute care and rehabilitation. Following adjustment for covariates, those identified as coming from an ethnic minority group were found to be 2-3.5 times more likely to be unemployed, or in precarious or unsteady employment. This study had clear, and acknowledged, limitations. One aspect being the grouping of the ethnic minority group as one homogenous group. However, the results suggest that the experience of employment can be particularly difficult for people with a brain injury who are part of an ethnic minority group. This again underlines how the social is intrinsically entwined with the outcomes, negative or otherwise, that people experience following brain injury.

Chien and colleagues (2017) investigated five injury severity measures and their value in predicting a return to work. Of those who did not return to work after their injury, higher rates of factors such as chronic conditions, cognitive impairment, posttraumatic seizures and symptoms of depression were observed. Within this study the variable of 'autonomy in transportation' was measured. Amongst the participants (n= 207), those who had 'autonomy in transportation' were 2.55 times more likely to be employed after a brain injury than those who did not. Whilst a lower rate of return to work may be expected with more complex or severe injuries, the link to autonomy of transport is revealing. This is an example of a social, and potentially also economic, barrier, which if addressed would offer potential of greater levels of return to work. It also raises the serious issue of how people with brain injury then access other spaces. Transport may then be understood to be a barrier to participation in multiple areas of life.

In Britain, benefits exist, ostensibly, that are designed to reduce the additional financial burden experienced as a result of living is a disabling society. How this relates to biographical disruption and possible reconstruction was the focus of Sveen and colleagues' (2016) study. Their study aimed to explore brain injury, in this case mild traumatic brain injury, in relation to biographical disruption and the process of reconstruction in respect to everyday life and employment. This study, set in Norway used seven focus groups involving a total of 20 people (female = 12, male = 8). In respect to daily activities, the greater effort required to plan these activities came at a cost to other areas such as family and social life. Impairments that are 'invisible' were considered burdensome, particularly in regard to the difficulty of those closest to understand what they cannot see. Positive reconstruction was evidenced. The injury was found to act as a catalyst for some to re-evaluate their lives, and the desire to not let work dominate as it had before. Respondents reported having little support to navigate the difficult process of identity change. Good relationships with employers, unsurprisingly, had a positive effect. This is an issue, as it then becomes reliant on the goodwill of individuals, as opposed to robust employment rights and suitable rehabilitation methods. A person's life prior to their injury was used as a reference to their current situation, and greater distress appeared to be undergone by those who focused more on the past.

3.16 Social (in)security

> "Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing" (Thomas, 1999: 60).

Recent changes to the benefits system in the United Kingdom have been a site of significant controversy. This section will not go into the framework of social security system but will examine the difficulties in accessing payments. Whilst academic research is still forthcoming at this stage, the initial information relating to the rollout of Universal Credit are indeed shocking and of great concern. Gateshead Council (2018) carried out a qualitative study that aimed to assess the impact of the change to Universal Credit (UC). This study involved interviews and focus groups with UC claimants (n=33) and people who worked for a range of local services (n=33) that provide support and welfare rights advice. Staff working for Gateshead Housing Associations reported that following UC roll out, rent arrears increased an average of 114% per person, fuel poverty support requests increased by 144%, and food bank support increased by 274%. Staff reported one week where five people claiming Universal Credit informed them of their intention to commit suicide due the financial situation they now found themselves in. Around the time of these reported increases, staff began to receive suicide prevention training. The study found that in key areas, Universal Credit is failing. It was not found to be meeting its key aims of simplifying the benefit system or encouraging people into work. In addition, it had negative impacts on housing, poverty and inequalities, and people's health. It was also placing additional burdens on wider services.

One methodological limitation observed in this study is the use of the term 'claimant' and a number in place of a name as a pseudonym. Staff were referred to as 'staff'. It is unclear if respondents were offered the option of using a pseudonym. By choosing a pseudonym, participants have a degree of ownership which can be beneficial for both the participant and the process and content of the research project (Allen and Wiles, 2016). It also offers a sense of dignity, a dignity that may have been compromised by having to navigate the UC system, and the negative outcomes evidenced in this process. This may also imply a hierarchy within the responses as it is presented as 'claimant' and 'staff'; a hierarchy that could have been limited by using real (still anonymised) names.

Other recent changes have also been troubling and suggestive of a targeted and hostile environment for disabled people. Davies and colleagues (2017) investigated how people with sensory impairments experienced the move from Disability Living Allowance (DLA) to Personal Independence Payment (PIP). This study involved interviews with 53 people with a visual impairment or dual sensory loss. In addition, the study also carried out a secondary analysis of DWP administration data relating to the number of people within this group who were moving to PIP from DLA. This study found the application process for PIP to be inaccessible, and support was needed to complete the process. In terms of the assessors themselves, some of the participants found that:

> "… assessors were insensitive about their sensory impairment, dismissive of experiences of their living conditions, and overall had limited knowledge of sensory impairments and how they affected participants' lives" (Davies et al., 2017: 55).

The authors highlighted that by having to ask others for support, taking part in the process made some participants feel less independent. Furthermore, participants highlighted a fear that appearing independent could potentially make their claim ineligible. Those who did demonstrate independence in their initial applications received ‘negative’ outcomes, which became positive on appeal. As the authors caution, this is just the data of one piece of research. However, it is of interest to consider if this is the case more widely, and what impact this has on an individual. It suggests that a narrative of weakness and dependence is necessary at least in certain areas, in order to claim benefits. By creating a system which may necessitate weakness and dependence, the government can be seen as structurally enforcing it.

A study conducted by the Citizen’s Advice Bureau (2017) analysed the impact of Universal Credit (UC) in East Lothian, the first Local Authority area in Scotland to roll-out the benefit. The study found that of the 134 clients analysed, 52% would see a median loss of £44.72 per week. The 31% of clients who stood to gain from UC had a median gain of just £0.34 per week. This suggests that the stakes are being raised and the need to be able to successfully navigate this system, and the difficulty in successfully achieving this, has increased. These examples of accessing social security raise concerns as to the realising of the right to an adequate standard of living, in addition to the presentation of social security as a negative reference point of past and future biography.

3.17 Media influence

If it is the government that enact these policies, how is this reflected in the media? Briant and colleagues (2011) carried out a study to explore how media reporting towards disabled people had changed, and how this had influenced attitudes towards disabled people from the general public. The media analysis compared two periods: 2004-5 during the Blair led Labour government, and 2010-11 Conservative/Liberal Democrat Coalition Government. Additionally, focus groups and interviews provided qualitative data. The study found an increase in negative reporting during the latter period. This included a reduction in empathetic or sympathetic stories and an increase in stories that related to disability benefit and fraud. Increased use of language such as ‘scrounger’ and ‘cheat’ were observed. The authors commented that:

> "Articles that explore the political and socioeconomic context of disability are rare as are articles that explore the impact that the proposed cuts will have on disabled people. There was a decrease in references to discrimination against disabled people or other contextualising issue" (Briant et al, 2011: 4).

At the time of this report, such articles, it would appear, have been successful in creating an environment where disabled people were cast as underserving, and legislated accordingly. This provides evidence of a coordinated campaign where policy influences media, and media influences policy. The landscape would appear to have worsened, particularly in terms of the outlook for disabled people. This appears consistent with a campaign to narrow the category of 'disability' (Roulstone, 2015). It is also of interest to consider how people who acquire injuries such as a brain injury, may also be affected by having held these views themselves before being possibly forced to navigate the benefits system.

Indeed, research which aimed to determine the general public's views towards survivors of brain injury found that – typically – the labelling was negative. There was a perception of dependency – which links into wider public views of disabled people – and unhappiness and aggression (Linden and Boylan, 2010). Using semi-structured interviews, responses such as survivors not 'being normal', that they 'can't think for themselves', and that they were 'sad' was presented (2010: 645). It is important to note however, that the research was conducted over a decade ago, and concluded that public awareness was increasing as to the challenges those with brain injury face. The research was based in Northern Ireland, which like Scotland has had a level of human rights understanding apparently embedded in its public services, and wider society for some time.

These changes can be seen as part of a general trend in a structured campaign against marginalised people in general. By sanctioning, delaying, or removing benefits from people who need them, they have the primary effect of impacts such as homelessness, food and fuel poverty. There are numerous secondary impacts such as poor physical and mental health, the impact on self and identity. This suggests that just as there is a medical prognosis following brain injury, there is also a social prognosis. Just as earlier studies discussed the possibility of neurodegeneration after brain injury, this shows the possibility of a social degeneration. Mills (1959) discussed the distinction between 'private troubles and public issues'; the situation faced by disabled people, and other marginalised groups is clearly the latter, but is presented as the former. Means to address the structural violence that people with brain injury can face would appear to be worth considering in the rehabilitation or support services that they access.

3.18 Chapter summary

The concept of biographical disruption, and its ‘derivative terms’, offer a lens with which to aid the sociological understanding of people’s lives following brain injury. Greater understanding of the processes involved in repair and reconstruction, and how people can be supported through these processes, appears critical. This chapter provided evidence of the complexity of societal navigation following brain injury and illustrates a range of barriers that people face to recovery and repair.

The impact on mental health and wellbeing was of serious concern and highlights a gap between knowledge and provision of additional support. A lack of understanding or focus of long-term impacts in the medical setting provided evidence of the need for more holistic approaches to treatment and recovery. Participation in rehabilitation settings was highlighted as unrealised and problematic, involving family who themselves require support in relation to managing the impact their loved one’s injury. People who experience brain injury are individuals with their own biographies and backgrounds, and this was reflected in research on the role of gender, which again raises the need for the people who have brain injury to be considered complex, as brain injury itself is.

Employment and return to work were highlighted as a complex and again intersectional experience, and foregrounded sections of analysis that follow in the thesis. This highlighted once more the complexity of recovery, identity and societal reintegration. The literature on social security in the UK revealed this to be a hostile environment whose navigation is uncertain and carries with it implications for human rights such as the right to adequate standard of living. The role of the media in setting the tone for cuts in this area concluded the chapter, presenting a very real and concerning example of discourse which impacts disabled lives and justifies and enables dehumanising treatment.

This application of sociology must contain space for a reflexive focus on the individual, a focus that medical approaches and government responses have been lacking. As evidenced in this chapter, the social world is one that can be understood to be in many senses' hostile. It should be remembered that people can and do make positive recoveries from brain injuries.

However, a one-size-fits all approach to brain injury, perhaps even in respect to blanket terms such as ABI and brain injury, which is often witnessed in the medicalised approach, is inadequate. Sociological enquiry has within its methodological store the tools to address this. Central to this will be methodologies that locate and amplify the ‘hidden’ and often oppressed voices that constitute this group of people.

Chapter 4 Charity, philanthropy, and the potential of human rights

4.1 Introduction

As the UK's welfare state bloomed into being through the 1940s and 1950s, it established care and support as a central provision, which had traditionally been provided by the charitable sector or religious frameworks, if at all. At the same time the United Nations was formed, and the principles of a human rights-based approach were set formally. While the latter may be a framework of principles and the former an operationalisation of welfare, both are underpinned by values of dignity and respect. The chapter will begin by charting the rise of the charitable sector in the UK and consider its contemporary state. Critically, the power the person represented by the charity has to influence and impact on the charities modus operandi, governance, and spend will be assessed. The chapter will then turn to human rights as a potential framework that delivers humanising experiences of health and social care. The chapter will not cover a historical view of human rights, but rather consider how it has been harnessed by academics, civil societies and charities in Scotland to make a difference to people who have been marginalised and oppressed.

4.2 The rise of the charitable sector in the UK, and its contemporary state

> "The free enterprise of philanthropy is, in a sense, the human face of capitalism, addressing the social and individual ills that capitalism often creates" (Prochaska, 2007: 10).

The roots of the charity system and culture of philanthropy we see today in British society can be found in Victorian Britain. During this time, society witnessed a large growth in philanthropy, and the creation of charitable organisations and similarly organised groups. The period of great social change and upheaval during and following the industrial revolution contributed to the creation of an environment where "organized charities proliferated in Britain, as elsewhere in the English-speaking empire. Literally millions of associations, typically local and religious, provided essential services and moral training for the citizenry in nineteenth-century Britain" (Prochaska, 2007: 11). The influence of religion on charity - given its position as a matter of religious obligation in the world's major religions (and beyond) - can be considered in this sense to be an ancient concept. Philanthropy emerged from a more secular and philosophical standpoint, and much of the thinking can be traced to the Enlightenment (Bremner, 2017). These terms are intertwined and often used interchangeably.

Charities in nineteenth century Britain received huge amounts of funding. The level of this giving was considered a measure of a nations standing and civility at the time (Prochaska, 2007), wealth drawn often from the exploitation and horrors of colonialism and slavery (Hall et al, 2014). This encapsulated a view of poor and disabled people as a group that, if conditions were met, were deserving of pity and sympathy, with subsequent acts of charity bestowed in accordance with the “moral or religious duty of decent people” (Hughes, 2012: 70). The culture of charity and philanthropy that emerged in the mid-nineteenth century was the belief of a philanthropic obligation that took precedence over any ideal of the right to state support (Prochaska, 2007). The charity founders of this period crafted these organisations in the mould of capitalist business models that utilised “some aspects of modern urban life – the market, communication technologies – in a crusade against others – chiefly poverty and its many causes and symptoms, but also secularism” (Roddy et al., 2018: 33). It could be argued that charities operate in spaces where the market has not operated successfully (Nordberg, 2021), and this early adoption of business practice at the inception of a business dominated model, is one which still to this day produces problematic practice and outcome.

Central to the philanthropy of this period was a belief in approaches that stressed the practicality of philanthropy (Cunningham, 2020). Philanthropic efforts were viewed then, as is still arguably the case, as a vehicle to engage and conquer the perceived ills of society. During this period, systems of measurement began to develop from groups such as the COS (Charity Organisation Society), which used methods of quantification to establish who amongst the poor were ‘deserving’, and who were not (Barman, 2007). The COS were particularly dismayed by what they considered to be an increase in opportunities (or requirement) for people to live off charities due to their proliferation (Cunningham, 2020). This practice of giving and apparent largesse has also helped to build an image of charity as being one where rich people give generously to the poor, despite the reality that “helping others is a deeply rooted tradition across all cultures. A necessity in poor communities, it is widespread across and within all social classes” (Prochaska, 2007: 11).

This focus on the individual began to shift partly to a focus on community as being the site of solution (Barman, 2007). A wave of new professionals began to appear that aimed to continue the process of accountability and efficiency, but also to understand and utilise "the quantification of community need to propagate and to legitimate their particular view of how the voluntary sphere should move forward" (Barman, 2007: 107). This turn towards scientific methods to understand and tackle poverty at a community level, as opposed to the distinction of deserving and underserving poor, can be found in modern organisations that carry the names of philanthropists of that era. One such example is the Joseph Roundtree Foundation (JRF), and its aim to tackle poverty "through research, policy, collaboration and practical solutions" (JRF, 2020). The physical legacy of this era of philanthropy and charity is still seen today. Guy's hospital in London, was created following a donation from Thomas Guy in 1721 as a hospital for the so-called 'incurables' discharged from nearby St Thomas Hospital (Bremner, 2017). The 19th and 20th century delivered a long list of philanthropists such as Joseph Rowntree and Thomas Barnardo, whose foundations continue to carry on their charitable and philanthropic missions.

During this period, charities such as the RSPCA (Royal Society for the Prevention of Cruelty to Animals) and the NSPCC (National Society for the Prevention of Cruelty to Children) based in London, allowed a process of spontaneous branch expansion, or franchising, to occur. This saw the establishment of groups that "had their own identity, but also represented the national brand in their localities and where they could innovate locally but still had to abide by certain strict administrative rules emanating from the centre" (Roddy et al. 2018: 128). This is a model that endures to this day, that enables large parent organisations to control the ethos and direction of the charity. It also ensures that areas such as 'brand authenticity', that is "the degree to which a brand object is perceived to be the quintessential exemplar of its type" (Wymer and Akbar, 2017: 371), is controlled and dictated centrally. This model of franchising is an example of another area of charity structure that exists, and is possibly influenced by, the commercial sector (Roddy et al., 2018).

4.2.1 Royal Patronage

The use of celebrities as patron's and fund-raising vehicles was well established in this period, with royal patronage being actively pursued (Roddy et al, 2018). The philanthropy of the royals of the day served further purpose than fulfilling religious obligation or the maintenance of the nation's standing. Mindful of their reduced role in political life, and the threat of revolution, Queen Victoria and Prince Albert recognised philanthropic endeavours could help improve their image, and build, what would be from their perspective, more positive relations between classes (Cunningham, 2020).

For the children's charity Barnardo's, this engagement with royal patronage went beyond "simple patronage with attempts not only to extend the lustre of royal celebrity to the organization but, also, to generate as much publicity as possible from it" (Roddy et al., 2018: 30). This transactional relationship between members of the Royal Family and charity continues to this day. According to Headway UK's 'The history of Headway', its own royal connections are proudly displayed. From 1991 until 1996, Princess Diana occupied the position of 'Royal Patron'. According to the charity, the Princess' "very real interest in the charity's work" led to "extensive media coverage and a much-enhanced national profile" (Headway UK, 2020). Indeed, Headway UK were "once again honoured by royalty when in 2013 Prince Harry made opening Headway's new home in Nottingham his first ever solo engagement" (Headway UK, 2020). This relationship ensures press coverage, an increase of brand awareness, and a royal approval of brand authenticity. Properly harnessed, it should also attract donations. For charities that recognise the inequality faced due to the replication of the class system, particularly relevant to charities that work with disabled people, this transactional relationship is not one without its ethical dilemmas.

4.2.2 Collective action

Charities as a form of benevolent action from the 'haves' is not the only form of support. Collective action, taken by communities of the 'have nots', is another form. The coal mining industry in the nineteenth century was exceptional in the sheer physical toll in terms of impairment and disability it took on the people who worked in the mines (Bohata et al, 2019: 249). Mine owners were, to differing degrees, mindful of the 'moral economy', and the responsibility that employers bore to those workers who became ill and impaired. The story of disabled coalminers receiving financial support, being welcome in their communities, and continuing to work is in sharp contrast to other areas of society in Victorian Britain. However, "Their presence reflects more the struggle for survival and the inadequacies of other sources of support than it does economic empowerment" (Turner and Blackie, 2018: 219). The 'moral economy' was not sufficient to prevent the need for "friendly societies, workers' medical schemes, disablement funds, provident societies, artificial limb funds, blind charities, permanent provident funds, convalescent institutions, truss schemes and other such organisations" (Bohata et al, 2019: 249-250). This collective organisation demonstrates that both the apparent philanthropic largesse and state support was inadequate, and of the necessity for collective action to protect interests.

Collective action that followed was the protest and lobbying carried out by The National League of the Blind. This organisation was responsible for the first recorded coordinated mass protest march to the British capital in 1920. Despite representing disabled or impaired people, this pioneering organisation were not a charity but organised under the banner of trade unionism (Reiss, 2005). This is an example of a path different to the prevailing model created under the collective banners of charity and philanthropy. At the heart of campaign that led to the march in 1920 was the need for recognition and redistribution. This was achieved to an extent with the passing of the Blind Persons Act in September 1920, but not before MPs had "unanimously recognised the blind as deserving poor" (Reiss, 2005: 140). The dichotomy of deserving and underserving was clearly well-entrenched and applicable even when disabled people self-organised.

4.2.3 Regulation and contemporary charitable structures

Charities operating in the UK are amongst the most regulated in the world (McConville and Cordery, 2018). Financial reporting follows a legal structure that sees charities in England and Wales report to The Charity Commission for England and Wales, and their Scottish counterparts report to The Scottish Charity Regulator (OSCR). These bodies aim to provide oversight and increase public trust in the charities.

Levels of public trust in charities was investigated by The Charity Commission for England and Wales and discussed in the publication of the 'Regulating in the public interest, the relationship between Charity, Charities and the General Public' report, published in 2020 (Charity Commission for England and Wales, 2020). Whilst trust in charities was found to have increased, the perceived importance in charity over time was found to have continued to fall. Fifty-five percent of respondents considered charities to play an 'essential' or 'important' role in society. These figures continue an alarming decline that has been evidenced since 2012 when the figure stood at 76%. This is despite the increased burden on the charitable sector due to the impacts of the systematic hollowing of the welfare state witnessed during this period as part of the current Conservative government’s austerity programme.

The Scottish Charity Regulator’s (OSCR) ‘Scottish Charity and Public Surveys 2020 Report’ (OSCR, 2020) similarly provides an insight into the public perception of charities, some of the challenges that Scottish charities face, and also the role played by the regulator. Levels of trust in Scottish Charities had increased to a mean of 7.02 (out of 10), up from 6.14 in 2018. This figure is higher than in England and Wales, which also saw an increase but to a mean of 6.2 (Charity Commission of England and Wales, 2020). Whilst a personal connection with the charity was identified as being amongst the top reasons the public gave for donating to a charity (35%), the most consistent reason identified was that ‘their cause is important’ (56%). With conditions such as brain injury, which are often preventable, awareness raising by charities can therefore be understood to be both a means to reduce prevalence of brain injuries, but also a driver of economic resources, if the charity is able to highlight the importance of the cause at the same time. Given the media attention that is now being devoted to brain injury and sport (The Economist, 2023; Lu and Convery, 2023; Kemp et al. 2022), and the consequent growth in public awareness of the potentially huge prevalence of brain injury, the cause and its supportive bodies have arguably never been more ‘important’.

These methods of reporting used by the ‘Scottish Charity and Public Surveys 2020 Report’ do not include figures such as self-determination outcomes, common within rights-based approaches and in areas of development (O’Leary, 2017). The non-financial information relating to a charity’s ‘performance’ is critical to gain the trust of the public (Yang and Northcott, 2019). A widening of accountability that stretches far beyond financial matters of regulation offer a possibility to build in greater accountability and further ensure that charities serve the people whom they have a primary responsibility to. This also offers another area to showcase the work that they do, and how the money that is donated is spent, which was highlighted as being an important factor to the public in both the OSCR and Charity Commission of England and Wales reports (OSCR, 2020, CCEW, 2020). A reimagining of how we report ‘performance’, and the possibility of an introduction of a rights-based approach, could also address criticisms that charities “draw on hand-me-downs in governance thinking, the way that charity shops deal in hand-me-down clothes and personal belongings” (Nordberg, 2021: n.p.). Such approaches are needed, particularly given relatively recent government ideological forays such as the ‘Big Society’, which amount to a “regressive move back to models of disability based on charity and pity and away from affirmative and rights-based models” (Runswick-Cole and Goodley, 2011: 884).

4.2.4 Contemporary governance

Charity governance, and the extent to which the members of groups are involved, is critical to understanding how groups are shaped, function, and decide how they wish to proceed. Hyndman and Jones (2011: 152) highlighted four key issues in this area of charity governance;

- accountability of charities to funders and donors;
- the impact of what they term volunteerism;
- the influence of marketization on this sector;
- the extent to which those who could be considered ‘beneficiaries’ should be embedded within the decision-making processes that guide these groups

Accountability raised the issue of whom the charity is accountable to, and the form this accountability should take. Hyndman and Jones (2011) stress that key here are the donors or funders. Their influence differs to traditional business investment as they usually would not be able to withdraw funds already donated. However, if they are not satisfied with how these funds have been used, they may withdraw their support in the future. In this regard they could be considered to be the “primary stakeholders to whom an account is owed” (2011: 152). Consequently, these donors or funders can be understood to enjoy significant influence in this sector. If we accept this position, it is also problematic as the significance of this relationship may not be clear to the members of a charity, particularly given its relatively low profile in comparison with traditional high-profile fundraising techniques that often involve members directly. Volunteerism was highlighted as it is a sector that relies heavily on people to volunteer to allow it to operate. This relationship is therefore key, and whilst it may differ from the practices and rules of most workforces, it does not diminish its importance.

The authors highlight how the charity sector has become increasingly marketised - a situation where market values and performance measurements, beloved by the private sector are installed. The authors call for approaches that are supportive and collaborative, as opposed to traditional private sector governance control which “has the potential to undermine the charitable ethos and discourage volunteering” (Hyndman and Jones, 2011: 153).

If members view someone that is working with them as their employee, is this problematic? Is this particularly the case when the employee provides a supportive or caring role? This is becoming more prevalent, as self-directed care packages can require the person receiving the support to become in effect the employer, and charities begin to move into this sector themselves. This as a development has potentially transformative ramifications particularly in respect to righting the often-skewed power dynamics at play but isn’t without its own potential pitfalls.

The authors also discussed that deciding the extent to which beneficiaries are involved in governance is also key. This, the authors highlight, can help to “encourage a much sharper focus by a charity and guard against mission drift” (Hyndman and Jones, 2011: 154). This approach also allows for members to feedback directly to ‘management’ which would, in theory at least, improve ‘performance’ (2011: 154). One aspect of this is the promotion of members to positions on the board of directors, with the public and third sectors having adopted structures similar to those seen in corporate governance (Velayutham, 2013). This again highlights the pervasiveness of corporate structures in this sector. Furthermore, it is a process that, if we take the example of members/beneficiaries having board membership, does not guarantee increased involvement.

4.2.5 Who volunteers?

The question of who volunteers, and who has access to volunteering, provides insight into how groups and services are shaped. The Scottish Household Survey (Scottish Government, 2019a) provides fairly comprehensive and insightful data on this subject. This survey found that women were more likely to volunteer in general. Specifically, women volunteered more than men in the areas of ‘health, disability and wellbeing’ (18%-16% respectively). Men volunteered at a greater rate in the area of ‘physical activity, sport and exercise’ (19%-11% respectively). This suggests that traditional gender roles are played out, with woman being more ‘caring’, and men more ‘physical’ in the field of volunteering. In addition, volunteers were more likely to come from rural areas, higher income groups, and less deprived areas.

Adults who were classed as ‘permanently sick or short-term ill health or disabled’ were the least likely to have volunteered to a group, club, or organisation’. In terms of formal volunteers, the figure stood at 12% (the ‘all’ respondents’ figure being 26%). For informal volunteering the figure was 19%, whereas the figure across the full participant pool was 36%. Whilst it could be expected that there are a range of factors that could prevent the possibility of someone from this group volunteering, these figures suggest that there are potential barriers to disabled people participating in this section of civil society.

Acting as a committee member or Trustee’ was the second most common formal volunteering activity (25%). This figure rose with age, ranging from 9% in 16-24, to 36% in those aged 36% for those in the 60-74, and 75 plus age group. This is of no surprise as one would expect people to gain more experience, networks, and standing in the community as they get older. There was a general increase in volunteering with groups based on persons’ annual income. Figures also showed that the level of deprivation (according to the Scottish Index of Multiple Deprivation) impacted on the levels of volunteering (both formal and informal) that respondents undertook. The figure of volunteers increased as the level of deprivation lowered.

The data presented by The Scottish Household Survey raises questions as to who are the people most likely to be governing the groups that support disabled people, and whether the experience and ‘standing’, may in fact make them less well-positioned to understand the issues, particularly in terms of areas such as poverty and lack of access across society, that are prominent for disabled people. The lack of young adults that take up governing roles is a further area of concern. If the services are shaped by older generations without the input of young people, then the risk is increased that the service will poorly reflect that group. This is particularly relevant to groups that support people with brain injury, given that young adults represent a particularly at-risk group.

4.2.6 Participation in society

Participation in day-to-day life can be severely altered and restricted following a brain injury. Whilst impairment can make such participation more complex, barriers to this participation can often be understood to be societal. Häggström and colleagues’ (2008) study aimed to explore this participation from the subjective experiences of the people with a brain injury themselves. This qualitative study based in Northern Sweden involved open-ended interviews with 11 adults (f=6, m=5) between the ages of 38 and 62 (mean=55) who were between three and six years post-injury. The authors highlighted that their study represented the beginnings of academic exploration of the "the subjective experiences of people with ABI regarding their participation in daily life and the factors influencing that participation" (Häggström et al, 2008: 40). Considering the extensive history of the study of brain injury, this lack of academic, and medical, interest is revealing. Participants discussed how not having the capacity to do everything they previously did, necessitated a process of re-evaluation where priority was given to tasks deemed most meaningful whilst those of less interest were often discarded. Being asked to do things for others, such as give advice to loved ones, was highlighted as an important part of participation. By taking part in this area of daily life, participants felt less of a 'burden'. This participation was critical in ensuring that people "could have reciprocal supporting and loving relationships" (Häggström et al, 2008: 93). Decision-making and self-management, combined with approaches to rehabilitation that are focussed on what is meaningful to the individual, have been further promoted in stroke rehabilitation as a means to aid participation (Woodman et al, 2014). This offers clues to the process of biographical disruption and repair. This desire to do things for others was evidenced on a wider societal scale in relation to people doing more voluntary work than previously. Intersubjectivity was key to a feeling of belonging.

This lack of research focus is not a situation unique to brain injury; "the subjective experiences of participation among other groups of persons with disabilities are also almost unknown" (Häggström et al, 2008: 41). The lack of understanding mirrors the importance, or lack of, that is ascribed to the quality of life of disabled people in wider society.

The barriers to participation were further explored in a study by Olofsson and colleagues (2020). Their study aimed to explore participation in life outside the home by focussing on two adults with ABI in a series of semi-structured interviews and participant observations. For the participants in this study, participation in life outside the home had become complex, draining, and both restricted and restrictive. One participant discussed food shopping, and how this previously flexible and socially engaging process had changed. Shopping was now an activity where participation was partial, engagement with others was restricted, as it compromised their ability to complete the task. This resulted in a change of meaning in relation to this social process. This is of particular interest as it may appear that by still engaging in an activity previously carried out, participation was being achieved. A form of participation is, but one where social interaction is limited, an interaction that the person may be in acute need of, and consequently the social becomes an area of exclusion.

A focus on the everyday activities of people with a brain injury, and the knowledge it generates, provides “a deeper understanding of situations that challenge each individual and how these situations are managed in different ways with various consequences” (Olofsson et al, 2020: 201). In this regard, there is a certain ‘insidious onset’ (Bury, 1982) of the participation of daily life being restricted. The full realisation of the injury, and its long-term implications in both the private and public spheres, is not immediately apparent, even if the injury is often of a sudden nature. This understanding of how the post-brain injury world is navigated by the individual is crucial to understanding the lived experience.

Winkler and colleagues’ (2005) ‘time-use’ study builds on this theme. This study focused on people with a brain injury, and who they spent their time with. The study found that people with a brain injury spent large amounts of time alone, at increased rates to the general population. The study concluded that it was unlikely that this was by choice, and that “the amount of time spent alone appears to be related to their level of disability in combination with social structures and attitudes” (Winkler et al, 2005: 76). Clearly, how people participate in the social world following injury is an area of concern.

Social participation is a wide-ranging term, and whilst an important aim and indicator, it does not automatically translate to improved quality of life for people with a brain injury. Exploration of the associations between social participation and subjective quality of life (SQOL) was the purpose of a study by McLean and colleagues (2014). This quantitative study analysed responses to a range of measures used to gain data on social participation and quality of life from 46 people with moderate to severe brain injury 1 year or more post-injury, who were back living in the community. There were groups within the data that showed high participation and low SQOL scores. The types of leisure activities that they took part in most frequently usually did not involve direct contact with others, for example listening to music, walking around a shopping centre, or physical exercise that was more individualistic such as swimming or running. The results of this study suggest that an increase in the variety and frequency of social and leisure activities doesn’t necessarily improve SQOL, “but, instead, increasing the opportunities for individuals to participate with others and enhancing the subjective experience of social and leisure activities may have a positive impact on SQOL” (McLean et al, 2014: 1415).

4.2.7 Community rehabilitation and self-management

Once people are discharged from hospital post-trauma, community-based rehabilitation programs can contribute to increased, long-term improvements in terms of societal participation and self-reported overall health (Domensino et al, 2020). These programs can be delivered outwith traditional settings with activities such as yoga, which, when offered accessibly, offer potential for both wide-ranging rehabilitation possibilities and community integration (Donnelly et al, 2020). These group settings should still be spaces that are able to cater to, consider, and meet individual needs of the people who attend them (Patterson et al, 2019). Dedicated case managers from the point of hospital admission would be beneficial in terms of integrating support and collaborating on approaches where people affected are more in control of the decisions made regarding care and support (Abrahamson et al, 2017). Such levels of support are not commonplace. Self-management frameworks as a method of support are rarely available for people with brain injury, unlike for a number of other long-term conditions (Mäkelä et al, 2019).

Mäkelä et al (2019) co-designed a supported self-management (SSM) intervention for people with a brain injury and their families. The underlying principle of this mixed-methods research was to develop an approach that challenged the traditional biomedical approach and power dynamic by attempting to engage all involved parties in partnerships. This comprised two distinct settings: a major trauma centre (particularly its acute and rehabilitation services), and third sector organisation ‘day-centres’, of which there were two. Focus groups and interviews were carried out that enabled all stakeholders (people with a brain injury, family and healthcare professionals) to produce a new intervention that involved three interrelated components, a training workshop for staff, a patient self-management book, and a book for family members and loved ones to share experiences and ideas on self-management. Families reported that the resources and strategies that emerged helped to address the lack of guidance faced when someone is discharged following a brain injury. The self-management book produced was beneficial as an aid for self-management from the perspectives of the people with a brain injury and their families. However, this group appeared to be unaware of the same utilisation by staff. Furthermore, the research revealed that staff were deciding that some ‘patients’ were not ready for the self-management intervention, commenting that “our findings highlight enduring power imbalances, when health-care professionals decide which people are “right” for an SSM intervention” (Mäkelä et al, 2019: 9). This provides a snapshot of a system that is in some ways ill-suited to approaches that incorporate methods that place early self-management for people with complex conditions firmly on an equal footing.

Increasing a person's awareness of their injury and the impact that has on their lives can motivate people to engage with further treatments or programs (Behn et al, 2019). Notably, this study reported that participants conveyed cognitive improvement which the researchers believed was more likely to be a positive reaction to completing the project and its tasks in an independent way. This further highlights the social nature of the injury. If people are accustomed to living independent lives where completing tasks is a part of daily life, the sudden and brutal denial of this can be expected to have a considerable impact. The resuming of such processes, therefore, can be expected to provide an area of repair and recovery, one that crucially may exist beyond traditional medical measurement and confines.

4.2.8 Peer support

The use of peer support officers - people with direct experience of living with a spinal injury - to support people with spinal cord injury (SCI) in general hospitals is an example of an early intervention strategy that has possible applications in areas where a serious, life-changing injury is sustained (Haas et al., 2013). An evaluation by Haas and colleagues (2013) found that SCI patients praised the support provided by peer support officers who offered "psychological and emotional support […]; advice on living with an SCI; practical advice and information; on-going support and friendship" (Haas et al, 2013: 296). Furthermore, health care professionals interviewed were unanimous in their praise of the service. One main benefit reported was the provision of a "holistic, humanistic element to care" (Haas et al, 2013: 297). By having a 'listening ear' of someone who had experienced a similar injury, a safe environment was created where people could discuss topics that could be considered highly personal, such as bowel and bladder management, and provide information on financial support, or on specific devices to support independent living. This provides positive early intersubjective dialogue and offers information on how to access resources. It would also appear to provide the possibility for biographical repair to begin, as complex and delicate a process as this may be.

Approaches that provide such peer support that bridges discharge from rehabilitation units back into wider society are being trialled and researched. Kersten and colleagues (2018) carried out an intervention study to explore the feasibility of peer mentoring for people with a brain injury in Auckland, New Zealand. This involved a formal training process, and mentoring began with an initial meeting between mentor and mentee prior to discharge from a rehabilitation unit. A total of 12 adults (mentors=6, mentees=6, f=2, m=4) took part in the study. Being able to talk with someone who had experienced a similar injury but was further on in their recovery was generally seen as positive. The opportunity to talk with this person was viewed as distinct from support that was received from family, friends and healthcare professionals. The sharing of strategies to deal with issues such as fatigue and concerns over social pressures with regards to alcohol consumption, were particularly valued. As previously discussed, mentoring appears to offer a space where topics that others consider taboo may be freely discussed (Haas et al, 2013). Peer support groups have been identified as “a safe place to make visible a brain injury that is invisible to the public” (Schwartzberg, 1994: 303), and this mentoring approach can be understood to be an early intervention along similar lines.

Given traditional power relations with healthcare professionals, and their role as gatekeepers to areas such as treatments, alongside the often complex, and fluid post-injury relationship within families, a peer-support environment may present the only location that such conversations take place in the early stages of recovery. People with a brain injury will often be admitted to acute trauma wards - a place “where biomedical concerns traditionally dominate” (Mäkelä et al, 2019: 8) - and so such peer approaches may present a unique resource. The established relationships and roles also “appeared to benefit the mentors by allowing them to be, and to be seen as, able to make a meaningful contribution, thus promoting a sense of self-value” (Kersten et al, 2018: 11). In this regard, solutions may exist within the community that both support those in the early stages and empower those further on.

Mentors who took part in this scheme underwent an interview process and were paid at the equivalent to that of a research assistant. Peer support is more commonly provided as a voluntary service, and whilst this may be suitable within many environments, in formal settings where others are being paid for their expertise, it appears exploitative not to similarly follow suit. In a capitalist society, it could also demonstrate a recognition of the importance of the role.

4.2.9 Peer-led groups

A systemic review of literature on the evidence for peer-support groups for people with acquired brain injury found a key difference in how support groups were led depending on the setting (Hughes et al, 2020). The total of 13 papers reviewed found that those groups based within an in-/out-patient setting were ‘professionally’ led, whilst those in the community were peer-led. The structure and the setting of the groups did not appear to contribute to the positive outcomes. The positive outcome was more due to “simply being surrounded by those with similar difficulties in a safe, contained environment” (Hughes et al, 2020: 855). The wide range of positive outcomes associated with these cost-effective groups, of which the evidence is mixed, should be seen as distinct or complementary, and not as a replacement to specialist medical support and rehabilitation (Hughes et al, 2020).

Tregea and Brown (2013) carried out research within a peer-led aphasia group, seeking to understand and interpret what made such a group successful. A key feature identified was the informality of the groups “as it preserved a natural environment where members could interact freely” (Tregea and Brown, 2013: 594). The informal nature of the four peer-led groups that were part of the study was thought to contribute to the peer leaders feeling that they had little need for training. Support to create new groups was gained from pre-existing aphasia groups, professionals in the field, and the national association (in this case the Australian Aphasia Association).

The lack of understanding of positive outcomes mentioned in the Hughes et al. (2020) review is perhaps understood as having been the result of the medicalised approach to brain injury research. Accounts of disability have been drawn from the medical world and “are written, virtually without exception, from the perspective of the non-disabled expert `treating’ the disabled person or the condition that was perceived as disabling” (Bredberg, 1999: 190). These accounts provide valuable historical insight into medical practice and treatment, and even the attitudes of the authors, but provide little in terms of the lived experience, and are “inevitably one-sided in their account of the disabled people, presenting them as depersonalised objects of institutional action” (Bredberg, 1999: 191).

4.3 The role of human rights

4.3.1 The Human Rights Context

Existing UK legal structures do not currently “marry our domestic legal system and the internationally enshrined human right to health” (Brown and Ferrie, 2023: 565). Legislation has attempted to close this gap. The Equality Act (2010), which draws on the seminal social model (Oliver, 1990), sets out in law the rights of disabled people, including, therefore, people with brain injury, to be treated equally under the law. Thresholds established as part of a Human Rights Based Approach (HRBA), a framework for operationalising human rights that requires the organisation/duty bearer to take responsibility rather than wait for the rights holder to report a violation, go farther by ensuring that a minimum standard is set (Flegg, 2021). This displays a key potential of the HRBA to go further than equality frameworks, which may challenge discrimination but “can lead to people being treated equally badly” (Brown and Ferrie, 2023: 565). Human rights are universal and apply equally. They belong to all, and are a guarantee that all humans have worth and have the right to live dignified lives. These fundamental rights are guaranteed in the UK by the Human Rights Act (1998), which brought the European Convention on Human Rights Act (1998) into domestic law, and was devolved to Scotland under the Scotland Act (1998). This ensures that “all public bodies and those carrying out public functions have to comply with this legislation; this means the courts, police, local government, hospitals and care providers” (Miller, 2019: 9). In order to monitor compliance, the UK is subject to oversight from monitoring bodies of the United Nations (UN) (Human Rights Consortium, 2022). Despite this, Economic, Social and Cultural Rights (ESCRs), within which sit the rights to health, social security, and work, have been neglected in UK constitutional law, which has contributed to a lack of accountability (Boyle, 2018).

In addition to the Human Rights reports that Governments are expected to submit to the UN, shadow reports are sought by organisations in the civil society space, to provide a holistic, and, crucially, independent, perspective of human rights as experienced in the country (Human Rights Consortium, 2022). Reports such as ‘Nothing about us without us!’, produced by Inclusion Scotland in collaboration with a steering group of national Deaf and Disabled people’s organisations highlight key issues, in this case in reference to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) regarding implementation (Inclusion Scotland, 2022). The report evidence how the operationalisation of human rights has continued to be a significant hurdle still to be overcome by policy makers (Ferrie et al, 2018). It is in this context that the Scottish Government has signalled its intention to incorporate the following treaties into Scots Law (Scottish Government, 2023a):

- International Covenant on Economic, Social and Cultural Rights (ICESCR)
- International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)
- Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)
- Convention on the Rights of Persons with Disabilities (CRPD)

This represents a potentially seismic shift in Scottish society, which carries with it the potential to transform all in society, but particularly those furthest from their rights, from passive citizens, to empowered rights-holders. Such a transformation, however, requires political will, civil society pressure, and crucially an increase in public awareness and ability to name and claim the rights that are theirs.

Whist incorporation is welcome, for some people who have acquired their disability, issues of identity may remain. The UNCRPD (United Nations Convention on the Rights of Persons with Disabilities) still carries with it a requirement for a person to meet the criteria of being a disabled person “which is difficult where people are awakening to their impairment and barriers to being and doing” (Brown and Ferrie, 2023: 567). This represents a barrier to people with brain injury, who similarly may take time to identify as being disabled, or indeed reject a term that carries negative societal assumptions and may be damaging to a person’s sense of identity. Whilst the social model of disability provides what is still today a radical reshaping of disability as being resultant of social barriers, and consequently the responsibility and failure of the State and duty-bearers (Oliver, 1990), it similarly (outwith its influence on policy) requires people to identify to some extent as disabled. Incorporation and awareness must, therefore, engage also with those who do not adopt this identity, or are not part of groups that advocate under this banner.

4.3.2 Human rights-based approaches (HRBAs)

The Human rights-based approach (HRBA) is a conceptual framework based on international human rights standards that aims “to ensure that people’s human rights are put at the very centre of policies and practice" (SHRC, 2022: n.p.). Central to this approach is the empowering of citizens to both be aware of what their rights are, and to then be empowered to claim them. Rights-based approaches can be utilised by duty-bearers themselves as a means to scrutinize their own service delivery and processes. This involves the engaging of people whom the duty-bearer has responsibility, rights-holders, in decision making processes and in doing so "set[s] a framework whereby the rights holder is considered at every stage of service planning and creates mechanisms for redress and access to rights" (Black et al, 2023: 9). The PANEL principles were developed as a method of breaking down the HRBA and what it means in practice and are underpinned by five central principles of human rights: Participation, Accountability, Non-discrimination, Empowerment and Legality (SHRC, 2022). Organisations who work with marginalised groups in Scotland are increasingly utilising human rights-based approaches as a means to empower those furthest from their rights, and in doing so challenge the lack of rights-realisation in Scotland (Pearson et al, 2022). Whilst these approaches are being embedded in civil society, they have already emerged in Government policy that impacts on disabled people.

4.3.3 Human rights-based approaches in existing legislation – The example of Self-Directed Support (SDS)

The Self-directed Support (SDS) Act (2013) is one example of Government legislation that aims to be "grounded in a human rights-based approach" (Scottish Government, 2022b). The SDS is part of a range of policies that aim to "support, promote and protect people's human rights and through access to independent living support people's participation in Scotland's social, political and civic life" and in doing so shift power from service providers to the people who use them (ibid: 3). This legislation allows people receiving support and carers flexibility to direct their own care, having choice and overall control over how the support is delivered and maintained (ibid: 5). The legislation requires duty-bearers to "follow both the letter and the spirit of the guidance" and are underpinned by four principles 'participation and dignity, involvement, informed choice, collaboration" (ibid: 5-6). Recipients of SDS have reported positive experiences of accessing SDS and having choice and control to select their SDS option (Health and Social Care Alliance and Self-Directed Support Scotland, 2020). Barriers to access however persist particularly for first-time applicants, and more than a quarter of respondents discussed having choices made for them by social workers (Health and Social Care Alliance and Self-Directed Support Scotland, 2020), which contradicts the underlying principles of empowerment and participation. Furthermore, the complaints procedure has been experienced as inconsistent for those accessing SDS (Gittens et al, 2021), which raises questions as to the strength of accountability procedures, a key principle in HRBAs.

Research that engaged those working in the field highlighted that duty-bearers such as social work departments struggled to realise this vision. This was highlighted as due to the pressures to maintain budgets set by the State, alongside their responsibility to deliver SDS that realised the human rights-based approach outlined in the act (Biziewska and Palattiyil, 2021). Scotland's social care budget has seen a real time fall since the roll-out of the act (Pearson et al, 2018), and this highlights the need for adequate funding. Recipients experiences provide evidence as to how these gaps are filled, with one report stating that "almost all people reported assumptions from social workers that family members, friends, and neighbours could provide some degree of unpaid care" (Health and Social Care Alliance and Self-Directed support Scotland, 2020: 51). This carried with it gendered assumptions relating to domestic labour; namely, that disabled men who had female partners were not offered support relating to household tasks, presumably as this would be carried out by women. Unison, Scotland's largest trade union who draw members from the public, private and voluntary sectors, highlighted the gap between rhetoric and reality that is not bridged by statutory obligations, contributing to a landscape where "human rights remain abstract, unenforceable, and ineffective", and a space in which care workers, due to inadequate resources and staffing, must "seek to fill the human rights gap" (UNISON, 2020, n.p.). This in turn places staff, rights-holders themselves, and the people they provide essential care for, further from rights realisation. Human rights must therefore be enshrined in primary legislation, and not "buried in guidance…thereby diluting or removing the legal recourse and redress - which is the point in incorporation" (Black et al, 2023: 36).

4.3.4 Human rights awareness

Whilst human rights have been a growing area of interest in Scottish civil society, the level of human rights awareness in Scotland amongst the general public remains unclear. Research produced by the Equality and Human Rights Commission (EHRC) in 2018 reported that only 5% of people felt that they knew a "great deal" on the topic, with less than half surveyed feeling that they had a “fair knowledge” (EHRC, 2018a: 7). The Scottish Human Rights Commission (SHRC, 2018) further produced research that aimed to understand public knowledge. Their report found that 45% of respondents were unsure as to what they would reply if asked to describe what human rights were. Of those who did provide an answer, ‘freedom of speech’ was the theme most reported. This may suggest that the public in general associates rights more with civil and political rights (such as the freedom of speech, the right to vote) than in relation to economic, social, and cultural rights (ESRCs), such as the right to health and adequate standard of living (Pearson et al, 2022). This highlights the crucial requirement that people know that they have human rights, and to know that key institutions have a duty to uphold them, in order for a rights-holder or advocate to then be able to articulate and challenge any barriers faced (Brown and Ferrie, 2023). This is not a straightforward process, as challenges take place “often during heavily structured exchanges that take place to a backdrop of unequal power dynamics” (Brown and Ferrie, 2023, 567). This journey towards rights, it must be remembered, is taking place in a context where oppressed groups who are furthest from their rights continue to face rights denial and regression. This is seen in examples such as children who are part of the travelling community, who faced rights regressions in regards to their right to education during the COVID-19 pandemic (Riddell, 2022), and disabled asylum seekers who face barriers to realising their right to health due to a lack of staff knowledge of eligibility of accessing specialist health services (EHRC, 2018b). These are just two examples but highlight that a relentless focus on those furthest from their rights is needed and will continue to serve as an acid test of the Governments progress regarding human rights.

The Scottish Government has provided funding for the specific purpose of advancing human rights to tackle inequality and advance the realisation of rights in Scotland, through the Inspiring Scotland ‘Equality and Human Rights’ fund (Scottish Government, 2021). This funding, whilst welcome and progressive, particularly in comparison with the UK Government’s approach to rights, is still potentially problematic given the role of the State as a duty-bearer and the current lack of human rights incorporation. For HRBAs to grow, and for people with lived experience to play an active role in their implementation, resources in the form of funding and time are required (Ferrie, 2019). The signalling of incorporation and allocation of funding to grow the understanding of human rights represents an important first step. Such steps have potential to engage those already aware of rights or those involved in activism, but also those to whom rights are abstract or unknown. The Equality and Human

Rights Commission (EHRC) carried out research that showed that in people who identify as lacking knowledge or feeling ambivalent towards human rights show an increase in interest when they have access to discussions on the topic (EHRC, 2018a). This has been shown elsewhere with marginalised and oppressed groups who face multiple discrimination, such as people seeking asylum who are HIV positive, who were able to highlight the violations they faced in areas such as health and housing, both in the countries from which they had fled, and indeed in the lives they now lived in Scotland (Palattiyil and Sidhva, 2021). This suggests a potential for HRBAs when people have access to human rights education and view themselves as rights-holders. A route towards this is increased awareness and use of human rights-based approaches.

4.3.5 Case studies

4.3.5.1 SNAP

Scotland's First National Action Plan for Human Rights (SNAP) ran from 2013-2017, and emerged as a roadmap for the progressive realisation of human rights, as outlined in the Universal Declaration of Human Rights (UDHR) (Scottish Human Rights Commission, 2022). SNAP engaged a range of actors to inform its development, including individual rights-holders, civil society and duty-bearers (Ferrie, 2018).

The mapping process that was part of SNAP provided evidence that participants of the process showed a strong awareness of barriers to remedying what they perceived as rights-violations in their own spaces (Webster and Flaningan, 2018). These barriers were identified as multifaceted and included political, attitudinal, and financial barriers. By positioning SNAP in this way, support for human rights in Scotland as a means of achieving progressive change has emerged "as more than the 'property' of the political elite, lawyers, and those with the financial means to access the courts" (Brown and Ferrie, 2023: 566).

SNAP 2 has since been launched, and aims to build on the success of SNAP 1. It has identified 8 key priorities (with 54 practical actions to meet these), born from the participatory process which brought to the fore the issues people in Scotland continue to face (SHRC, 2022). SNAP is a process which highlights the role of civil society and rights-holders in imagining what a rights-respecting Scotland can become. This roadmap also provides the steps through which this can be achieved. Such processes are crucial for disabled people and represent an opportunity for the creation of a safety tarp, rather than net, through which people do not fall.

4.3.5.2 HRBA in practice: Leith housing project

Human rights-based approaches are beginning to be utilised as a tool to empower rights-holders in Scotland to claim their rights. One action that arose from SNAP 1 was to pilot a HRBA to tackling poverty and social exclusion. This led to ‘Housing Rights in Practice’ - a collaborative project, delivered by the Scottish Human Rights Commission (SHRC), Edinburgh Tenant Federation, and Participation and the Practice of Rights (PPR) - which supported residents, many of whom were living in conditions that were substandard, to frame the issues they faced in relation to housing using human-rights language, and to then take action (SHRC, 2020). The participatory process included a face-to-face survey which consequently informed the development of indicators. These encapsulated the priorities of residents and the improvements that were needed to realise the right to an adequate standard of housing, and indeed other rights such as the right to health and adequate standard of living. The project engaged the duty-bearer in the process, and it led to funding in the region of £2.3 million to improve the standard of housing.

Whilst the project engaged the duty-bearer (Edinburgh City Council), and provided training to council officers in human rights, the duty-bearer still failed to acknowledge the residents’ right to housing, and reported finding a rights-based approach challenging (SHRC, 2020). Arguably, it was the involvement of the SHRC and the optics from a short video that went viral on social media that led to the investment in social housing. It suggests that even when HRBAs are utilised as successfully as they were in this project, tensions between rights-holders, organisations supporting them, and duty-bearers remain.

4.4 Chapter summary

The charitable sector continues to play a significant role in disabled people's lives, and indeed the UK public’s consciousness. Its roots, which stem from the Victorian Era in Britain, endure. This is seen in the continuation of a - somewhat covertly (as it is rarely presented as so) - transactional relationship between charitable organisations, who can ‘trade’ respectability for the resources of others such as wealthy donors and people prominent in the public mind.

This, however, was not a linear and homogenous model. Organisations that were led by and for disabled people emerged as a reaction to the failures of the State to provide adequate social security, and indeed an adequate standard of living. They were also born out of the failures of those who belonged to the philanthropic circles of the time. Such examples demonstrate a form of resistance to power imbalances. Imbalances which remain in society.

Charities rely on the labour of volunteers, and the literature displayed intersectional elements of groups who were able to, and did, volunteer. These included factors such as gender, age, and income, and offer insights to and beyond governance. It adds to our understanding of who is likely to be there – in positions of responsibility - when you attend a charity or support group. This literature further unpacked an environment that can produce unequal power dynamics. The chapter then related back to the literature on the participation of people with brain injury in society. In doing so, insight was added as to the reality of hidden voices and society's failure to empower participation. Forms of support groups that have peer-involvement offered further understanding of the value of connection and reciprocity that can be provided by peers, suggesting the strength of the approach of the support group featured in this research.

The chapter then turned to a focus on human rights as a potential framework that challenges unequal power dynamics and delivers humanising and dignified experiences of health and social care. The lack of knowledge was evidenced alongside a willingness by groups, often those furthest from rights-realisation, to grow their knowledge and utilise human rights based-approaches. The example of Self-directed Support evidenced a HRBA in policy, and one which, whilst a step in the right direction, was undermined in parts by a lack of realisation for all. The chapter concluded with the example of the 'Housing Rights in Practice' project, which demonstrated the great potential and transformative possibilities of a rights-based approach, but also the tensions that can emerge between rights-holders, organisations that support them, and duty-bearers. The following chapter will now delve into the methodological approach taken to this study, and outline the methods that were employed.

Chapter 5 Research methodology

5.1 Introduction

As discussed in the review of literature, greater understanding is needed of how people navigate life phases following a brain injury. This study originally set off to explore the impact of support groups on the process of biographical disruption and repair following a brain injury. As explained in Chapter 1, the collection of data began shortly before the COVID pandemic and was unfortunately abruptly brought to a halt through the public health restrictions of March 2020 and the significant subsequent period of disruption to life. During this period, the support group was suspended. A period of waiting and hoping that life and research could resume led to a realisation that I would need to work with the data that I had. The support group did not reform in this period, and this dramatically impacted this research, and a new plan had to be devised, significantly changing the course of this study. The new direction built on the exploration of biographical repair following a brain injury and added in the analytical lens of human rights. The new analytical lens imposed another layer of scrutiny on the data which worked well with a smaller-than-anticipated data set.

A human rights-based framework offers the potential to deliver a humanising experience of life following a brain injury, and this is, as far as a lengthy desk-based search can tell, the first time it has been applied in the field of brain injury and biographical disruption. This study analysed the data from a human-rights perspective in order to achieve the thesis' main aim: to contribute to the understanding of how people navigate life and recovery following a brain injury, and to explore the extent to which support groups contributed to the moving out of a disruptive phase. In order to achieve this aim, the following three objectives were set:

1. To investigate the extent to which the concept of biographical disruption useful in understanding the recovery after a brain injury
2. To investigate the extent to which face-to-face support groups contribute to adults moving out of a disruptive phase
3. To investigate the extent to which a human rights-based approach enables biographical repair

This chapter will outline the methodological framework of this research. It will explain the ontology and epistemology underpinning the study, and how this has informed the selection of appropriate research methods. Furthermore, it will address the role and attempt to mitigate confirmation bias, and explore researcher positionality, and how reflexivity informed the research and was practiced. To explain the necessary change in direction mid-way through data collection, this chapter will slightly deviate from the usual structure of a methodology chapter, ordering sections in a way not to disrupt the flow of the chapter. The chapter will cover the original methods planned and the adaptations made to manage the disruptions caused by the COVID pandemic. Furthermore, a detailed, itemised explanation of the use of framework thematic analysis will be provided. The chapter will then close with an overview of how the collected data was analysed, and what ethical precautions were taken.

5.2 Research underpinning and ontological and epistemological basis of this work

In considering my position as an insider, with experience of traumatic brain injury, I was drawn to feminist approaches that amplify the voices of those with expert experience. A feminist approach to disability reflects an acknowledgement that disability must be understood through a lens of intersecting identities – not only the intersection of disability and gender, but also the lens of age, class, race and sexuality (Carlson, 2016). This thesis is particularly informed by the post-qualitative movement that embraces affect and emotion, as central to understanding experience (Lather and Pierre, 2013). Throughout the interviews and time spent with the support group, I aimed to avoid categorising people, but rather recognise and value their multi-faceted characters and identities.

In line with the desire to shine light on the experiences of biographical disruption and repair after a brain injury, and in order to amplify the expertise of each participant, this study was grounded in a phenomenological approach. In using a phenomenological approach, I sought to understand human experiences from the perspective of the people living those experiences, and appreciate that the data would, and should, prioritise a subjective viewpoint that aims to understand individuals' perspectives, feelings, and perceptions (van Manen, 2014). As I was seeking an understanding of participants' interactions with society and how it impacts them, and their sense of biography, it is a logical philosophical framework with which to approach the research. Core to developing understanding of biographical disruption is appreciating the participant's view of the world as immediately experienced in the subjectivity of everyday life, including cultural considerations and their social networks and relationships. Understanding my own experience and investment in brain injury, phenomenology as an approach was employed in an attempt to arrive at the essence of the participants' experiences, away from my own understanding that each individual's experience of brain injury (and indeed disability) is different. Boylan and colleagues (2009) concluded that research into the lives of children with brain injury often fails to integrate them as participants. The researchers contend that, often, there is a deliberate attempt to instead seek the views of their adult carers. This is prevalent throughout research on brain injury, and is often the experience of those with brain injury – including adults - in their daily lives and in navigating public services. While impairment can sometimes make the involvement of carers – or those who support individuals - necessary, the use of the philosophical approach and methods in this research is intended to capture the 'raw' voice and experience of participants.

Indeed, those who experience brain injury are not a homogenous group, and the research aims to not make vast generalisations, but remain embedded in the individual experiences that were shared by group members in the research. This led me to consider epistemologies that are grounded in lived experience, that allow the participants to discuss issues important to them, and in ways that feel accessible to them. More than anything, while protecting the identity of participants in line with strong ethics and consent, I wanted the findings to feel authentic to the participants.

The research, and its ontological and epistemological underpinnings sit within an interpretivist research paradigm. The interpretivist approach recognises that whilst the researcher may understand aspects of the experience prior to the commencement of the research, the researcher cannot have "a priori knowledge of the many socially constructed realities" (Hudson and Ozanne, 1988: 513). The adoption of this paradigm reflects that there is no single objectively appraised truth, and living with a brain injury is shaped by the individual experiences of those who experience the phenomena. In the case of this research, my awareness also emerged through my own lived experience. The interpretative paradigm considers that "individuals form their own reality of the world in different contexts through interactions with others. Every individual perceives the world differently and views it in different contexts" (Khan, 2014: 224).

A phenomenological approach was employed that aimed to foreground and interpret the "lived experiences and the meanings that emerge as individuals experience phenomena in their everyday lives—in the lifeworld" (Hiller, 2016: 115). Phenomenology is a theoretical perspective which contends that "any attempt to understand social reality has to be grounded in people's experiences of that social reality" (Gray, 2004: 214). This approach is consistent with attempts to generate knowledge of the experiences of groups whose voices are hidden, and as is the case of people with brain injury, rarely sought.

Following the shift from phenomenology to the adoption of the PANEL principles as an analytical framework, the ontological relativist position persisted given the focus on the individual subjective accounts. The use of long quotes in the finding's chapters reflected this. The shift towards the analytical framework of the PANEL principles was a pragmatic decision, but one that enabled knowledge production that was rooted in the participants' subjective lived experience and thus maintained an interpretative epistemological stance. The drawing on fieldnotes and use of the autoethnographic method reflect that "as an interpretivist researcher's understandings grow within a study, alterations in how subsequent data are generated and analysed may change as well in order to more fully understand the phenomenon of interest" (Hiller, 2016: 124). The reflexive practice detailed in section 5.4, is central to the epistemological awareness, given its role in highlighting the subjective nature of both the researcher's position, but also of the knowledge produced. Furthermore, this contributed to epistemological transparency, as the subjective influences and biases were laid bare and interrogated.

The social model contributes to both the ontological and epistemological framing of this research. The social model, first encountered as a University Access student prior to my injury, reframed how I conceptualised disability. The exposure to the social model of disability whilst an Access student was pivotal in my own conceptualisation of disability, and to an extent, in how I view my own experience. I consider society to be disabling, with clear (and some less clear) barriers that can be identified and therefore removed. My conceptualisation of disability predates my academic awakening as my sibling's experience had demonstrated this to me in very real terms - an awareness focused less on the radical political stance, and more on the access to resources, i.e., what (I believed) my sibling had a right to receive (but did not receive) in terms of medical and wider state support. Biographical disruption and its focus on access to resources made sense in this regard, and whilst not strictly ‘social model’, is an example of the choice of theory and its contribution to research questions being a ‘political decision’ (Stone and Priestley, 1996: 712), as it captures elements of the experience which the dominant medical model fails to adequately capture. An area in which my paradigm splits with a social model epistemology is that there is little space to explore or recognise the sustained emotional impact on the self, which directed the literature review in areas that explored self and identity and borrowed from other disciplines including psychology and neuroscience.

Elements of the research also fit within an emancipatory research paradigm, and its six core principles identified by Stone and Priestley (1996: 706):

1. The adoption of a social model of disablement as the epistemological basis for research production
2. The surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation
3. The willingness only to undertake research where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers
4. The evolution of control over research production to ensure full accountability to disabled people and their organizations
5. Giving voice to the personal as political whilst endeavouring to collectivize the political commonality of individual experiences
6. The willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people

Positivist claims to objectivity were rejected, in keeping with both interpretivist and emancipatory approaches. The research was emancipatory in its aim to highlight, as a means to then remove, disabling barriers. However, to claim that this was purely to be of practical benefit to disabled people is problematic as PhDs are not the only method of producing research, and the researcher stands to gain significantly from the award of the title.

Control over research production was limited. The design, whilst consulted with the co-funder (which was at the time led by disabled people) still rested mostly with actors within the academy. Changes in methodology were not consulted with participants, for example, so claims of full accountability are difficult to make. The experiences were collectivised, in keeping with the principles outlined in the emancipatory paradigm to an extent, as the experiences of the participants were presented as a collective rights-issue. However, there is a rejection of a monolithic experience throughout the data, and in this sense, phenomenology was the guiding theoretical perspective.

In this regard, the research paradigm is interconnected. The phenomenological approach placed a focus on the individual experience, recognising that this exists outwith the collective group experience. However, the use of the PANEL principles and conceptualising of brain injury as a rights-issue, particularly at a time when the Scottish Government is signalling incorporation of Human Rights Articles (including the CRPD) into Scots Law, reflects the emancipatory aim of removal of disabling barriers.

Problems in claiming such epistemologies persist when the philosophical turns to the practical. Stone and Priestley (1996) underline that within the emancipatory paradigm, research must aim to achieve “more than furthering academic careers and publication lists” (1996: 703). Whilst the researcher may draw on existing relationships within the academy, and draw on the relationship with the co-funder, this alone is unlikely to meet these aims. Dissemination requires time, effort and money, that the PhD funding does not provide for. Whilst other means of funding exist that could contribute to this aim, the burden to meet this aim therefore falls primarily to the researcher. An inherent risk therefore endures that the potential of epistemologies that provide a framework to produce knowledge to foreground hidden voices and make change to oppressive societal structures risk remaining partially realised.

5.2.1 Confirmation bias

The following section will discuss confirmation bias in relation to the present study, the measures taken to mitigate its risk, and how it impacted on the knowledge production that emerged from the study.

Confirmation bias refers to when evidence is sought or interpreted in a manner that aligns to “existing beliefs, expectations, or a hypothesis in hand” (Nickerson, 1998: 175) and has been associated with restricted human capacity for processing information (Befani, 2020). Its presence has been theorised to occur in both the searching for and interpretation of information (Tappin and Gadsby, 2019). Confirmation bias can lead to a form of partial, and therefore less reliable, information processing (Peters et al, 2020). Confirmation bias is unintentional, and therefore not deliberate (McSweeney, 2021) and has been considered to emerge more as an inclination, as opposed to consistently flawed judgement, due to the implication in the of “some standard of optimality” (Klayman, 1995: 442). These factors suggest that the presence of confirmation bias is difficult to trace and consequently requires self-awareness, vigilance and methods of mitigation from the side of the researcher. Extensive prior knowledge and experience of the field represents a factor that may create heightened risk of confirmation bias, and therefore warrants discussion of the measures employed to mitigate.

5.2.1.1 Methods to guard against confirmation bias

5.2.1.1.1 Reflexivity

The role of reflexivity was central to attempts to uncover and engage with the researcher’s own bias and was a powerful tool in addressing confirmation bias. In respect to confirmation bias, bracketing, which took place initially and during the research process, enabled a raising of awareness of prior biases and preconceptions that could lead to confirmation bias. The importance of embedding reflexivity within research that is collaborative has been highlighted by Olmos-Vega and colleagues (2023), and whilst this was largely a personal undertaking, it also encompassed a level of peer review via the supervision team, adding a level of accountability and transparency to the process.

5.2.1.1.2 Data source triangulation

Triangulation has been cited as a method of testing validity within research by incorporating data from a range of sources (Carter et al, 2014). The use of both interviews and observation notes enabled triangulation of data sources, which in turn contributes to a guarding of individual researcher bias (Patton, 1999).

5.2.1.1.3 Theory confirmation

Confirmation bias has been identified as a threat when researchers seek to confirm a theory (Greenwald et al, 1986). In the present study, in terms of theory, the aim was to explore the extent to which biographical disruption was useful in understanding recovery following a brain injury. In that respect, there was no pressure to prove, or disprove the theory. Furthermore, the use of long quotes provided transparency and credibility to the researcher’s interpretation (Onwuegbuzie and Leech, 2007), giving clarity to where linkages to theory emerged from.

5.2.1.1.4 Personal history as a method of mitigation

Awareness of the role of personal history served as a consistent form of mitigation of confirmation bias. As discussed, my own conceptualisation of brain injury consciously began following the brain injury sustained by my sibling. As mentioned, I witnessed my sibling’s experience for a decade before my own and made many assumptions regarding recovery. The experience of my own injury underlined how poorly I had understood it at the time. Whilst my own knowledge has been subsequently augmented by my own personal and professional experience, there remains an awareness that I was ignorant, and that I perceived and judged my sibling’s experience based on what I wanted to see, rather than attempting to understand more from their perspective. Furthermore, I am acutely aware that my sibling’s experiences, whilst having some overlaps, diverged sharply from mine from the point of the onset of the injury. It is a humility that was forced on me and is still the subject of some pain. This does not ensure that confirmation bias is erased but contributes to a principle regarding the need to foreground participants’ experiences and perspectives in addition to an awareness to be vigilant of any tendency to second-guess based on prior experience.

5.2.1.2 What did I want to confirm?

When considering the presence of confirmation bias, it is worthwhile to consider what it is that I, both as a researcher and a person with a brain injury, wanted to confirm. The following section will provide examples of three areas in which I believe this was the case, beginning with a desire to confirm a bias regarding the social model of disability.

5.2.1.2.1 Critiquing the Social Model

McSweeney (2021) highlights that whilst research that is ‘trustworthy’ can still reflect beliefs held or anticipated prior to the research project, “to be trustworthy it must be open to surprise” (2021: 1065). One area in which I was ‘surprised’ was my expectation that the research would provide more data relating to the experience of living with pain and impairment. I align with feminist critiques of the social model (Morris, 1991; Crow, 1996; Thomas, 1999), which highlight the model’s struggle to adequately encapsulate impairment.

In respect to my own experience, Crow’s (1996) call to renew the social model, and her writing on pain particularly resonated with me. Pain (discussed in Chapter 12) is perhaps the most overt and consistent aspect of my injury that affects my life and is an aspect of brain injury that is poorly served in the literature. It is wrong to say that I ‘hoped’ for the participants to provide data regarding this, as I would rather nobody else experienced pain, but I suspect I would have been at risk of giving such data extra prominence. I would contend that this was not to give validation to my own experience, but to tell the world that people experience this, and it deserves more recognition. Data relating to pain wasn’t, however, plentiful. The possibility that such data could have been more present had semi-structured interviews taken place, and how I would have interpreted such data, remains unknown and serves as a reflexive learning for future study in the area.

My practice was also informed by my own experience as a research participant following my brain injury. I had taken part in a research project on identity following my own injury where I believed much was lost due to the rigidity of the questions not leaving space for me to say what was important to me. At the time of the interview, I was very much the product of a process of medicalisation, and so the clinical nature of the interview probably felt familiar and, in its own way, comfortable. Critically engaging with this experience, informed by my subsequent immersion in the social model, contributed to me seeking methods which foregrounded the voices of the participants. By asking one question in my interviews - ‘can you tell me about your life?’ (see Appendix 7 Topic guide for interviews) - I attempted to negate a repetition of pre-existing medical power dynamics that my participants were likely to have been exposed to. Reflexivity further shaped my interviews as I chose not to take any notes during the interviews to avoid replicating the physical environments such as medical and social security assessments.

5.2.1.2.2 People like me

Did I want to talk to people whose experience mirrored my own and so confirmed my own personal biases? I don’t believe this was the case, but the sampling within a support group ensured that participants were older, from a range of different backgrounds, and had sustained an injury which, whilst grouped under the term ‘brain injury’, are unique in terms of injury and its resultant impacts. Furthermore, my previous research in the area engaged mostly young adults which this support group had little representation of (as highlighted in section 7.9), and so there was an expectation from the outset that experiences and perspectives would be different, constraining the likelihood of confirmation bias in this respect.

5.2.1.2.3 Issues with the parent organisation

As the research developed, I became more aware that I was beginning to question the role of the support group's parent organisation, particularly in relation to its general messaging and portrayal of people with brain injury, as well as the organisational structure of the support group itself. Within the thesis, there is data relating to a specific instance of the dichotomy between trustees and members (section 10.7). I was aware that my own opinion (and emotions) was potentially an issue in this regard. To address this, I returned to the literature to interrogate the historical foundations and development of charities themselves (see section 4.2). Furthermore, the adoption of human rights helped me consider the role of the charity as a duty-bearer, which helped to conceptualise the unease I had felt. In doing so, I was able to situate what was prior more of a private trouble, as a public issue (Mills, 1959), and in doing so confront a fertile ground for confirmation bias.

5.3 Research design

With a desire to bring out the lived experiences of hidden, marginalised voices, qualitative methods of data collection were deemed most appropriate, and this section will defend this decision. Qualitative methods allow for an in-depth exploration of people's experiences and the contextual structures that shape these experiences. Interviews allow participants control over the story that they tell. It is a form of communication that they have practiced, even if they have not participated in research before. I wanted the themes and issues addressed in the findings chapters to emerge from the data, and directly and authentically reflect the issues most relevant to the participants.

Given the focus of the research, it was deemed that the use of such methods would allow for a fuller appreciation of the barriers facing participants and facilitate a better conceptualisation. Urrieta and Hatt (2019) contend that qualitative approaches allow a 'more intimate' exploration of experiential knowledge of identity. Roger and colleagues (2018) also set out that exploring identity is at the core of qualitative research. Their paper, which employed autoethnographic methods, concluded that qualitative research can act as a 'social bridge, and provide "new ways of looking at what is real and what daily lived experience can be like” (Roger et al, 2018: 538). Further, the work of Bury (1982) which proposed the theory of biographical disruption was based upon qualitative methods, and this gave further inertance to the decision to employ these methods as an approach to the research questions. Quantitative measures rely on the researcher knowing what questions to ask. Further if the participant misunderstands the question, there is no negotiation available to arrive at a shared meaning. They do not typically help generate new theory, being better suited to deductively test the validity of an existing theory. As one of the first sociological explorations of what it is to live with a brain injury, I wanted to produce data and use an analytical framework that permitted deep understandings that could potentially, generate a theoretical base for further study.

The theory of biographical disruption worked as an anchor. It anchors this work into a particular literature, but also helps frame the research as being able to acknowledge the trauma (disruption) while also centring around living and experience (biographical). The use of biographical disruption - developed to capture life lived with chronic conditions - was an exploratory ‘experiment’ when applied to brain injury. Qualitative measures are useful in this case as they provide an in-depth understanding of social phenomena, capturing the complexity of human experience and allowing for detailed and nuanced analysis. Further, they are conductive to detailing the experience of a small number of individuals, who robustly detail personal and intimate data. Indeed, the interviews were richly detailed, and participants shared their perspectives, emotions, motivations, and shared other contextual factors. Instead of constraining responses to predefined categories, these methods enable the exploration of a range of responses.

5.3.1 Ethnography

Ethnography was selected as a method as the research required a deep understanding of both the holistic experience of brain injury, and to enable observation and subsequent knowledge production relating to the support group. Exactly what constitutes an ‘ethnography’ is contested. O’Byrne contends that the objective of an ethnographic study is “to describe and interpret a specific culture or social group” (O’Byrne, 2007: 1382). Krefting (1989) builds on this, contending that there is a requirement to “gain insight into the experience of a member of a particular subculture” (1989: 69). Its observation can provide information of the physical environment (Mulhall, 2003), which is of particular relevance when investigating the lived experience of disability. It is clearly an approach to research that encompasses a wide range of approaches. Davies (2008) discusses her adoption of

> "…a broad interpretation of ethnography as a research process based on fieldwork using a variety of mainly (but not exclusively) qualitative research techniques but including engagement in the lives of those being studied over an extended period of time" (Davies, 2008: 5).

Ethnography aims to combine knowledge "gained from the people in a particular culture in addition to the knowledge gained about them" (Krefting and Krefting, 1991: 429). The time spent gaining this knowledge amongst the lives of those you are researching, appears to be central to the practice, even if it is itself, an area of contention. Ellis (2007) described the effect of time spent in the field, and how participants

> "…seemed to forget I was doing "research" and did not respond as though that were a salient part of my identity. After all, I was involved in their lives, and there were more important things to think about—funerals and doctors to go to, killings to be straightened out, sick babies to tend, and welfare checks that didn't arrive on time. Writing a research paper hardly measured up to the trials of everyday life" (Ellis, 2007: 6-7).

It is an approach to research that can be understood to be receptive to the understanding of marginalised, or 'hidden' voices. From this the possibility emerges that the insight gained can be applied to create a research process that is collaborative and places these precious experiences at the forefront of the knowledge or outputs that are produced. Lawlor contends that "the social aspects of ethnography are also fuelled by the ways in which research participants and researchers develop a shared repertoire of experiences" (Lawlor, 2003: 34). This 'shared repertoire' does not ensure that it is a process where ethical and methodological questions will not feature. The changing nature of these relationships requires that "as part of relational ethics, we seek to deal with the reality and practice of changing relationships with our research participants over time" (Ellis, 2007: 4). This highlights the need to embed reflexive practice, and to apply it as a tool "to demonstrate one's awareness of the research problematics and […] to potentially validate and legitimize the research precisely by raising questions about the research process" (Pillow, 2003: 179). Given that the researcher has pre-existing insight of the experiences of living with a brain injury, a level of insight, necessary for ethnographic study, into the experience of the group exists (Krefting, 1989: 69). This does not however necessarily cover the intersectional experiences of participants, which dictates the need for reflexive practice and methods, to be discussed, which aim to provide further insight and foreground participants voices.

Participant observation provides an opportunity to both engage in and observe the scene, capturing the wider social setting (Krefting, 1989; Mulhall, 2003). Participant observation in the context of brain injury research has been found particularly useful, because "what people say is not always reflected in what they do" (Krefting, 1989: 69). Mulhall (2003) discusses two main 'stances' in observation - structured and unstructured - that can be adopted. The first, structured, involves the aim to be apart from what you are observing and to maintain (if this is even possible), a sense of objectivity. Unstructured observers enter the field from the position "that it is impossible to separate researcher from 'researched'" (ibid: 307). Fieldnotes from participant observation support the construction of "thick, rich descriptions of the study context, encounter, interview, focus group, and document's valuable contextual data" (Phillippi and Lauderdale, 2018: 382).

Fine (1993) discusses issues with recalling quotations of conversations carried out during participant observation:

> "One would need a gifted, encyclopaedic ear: an ear never seen. When conscientiously compiled, the quotations are both true and false. They are true in that, with conscientious researchers, they represent something "along the lines" of what was said – transformed into our own words that we place in a methodologically unsanitary way in the mouths of others" (Fine, 1993: 278).

Interviews separate to the observations, therefore, provide an opportunity to provide a platform, albeit one that is altered from the environment that the observations may be taking place in. Mulhall (2003) uses the analogy of a jigsaw puzzle to describe the relationship between interviews and observations, and its value as a method within a wider ethnographic approach: "Interviews with individuals provide the pieces of the jigsaw and these pieces are then fitted into the 'picture on the box' which is gained through observation" (Mulhall, 2003: 308). This recognises that the value of what goes on outwith the traditional, organised, and clearly delineated spaces where researchers gather their data. The figurative 'research space', or period, between the recording of what is encountered in the field and the more 'formal' method of data collection has been referred to as the 'waiting field' (Mannay and Morgan, 2015). This 'waiting field' is of particular interest in ethnographic research as it uncovers valuable observations of others and the self that take place whilst 'real' life carries on (ibid).

Ethnographic approaches ensure that “researchers are immersed in the field where spaces are never empty” (Mannay, 2015: 170). Ethnographic - and other - fieldnotes may also include information relating to societal pressures, of local events that have had an impact; this may further include information on any tensions that relate to particular groups such as ethnicity and socio-economic status, paying particular attention if those who are taking part in the study belong to a marginalised group (Phillippi and Lauderdale, 2018). This is of particular importance in the case of brain injury research given that everyone in the group is marginalised due to their injury. Beyond the primary function of recording what we observe or experience, fieldnotes shine a light on the process between what we see when we are in the field, and what leads to our analysis, serving as “…illustrative examples of ways in which shared cultural understandings and our more local pre-assumptions have a bearing on what knowledge we produce and how” (Erikkson et al, 2012: 19). In this regard, an awareness of what these notes contain, can help build a more robust analysis, and produce a more aware and reflexive research practice.

This reflexive practice can also be understood to be physical, where our body and its senses can enable reflexive practice (Ellingson, 2006). Ellingson (2006) promotes the incorporation of autoethnographic narratives into ethnographic research by giving greater prominence to the ‘body’ of the researcher “as a site of knowledge production” (Ellingson, 2006: 303). This involves “drawing on all of the researcher’s senses, interrogating the connections between researchers’ bodily signifiers and their research processes, and engaging in serious play with the semantics of the self and body “ownership” (Ellingson, 2006: 303). The author encourages researchers to pay more attention to (and record) their senses beyond their sight, to utilise their smell, taste, touch and hearing in fieldnotes. Similarly, Ellingson (2006) advocates for approaches that interrogate “the specific ways in which bodily inscriptions affected a researcher’s process” (2006: 305). In Ellingson’s previous research which involved participant observation in an oncology clinic, her “misshapen leg and knee brace”, a result of bone cancer, helped her to connect with other oncology patients. This, she reflects, also proved a hindrance: it “drew unwanted attention that affected my participant observation. I am marked physically as a patient, even when I want to be perceived as a researcher, demonstrating the slipperiness of categories” (2006: 306). A separate process occurred in this research, where my own lack of visible injury was commented on, and highlights that observations are a two-way process.

Carrying out research in the field of brain injury, whilst living with the effects of a brain injury myself, has instilled reflexive practice throughout every step of this study. Autoethnographic narratives have been central to this process. Birk (2013) captures this profound relationship between the body and our narratives in the following quote:

> "All ideas arise from within the walls of the body. All thoughts are shaped by the contours of our ultimate material condition. No idea or experience is free from the constraints of the absolute structures of skin, muscle, and bone. Broken bodies whose wounds have been sustained through trauma often produce narrators whose voices are as halting as their gait and whose narratives are as fractured as their bodies" (Birk, 2013: 396).

This links into a further method that was employed during this research, incorporating my own lived experience of brain injury, both in caring for someone who suffered one, before suffering one myself.

5.3.2 Autoethnography

Autoethnography is a method that contains and joins elements of both autobiography and ethnography (Ellis et al, 2011). The autoethnographic approach, whilst gaining popularity more in the last two decades (Chang, 2016), has its roots in early sociological practice (Anderson, 2006). It is a contested term and one which encapsulates "interesting, boring, and revealing memoirs, recollections, personal journals, stories, and ethnographic accounts under the same name" (Charmaz, 2006: 397). It goes beyond mere recollection by placing the experience of the researcher within specific social contexts and using this to generate enquiry into areas of social agency (Naidu, 2014). This connection between the personal experience and the social is key, as is an understanding of the social context of the phenomenon beyond their own experience (Chang, 2016). The narratives produced can "…(potentially) offer embodied details, celebrate the author's position, problematize the production of knowledge, and reveal the profane in the sacred processes of research" (Ellingson, 2006: 304). It is an approach, that in narratives that explore illness, is "uniquely suited to acknowledge the role of one's own body in knowledge production and reflexivity" (Birk, 2013: 391). It can enable the voice of the 'patient', often silenced, to become prominent, and be utilised to explore the experience of injury and disability (Shankar, 2018).

The form of autoethnography that is employed is dependent on the level of focus that the researcher decides to place "on the study of others, the researcher's self and interaction with others, traditional analysis, and the interview context, as well as on power relationships" (Ellis et al, 2011: 278). What constitutes autoethnography, and the analytical approach required, has been the subject of debate. This is exemplified by the debate surrounding the two main approaches: evocative autoethnography and analytic autoethnography. Evocative autoethnography, has received critique to what is perceived to be a lack of traditional social science analytical approaches (Anderson, 2006; Charmaz, 2006; Learmonth and Humphreys, 2012). Autoethnographic approaches where personal narratives in particular do not contain these traditional analytical approaches, have been considered particularly controversial (Ellis et al, 2011). The method has been critiqued for a lack of clarity in terms of the extent to which autoethnographers claim to speak "for the described experience" (Charmaz, 2006: 398). This suggests the need for caution, and reflexivity (layered as it is within an approach that aims to embed it), when attempting to combine an evocative approach, with research that aims to project the voices of research participants that have previously remained hidden.

It has been suggested that to carry out an autoethnography the researcher must be "a complete member in the social world under study" (Anderson, 2006: 379). What constitutes a complete member is a problematic term. Do we always maintain membership of groups? Does a diagnosis - given under very different circumstances to that which a researcher may find themselves today - still ensure this 'complete membership? This membership, or the complexities of it will be challenged in the process; a process that carries with it "the possibility of seeing more of what we ignore in both ourselves and others, asking why it is ignored, and what we might need to do about it" (Dauphinee, 2010: 818). Taber (2010) builds on this, considering whether "by researching others, was I finding a way to hide from my own experiences, and keep them at a safe distance in the background? Should I not foreground my own experiences, and explore them myself, instead of asking others to do it for me?" (Taber, 2010: 8). The researcher can therefore expect to reveal these areas of 'membership' that are difficult to acknowledge, or that they have abandoned. This highlights its possible application as a device for researchers who apply the method to consider how their experience impacts, both positively and negatively, on the research process. Pillow (2003) describes reflexivity as being a tool that highlights "one's awareness of the research problematics and is often used to potentially validate and legitimize the research precisely by raising questions about the research process" (2003: 179). Autoethnography offers great possibilities in enabling those undertaking it to embed strong reflexive practice in their work.

It is critical within social research that there is both connection and separation from the research subject (Davies, 2008), and this is particularly relevant in the case of autoethnography.

Autoethnography is a method that brings with it unique issues for the researcher to consider, issues that stretch beyond matters methodological. Lawlor proposes that “the ethnographer must learn to be open to vulnerability and to negotiate the often ambiguous implications of a vulnerable stance” (Lawlor, 2003: 33). This vulnerability in the case of autoethnography requires a degree of disclosure that once out cannot be returned. Is it worth it for the sake of a piece of research when other methods allow (and insist on) reflexivity without this level of disclosure? Is it possible to really know the impacts of this before it is too late? Where this approach takes the researcher, and the implications for the research, are areas that require careful consideration prior, during, and even after the culmination of the research process. The autoethnographic chapter (see Chapter 12 provides an account of how I became an ‘insider’, and my pre-existing knowledge of brain injury. The autoethnography positions my experience of becoming ‘brain injured’ within the wider story of becoming a researcher. The chapter employs Frank’s (1995) illness narratives as an analytical framework to analyse my own account of the fieldwork, from which a dominant ‘chaos narrative’ emerged. Furthermore, it details my precarious growth as a researcher, and the embodied challenges I experience as a person with a brain injury.

5.4 Researcher positionality, reflexivity, and the insider perspective

As already mentioned, this thesis was born, in some ways, from an emotional engagement with brain injury. Before it could be understood as a neutral or objective area of academic study, the field of brain injury was known subjectively. In this section, I will outline how I used principles of research integrity and reflexivity to better understand my positionality in order to expose to myself and to the reader my insider status. By making this apparent in my introduction and throughout the thesis (including an autoethnography chapter), I make it open to scrutiny in the hope that this transparency frees my approach and work from harmful bias. As discussed above, I did not feel the need to produce a thesis that was entirely neutral or value free; I hold that disabled people should live in a world where they are not unreasonably disadvantaged. As Ferrie and Greenwood (2023) argue, emotion is part of our realities and acknowledging it during fieldwork, and in writing about research is essential.

Failure to acknowledge emotion limits our data, and, as a result, our "understandings of the social world will remain impoverished" (Hubbard et al, 2001: 119). This is developed further in the section on Ethical considerations (5.7) found on page 143.

Insider status is a fluid concept with many benefits, but one which requires consideration of its complexity and consideration of how and to what extent it shapes the production of knowledge (Hayfield and Huxley, 2015). Insider status can enable the development of relationships and trust to develop more quickly, alongside a heightened sense of accountability (Voloder and Kirpitchenko, 2013; Rosenberg and Tilly, 2021). For oppressed groups, insider status can encourage participation in the study and contribute to interview environments that are safe and encouraging (Rosenberg and Tilly, 2021). Having insider status, whilst being of benefit, does not automatically equate to a researcher being the most suitable person to carry out the research, and is itself a category that is not clear-cut (Gair, 2012; Hayfield and Huxley, 2015). There is a risk that participants react to this insider status by assuming that shared knowledge is always understood (Hayfield and Huxley, 2015). Whilst sharing a common experience or condition may provide insider status, different characteristics and personal and social experiences may diminish the shared experience (Bridges, 2001). Being open about one's own experience can help build trust and rapport and bring understanding regarding the researcher's motivation for carrying out the research (Hayfield and Huxley, 2015).

Previous research into brain injury carried out by a researcher with a brain injury discussed insider status and considered the use of three different lenses – that of acquired brain injury (ABI) survivor, that of a researcher, and that of a clinician (Harvey, 2018). Awareness of these three separate lenses, Harvey (2018) believed, made him "ideally placed to provide insight into the life of ABI survivors" (2018: 57). To adopt the same thinking, the four lenses applied in this research would be: person with a brain injury, researcher, volunteer, and family member of an ABI survivor (given the serious brain injury that my sibling sustained ten years prior). These were not lenses that were neatly applied and removed in this current thesis. Each lens was subject to flow and revision, depending on the context. This was not always conscious as it is a part of my everyday life and came more to the fore when I was experiencing pain or tiredness, or when someone asked me about my own experience. I have never identified with the term 'survivor', although I recognise that the term can be a powerful tool and emerges in illness narratives across a range of illnesses and health conditions (Frank, 1995).

Harvey (2018) viewed notions of insider/outsider status in his research to be problematic, but still considered that he

> “benefitted hugely from my joining an ABI support group and forming equal and reciprocal relationships with participants prior to data collection. I created these reciprocal relationships largely due to my personal experience of identity (re)construction together with my reading of literature concerning identity which suggest that it is constructed of a plethora of divergent and fluid strands, meaning that the sharing of a single aspect of identity does not render any person the same as another” (2018: 131).

The reciprocal relationships that were formed in this thesis were less due to academic understanding, and more due to my personal experience and my willingness to take part. Whilst this was a different group, my previous experiences of brain injury and support groups ensured that it was a space - minus the usual social anxiety - that I was comfortable and safe in, surrounded by peers.

5.4.1 How reflexivity was practised

What reflexivity is, and how it is practised in research, is subject to a range of interpretations (Day, 2012). This debate extends to reflexive methods such as bracketing, with decisions such as what specific methods are employed and when, and who should take part in the process (Tufford and Newman, 2010). Its use may raise more questions than answers and does not serve as a panacea to all research problematics, but as a means “to bring methodological dilemmas to the forefront in the first place (Day, 2012: 82). When reflexivity is present it should transparent, highlighting and unpacking how reflexivity was addressed throughout the process (Dodgson, 2019). The following section will detail how reflexivity was practised during the research process, why these specific approaches were selected, and the impact and learnings this produced in relation to the research.

5.4.2 Reflexivity through initial bracketing of experiences

I felt prepared to bracket my own experiences as I had previously in similar research, both in written form (by making and reviewing fieldnotes) and in discussions with my supervisors and colleagues throughout the research process. As discussed, bracketing off my own experience of brain injury was fairly straightforward as there were many experiences the participants had that I did not, and vice versa. From the earliest days of my own injury, I was also acutely aware that my own experience was different to that of my sibling, which has encouraged humility and awareness that our experiences, whilst linked, are individual and unique.

5.4.3 Reflexivity in method selection

The selection of biographical interviews served a key purpose that was informed by my own reflexive practice - to mitigate the influence of my own perspective and ensure the research data was driven primarily by the experiences and perspectives of the participants. By engaging in methodological reflexivity, I was able to examine the "ethical, social and political considerations that govern the field of enquiry" (Patnaik, 2013: 101-102). Davies (2020), reflecting on their own reflexive practice throughout their PhD, stated the need to engage methodologies "that resonated with my world view and cognitive style and matched my research goal" (Davies, 2020: 39). The selection of the biographical method, and the shaping of the research along phenomenological epistemological lines, matched my 'world view' that disabled people are themselves best placed to provide their own perspectives and experiences. Given that phenomenological enquiry is concerned with the description of phenomena that is drawn from subjective life experience (Wall et al 2004), my methodological approach, informed by my own reflexive practice, also met my research goals. Reflexive practice did, therefore, emerge as a methodological contributor.

5.4.4 Reflexivity through self-disclosure

I was open with my own history of brain injury throughout my engagement with participants, primarily by speaking to the group, and to members individually – including to those who were new and those who had returned to the group during my fieldwork. A similar form of disclosure took place with the relevant stakeholders, i.e., the organisation co-funding the research (who knew my history well prior), the organisation that granted me access to the support group where fieldwork took place, and the University of Glasgow's ethics committee. Whilst this can be a challenging undertaking, I felt more comfortable discussing my status with peers than with the host organisation's board of people who I had (with one exception) never met before, or the ethics committee (whom I did not meet but submitted my application to). Self-disclosure contributed to a greater appreciation of the "intersubjectivity of qualitative work" (Patnaik, 2013: 101), and provided, alongside my disclosure of my academic credentials and research purpose, transparency as to where I was coming from and where I was attempting to go.

5.4.5 Reflexivity though fieldnotes

I recorded fieldnotes throughout the PhD journey. At the beginning, these were mostly loosely structured and captured any ideas and questions that were raised. Once in the field, I kept a field diary where I followed a proforma (see Appendix 6 - Participant observation proforma). These notes served as a record of what I perceived to have taken place at the support group. The fieldnotes provided insights into those aspects that were not captured in interviews, such as power and interpersonal dynamics (both between me and the participants, and within the group itself). By returning to these notes repeatedly (including when the formal decision was made to incorporate the fieldnotes as a prominent data source), an awareness was embedded that "What we 'see' in our qualitative investigations must thus be reflexively thought of as 'what we think we see,' questioning the basis upon which we have made this interpretation" (Day, 2012: 64). Reflexive engagement at this stage informed methodological choices. Most explicitly, this is evidenced in the incorporation of an additional section of 'embodiment' to the fieldnote proforma. In this regard, reflexive practice, borne through bracketing both recognised and altered the process of knowledge production. The additional data recorded is discussed at length in section 5.5, and reflects that my attempts at reflexivity were not neat and linear, but were messy and more redolent of "examples that may not always be successful, examples that do not seek a comfortable, transcendent end-point but leave us in the uncomfortable realities of doing engaged qualitative research" (Pillow, 2003: 193).

5.4.6 Reflexivity during interviews (or lack thereof?)

I did not afford myself the same accessibility options, whilst I informed participants of the possibility of breaks, I did not consider the possibility that I may too need a break, be it because of cognitive fatigue or of feeling ill. Considering the longest interview took over an hour and a half, I may have needed that. In that sense, I imposed a power dynamic and separation between myself and my participants, I was a brain-injured peer elsewhere but not in that space, where the competent and able researcher social role subconsciously emerged. Whilst there are various pressures that may contribute to keeping interviews going regardless of how one feels physically, cognitively, or emotionally, I could have explained that I too may need to pause or suspend the interview, which in turn may have empowered my participants to do the same. Such an approach, beyond making the process more accessible to me, could have further addressed power dynamics within the research.

5.4.7 Reflexivity through bracketing interviews

Specific interviews took place during and after fieldwork between myself and my supervisor with the aim to bracket my experience, reflect on fieldwork and explore the use of autoethnography. These interviews took place over Zoom, which provided a transcript following the meeting that enabled me to simply 'take-part' rather than take notes. These interviews held a two-fold purpose: to engage reflexively with the fieldwork and data, and to explore the possibility of an autoethnographic component to the research. During these interviews, my own positionality with regards to my questioning of the structures and roles of charities that grew during fieldwork, became explicit. This informed the decision to engage with the literature on this subject (see Chapter 4) and enabled me to interrogate its value and relevance to the overall thesis. Secondly, these interviews enabled space to explore the integration of my own experience into the thesis itself. By engaging my supervisor as an 'outside source', these served "as a means of both managing and engaging with the potentially powerful presuppositions and emotions born of lived experience" (Tufford and Newman, 2010: 87) which contributed significantly to the autoethnographic portion of the thesis found in Chapter 12 .

5.4.8 Reflexivity through autoethnography

My use of the autoethnographic method is a further example of a method of reflexivity used in the research. My use of this method reflects a commitment to reflexivity that goes beyond an examination of the researcher's influence on the research, but also the influence of the research on the researcher (Wiant et al, 2022: 99). The chapter on autoethnography, whilst specific, represents an explicit examination of the interplay of biography, material conditions and the effects of my own injury.

5.4.9 Reflexivity through analysis

During the analysis process, emergent codes, themes and sub-themes were discussed in supervision meetings. As I had previously held reflexive interviews with a member of the supervision team, who also knew me and my experience well, these discussions provided a further layer of reflexive practice.

5.5 Methods and sampling selected for this research

5.5.1 Brief overview

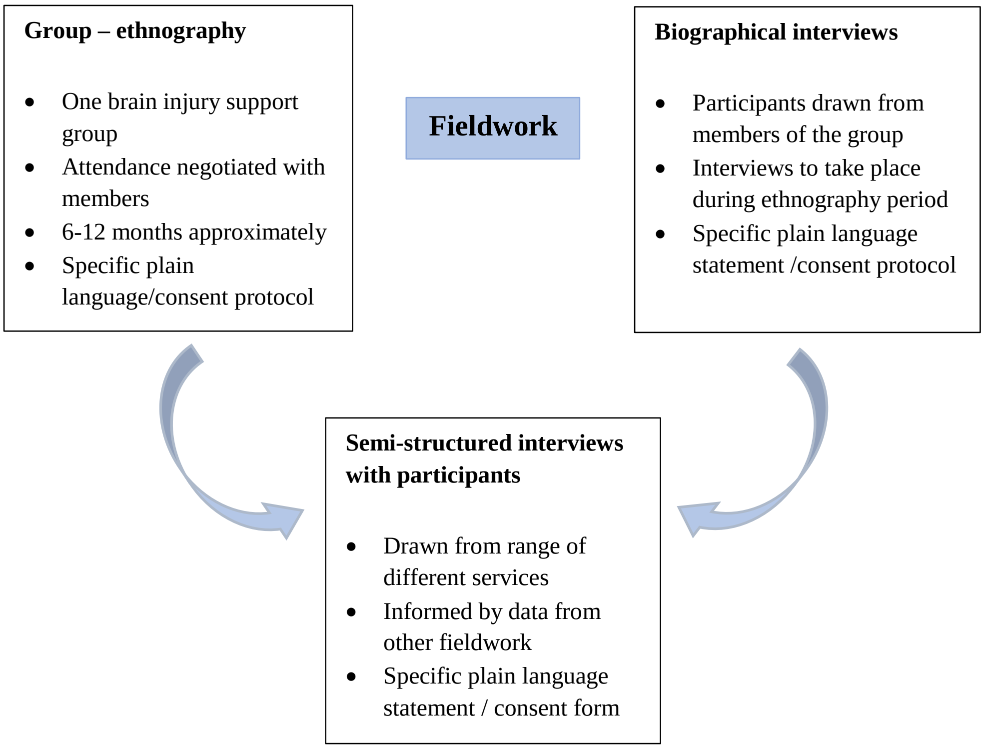
Setting up this research, I hoped to create spaces where participants felt safe to engage in an emotional presentation of their stories and narratives. As emotions are relational (Olson, Bellocchi and Dadich, 2020), I started by joining in with the existing peer-support group. The group aimed to support people with brain injury and their families (see Appendix 1 – Aims and objectives of the group). It was formed eighteen months prior to the beginning of my fieldwork, replacing an almost identical group that had folded previously. The group met every two weeks, with occasional informal meetings in between.

I was seeking a small number of individuals to partake which could provide a rich set of experiences and perspectives. A form of convenience sampling was, therefore, employed with regards to the selection of the group I approached to involve participants from. It was my judgement, that due to the subject matter, and the partnership element of the thesis, a support group would be an interesting and appropriate place to embed the research in order to ensure a representative cohort of the community of those with a brain injury. Convenience sampling can, in some cases, restrict the diversity of the selected sample (Ritchie et al., 2014). In the case of this research, the diversity of the sample was predetermined by its group members. Whilst this was not a homogenous group, its diversity could have been greater.

To gain a holistic understanding of people's experience of biographical disruption following a brain injury, a multi-method approach was selected consisting of two parallel phases. Phase one consisted of participant observation within a brain injury support group, and phase two entailed in-depth biographical interviews. A third phase of semi-structured interviews was planned, but unfortunately got broken off by the COVID pandemic.

Figure 5-1 below demonstrates the original planned process, and Figure 5-2 outlines how this has been adapted in response to the COVID pandemic:

Figure 5-1: Initial fieldwork plan



Fieldwork

Group – ethnography

- One brain injury support group
- Attendance negotiated with members
- 6-12 months approximately
- Specific plain language/consent protocol

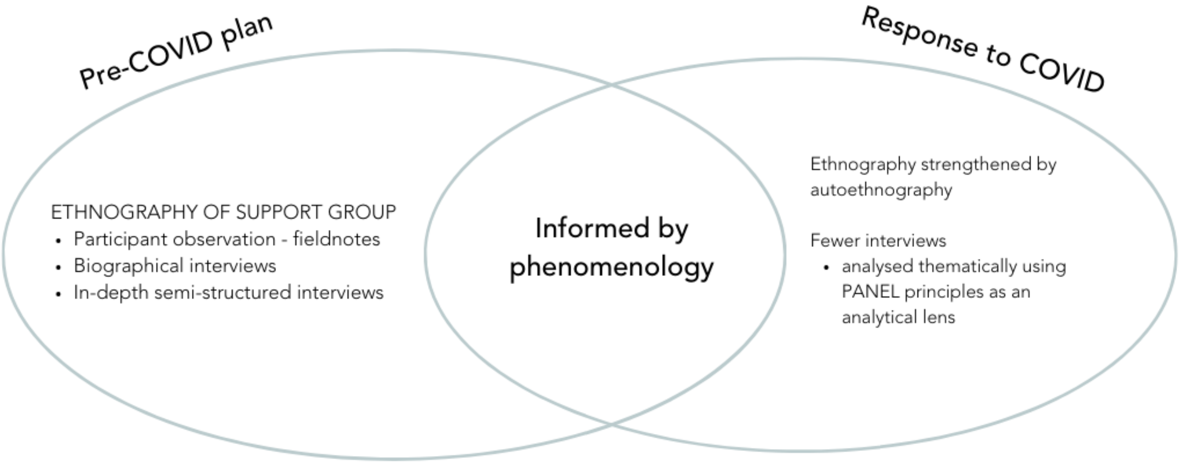
Biographical interviews

- Participants drawn from members of the group
- Interviews to take place during ethnography period
- Specific plain language statement /consent protocol

Semi-structured interviews with participants

- Drawn from range of different services
- Informed by data from other fieldwork
- Specific plain language statement / consent form

Figure 5-2: Fieldwork response to COVID pandemic



ETHNOGRAPHY OF SUPPORT GROUP
- Participant observation - fieldnotes
- Biographical interviews
- In-depth semi-structured interviews

Ethnography strengthened by autoethnography

Fewer interviews
- analysed thematically using PANEL principles as an analytical lens

This section will begin with a brief overview of the process of the group with which this research took place, covering the process of gaining access to the group, before delving into the three stages of data collection.

5.5.2 The initial stages

To begin fieldwork my research required that I pass through a range of gatekeepers. The first was the University of Glasgow ethics committee. The second was Headway Glasgow, whom are the main collaborative partners of this research project. This involved me meeting with staff at the charity and going through my approach. This had three objectives, to keep them informed of the progress of the research, but also to explain how the ethics system at the university works. This also presented an opportunity for the organisation to input their expertise and reflections on the process.

The third step was to attend a meeting with the board of the support group. This consisted of group members, professionals from related services, and local lawyers. The meeting was held at the offices of a legal firm who have representatives in several branches of the charity. I had previously gotten in touch with the Chair, whom I had met at previous events related to brain injury. I then sent an overview of the intended research and was invited to discuss it at one of their monthly board meetings. The meeting was positive, and access was granted.

The members of the group represented the most informal, but most critical, form of gatekeeping. Whilst this may have been received officially in the form of consent forms, it happened on a meeting-to-meeting basis in the form of the acceptance of my being there.

5.5.3 Seeking consent

As part of a commitment to emancipatory processes, during fieldwork consent was sought on several occasions. As memory impairments are a possible consequence of brain injury, a careful approach to informed consent was employed. At the first meeting of the group, after ethics had been approved, I spoke to the members and explained how the process of consent worked in regard to participant observation. I took time to discuss this individually and repeated this process the following meeting. After this I then gathered signatures at the next meeting (see Appendix 2 – Consent form for participant observation).

Copies of the plain language statement (see Appendix 3 – Plain language statement for participant observation). were at hand at every meeting, and if there was a new member or someone I had not met before, I would give them a copy, though not initially ask for consent. This was to give new members the same space that others had been afforded, and to try and keep things simple and relaxed as possible. It was also the aim to strike a balance between highlighting that the group was a research site, but that its main purpose as a peer support group was respected, and that I was committed to each member feeling that participation in the group did not require participation in the research.

Consent for the interviews followed a similar process. At the beginning of the interview, I gave the participant the Plain Language Statement (see Appendix 4 – Plain language statement for interviews) and either read through it with them or sat silent if they preferred. I showed them the consent form (see Appendix 5 – Consent form for interviews) and explained that I would like them to sign it at the end of the interview, if they still wished to consent.

In both cases I discussed the potential benefits to members (from both my own and their perspective) as I saw them, that the research could teach people something about what it is like to live with a brain injury and allow people to understand the groups better. Research participants can find the process of taking part in an interview to be positive "as it gives them a chance to express their opinion or unburden themselves to a sympathetic outsider" (Davies, 2008: 56). Whist this has been the case in my experience, and, I think in the interviews that form part of this ethnography, I did not present this, or encourage this view in anyone that shared it. This was also complicated in that I am an outsider to their own experience, but not in terms of experiencing the phenomena myself.

5.5.4 Data collection phase 1: participant observation

In this section, I outline the detail around the support groups. In borrowing from van Manen's (2014) use of phenomenology as a research tool, the rich detail here aims to deliver transparency and allows the reader rich insight into the setup of the support group and the research as it was articulated with the group. The transparency is also useful for positioning myself as a researcher, when indeed, I was eligible to be a support group member.

5.5.4.1 Why observe?

Phase 1 of the study consisted of participant observation. This method of data collection was selected as I was seeking to fulfil two aims. Firstly, to observe the support group environment itself to understand more about how members used the group for support, what they ‘got’ from the group, how they interacted within the space and learn more about how power, inclusion, participation and equality was ensured (or indeed if it was). Secondly, this enabled me to draw my own reflections on these matters through keeping fieldnotes and relating these understandings to both my own experiences, and the broader research questions.

5.5.4.2 Travelling to the group

The journey to the research site represented the liminal space between my home life and the field. I would leave my house, and depending on time, get the train to Glasgow Queen Street (12 mins). This changed after a few meetings, and I started to walk to the station (50 minutes). I would usually leave around 10:20 to give myself ample time to walk in my preferred route (past my university and through a park) and buy a coffee and my train tickets. This was slightly time-consuming as it required buying three separate tickets to save money due to a slightly Kafka-esque ticketing system. The platform would be announced at 11.30am (always the final platform to the right). The train itself was rarely busy and I would take a window seat on my own.

I would generally get the train around 11:30. Initially, I tried to use this time to work (PhD, prep for the undergraduate teaching I was doing at the time, answering emails) but in time found that I would be stepping off the train feeling tired. This changed to a rule (sometimes broken) that the trip up was for nothing more than chilling out and attempting to not eat my lunch.

The train would usually arrive around 13:00. The group took place in a central location around 10 minutes’ walk from the station. I would generally eat whatever lunch I had not eaten on a seat in the nearby shopping centre if it was cold or raining, or outside the location on a bench, and ‘people watch’.

5.5.4.3 Getting to the group

The group met in a church hall located in the city-centre of a Scottish City. The group meeting was located close to a bus stop and a train station is within close walking distance. To my knowledge, I was the only person who took the train to the group. A range of buses stopped outside and served rural areas, which were poorly served by rail transport. The group leader, regularly gave people lifts to help them attend. One member was able to park directly outside (a pedestrianised shopping area) due to their blue parking badge.

Some members had bus passes that provided free bus travel. This was dependent on the classified level of disability, as classified by the government in the case of Personal Independence Payment (PIP), or other factors such as someone having a specific condition that meant they were unable to drive, such as epilepsy, of which the brain injury community have a much higher incidence of, or for being over the age of 65 at which age people in Scotland receive a free bus pass. Train reductions are available on some of these cards, but are at a reduced, rather than free rate.

5.5.4.4 The Space

On entering, there was usually a member of staff at the reception desk which served both the church and the meeting rooms upstairs. This person was well known to members and became a friendly face for me which added to what I felt was a consistently warm and welcoming atmosphere at arrival.

The church itself had undergone extensive refurbishments and had the feel of a modern building in the interior. The group was held on the first floor, and was accessible by stairs, or lift. The closest accessible toilet was on the ground floor. There were two single cubicle toilets available via a small (4-5 steps) set of stairs next to the meeting space.

The group was held in a meeting room upstairs with accompanying kitchen space. The main room consisted of a set of tables arranged in a rectangular shape with seats all round. Seats were not allocated in any way although some people sat in the same seat at every meeting. The kitchen space served as a functional drinks and food preparation area. It also doubled as a chillout space and a quieter spot if people wanted to discuss something more privately with a staff member.

5.5.4.5 Time

The group informally started at 13:30 with a loose finishing time of 15:30 (the centre did not seem to impose the closing time). Members arrival times stretched from before 13:30 (there were usually a couple of people there when I arrived) to a steady stream over the next half-hour. People left in a steady stream and were usually gone by 16:00. I would generally leave with the last members.

5.5.4.6 The members of the group

Group meetings ranged from eight to twenty-five members. This included a range of people who had a brain injury, people who were there to support people, or had been affected themselves in some way. The group advertises on social media, Facebook, and is part of a referral system and directory of brain injury support groups. Also, word of mouth referrals happened from medical practitioners and other support groups.

5.5.4.7 Workers/Volunteers

The committee employed one person as the group leader. There were three regular volunteers, one of whom was the wife of a member, a volunteer student from the local university, and me. The committee or board of directors consists fully of volunteers

There were also two members who effectively volunteered within the group whilst taking part as full members: Sadie who delivered a variety of workshops, and Colin, who helped with making the tea each week. They may not have been registered as volunteers but carried out the same, if not enhanced, duties as me. My duties extended to helping to prepare the room and pack up at the end, alongside anything else I was asked to do.

5.5.4.8 Cost

There was a tub that was passed round during the meeting and members had the option of contributing £1 each. This was consistent with the other brain injury groups I had been a member of and worked with previously. Paying this was not a requirement of attending.

5.5.4.9 My role

My role within the group was primarily one of a volunteer. This involved helping set up whatever activity was on, making cups of tea, and sitting with the members and taking part in whatever was on. By taking orders and delivering the tea or coffee, I was able to say hello and talk to most members at the start of every meeting.

5.5.4.10 Activities at the group

At most meetings there was a distinct activity for members to take part in if they wished (see

Table 5-1 Overview of group activities). These activities were generally held in the same location; however, there were occasionally ‘trips out’ to locations such as concert halls. Workshops were led by both members and people who came in to deliver individual sessions or talks. The activities tended to take place in the middle of the meeting (e.g. 2pm-3pm). This allowed people to arrive and have a cup of tea, and ensured that the meeting did not end abruptly. Additionally, members of the group were occasionally offered the opportunity to attend events for free (such as the orchestra, whom members of the group had links with through an outreach programme). These constituted meetings in that members came together, but would not have a member of staff present.

Table 5-1 below outline the activities that were held throughout my time with the group:

Table 5-1 Overview of group activities

Date	Group Activities
11/09/2019	Talk on the Titanic
25/09/2019	Trip to Holyrood Palace, Edinburgh
03/10/2019	Classical music recital, RSNO, [location]
09/10/2019	Craft making (picture frame)
23/10/2019	Halloween party
06/11/2019	Talk on exercise/JFK talk
13/11/2019	Maggie's Centre (Outreach trip to brain tumour group
20/11/2019	Alternative therapies (Reiki/Head Massage)
18/12/2019	Christmas dinner at restaurant
08/01/2020	CAB talk on energy suppliers
22/01/2020	Burns Supper
05/02/2020	Valentines card making
19/02/2020	General chat/Corona hand washing

5.5.4.11 Note writing

> "Writing is done with fingers and arms and eyes: It is an embodied act, not mental conjuring, and we should reflect on the experience of writing our research just as we reflect on our experience of being at a research site" (Ellingson, 2006: 304).

I began with a basic proforma adapted from (Chiseri-Strater and Sunstein, 1997) (see Appendix 6 – Participant observation proforma). I practiced participant observation using this proforma and found that I was able to record what seemed like a reasonable number of interactions which I could then use for analysis. I had doubts as to how much information I would remember from each session due to the effects of my own brain injury and wanted a template that was simplistic primarily. The proforma developed organically. The main addition was the final title 'embodiment', which became the reflexive/auto-ethnographic element of the initial notetaking. Here I took care to see and record the embodied manifestations of social interaction (Williams and Bendelow, 1998). In so doing, I hoped to develop an understanding of the support group space as experienced by the members. Initially, as I learned how to record this, I focused a great deal on my own embodied positioning and interaction with the space. Over multiple visits to the group, I was increasingly able to understand and record how others related to the group and to the space.

The notetaking was not always consistent and was impacted by how I felt physically and cognitively at the time. This is also why I aimed to record the notes straight after the group was over. I recorded these notes in a local café close to the research site where I was able to access a quiet space.

I took a later train that allowed me to go for a walk as I often felt tired and at times emotional following the notetaking. I would generally phone a friend or a member of family and go for a walk. When I got off the train at Glasgow, I felt that I had slipped off my work boots so-to-speak and resumed my domestic identity. I generally took the next day off or tried to only do light duties as much as possible, as I was usually wiped out.

5.5.4.12 The ‘system’

> “The body as author of one’s thoughts, however, is invisible, a ghostwriter, to those whose able, painless bodies make embodiment feel effortless” (Birk, 2013: 397).

Carrying out the fieldwork exacerbated the effects of my chronic illness. By the end of my primary fieldwork gathering period, I had developed a wellness strategy to help ensure I was able to carry out the fieldwork in optimum condition and with as little impact as possible to the rest of the week. This made a positive impact on my quality of life during the process. The following is a collection of steps that I took to promote my own wellness during this time:

- All preparation is complete the night before, or if something pops up, prior to the walk into town
- Walk to the train station in the city centre regardless of the weather
- Leave with extra time to avoid stress with tickets or getting my coffee
- No work on the train to the group
- Write notes after

- Record truthfully how I felt cognitively
- No work on the train home from
- Commit to nothing social or otherwise on the evening of research unless it can easily be cancelled
- Avoid any work, when possible, the next day that is mentally draining
- Review the steps if I have a bad week

5.5.5 Data collection phase 2: biographical interviews

5.5.5.1 Why biographical interviews

With the interviews, I was seeking to learn much more about the personal experiences of group members, and in particular the barriers they face in their life since diagnosis. I was seeking to – as far as possible – get an appreciation of the disruption it had caused them – in their daily lives, but also in their biography and understanding of their self.

Biographical interviews play a crucial role in disability studies research for several reasons. Firstly, they provide a platform for individuals with disabilities to share their lived experiences, giving voice to marginalised perspectives. They should allow for a raw, and true expression of the self, away from the labelling and stigma that can be externally attached to understandings of disability.

These interviews capture the nuances and complexities of disability, shedding light on the social, cultural, and personal dimensions of disability identity. They reveal how disability intersects with other aspects of an individual's life, such as family dynamics, employment, and social relationships - which was key to developing understanding of biographical disruption. Biographical interviews also contribute to a more comprehensive understanding of disability, and empower individuals with disabilities, fostering inclusivity and social change.

The form of unstructured biographical interviews was selected to allow the interviewee to provide an understanding from their own perspective. This approach is seen as beneficial as it helps to make participants feel unassessed and at ease (Hannabuss, 1996). Each interview opened with the question ‘Can you tell me about your life?’ (see Appendix 7 – Topic guide for interviews). This opening question was selected as it allowed participants to speak about what they deemed important. This also served as a good preparation for what was going to be a follow-up semi-structured interview.

5.5.5.2 Recruitment

I mentioned when I first spoke to the group, that I intended to carry out research interviews. This was at a meeting a few months prior to the start of my fieldwork. I then reiterated the plan for my research when I joined the group formally. Interviews began around four months later.

The process of recruitment was informal. Prior to the interviews beginning, I spoke again to the members to let them know that I was now starting to interview people in the coming weeks. I then spoke individually to people over a number of weeks to give them more detail if they were interested.

I decided that I would interview any group member that wanted to take part, which averaged around 15 members. This could have led to more interviews than I may have been looking for. However, I considered it integral to my relationship with the members of the group that nobody was excluded should they wish to take part.

Once someone had expressed an interest, I would discuss in detail and take any questions. This also provided an opportunity to discuss any issues around access. We would then pick a provisional date to interview. All the interviews took place on alternate Wednesdays to when the group was on. The times were selected by the participants and ranged from 11am-3pm. The interviews lasted between 25 and 90 minutes.

5.5.5.3 Participants

There was a total of 6 interviews with 7 participants. Six were members of the group, one participant was the partner of a group member, who in addition to being a member themselves, also volunteered at the group (see Table 5-2 below for demographic data). All interviews were one-to-one apart from the interview with Sarah and John, where John’s support worker was also in attendance.

Table 5-2: Participant information demographic data

Participant data					
Pseudonym	**Gender**	**Age**	**Ethnic Background**	**Marital Status**	**Employment Status**
Colin	Male	55-64	White Scottish	Single/unknown	Retired on health grounds
Sadie	Female	45-54	White Scottish	Married	Retired on health grounds
Andy	Male	45-54	White Scottish	Single/unknown	Student
Tommy	Male	55-64	White Scottish	Single/unknown	Retired on health grounds
Vaila	Female	55-64	Asian British	Married	Unemployed
John and Sarah	Male (John), Female (Sarah)	55-64 (both)	White Scottish	Married	Retired on health grounds (John) Carer (Sarah)

5.5.5.4 Ensuring accessibility

Interviews were held in a meeting room on the 2nd floor above where the group was held. The room contained three sofas and a table. This floor was accessible by stairs and a lift, with the nearest toilet being accessible by a flight of stairs or by the lift. This room was also familiar to the participants as it was where the ‘alternative’ therapies were carried out.

At the interview, participants were offered a yellow and red card to use as a means to suspend or terminate the interview should they wish to do so. Participants were also asked if they would like to bring along any archival material that they feel is relevant to their life story. This could, for example, be a photograph or an old train ticket; anything that the person feels is particularly relevant. Bringing something along may help the participant dictate how their story is told. It may also make the process more accessible to people who find traditional forms of communication, or the interview process, difficult.

5.5.6 Planned phase 3 – semi-structured interviews

Phase three of the research planned to employ follow-up semi-structured interviews with previously interviewed participants. Semi-structured interviews enable in-depth discussions of participants’ experiences whilst ensuring the meeting of the research objectives (Yeo *et* *al.*, 2014). Planned discussions were centred around participants' experiences of life following a brain injury, and their attendance of a brain injury support group. The process of biographical disruption and repair, such as diagnosis, understanding of injury, access to resources, and the barriers that people identified as facing, were also of particular interest.

5.6 Disruptions due to the COVID pandemic

The last group that I attended as part of my participant observation took place on the 19th of February 2020. I had interviews planned for the following week which I cancelled at the group on the 19th as I was concerned that I was putting people's health at risk given the heightened media attention to the pandemic and its emergence in Europe. Meetings of the group were consequently put on hold, and the group existed primarily as a social media presence.

Awareness, and concern, was rising in the group leading up to this period, as it was in the rest of society. In late January, the World Health Organisation designated COVID-19 as a pandemic, and the media was informing of the impact of it in China, and then across Southern Europe. In keeping with the advice coming from UK public health agencies, the group was informing members of ways in which they should be vigilant of the disease, including a session on handwashing which took place at what was the final meeting before the national lockdown.

After months of lockdowns and national restrictions, I was very aware that the conditions of this research were no longer the same - people's lives had changed, the group had temporarily dispersed - and, as a result, I no longer had contact to my participants. In keeping with my planned fieldwork, I began to analyse the data I had collected pre-COVID phenomenologically, hoping that a return to the field would be possible to create the richer, detailed data required. When it became apparent that COVID was going to impact for years rather than months, and that the group was not going to reform within the period of my PhD study, I considered alternatives. Early sight of a chapter written by Brown and Ferrie (2023) influenced my decision to use PANEL principles to shape my analysis. The PANEL principles were developed by the Scottish Human Rights Commission in response to requests from civil society for an auditing tool that allowed them to demonstrate that they were using a human rights-based approach in their day-to-day work. Participation, Accountability, Non-Discrimination, Empowerment and Legal were considered the 5 pillars required. As Brown and Ferrie (2023) found, by anchoring their work in ‘real voices’ (their chapter focuses on people with Motor Neurone Disease and Stroke, and their experience of diagnosis) the legal element was difficult to evidence. However, the other elements of PANEL were able to offer a critical analysis that revealed power imbalances and practical points where change could deliver progression in terms of dignity and respect. In addition to this, the funding for this study was running out and all this meant that I could no longer return to the field, and had to make the best with whatever little data I had, and ensure the elevation of the voice that participants had entrusted me to be the steward of in their biographical interviews with me.

On reflection, the COVID-19 pandemic had a significant impact on the thesis (see Table 5-3: Chronology of COVID impact). Primarily, this led to the suspension of the support group which had been the site of the fieldwork. The final meeting of the group that I attended was on the 19th of February 2020. This session involved a member (who had previously worked as a healthcare professional) delivering ad-hoc training on proper handwashing as this was emerging as a mitigating protection measure against COVID. I took the decision to cancel two planned interviews for the following week, as I considered it to be unsafe for me to travel across the country on public transport, and to put my participants at risk.

Shortly after this period a family member became seriously ill due to COVID and was hospitalised in Germany. This was symptomatic of a period of general high stress and uncertainty. During this period, it was still hoped that restrictions would be temporary. An opportunity then arose for me to work on the ‘Scotland in Lockdown’ project (Scotland in Lockdown, 2020), a project funded by the Scottish Government that aimed to understand how COVID restrictions were impacting marginalised groups already facing isolation and exclusion. I worked part-time (enabled through a thesis extension) on the disability strand of the project for six months from July 2020. This work was extremely emotionally demanding. On reflection my own mental health suffered significantly during this period. Following discussions with my supervision team, we took the decision to not continue fieldwork as planned (the second round of interviews and further participant observation) and decided to give more prominence from the fieldnotes I had been taking during the project.

The following year then focused on the restructuring of the thesis. This involved analysis of the participant observation data, a revisiting of the literature review, and a restructuring of the methodology section.

In 2022 I had begun to write a draft of my finding's chapters. In February of that year, I contracted COVID for the first time and became ill for a period of multiple months. This extended period of illness disrupted my thesis significantly, as did the pressure to return to work prematurely due to funding constraints. I did however return to work and produced a draft of my finding's chapters later in the year. During this time, I had begun to develop my understanding and engagement of human rights. On review of my chapters, it became clear that the experiences of the participants were rooted in the failure of duty-bearers to uphold their human rights. This led me to explore human rights, and a sustained period of literature immersion in a field that I previously had little experience of. I then began redrafting my chapters using the PANEL principles as an analytical framework. In October of that year, I again tested positive for COVID and once again became ill for a period of several months.

In February of 2023, my best friend died suddenly. Whilst this was not attributed to COVID, I believe that the pandemic contributed to their death. This had a devastating effect on me and impacted on my ability to work. In March of 2023 I again tested positive for COVID, and once more had a sustained period of illness. During this period, I completed my redrafted findings chapters. In June 2023, a sibling was admitted to hospital and spent a week on a life-support machine due to a health condition which had been exacerbated during the pandemic when support services, and consequently their care, were reduced. Following my sibling's discharge from hospital, I completed and submitted my PhD in July 2023.

The impact of the pandemic was severe and multifaceted. It had a significant impact on the data collection and consequent direction of the thesis. It impacted on my health significantly and led to long periods of illness and uncertainty. My own stubbornness and stress in relation to the timeframe led me to work for long periods when ill, which, on reflection, I believe lengthened my periods of illness. This also exacerbated the symptoms which I live with following my brain injury. Despite this, I believe that the impact of the pandemic enabled the fundamental shift towards human rights, which may not have taken place otherwise. In conclusion, navigating the pandemic, beyond its significant impact on my personal life, profoundly influenced both the trajectory and content of the thesis, and my own personal PhD journey.

Table 5-3: Chronology of COVID impact

Date	Event
19th February 2020	Final Group Meeting
w/c 24th February 2020	Cancellation of research interviews
23rd March 2020	National lockdown announced
April 2020	Family member hospitalised with COVID
July 2020	Part-time suspension of studies and undertaking of research post
2021	Restructuring of thesis
February 2022	COVID infection
May 2022	Pivot towards human rights focus
October 2022	COVID infection
February 2023	Bereavement
March 2023	COVID infection
June 2023	Hospitalisation of family member
July 2023	PhD submission

5.7 Ethical considerations

The research was subject to the ethical approval of the University of Glasgow. There are bureaucratic elements, with policies that safeguard the University central to this process. With some sociological imagination (Mills, 1959), the ethics form, can be used to consider the impact of research design on participants, and on self. Whereas the form and process signal emotions to be risky and potentially harmful (Olson, 2021), I was aware that for this research to be 'real' and authentic, participants would at times engage with difficult emotions. The ethics committee initially felt my research was too risky, yet with support from my supervision team, I appealed this decision. The reasons for my appeal were that emotion is normal in research that meaningfully connects with participants (Shaw et al, 2020); that participants would be given the right not to take part in the interviews; that participants will know before consenting to participate about the emotional quality of their stories and so will be informed; and that as someone with a brain injury, invalidating 'our' expertise to give informed consent was separating us (researchers) from them (research participants) in ways that amplified their vulnerabilities (Feltham-King et al., 2018) rather than acknowledging our responsibilities to take care. Care was taken to prepare for interviews, to take my time, to give participants time and control. This preparation meant that emotional harm as a form of exploitation (where participants are hurt for my own gain as a researcher, rather than because their narratives are full of difficult emotions) was avoided. Talking about difficult times is not inherently harmful as the emotions pre-exist the interview (Scheff, 2015).

Participants were also offered the opportunity to choose a pseudonym to represent their data. This approach serves a dual purpose; it safeguards the participant's identity and grants them a feeling of autonomy and possession over their contributions to the study (Allen and Wiles, 2016). This can also lead to more trust and comfort with the process. The act of choosing a name can itself be a revealing narrative and may enrich the substance of the research (ibid). Nevertheless, caution was exercised to avoid the selection of inappropriate or potentially identifying pseudonyms.

As mentioned, informed consent was sought throughout every stage of the process. As set out, I ensured that I was embedded within the group, but that all members knew the purpose of my attendance, and the research was explained on different occasions with the opportunity to ask questions as they arise. As soon as the interviews were complete, the audio recordings were transcribed verbatim. The complete transcripts were thereafter stored safely on a university-specific OneDrive folder on a password-locked university laptop. Once this had been done, the collected audio recordings were safely destroyed.

5.8 Establishing rigour and integrity

Research integrity is a fairly new way of thinking about doing good research. Before Universities UK (2019) published their concordat, the term research integrity was not well embedded in methods courses. To evidence this, methods textbooks published before this, do not include mention of it. Rigour in quantitative methods was established with validity and reliability, though a series of scandals in psychology and political sciences championed the need to be able to demonstrate reproducibility. The focus of research integrity on quantitative approaches went beyond demonstrating statistical competence. The focus looked at researcher behaviours that contributed to good (or bad) research including who should be a named author on published work, how to avoid omitting results that would shape knowledge differently, and the politics of making research data open. The impact on qualitative methods has been very useful. Research can be considered to have rigour where it is honest, respectful, inclusive and authentic.

5.9 Approach to analysis

In this section I will outline why phenomenology was chosen for this PhD research and why ultimately, I can, at best, claim to have only partially used this approach.

From the start of the project I had planned to use phenomenological analysis. Interpretative phenomenological analysis (IPA) enables a detailed investigation of a subject, or event thorough an 'insider's' point of view (Smith et al, 1999), through a focus on the four sites of temporality, spatiality, embodiment, and inter-subjectivity. In the case of this research, a phenomenological understanding of brain injury, particularly in relation to biographical disruption and repair, was sought to "establish points of reference between body, self, and society and to reconstruct a sense of order from the fragmentation produced by chronic illness" (Williams, 1984: 177). The lifeworld was a central element of my toolkit as I attempted to foreground the voices of participants. Further, the significance of embodiment to phenomenological analysis was an exciting opportunity to acknowledge the body as a site of resilience and resistance as people discussed their experience of life with a brain injury. However, the longer and more detailed interviews championed by the phenomenological approach were in practice difficult to produce because participants became tired. Anticipating this, I had planned to interview people, with their consent, multiple times, yet COVID prevented me. As a result, the careful foundation-building work that I had done in attending the group and interacting with members and the early interviews, became my data.

5.9.1 Framework thematic analysis

Once the decision was made to take a human rights-based approach to the analysis of the available data, the process of analysis was repeated, using a form of framework thematic analysis (Srivastava and Thomson, 2009; Spencer et al, 2014; Ritchie and Spencer, 1994) with the PANEL principles as the five core themes (Scottish Human Rights Commission, no date). This method of analysis enabled a systematic approach to the coding and analysis of data that is located within "specific questions, a limited time frame, a pre-designed sample and a priori issues" (Srivastava and Thomson, 2009: 72).

Framework thematic analysis is known for its applicability in the field of policy and has previously been applied in the field of health and disability research (e.g. Leal et al., 2015; Kinghorn, 2010; Velez et al, 2023, Smith and Firth, 2011; Gale et al., 2013). Employing this method consists of two main stages, developing the analytical framework and then implanting the framework (Goldsmith, 2021). Within these stages there are five key steps that are typically followed. These are: (1) familiarisation; (2) identifying a thematic framework; (3) indexing; (4) charting; (5) mapping and interpretation (Ritchie and Spencer, 1994, Goldsmith, 2021). Below I will detail step by step how this method of analysis was applied in the current research (see Figure 5-3: Step by step guide to analysis processFigure 5-3 for a visual representation of this process).

Figure 5-3: Step by step guide to analysis process

1	Familiarisation	• Initially during phenomenological analysis and then repeated on adoption of PANEL framework • Listening to interviews and writing notes • Re-reading individual interview transcripts and written notes
2	Identification of framework	• Human rights' PANEL framework selected as main pillars of the framework
3	Initial indexing	• Interview transcripts and fieldnotes coded in NVivo using the PANEL principles
4	Refinement of framework	• Framework modified in response to the data • Legality removed due to a lack of corresponding data • Participation split into two distinct themes
5	Indexing data within each thematic pillar	• Secondary coding of individual framework pillars (Participation 1, Participation 2, Accountability, Non-discrimination, Empowerment) • Sorting the data according to identified sub-themes
6	Charting	• Separate matrix produced for each thematic pillar (Participation, Accountability etc)
7	Mapping and interpretation	• Data written up using quotations • Literature brought in to test and situate the data in relation to human rights, biographical disruption, brain injury, and policy

(1) Familiarisation

Much of the familiarisation had already been completed in the initially planned phenomenological approach to analysis. Following the decision to adopt the PANEL principles as an analytical framework, I then repeated this process of familiarisation, with a greater focus than prior on the fieldnotes which were now to be given greater prominence in the analysis. I first listened to the audio recordings making notes with the PANEL principles and my research questions in mind. I then carried out the same process with the transcripts of each interview and fieldnotes. By re-reading the transcripts I was more able to begin to orientate my data within the thematic framework. This was an important step in relation to my confidence in the method's application, as whilst I recognised the individual experiences of the participants (and eventually also the collective experience) as being rights issues, I had not previously used the PANEL principles as a thematic framework, itself a novel approach (Brown and Ferrie, 2023).

(2) Identifying a thematic framework

As discussed above in section 5.6, the decision was taken to employ the PANEL principles as a thematic framework. Indexing took place at this stage as the data (both interview and fieldnotes) were coded according to the five thematic themes of participation, accountability, non-discrimination, empowerment, and legality.

(3) Initial indexing and (4) refinement of framework

I coded the data as (generally) large, verbatim quotes using the NVivo data management software to assist with the process. I was conscious of maintaining the prominence of the voices of the participants and felt that the data did not require my summarising at this point given the strength and directedness of my participants and their data. The quotes from the interviews (which made up the vast majority of the data) and my fieldnotes were then indexed into a matrix representing the 5 thematic PANEL principles.

A process of refinement occurred at this stage as the fifth principle of 'legality', initially used in analysis, matched little of the data and was therefore removed. In this regard the framework underwent a process of refinement that may take place when identifying the thematic framework and testing against a portion of the data (Goldsmith, 2021). A further process of refinement took place with the splitting of the pillar of participation into two distinct themes – 'Participation – personal perspective' and 'Participation – public perspective'. There were a variety of factors for this decision. Re-reading my notes made during the stage of familiarisation, I noticed that I had made several notes highlighting that data referred to the 'public self' or the 'private self' at various points. The participation findings chapters are loosely chronological but not uniformly, as is seen in the example of the inclusions of '6.7 John and Sarah get married' in the first participation chapter, and '7.2 Participation and temporality in the rehabilitation phase', due to their alignment with both the private and public spheres.

(5) Indexing data within each pillar

Using NVivo, the data for each of the 5 pillars was then systematically reviewed and coded, creating sub-themes within each pillar. The codes were also discussed at this stage with a supervisor, to sense-check and guard against forms of confirmation bias, which was particularly relevant given the depth of my own private and professional experience. Following this step, data was then re-indexed. Indexing involves subjective judgement on the part of the researcher but evidences a systematic and transparent process which enables the analyst and others to "'check out' the basis of his or her assumptions" (Richie and Spencer, 1994:182), which was of further importance considering the use of a novel analytical framework.

(6) Charting

Following the process of indexing, the coded data was organised into a framework matrix to gain a comprehensive overview of each participant's contribution in relation to each pillar of the framework (See Table 5-4 below). This process involved taking both the full verbatim quote and a summary of each quote. The summaries consisted of a mix of paraphrasing, linkages to the theory of biographical disruption, human rights, research questions, and general thoughts and ideas.

Table 5-4: An example of a framework matrix using the refined thematic framework

Participant	Participation – Private perspective	Participation – Public Perspective	Accountability	Non-discrimination	Empowerment
1					
2					
3					
4					

5					
6					

This process of charting was thereafter separately followed for each thematic pillar and its sub-themes (see Table 5-5 for an example of the pillar-specific coding matrix). I took the decision that this would contain quotes and my own summaries. I left both my own summary together with the quote as I was keen to be able to have clarity as to the summary when it came to mapping and interpretation, and as I intended to foreground my participants' voices using long quotes. The use of my own summaries at this stage was helpful in processing the content of the data, helpful (at times) for providing context and links, as well as for the process of writing-up.

Table 5-5: Example of matrix for individual thematic pillar produced in step 6

Participant	**Sub themes of Non-discrimination thematic pillar**					
	RTW Process	Workplace adjustments	Treatment from colleagues	Process of leaving job/labour market	Support to deal with process of leaving labour market	Still accessing or attempting to access the labour market
1						
2						
3						
4						
5						
6						

(7) Mapping and Interpretation

I began to write up the individual sections and at this stage brought in literature that related to the data. This linked the data to the literature on the guiding theory of biographical disruption, identity and self, and human rights and policy. By doing so I was able to test and situate the data as a rights issue. Whilst I was confident that the experiences of the participants represented a clear rights issue, engaging with the literature at this stage was important as neither the participants had explicitly used rights-language, or explicitly conceptualised aspects of the experience as being one of rights denial or realisation. By using a rights-lens, the relationship between disruption and rights emerged, as did the role of duty-bearers. It was in this space that the data shifted from its powerful, mostly descriptive form to a collective sociological form that is evidenced in the written-up finding's chapters. It is this shift that enabled a mapping of the experiences of the individual participants as a collective rights-issue.

5.10 Chapter summary

The chapter began by exploring the foundational philosophical assumptions which underpinned the thesis. As discussed, this was informed by feminist approaches which complimented the interpretivist stance, recognising and reflecting that there is no single objectively appraised truth, and the need to engage the phenomena from the perspective of those who experience it. The research was grounded in a phenomenological approach, to aid the foregrounding of the 'hidden voices' of the participants. Following the adoption of the PANEL principles as an analytical framework, a focus on the individual subjective accounts remained. The ontological and epistemological stance was informed by the social model, however, as explained, claims to an emancipatory paradigm were partial. The role of confirmation bias, and the efforts made to mitigate this, were highlighted. This was of particular relevance given the researchers prior knowledge and experience of brain injury.

The chapter then discussed the decision to take an ethnographic approach. By embedding within the group, a deeper understanding of the holistic experience of brain injury was enabled. By employing observation alongside interviews, a deeper understanding of the role of the support group was realised. The autoethnographic method was unpacked, and discussed as a method which aimed to contribute to the knowledge production, born from reflexive engagement to fieldwork.

Positionality, insider status and the approach to reflexivity was critically engaged. In particular the reflexive practice was unpacked, detailing the methods employed and the ways in which this was practiced. The methods utilised in relation to data collection were detailed, including the sampling and consent process followed. This included a description and justification of the planned data collection prior to the impact of the COVID pandemic on data collection. The disruption caused by the pandemic was significant and multi-faceted, and thus was a further area of focus. Ethical considerations and rigour were centred around the research design and practice in the field, which aimed to be honest and transparent, and to be inclusive and authentic to the experience of brain injury described by participants.

The chapter concluded with an itemised description of the use of framework thematic analysis, which utilised the PANEL principles as a thematic frame. This section explained how each step was followed in practice, and provides a guide and reference point for other researchers who may wish to adopt a similar approach. In closing the methodology section, attention will now turn to the research findings that emerged following the design described in this chapter.

Chapter 6 Theme 1a: Participation – personal perspective

6.1 Introduction

> "Human rights are rooted, as are theories of participation, in the experiences of ordinary individuals, and are expressed as the entitlements of individuals" (McMurry, 2019: 1064).

This chapter will explore, what the concept of participation has to tell us about the experience of having, and living with, a brain injury. This chapter forms the first section of two that will use the concept of participation, with this chapter focusing on the private self, with the following chapter focusing on the public. A human-rights based approach will be used in all three analysis chapters as a lens to critically analyse how people with a brain injury experience biographical disruption.

Brain injury is viewed often as a very personal injury that is unique to each individual. By posing the question of what the data has to tell us about participation; social processes, power imbalances, and a lack of human rights realisation will be highlighted and unpacked. By doing this, an understanding of how a human-rights based approach to brain injury could alleviate tensions and barriers will begin to emerge. This chapter will begin with the period when participants have acquired a brain injury, and human rights begin to disappear. It is a situation where peoples' "internal and external reality" (Bury, 1982) was disrupted, that rapidly sees people trapped in a passive state where they are removed from decision-making and offered few routes to assume an agentic position of resistance. This initial period of engagement with medical services will form the first section of this chapter. This will be followed by an exploration of participation from a mostly private perspective, as people begin to attempt to carry out biographical repair. The analysis is that of 'ordinary individuals' undergoing an extraordinary experience, and is one in which familiar power structures, oppressive social processes, and removal of rights, emerge.

6.2 'My head went bang'- The full emergence of the injury

> "...my head went bang and I had a subarachnoid haemorrhage, and at the time that it happened I, I knew I was having a stroke, but I couldn't get any words out to tell my husband, but I feel it was really obvious at the time that something was wrong, because I was unconscious a few seconds later." – Sadie

Participation, in the human rights sense, refers to either the active involvement of people in decisions that affect their lives, or the denial of an individual's participation in such processes. Brain injuries often reveal themselves suddenly, and mark "a biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging" (Bury, 1982: 171). Participants described the emergence of their injury as an experience that was sudden and involved the complete surrendering of any control and bodily autonomy:

> "I do remember that day, because I think I was at work, I used to work in, in Welfare Rights, and I just remember my leg, I got, I got up and I just remember one leg just giving way and I just thought it was an, I remember a pal, my friends at work were saying that I could speak, but nobody thought to say anything. So I, I went home, went to bed and I, I wasn't feeling well, but I just made myself go back to work because I thought, it's just something, I'm just tired or you know, with the kids and, because the kids were little then and, and then I had another one, and that's when I was admitted for, I think it was seven months" - Vaila

Vaila's participation was very physical and present. She did not know what was happening to her at that time in respect to her brain injury but was making decisions such as returning to work. Decision making in this sense was active, but socially pressured. At the same time, it was done privately with no easy access to medical or social support. In this sense the experience was personal and to some degree passive. The full onset of Tommy's injury was rapid and typifies experiences of brain injury where people become very ill, very quickly.

> "one night I was in my bed and she said I was breathing funny and couldn't waken me up… an ambulance… turned up and carted me off to a hospital and I ended up waking up in ICU [Intensive Care Unit], with a very large hole in my head and a pair of the heaviest sports shorts on...what had happened was that I had had a stroke." – Tommy

Decision making in this environment is frantic, simplistic, and made on behalf of another. The private life and bodily autonomy are jettisoned. Colin's account of the full emergence of his injury detailed the mobilisation of resources in his acute phase, and the beginning of the intersection between the private and the public:

> "...and I was waiting to go for another investigation, when I, I came up to visit my sisters in Arbroath for Easter… when I got there had a nasty headache and I went off to bed early after taking some pills, and it took quite a while to get to sleep as far as I remember. When I woke up in the morning I couldn't see out of my left eye and had an absolutely splitting headache, this was Easter weekend,

> so couldn't go to our own doctor, so they got on to NHS 24 and they sent out a doctor who immediately called an ambulance. This next bit I don't really remember and went up to [hospital name] and had a CT scan, I believe, I don't remember that. I vaguely remember being in an ambulance on the way to [city], because they had no surgical places at [city], but they did have a surgical place at [city], and they thought this needed immediate attention. So taken through [city], flashing like job all the way, I have got a vague recollection of being in the ambulance, but it's very vague and a very vague recollection of being in a hospital in [city], but it's very, very vague." – Colin

Whilst these events took place at what could be considered to be the period that was most dominated by the neurological/medical, what is clear from these descriptions of the injury's onset was that it was also a social process. The injuries revealed themselves in front of others, and very quickly instigated a social process of resource mobilisation. Participation was essentially suspended at this stage.

The testimony of Sarah provided the perspective of a loved one during this initial phase. Sarah's narrative was one of growing alarm as she registered numerous warning signs and seeks, but does not find, reassurance that everything is alright, or as it should be:

> "when I came home at night, which was again about six o'clock in the evening… I couldn't find him, I thought gosh, the curtains are shut and that's not like him, and the bin was still out, so it was Thursday, and I thought God, he's not took the bin in, it's not like him because he was really quiet, everything in its place, yeah. So I said, aye oh, so when I went in I shouted and I got no answer and I went through you know, there was no sign of him and then I thought he was in the toilet, and nah, and looked in the bedroom, no. I thought, where is he?" - Sarah

This exemplifies the lack, or at least relative subtlety, of an 'insidious onset' in cases of brain injury, underlined in the case of Sarah and when she found her partner John unconscious. An experience that brought with it its own 'insidious onset' (Bury, 1982). Sarah went into detail about her realisation that something was very wrong with John, and the immediate events that followed:

> "I found him at, at the other side of the bed, so I ran and I got a neighbour, I said, there's something wrong with John, he's not moving and so the neighbours come through and they, they tried to get him up, and they said, no, phone an ambulance. So I phoned an ambulance, so the ambulance when I was on the phone, they said, stay on the phone and like, Willy our neighbour, he, they were giving me questions, is he still breathing?" - Sarah

Participation, and decision making, in this early phase was assumed by those in close proximity. The private experience of the injury quickly becomes public, and the injury moves from being one of singular experience, to one that involves others and becomes a social process parallel to the perilous process that has begun. This shocking and traumatic familial experience was similarly experienced by Sadie's family:

> "I was very lucky in the fact that my hubby and my two kids were in the same room as me when it happened, it gave everybody an almighty fright. So you know, especially my two kids, I think my son really was very traumatised over what happened." – Sadie

This illustrates the involvement of others in the immediacy of the injury, and its immediate amalgamation into the social. It also speaks of the almost instant biographical disruption (Bury, 1984) that was experienced by the wider family. A secondary mobilisation of resources was highlighted by Sarah, who having got John into an ambulance, enlisted the support of her family:

> "John went away in the ambulance and I phoned my mum, I said, I, I need, I need to go to [hospital] to see John, but I need someone to come with me, and my mum doesn't drive in [city]… so she phoned my brother, my brother came down and we went to [city]." - Sarah

Here participation is dependent on moving social supports. Participation is lived and mitigated through social relationships and structures. These testimonies highlight the emergent and complex relationship of the medical-social experience of brain injury. In this acute early phase, the reactive nature of the social side of the medical-social dichotomy emerges alongside the emergence of the condition itself. This is a unique phase of the relationship as it is a time when the condition leads, and the social follows. These experiences are also a stark reminder of the violence of the injury, and the severity of the impairments that can be caused; The sudden loss of the ability to speak and walk as described by Sadie; the loss of the use of her legs described by Vaila; Tommy's description of waking up with a hole in his head; the losing of consciousness described by Colin.

This underlines the need to understand and consider the sheer magnitude of the neurological condition and its initial impact. The fusing of the neurological condition and the social circumstances that occur in this initial space, when the illness first occurs, can be understood as the first step in a life-long partnership. It is also the key first location where decision making, and active participation, is ceded. By having an injury, participants were also unknowingly thrust into the historic debate of how rights apply to people with conditions that do, or are seen to, impact on their ability to make decisions on their own behalf (Ferrie, 2010).

6.3 Diagnosis and the absence of participation

Central to the understanding of any medical injury is the diagnosis of it. With many brain injuries this is a critical step, primarily as it can direct interventions that will save someone's life. It is also vital in terms of both physical and biographical repair. Furthermore, it is revealing of the power-relations at play, and what this tells us about participation. This is also an area where the individual sense of self is at risk "through diagnostic discourses that indicated change and damage to the inner self" (Gelech and Desjardins, 2011: 67). It is a process that is made more complex in brain injury due to the neurological nature of the injury and possible impairment, and the fact that in the initial phase people are often at serious risk of death. The experience of Sadie's diagnosis, and subsequent absence of participation and control, is revealing of the deepening of an observable sociological process where the participation that was absent at the full emergence of the injury, was not reinstated.

This section focuses primarily on Sadie's account of her experience of diagnosis, as this was an account of someone who had vast professional experience of the process of diagnosis as a health professional prior to experience of her own injury. Her account of the process begins with a description of 'coming round' (waking up post injury), and the realisation of what had happened to her:

> "when I came round, even though I couldn't remember anything like, couldn't really remember what, I knew something had happened, but I didn't, I didn't know what it as and there is this e-booklet on the bedside table that had subarachnoid haemorrhage on it, and all I could think of was, I've had one of them." – Sadie

This process of informal diagnosis was completely passive, without control, and lacking in any meaningful participation. The process of diagnosis comprehension was complicated by Sadie being unable to initially remember what had happened and why she was in hospital. In this case, Sadie's husband was an example of a mobilisation of resources:

> "it was my husband that told me, I didn't actually speak to any doctors or anybody at all, clinical, nursing, health care assistant, nothing, when I woke up

> a few days later and my husband was sitting there at the bed, and he just looked really pleased to see me like, hi, and I said you know, where am I, what's happened and he looked really exasperated. At the time I thought, phew, you know, what's wrong with your face and he said, right Sadie, you have had a subarachnoid haemorrhage and you are in [city] Hospital you are in the General and you have had surgery to your brain, did I just say that, no, I did yeah. He said you have had surgery to your brain and you need to you are going to be here for a few weeks, and I was like, oh right, okay. Like it was the most normal thing you know, like oh, you know. The reason he was exasperated was because I had woken up loads of times and every time I woke up I asked him the same thing and I would fall asleep again, wake up and I wouldn't be able to remember." – Sadie

This highlights the complexity of diagnosis reception in cases of brain injury, and an early site of absence of participation. Sadie had moved from someone who worked as a medical professional, to someone who received life-changing diagnosis repeatedly from her husband – in effect a gatekeeper – and like the vast majority of loved ones in this position not medically trained. This was however an important resource that Sadie was able to draw on for support to help begin to comprehend what had happened to her. However, the lack of participation of Sadie herself in this process was clear, as Sadie – the person who had suffered the injury and a healthcare professional herself - was now reliant on her own resource, her non-medically trained husband, to relay the details of a complex injury and the resulting disruption. This lack of participation and mismanaged diagnosis also prevents the person with the injury having what Bury (1982) described as "something firm to relate to" (1982: 173), even if the "actual nature of the disease remains elusive and the treatments empirical" (ibid).

This initial period where diagnosis occurs is also one where the concept of time can alter. Elsewhere from Sadie's account, Colin described being moved closer to his then home, having initially been admitted to hospital in [name of location]:

> "Next thing I really knew was, I was in [name of location], which was my home hospital, and, and I had been there for more than a month, which I have no recollection of at all, so they had operated on the aneurysm but it definitely caused brain damage in the process, and for a little while things were very confused." – Colin

This is a period that was exemplified by a warped temporality, as days, weeks and months passed quickly in the aftermath of the injury. How participation can figure for someone in this initial phase of brain injury may seem unclear and complex. Participation in decision making following brain injury has been highlighted as a human right central to the provision of ‘patient centred care’ (Knox et al, 2013). The establishment of thresholds where participation is formally ensured for patients and next of kin, would contribute to the realisation of human rights for people at this critical phase of brain injury.

6.4 Doing the rounds

Doctors’ rounds – from the patient’s perspective – offer, in theory, a regular opportunity to engage with a key director of your care. It is a social process that offers the possibility of both empowerment and participation of the patient. Sadie described her experience of this mainstay of medical social practice:

> “you would get the doctors coming in and they would be having a good old chinwag [with her] and everything and sometimes it would make a lot of sense and other times it wouldn’t, it just depends, you know, just depended how you were that day.” – Sadie

Sadie’s ability to engage meaningfully with doctors during the ‘morning round’, was reliant on her ability to comprehend and engage with a group of strangers standing at the end of her bed at a time that suited the routine of the healthcare system. Listening and empathy are essential components in order to encourage feelings of security and a sense of dignity (Jumisko et al, 2007). Indeed, student nurses in one study equated dignity in the care sense with a patient ‘being heard’ (Macaden et al, 2017). Sadie at this point was within a social process that begun with the surrendering of bodily autonomy, and one where empowerment would reasonably be required to engage in a meaningful process of participation. Neurological impairment may complicate this process, but this added barrier to participation reinforces the need for participation itself.

Sadie described having one opportunity in this initial period to speak to a doctor about what had happened to her:

> “there was one doctor in [city] who sat down and all he said was, you know, you had a really big bleed and you are really lucky, but I didn’t really get much more of a chance to speak to him, which I wished I had been able to, but I didn’t ever have like a sort of debrief or anything, which I would have really enjoyed to have something like that. Because having come from working in midwifery, if we had women that had difficult deliveries, or you know, a traumatic delivery, they could come back a few weeks later and talk about everything from beginning to end, just so that everything was made really clear to them, whereas I just found

> that for me it was like, well you have had a brain injury and you have had surgery, so off you go." - Sadie

This typifies the lack of control over a social process that Sadie faced following her injury. Munoz et al (2017) observed that "it is at a social and interpersonal level that dignity 'happens' most immediately" (Munoz et al, 2017: 2), and it is these important interactions where dignity needs to 'happen'. The lack of control, and the power imbalance between Sadie and the healthcare system, erected a barrier to recovery and biographical repair. This essentially solidifies the 'black hole' in Sadie's memory and self-narrative. She has been left knowing that someone knows what happened to her, but that someone has not shared this knowledge. This social process is not passive, it is active, and it can cause damage to the person who goes through it. Sadie's experience speaks of a diagnostic process that is inadequate and does not serve the person being diagnosed as widely as it could. Sadie's previous knowledge of a process where patients were more involved over time and were in theory empowered to understand what had happened to them, demonstrates the failure of social structures and processes to support empowerment and participation. Her previous medical knowledge influenced her understanding of the diagnosis process but also her perception of the probable outcomes of having such an injury:

> "you know most people don't really kind of wake up from having one of them you know, I hadn't actually ever met anybody that had. So I found it quite scary to be in that position, that I had had this brain haemorrhage, that nearly everyone that I knew that had one, had died." – Sadie

This demonstrates how previous engagement with the injury cannot fully prepare someone for participation in the medical environment. It further highlights another inherently social aspect of the injury, that it takes place within one's own social relations and life experience. Social processes, as will be highlighted throughout, are evident from the emergence of the injury, and so a medical focus on brain injury can be understood as extremely limited when seeking to understand the lived experience of brain injury.

6.5 Barriers to getting home

Returning home can be understood as a significant milestone in someone's recovery from a brain injury, particularly following the sustained stays in medical facilities that many people experience following suffering one. This takes place following a process where common-sense assumptions have been removed, "and yet alternative explanations do not readily present themselves" (Bury, 1982: 171). A return home offers a platform for the repair process to gain traction. Participation in this sense would involve people having input to the creation of homes that are suitable and safe for domestic life. This clearly is another area where participation is vital but prevented. Sarah highlighted barriers that she and John faced before John could even get home, when attempting to get the necessary adaptions to their home:

> "we had to get John's house extended so he could come home, and ended up getting, so that seemed to take a, I was so annoyed, to this day I'm so annoyed… we had to wait for planning permission...you still had to wait, the, your turn with the process to get planning. For me, we had to wait, because somebody wanted a conservatory for leisure, leisure, we had to wait and I think that's, that's a system that needs to be changed… we waited eight weeks and I didn't, I had never done anything like put on an extension or anything before and I didn't know there was a restrained planning permission and planning permission and building warrant, and so we got the planning permission only to find that we had to wait another eight weeks for building work, I thought, so there's another eight weeks wasted." - Sarah

These barriers ensured that John, who hadn't been home for over a year, did not have a suitable home to return to due to bureaucratic processes that did not consider his, or others', level of need. This relates to a lack of an adequate standard of living. Again, an absence of a threshold. Similarly, for Sadie, it was the lack of resources (in her case an occupational therapist) that prevented her from being able to experience her home in a similar fashion to before:

> "My plan was once I got home from hospital, and a few sort of strategic changes in the house, and what not, and we managed, just took a long time, but I really kind of fell through the net because I didn't get any help at all once I got home, nothing, no OT [occupational therapist], no physio, nothing." - Sadie

This lack of resources was a barrier to empowerment which then in turn led to an absence of participation. Sarah and Sadie's examples add to the picture of a barrier-strewn environment that compromises people's participation in their home life. By compromising this participation, the sanctuary of home, arguably more crucial, considering the barriers and oppression likely to be faced outside of it, is compromised.

With the absence of an acceptable threshold, participants were left to deal with what was available to them at the time. Tommy described the daily issues caused by inadequate housing provision:

> “I was on my own, so I had to do a lot of things for myself, which was difficult because I had never been on my own. Social work, they got me another place to live...it’s a nice flat, but only one problem is that it was up the stairs, so I kept going up and down the stairs… at that time I had lots of falls.” – Tommy

The risk from falls is severe (and is a significant cause of brain injury), and in Tommy’s case, a dangerous barrier to participation in domestic life, in effect erected by the State. The threshold in this respect was non-existent. Again, this demonstrates the relationship between the injury which has caused the impairment, and the social, that creates a situation that exacerbates the impairment, creates barriers (even danger), and removes participation from the equation.

6.6 New strategies and evidence of participation

The adaption of new strategies to allow participation in previously routine elements of life was a theme in the biographical discussions that took place. Colin described how he developed new strategies to engage in what could be considered relatively mundane parts of people's lives, encapsulating how the stated aim of the state to have people living with as much independence as possible can be seen as a precursor for participation:

> “The other thing I had to do was come up with a better way of actually shopping, because I was only getting out to shop once a week, and I really had to start making shopping lists and so I got my sister to make up a laminated sheet with the things I bought on it, so I could then just tick with a pen, if that was the thing that was needed and then erase it again once I got it, and similarly, having locked myself out a couple of times, I made up a list of what it was I needed to do, so beside the door, have you got keys, wallet, phone, shopping list or something about where I was going and what I was doing, so that I didn’t get there and found I had no idea why I had come.” - Colin

Learning these new skills at a time of recovery was of obvious importance and critical to Colin’s ability to live as independent a life as possible. This example typifies the difficulty of doing even mundane daily tasks following a brain injury, and the need of the development of new strategies. However, it also demonstrates an area where Colin was able to experience participation. Colin was able to select and buy the shopping that he wanted in a fashion that was altered, but one where dignity was present.

The ability to successfully repair or modify the carrying out of these tasks has clear implications for a person’s ability to participate in society, and the control that they have over their own lives. For Colin, the passing of time and recovery saw these issues reduce and participation increase:

> “as time progressed I found I didn’t need these things as much, I still make up shopping lists because I still do forget things, but I’m much better than I was. I wouldn’t do like I used to do where I would go out to do shopping and then get there and have absolutely no idea what it was I wanted.” – Colin

This highlights the fluid nature of recovery, and the likelihood that the barriers that a person faces after a brain injury will change as their lives progress. As people attempt to do different activities, they may face new barriers, and this underlines the need for a flexible, and continuous, approach to recovery and support. Sadie discussed the need to set her own targets, identifying this as a key strategy in her own recovery. This shows how the previously mundane routine elements in life took centre-stage as both a barometer of recovery and evidence of repair:

> “having the healthcare background that I’ve had, that helped me because I knew that I had to get better and sitting in my house just like sleeping and waking up, sleeping and waking up, sleeping and waking up, I wasn’t going to get better doing that, so I had to set myself little sort of targets every day like, you know, today I am going to do this, tomorrow I am going to do that. Set myself like you know, limits that, this is as much as I’m going to manage this week.” – Sadie

Sadie was able to draw on her biography prior to her injury as a resource when carrying out biographical repair. This underlines the importance in approaches to recovery to understand individual biography, biographical disruption, and its repair. What is also clear from the data is that participants desired participation in their lives, and that this desire did not feature within their rehabilitation. This is underlined by the need for this to happen in the mundane and routine areas of the private life. Biographical repair and the resetting of foundations of recovery require participation, but also a lot of labour on the part of the person doing this complex, and difficult work.

6.7 John and Sarah get married

Previous research (Kreutzer et al, 2007) has suggested that people that have a brain injury have a higher-than-average rate of divorce, although these figures vary widely. What is clear is that a brain injury will certainly introduce new, and often stressful elements to a relationship. There is little academic understanding of data relating to the experience of people who marry following a brain injury, which may in itself reveal the societal assumption that such relationships are unlikely to form or are more likely to be ‘doomed’. In this research, members discussed relationships breaking up, but mostly remaining intact. In addition to this, relationships offered evidence of biographical growth. Sarah discussed how John had proposed after his injury:

> “on Christmas Day the year he come home from hospital he, he’d been away to, he goes to groups and he goes to a stroke group in Fulford and they’d, he’d made a box, created this heart shaped box and lined it and put a box, a ring box in it and he gave it to me, it was to be the last, it was the last present that I had that year, … I said, oh this is nice, and it was a ring obviously, and I said, and, and it must have been an hour later, an hour and a half later and I said, John is this an engagement ring, aye!... he had put in so much effort and now, looking back it is so obvious, but I just wasn’t expecting it. See he is quite romantic.” - Sarah

Participation in this example was evidenced by John making the decision to propose to Sarah. It again highlights participants as agents of participation and change. This took place following a stroke that doctors had rated as the most severe (“the worst”- Sarah). This shows evidence of biographical growth, and the ability of people with brain injury to participate fully, and indeed enhance their life in comparison with that before their injury.

Eight months later they were married in a wedding that considered John’s impairment, and ensured that he was able to be involved in all aspects of the big day:

> “one of the things was, there was no two dancing, we couldn’t dance because John couldn’t dance, I thought we can’t have everybody dancing if he can’t dance himself. So, we did a treasure hunt… And we did, we did a quiz on us, so, so that was the entertainment, so it was good, it was.” - Sarah

This demonstrates that ritualistic practices such as those experienced at a wedding, for example dancing, can be easily modified for the people involved. Social rituals that have been developed over centuries, such as a wedding reception, are not as solid as they may appear. Disability has been described as “a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing” (Thomas, 1999: 60). By ensuring participation in respect of the wedding, their big day was one where elements of social oppression were nullified, activities were inclusive, and psycho-emotional wellbeing was not threatened by design. Our sense of self is influenced heavily by our relationships, and links to our social worlds, which leaves us vulnerable to others delegitimising or refuting our personhood (Gelech and Desjardins, 2011: 66). Participation may have been in this case a further method of gaining control and protecting personhood. This offers insight into the potential of using a human rights-based approach as a method of tackling societal barriers and ableism. The main barrier to participation, biographical repair, and growth, lies not with the impairment and the individual, but with the society at large. A human-rights based approach to brain injury would recognise this, but also recognise the need for the establishment of thresholds that ensure that it is not the responsibility of the individual to fight for participation, but that it is inherent.

6.8 Employment abruption and the impact on peer-peer status and friendship

Participants' accounts consistently illustrated the interconnection of the private and public spheres. The participation experienced prior to the injury ensured that friendships were established and maintained in a way that did not endure following people's injury. Sadie's brain injury acted as a catalyst for the ending of her career, and this had an impact on her ability to maintain the friendships forged in that environment:

> "I have got lots of friends from when I worked as a midwife, but the funny thing is like, now it's like I can only see them once in a blue moon whereas I saw a lot more of them when I actually worked, which is a bit strange because you just think, well how did I manage that, but I can't see them, although I have got all this time off, I just can't seem to fit in with when they are off, and when they are off they don't want to be meeting up, because they are catching up with their lives, do you know what I mean. Like their day-to-day shopping, housework, whatever, so I think in some ways because I have left, you kind of lose some of your friendships as well you know." – Sadie

Sadie's injury was deemed, by a social process, as making her unable to work, a process she disagreed with. The impact of the change in relationships would be false to attribute solely to the loss of Sadie's job. However, Sadie's role in this process was passive, she lost her job and with it a degree of depth of the friendships that was previously part of it. This highlights the insidious impact of social processes on the individual's ability to carry out biographical repair, and how the lack of participation in public life impacts on that of the private.

6.9 Status and biographical growth: Support and care providers

Medicalised framing of brain injury contributes to the building of a picture of people with a brain injury being passive recipients of care. Research into brain injury (and disability more widely) and its impact has often sought to understand brain injury through the perspective solely of medical professionals or family members. In this research, evidence was found that provided an alternative picture, that of people living with a brain injury providing support and care. Illness and health conditions did not exist solely in an individual sense, group members acted as carers and support for loved ones (and indeed for each other as part of the group). Colin described moving back to the town where his family lived following his brain injury and retirement, and becoming a carer for his sister:

> "my sister looked like she was going to need a lot more chemotherapy again. So we decided that I would move up to Arbroath, I had been given early retirement from my work, so I didn't have to go back to work. So I decided I would move up to Arbroath, so initially I went and bought a house" – Colin

This typifies responses which showed participants were important members of the family unit. Participants both received and provided practical and emotional support to family members. This contests the dominant narrative of people living with a brain injury as passive entities who receive support but are unable to provide consistent support themselves. It also suggests that the experience and navigation of their own injuries may be a valuable resource in the supporting of others facing crises, be it medical or otherwise. Colin went on to describe how his sister's health deteriorated, and how he then formed, along with his sibling, the principal care team for their sister as she became more ill, and subsequently died:

> "my sister took unwell again, so, and it then became clear that she had got bad secondary cancers, particularly in her spine, which had started causing her a tremendous amount of pain. So she was getting chemotherapy and radiotherapy, but it basically meant she was bedbound, so, or more or less bedbound. So I, I moved back in with my sisters, and as the cancer progressed it was very clear that I needed to be there because she needed somebody with her the whole time, we actually got a nurse to come in overnight to give us some respite at times, because as I said, she needed somebody there constantly, so, but eventually things took its toll, so we had a bit of a, we were sort of in shock for a while." – Colin

Colin provided care which would have demanded a huge emotional and physical toll. This would have required a range of skills, the learning of new strategies, the drawing on of significant emotional reserves. As seen in the case of Phineas Gage, Colin was able to carry out a complex and hugely demanding task following his injury, in his case providing palliative care for his sister. This challenges societal assumptions regarding capabilities following serious brain injuries. Just as Phineas Gage's work life following his injury was arguably more demanding than prior to his injury, Colin undertook what was arguably the most important role he had undertaken in his life, a role undertaken following his injury. This is an example of the vital (and woefully underacknowledged) societal contribution made by carers, and people such as Colin who live with a brain injury. Society profits from this labour. In Scotland, Carer's Allowance (a benefit many unpaid carers still do not receive) totals around £5000 per year. The figure an unpaid carer should receive for the hours they provide care (according to the real living wage) is estimated in one study to be in the region of £78,000 per year (Fraser of Allander, 2021). This is also an example of areas where roles in society that have a reduced status (in this case carers and disabled people) intersect.

Alongside her career as a nurse and midwife, Sadie recounted a history of providing care and support for family members who were ill, initially for her mother and then subsequently her husband:

> "he had been quite unwell, he was unwell from around about like May of 1999 he took unwell, and at the time it was I thought that he would be recovering very easily, and he didn't actually, that wasn't the case and he became worse and worse and worse until the point that, around about 2004 he had surgery… he was a, quite an unwell man for quite a few years, he lost his job… everything sort of fell to me to manage the, the house, the home, the income and everything. He had had his surgery he'd had two or three years recuperating and then he finally went back into the workplace"- Sadie

Being a carer had become part of Sadie's biography and a role that she had performed both privately and as part of her job as a nurse and then midwife. These experiences, in addition to her career in healthcare, ensured that the realities of serious illness and recovery were not abstract for Sadie, or indeed other group members. Williams (2000) urged the need for caution when automatically equating simplistic biographical disruption and chronic illness as illness may have already been a prominent feature in people's lives. In the case of Sadie, serious chronic illness and biographical disruption in others had been witnessed and experienced prior to her own injury.

6.10 Chapter summary

By taking a human-rights based approach to analysis, this chapter explored how participation was experienced for the people the research engaged. The accounts of the participants provided rich evidence of a lack of participation, evidence of biographical disruption, and the need for the establishment of thresholds that ensure that human rights are realised. The point of the full emergence of the injury is a clear starting point where things quite drastically begin to go ‘wrong’ for the person who has a brain injury. This also marks the point where the biographical disruption begins, and where participation is suspended, or is at best inconsistent.

Rights have been described as “the route to ending the dehumanising, undignified and un-autonomous lives lived by many people in receipt of care” (Ferrie, 2010: 875). What the data underlines is that to achieve the realisation of rights, participation needs to be inherent in all areas of life following a brain injury. Participation was suspended when someone had an injury and was never fully returned. In the medical environment participation should be inherent, even though it is complex, particularly as seriously ill people are particularly vulnerable to rights denial. Whilst these accounts are individual, it is clear from the data that participation cannot be achieved individually. Its denial sits alongside the denial of rights historically experienced by disabled people evidenced in the story of Phineas Gage and long before.

This section illustrated that a lack of participation negatively impacted on peoples’ experiences of brain injury in areas such as the medical world and the private life. The next chapter will explore this in more detail, but it can also be expected that the lack of participation occurred elsewhere not recorded in the data. One example being the extremely concerning evidence emerging of failures in processes and a lack of participation in relation to ‘Do Not Resuscitate’ (DNRs) orders during the pandemic (BIHR, 2020). What the accounts do illustrate is that people with a brain injury are capable, willing, and should have the inherent right to participation in all areas of their lives.

Chapter 7 Theme 1b: Participation – public perspective

7.1 Introduction

The following chapter forms the second section of analysis that explores the concept of participation from a more public perspective, as society is navigated, and sites of disruption and repair continue to emerge. For people who have had a brain injury, independence has previously been conceptualised “as being autonomous: making decisions and exercising control in their lives” (Knox et al 2017: 2255). How this was experienced in practice by the participants of this study, and the role of intersectionality within people’s individual experience will also be further examined. This chapter will also begin to consider the role of peer-support groups, a format of support that despite its prevalence as a method of support, is an area of limited academic understanding (Hughes et al, 2000, Morris et al 2017). Underpinning this chapter is the use of human rights as an analysis tool. This will enable a consideration of the possibilities of what a human rights-based approach (HRBA) has to offer to people following a brain injury where human rights are unrealised.

The data in this chapter is drawn from two sources: in-depth biographical interviews (as seen in the previous analysis chapter), and data from participant observation notes (referenced in text as, for example ‘Meeting: 1’) from the researcher’s time spent with the brain injury support group.

7.2 Participation and temporality in the ‘rehabilitation’ phase

Whilst recovery from a brain injury takes many forms, access to rehabilitation is crucial in order to maximise recovery in a medical, if not social sense, at least. A lack of certainty of the prospects of recovery, and the time required following a brain injury has been reported as being damaging to people’s sense of self and self-esteem (Cutler et al, 2016), and may in turn have knock-on consequences for medical aspects of recovery. The rehabilitation phase can be considered a key period in terms of biographical disruption, as following the often-rapid onset of their injury, this phase, an often-prolonged period, may represent the first opportunity for people to begin to process what has happened to them. Research that explores the concept of time is noticeable by its absence in medical research into brain injury (Harvey, 2018). The medicalised framing of recovery at this stage, and the categorisation of ‘rehabilitation’, does not encapsulate the sheer length of time not actively engaged, and ultimately the holistic experience. After the initial temporal shift of the critical phase of the injury, participants who spent long periods of time in healthcare settings described a significant reduction in control over the possibilities of what a day might entail:

> "So like I say, seven months in there doing my sort of various exercises and things with the physios until I managed to get about myself. If I asked I got pushed in to watch the TV in a chair, but as I say, half an hour watching TV and then get pushed back to go to bed, every night, because you didn't have your own TV." – Tommy

Participation here can be understood as being extremely limited. This was exemplified by the need to 'ask' to watch the TV. The private space here became the public space and vice-versa as the healthcare setting has become a person's home, or at least the place in which they reside. Colin touched on a similar experience during his time in hospital, where a lack of choice combined with his impairment and inability to concentrate ensured that he was similarly deprived of a form of entertainment that he enjoyed and was happy to engage in:

> "didn't help that because with nothing to do in the hospital, I couldn't concentrate to read, and I couldn't really remember what it was I was reading. At that time they were only just putting in… sort of individual entertainment things, into hospitals, so it was a ward TV, which is mostly tuned into soaps, which I wasn't at all interested in." – Colin

At a time when biographical disruption is emerging for the person with the injury, the ability to make decisions as to how you spend your free time, of which there will potentially be much of, would seem crucial. By not playing a role in deciding how you spend your free time, the change in participation is one that is socially imposed and is therefore subject to change. Stochetti et al (2017) discussed the treatment of severe traumatic brain injury in intensive care units, discussing the tendency to treat the injury based on the collective population rather than one "that includes a range of brain lesions with separate—sometimes diverging—pathophysiological pathways and therapeutic needs" (2017: 452). This process of a collective approach can be seen to continue here in the more social, but still medical, environment of the rehabilitation ward.

Tommy discussed moving to a new healthcare setting and phase of rehab he was told would be more intense. This did not correlate to his view of what rehab should be like for him:

> "intense rehab… it was not intense, you sit there and it's got this big blackboard with ticks on it, saying one day next week you are getting physio and things, half

> an hour, and you get to go down and watch the TV in one of these big chairs with wings on them, oh like I said, it wasn't my idea of rehab, my idea of rehab is a lot more, a lot of running about or doing physical things, but there's would seem to be more to do with OT and things… So we used to sit watching this board, which obviously didn't change, just had ticks on it for what was going to happen, whether it was OT, physio and various other activities, of which there wasn't many." – Tommy

Participation and control here for Tommy was absent. This was typified by the authority of an inanimate object, the blackboard. A disconnect in what Tommy believed rehab would or could be, with little apparent input or control, was coupled with a disruption in routine temporality. The slowing of time experienced in rehab – where variety was announced by the ticks on the blackboard, or what was on the communal television – is clearly influenced by absence of participation in this process. Birk (2013) described how people living with chronic pain "inhabit a world where their strained voices are too easily invalidated and rarely even heard" (2013: 390). At this stage of recovery from a brain injury, where people's voices are re-emerging following severe trauma, participation requires that people are both heard and engaged with. The need to also understand a person's previous life, their biography, unsurprisingly appears key to the rehabilitation process. Participation in this area supports holistic approaches where the control that has been compromised is regained. This is important from a rights-perspective given that by acquiring a brain injury, a person is likely to find themselves further from the realisation of their rights. It also offers the possibility that someone who has regained control and is able to link their recovery to their own biography, may well in turn be a more successful rehabilitation patient in terms of medical measures of outcome.

7.3 Getting home

The environment in which recovery takes place is one in which impairment and social barriers collide. Discharge for participants required the meeting of resources, physical milestones and favourable social-environmental conditions. Ultimately, the decision of where Tommy would go following this phase was planned at a meeting of his multi-agency care team:

> "they had a nice little case conference about what they could do with me, and how I could get home and what progress I had made. So, what they had done, was they took me home one day, the OT and the physio to the house that I had… which had stairs, which they decided was not suitable. So, it meant to get out of the hospital we hired another house, a bungalow and a flat, which cost an awful

> lot of money and was a waste of time because I had been and going up and down the stairs prior to that, so it was a waste of money, so it was an ill-advised decision… I got out of the hospital without a care manager, so I had lots of problems trying to get things and get things started, but we were fairly lucky that we moved into that house and the flat, I did, changed the bathroom so it was suitable, which I got to pay for that, which was thousands of pounds, to convert into a sort of, or a walk in sort of a shower." - Tommy

What is evident is that this social process was one in which Tommy did not feel that he had full control over. This involvement of medical professionals "in decisions and assessment procedures which had little to do with medicine, such as housing, education and employment" (French and Swain, 2001: 737), continues clearly, and is a process where a human rights-based approach could have arrested or at least mitigated, the lack of participation and control. When supporting decision making with people with an acquired brain injury, healthcare professionals' risk being steered by 'implicit assumptions' regarding relationships, cultural norms, and perceived structural constraints, whilst lacking knowledge about the persons' own preferences (Knox et al, 2013: 1927). A human rights-based approach in Tommy's case would have provided a framework to enable participation, and indeed challenge the "medicalisation of many areas of disabled people's lives" (French and Swain, 2001: 737). The implementation of a HRBA in this case should also ensure that considerations are giving beyond that of adequate housing, and that discharge conferences encapsulate and empower the realisation of a person's economic, social and cultural rights.

Discharge for Tommy required significant financial resources. These resources were utilised in order to realise an adequate standard of living, as was the case with the bathroom modification. This raises the question of what meaningful participation requires in practice and illustrates the need for thresholds that ensure that independent financial resources are not required for the realisation of rights. The lack of participation that was demonstrated, also hinders biographical work, "an ongoing process whereby individuals revise their past and future identities aligning them with future goals" (Morgan and Burholt, 2020: 2036), as without participation, this revision is barrier-strewn, and repair, growth and rights-realisation is compromised.

7.4 Transport

The ability to travel is central to people's ability to take part in society and is an area in which disabled people continue to face a range of barriers. The loss of a driving licence due to illness brings with it obvious practical obstacles. The potential freedom regarding where you depart from, timing, comfort, and, in the case of hostile societal attitudes, safety. The removal of a driving licence due to a neurological condition can also represent the loss of a previous source of pleasure, and the disruption of normality (Stepney et al, 2018). Tommy discussed how, following his brain injury, his transport options were limited, at first by having his driving licence revoked due to his injury, and then following the breakdown of a relationship:

> *"I've no longer got a car either. I had to sell my car, because another thing is you had to hand in your license, they say kindly send it off, so I haven't got a license anymore, although I did have a mobility car which she [partner?] used to drive about in backward and forward, and me, but she left, I said, you can leave, but the car is staying here. So, then I sent my car back, so I have no car at the moment, which makes it very difficult for getting about, although I do have a bus pass and my plus one."* - Tommy

The legal requirements regarding driving following a brain injury are not uniform, and in Tommy's case represented another example of a surrendering of agency cloaked in a bureaucratic process. The absence of his own license and the reliance on others, be it a partner or a public transport provider represented a further limit placed on Tommy's independence. Access to mobility car schemes typically require the surrendering of a portion of Disability Living Allowance (DLA) / Personal Independence Payment (PIP) which requires the successful navigation of the social security system. This illustrates clearly the complexity of the merging of the injury and its effects, and the social relations and bureaucratic structures that a person navigates following an injury. Participation is made more difficult, precisely at the time in which it is needed to be safeguarded and supported.

The loss of Tommy's license carried with it a potentially gendered component. In previous research into driving following the diagnosis of neurological conditions, some male participants discussed driving "through conversations about their abilities, skills, strength and power which fitted hegemonic cultural conceptions of masculinity" (Stepney et al, 2018: 1196). In this respect, how Tommy experienced the loss of his licence may be different to that of other members of the group, depending on how they frame their sense of self in relation to masculinity. A medicalised approach to brain injury leaves little space for cultural considerations and impacts, such as the relationship between driving and masculine identities, and consequently provides little consideration of biographical disruption, and indeed paths to repair. Tommy further discussed the vital role the bus played in his ability to access places and participate in society. Whilst this was the case for Tommy, it brought about dangers in itself "the buses are sometimes an issue, they don't wait till you sit down and thing, which basically I find precarious, or they go straight past you at the bus stop" (Tommy). This represents a barrier that emerges as disabled people navigate built environments that are not built for them. The stark contrast as to how such a journey would have been considered prior to a person's injury highlights a potential site of disruption. This underlines the fluidity of biographical disruption, and its possible re-emergence as people navigate society.

Public transport has been described by participants in previous research "as hot spots for everyday hate" (Burch, 2021: 143). Despite this, hate crime towards disabled people on public transport is an under-researched area (Wilkin, 2020). In discussions at the support group, one member discussed having recently been assaulted whilst waiting at a bus stop in the city-centre:

> Meeting: 12 - [group member] told me about being pushed over in the street in [city] waiting at a bus stop. Think he got quite hurt physically and seems (understandably) to have knocked his confidence.

Access to transport is complex, and, in cases, dangerous environment to navigate. It is a junction where barriers collide. Firstly, people with brain injuries are less likely to hold a driving licence due to some of the impairments that are a result of having a brain injury. Furthermore, disabled people are likely to have fewer financial resources and thus are less likely to be able to own and maintain a car. As described by members and from what we know from the literature and testimony of other disabled people, the risk of injury from using transport whose design and or use does not fit your requirements, and that of injury from assault, is increased when using public transport. These factors combine to reduce people's ability, and possibly desire, to take part in society as they did prior to their injury. As this emerges following injury, it can be considered to be part of the process of "recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others" (Bury, 1982: 170), discussed in Bury's original research.

Access to healthcare following a brain injury may also require an increased reliance on public transport. Lack of access to public transport makes the realisation of the right to health barrier strewn and potentially unrealised. The Mobility and Access Committee for Scotland

(2019) reported “The planning and design of buses, bus routes, bus stops, information points, and public toilets are not geared towards disabled people and older people getting to hospital and other essential services” (2019:22). Alternative methods of transport were found to be lacking, and more difficult for people in rural areas. Furthermore, recommendations made in an audit eight years previously had not been met, which suggests a culture of neglect. The continuation of a driving licence following diagnosis of a neurological condition has been described as enabling “temporary moments of enjoyment, defiance and pleasure which offer an important apparatus against a backdrop of difficulty and challenge” (Stepney et al, 2018: 1195). In contrast, disabled people’s use of public transport following brain injury appears to be at best a site of resistance, at some potential cost, and ultimately an example of the sustained failure to uphold human rights by duty-bearers.

There is also the spectre of eco-ableism, where environmental activism fails to recognise the significant impact on the lives of disabled people of the measures proposed to tackle the climate crises (Inclusion Scotland, 2021). Inclusion Scotland highlighted a number of examples of urban planning for low-carbon city-centres that impact disabled people where car travel is restricted or banned, the removal of disabled parking bays due to the roll-out of cycle lanes, and the promotion of active travel that ignored that some disabled people cannot travel in a way that is by their definition ‘active’. Participation for some disabled people is again in this respect absent, and measures to redress this barrier to transport require both the tackling of existing barriers, but also the ableism that is being built into our transport system and cities in the future. Participation in this regard would ensure that planning for disabled people is not a retrospective act. More widely, a HRBA to transport would be part of a wider framework that realises people’s economic, social and cultural rights, and the central role that transport has to play.

7.5 Toilets as a barrier

Barriers to travel and taking part in society existed beyond that of being able to access appropriate modes of transport. Tommy discussed how following his injury he had to be particularly aware of available toilet facilities:

> “So you are always thinking, where’s the next one, even coming here I know there’s one downstairs… I know exactly where it is, aye, otherwise a big disaster could happen.” – Tommy

The importance of access to toilets is a major issue for many groups in society, particularly disabled people. A lack of provision completely undermines notions of participation as every area of life will be governed by this access, or lack thereof. The constant need to identify as disabled to use resources such as disabled toilets, combined with what can be a wait for a key is dehumanising, and limits access to public spaces and a person's ability to take part in society. The absence, or poor provision of toilets, to do what everyone does, "is fundamentally destructive to a person's sense of self, value and personhood" (Wiseman, 2019: 790), and a site of potential disruption and barrier to repair.

Despite these barriers, Tommy discussed how he intended to continue travelling and indeed extend his geographical reach following his injury, opening the door for a form of biographical growth to take place:

> "I will keep doing that [travelling] and going further and further, just have to have a nappy with me if it comes to it." - Tommy

This shows the potential of public services such as transport and access to toilets to support, rather than prevent, biographical growth following brain injury. Tommy's potential use of incontinence products appears to be necessitated by a lack of accessible transport and toilet provision. Tommy's attempt to mitigate these barriers by the use of incontinence products is an example which also highlights a further significant societal barrier. The use of incontinence products by adults is taboo in society, and the dominant image of such use is that of young children, who are incapable and in need of care. Thus, a reduced status is applied to people who use them in adulthood. Whilst a person may become familiar with their body again over time, how their body is perceived by others in wider society can reinforce the estrangement of body and self (Nasr et al, 2016). Tommy's use of the term 'nappy', the term used for young children's use of the product, may be pejorative, and its use signalling the emotion tied up in its use. A reaction to its use reflects the taboo, and highlights the discomfort of bodily function in society, and a contradiction on the part of the disabled body of the 'myth of bodily perfection' (Hughes, 2000: 560). This illustrates a desire by society to deny that our bodies, and our lives, are often messy and unpredictable, and to censor and stigmatise actions and consequently people, who highlight this reality.

7.6 What is participation without choice?

Social re-engagement was a further process where participation was a negotiated, and thus compromised, one. Beyond meeting medical needs, participants discussed interacting with services that recognised and provided a level of support to re-engage with social activities:

> “I was very lucky that I had a fairly nice young social worker who was just finishing training and was very keen. She got me involved in various things that I still do today, like cooking, various activities around the town, cooking, then she got sent to Stirling unfortunately, to finish her training, and then got the girl I have got now, who is certainly nice, but shall I say sort of reactive rather than proactive, although I think this is down to caseload, although when I need it, she done what she is supposed to do.” – Tommy

This again highlights the lack of certainty faced with regards to participation and opportunities for repair and growth. When relationships and support worked well, such as Tommy’s relationship with his previous social worker, they were still temporary and liable to change. This lack of consistency erects a barrier to repair and recovery and inhibits participation.

Evidence of possible biographical growth was present throughout the data. Within the data relating to the support group, a recurring theme was of people engaging in activities where biographical repair may take place:

> “The little bits that I missed about the old me, I thought, well I will just have to find new things about new me.” – Sadie

Evidence of biographical repair or flow was exemplified by examples of members taking part in cultural life. The importance of cultural life was recognised by the support group itself, who acted as a bridge for both official and unofficial group events that people attended sometimes without formal group support at the event itself. One example of this was the trip to see a national orchestra at a local music hall.

> Meeting 3: 10 people came along, which isn't much less than an average group. Demonstrates that the desire and capability, despite often significant barriers, is there to take part in cultural life.

The tickets for this event were free (provided through links to the orchestra), which helped to remove the greatest financial barrier to attending (though others such as transport persist).

The hall itself appeared accessible in that none of the group experienced obvious difficulty (from what I observed only) in accessing the venue or their seat. It was close to both rail and bus links and close to the venue where the support group normally meets.

> Meeting 3: The orchestra has a link with some of the members from an outreach programme that the RSNO [Royal Scottish National Orchestra] run. I thought they were really friendly, a few of the musicians spending time [with the group] before and during the break.

In this regard, the group was afforded a different status to the other people in attendance that night, as they were received prior to the performance by members of the orchestra, and during the interval. The musicians had worked closely with many members of the group previously as part of a community outreach programme, and the conversations took the form of a catch-up. The choice in this respect that was available to members was whether to attend the event or not. Not being able to take part in activities that a person did before a brain injury, or the ability or access to do so being lessened significantly, can increase a person's sense of disruption (Cutler et al, 2016: 272), which reiterates the importance of access to cultural life. Empowerment was to an extent enabled to access cultural life, but what this did not offer was a choice on what kind of cultural life or event that they wished to engage with. This is in sharp contrast with those who attended the orchestra with a paid ticket for whom participation was enabled by access to financial and cultural resources, and reflects their agentic pursuit of personal interests.

Social class may have traditionally presented another barrier which some of the members faced, as orchestras and classical music are spaces that could be understood to traditionally be the preserve of those rich in social capital and financial resources.

> Meeting 3: Got a sense that it (the crowd) was quite posh based on the accents I heard (not local to my ear), and the clothes people wore.

However, the high numbers that attended from the group (equivalent to some group meeting) suggests this was not the case. Members' attendance was an example of how a myriad of barriers, can be overcome and in this case lead to people with brain injury to participate in cultural life. Two main structural factors appeared to combine to enable this. A successful outreach music programme, where members of the orchestra and some of the members of the group had met and learned music together, and the provision of free tickets for the concert. This does arguably represent a ‘charity model’ approach, but one where biographical repair and/or growth could take place.

Biographical growth represents a key departure from narratives where ‘getting back to normal’, in essence neurological repair, is a target. Sadie, discussing her own injury, described how she thought this was an unachievable goal:

> “they might have fixed the problem getting worse, but the damage it’s, the damage that’s been done, you can only recover from that to a certain point. You know, you can’t recover from it 100%, you never will get that 100% back. And I think that’s the hard thing, people just don’t really, don’t really realise that at all, they don’t realise the extent of you know, the problems that you can have after a brain injury, regardless of well, they look fine.” – Sadie

Opportunities for biographical growth may offer an alternative path that may side-step (to an extent at least) the arguably impossible task of ‘full recovery’. Meaningful participation therefore presents an opportunity to further enable both repair but also an enhancement of people’s lives in comparison with the lives they lived before.

7.7 Running the show? Routes to further participation

The support group appeared to offer further options for involvement beyond attendance. Sadie became more involved in the running of the group (Sadie was an active volunteer who delivered art workshops and was a member of the board). This offered further opportunities for biographical repair and growth, and the opportunity in theory at least, to be involved in decisions relating to the group’s present and future direction:

> “I did get quite involved, but I was very much like just, a member previously, whereas now I have kind of move on from being a member to being a bit more of a help” - Sadie

This highlights the possibility for support groups to provide a space that can enable biographical repair and growth beyond areas such as peer-support, forming new friendship and taking part in new activities. Discussions on the direction of the group and its activities took place informally as part of the sessions. Involvement at board level reflects the historical turn towards ‘nothing for us without us’, in essence, participation. How members were selected to take part in the decision-making process at board level by becoming directors was, however, unclear.

7.8 Engaging new members

Whilst the group was a service open to everyone affected by brain injury, a relatively small number of people, in comparison with the large numbers of people affected, attended. Sadie discussed her surprise at a lack of members when first attending a previous incarnation of the support group:

> "I ended up getting in touch with somebody and then eventually got to go to a meeting, and it was all about like, I hadn't been, like I was the newest person for about five years. Not kidding." - Sadie

There is a relative paucity of services and support available for people with brain injury. The relatively small numbers attending the support group, and the previous group, as reported by Sadie, is suggestive of services that are unable to reach those who could benefit from what the group offers. This was apparent, on a micro level, to Sadie from her time as a patient on a neurosurgical ward:

> "that ward I was in had loads of people in it, and like, now there's, now they are telling you that this brain injury support group hasn't had anybody coming to it for extra, new for five years. What? It's a bit unusual this." - Sadie

The importance of raising awareness of the group was something that Sadie recognised: "every time I'm at [hospital] I go and give them some leaflets, and I always make sure that they have got some bits and pieces that they can hand out to anybody and I have quite a good rapport with some of the staff on the ward, and I just think it's really important" (Sadie).

For groups that do not have significant resources to devote to areas such as advertising, members such as Sadie provide a vital resource. Sadie's previous experience of the medical field, and its habitus, enabled her to navigate this area which may have otherwise been more difficult. This also suggests that outreach work, however informal, is a more complex process than it initially appears. The reappearance of the medical setting here also underlines the enduring medicalised relationship evidenced throughout the data.

7.9 Where is the young team?

> Fieldnote from meeting 2: Where are the young people?

The activities offered as part of the group were varied but would not be considered to be compelling pastimes for the average young adult in Scotland. Furthermore, the group consisted of members who appeared to be almost uniformly middle-aged and above. The group was running on what appeared to be a tight budget, and understandably catered for the people who attended. It would however be difficult for those in the younger age group to attend. Young people who have had a brain injury are at particular risk of disruption due to the life stage they are at, and peer-support from people of similar ages has the potential to benefit their psychosocial adjustment (Bakmann et al, 2019). This suggests that services that hope to include this demographic must again place participation at the centre in order to provide a service that is attractive, and appropriate to people of that age. One benefit reported of peer support groups for young adults was that "by meeting like-minded peers, they got reliable basis of comparison" (Bakmann et al, 2019: 9). This is an important consideration as the support group did not provide this, as there would be little or no reliable basis of comparison for a young adult. A failure to empower participation, which could mean the establishment of a separate group, therefore would appear to carry the risk of causing further biographical disruption.

7.10 Deconstructing the monolith - Intersectional experience and status

Accounts of people from ethnic minority backgrounds are underrepresented and hidden throughout society and can consequently be expected to be similarly in accounts and research on brain injury. One participant from the research, Vaila, discussed some of the societal and cultural pressures she experienced that being a woman from an Asian background brought:

> "because you are a woman and because you are from an Asian background you, you, you are meant to just carry on, if it's that, you know you are not meant to complain or say you are not feeling well or even if you are, aren't feeling well you still get up and make the dinner, hoover and, and do you know, you just, because you are always scared about what, what people will think, you know." - Vaila

The pressures described, which will be familiar to women of many backgrounds, are the result of societal expectations where women are expected to carry the domestic burden. The social requirement to do this demonstrates an absence of participation, and an absence of an exemption from social obligation owing to being 'sick' (Parsons, 1991). Furthermore, the domestic burden placed on women following brain injury is a barrier to the realisation to the right to health. This provides an example of the need to deconstruct monolithic, medicalised approaches to brain injury that cannot account for or respond to the intersectional nature of patient identities. Vaila went on to describe how dominant cultural norms and social pressures added additional burdens:

> “I think they need to, especially in my culture, it’s really difficult because you are just meant to carry on and you know, not complain and, and I think there needs to be more around cultural barriers that women with strokes may have or have had, because I don’t think people really open up about that kind of situation, even when they are in the hospital because they are scared that somebody might say something or it might get leaked out, she’s not worthy to do this and you know what I mean, it’s really difficult.” - Vaila

This illustrates that the experience of brain injury, even at a relatively acute stage is one that is societal and cultural. Vaila highlighted the link between her status as a woman within her community to be intrinsically linked to her ability to perform these gendered domestic tasks. As such, the inability to carry out these socially imposed, gendered tasks carried with it the risk of disruption. The managing of this site of disruption is a complex process, where a removal of a responsibility or lessening of a role does not necessarily prevent disruption. The reversal of the role of caregiver to that of being cared for following a brain injury is a possible site of biographical disruption as it can contradict both a person’s expected life path and roles that previously contributed to their sense of self (Cutler et al, 2016). Elements of this disruption were captured in Vaila’s account, and were exemplified by the highlighting of the need she felt to return to the home to perform domestic tasks:

> “you are worried, because straight away you are thinking, I can’t go home to make the tea, I can’t do the washing, do you know, stupid things like that and, and I understand now, but at that time I was like, oh you know, I need to get home.” – Vaila

Vaila’s role as a primary caregiver and mother also ensured that her illness was not conceptualised individually, initially, at least. This mirrors Wilson’s (2007) study that showed mothers with HIV aimed to limit the impact of their condition and biographical disruption on their children. Vaila’s experience highlights her attempt to navigate this complex post-injury site of disruption. In previous research, family members who were providing support to family members who had a brain injury voiced need for resources and indeed peer support for themselves (Gagnon et al, 2016). In research that did focus on peer support outcomes for families following brain injury, three main areas of benefit were identified; the opportunity to connect with others with a similar experience, access to information on life after brain injury, and the chance to ‘give back’ and provide support to others undergoing a similar experience (Bellon et al, 2017: 211).

Vaila identified that the understanding of the diagnosis, and what this may entail, needed to be explained and understood by the family:

> “it’s not just the woman, it’s the whole, the extended family if that makes sense, that, that need to be educated as well, that this is the reason she has had one, or this is the reason why this has happened, that, and keep drumming into them that you know, she’s not, she’s not as well as you think she is you know, and, because I think that’s the problem again, because people look okay, she’s fine, you know, she is making [it] up you know.” – Vaila

This highlights the need for ongoing access to explanation of the injury for both the person who has suffered it, and their family and loved ones. A lack of acknowledgement may be more likely when an injury has a ‘hidden’ element. However, for women who are less likely to be ‘believed’ by medical professionals and wider society, this carries additional weight and consequences. It raises the reality that social norms and customs that oppress people represent a hidden barrier to participation. To navigate these norms and customs requires labour, emotional and physical, and can in itself be considered a barrier to the realisation of rights. Vaila highlighted the overall gendered experience, and the need for this to change.

> “I think people need to understand the barriers that women can feel you know, when, when they… have become unwell… just to delve a bit deeper.”– Vaila

In Vaila’s case, for the continuation of her role and status in her family in the eyes of her community at that time, being able to present as being ‘well’ was required at the hospital bed. This management of presentation of one’s condition is required more later in recovery to navigate friendships, employers and bureaucratic processes such as employment and the social security system but could be understood as being required as soon as consciousness was regained for Vaila. By ignoring these social processes, our understanding of how people begin to process and deal with their disruption is limited. Such a monolithic approach also denies intersectionality and contributes to discourses that present brain injury as “a homogeneous, stable phenomenon with definite outcomes” (Harvey, 2018: 133). Societal pressures and processes, which invade the sterile, and clinical, environment of the hospital ward, are a clear barrier to rights realisation as demonstrated in Vaila’s account.

7.11 Hiding the injury

Brain injury, despite the wide range of physical impairments that can result from it, is often described as being a ‘hidden disability’ (Headway UK, 2022). The topic of a hidden injury was consistent throughout the data. This was often presented as a negative, as wider society lacked understanding of the extent or impact of a person’s injury because they appeared well:

> “Again, because I look okay… I should be doing everything, if that makes sense… when people, people have had a stroke, just because they say they are okay, doesn’t mean they are.”- Vaila

The navigation of the sick role (Parson, 1991) can be seen to be complex, as the classification of the injury by medical, bureaucratic entities such as the Department of Work and Pensions (DWP), and wider society is complex and ‘hidden’. Specific societal fields bring with it a required habitus in order to successfully navigate them (Bourdieu, 1989). This is particularly problematic to someone with a hidden injury, and particularly challenging when it has been acquired, as a new habitus, and with it a new “sense of one’s place” (Bourdieu, 1989: 19) must be learned. When that injury is neurological in nature, this navigation has the potential to be even more challenging. This is a barrier to biographical repair as the ability to navigate these fields is central to a person’s ability to navigate society as whole. Conversely, the medical field requires a performance of people’s condition in order to successfully navigate the areas in which it acts as a gatekeeper, such as treatment, access to wider holistic support, and, through diagnosis, overall credibility. The importance of carrying biographical work, narrative reconstruction, and access to adequate social support has been highlighted as central in dealing with one’s own biographical disruption (Pranka, 2018). Societal expectation to ‘hide’ the injury would appear to be a significant barrier to doing this.

Wider societal understanding of what a brain injury can mean, and the impact it can have, also brought with it potential pitfalls. This recognition could be negative, as societal assumptions of brain injury making people less capable represented a destructive form of recognition:

> “my colleagues have got health related illnesses, everyone understands diabetes, asthma, epilepsy, but when it comes to me everyone just couldn’t seem to grasp that I was okay, and I could do this and that, maybe couldn’t do that, but could do all this.” – Sadie

In this regard, outing yourself as being brain injured, is potentially a damaging act. Disclosure of a health condition can lead to biographical disruption in itself (Campbell, 2021), which suggests that the 'hidden' aspect, and an individual's ability to hide their injury, may provide a shield to navigate and participate in, the social world. Beyond possible emotional impacts this will also require a potential trading of support and resources. In this respect the presentation of a diagnosis may in fact hinder participation if people who have a brain injury are viewed as being less able to fully advocate for themselves.

Given the relatively large numbers of people who have a brain injury, it will not be uncommon for people to know someone who has had one. Sadie discussed that disclosing her injury did reveal a level of understanding based on a level of experience from others:

> "More people survive now than they did before, and I think the problem that I had, wasn't how I felt about it, it's how other people felt about it, because there is always somebody that knows somebody that has had such and such, and they then project their image of what they think you should be like." – Sadie

Knowledge of 'brain injury', or even specific injuries that fall under the collective banner may not in itself lead to positive outcomes. A level of understanding may lead therefore to a perception that people with a brain injury are less capable to carry out tasks and roles that they did prior to having their injury, or indeed more capable due to examples of others. This damaging perception was discussed in relation to employment, where the societal view was perceived as having erected a barrier to the labour market. Sadie discussed this in relation to her job, and her belief that this experience was not unusual:

> "I'm not the only person in the workplace with a brain injury of any kind, that's found that kind of situation" – Sadie

This barrier, and indeed discrimination in the workplace, was discussed elsewhere in reference to jobs people already held when they had their injury. A negative perception of a person's capability following a brain injury was also highlighted as another barrier to accessing new employment:

> "I find it very difficult to not have a job, I mean I find that very hard now, because nobody, nobody will give me a job because of my health…" – Vaila

A reduction or absence of choice in terms of employment was evident for the participants in this research. At the time of the interviews, none of the members interviewed were in paid employment (one person was in further education). The support group itself took place on a Wednesday afternoon, during the traditional working week, which suggests that people with a brain injury in full-time employment would be less likely to access the group. These examples however offer a valuable insight as to the value, or at times need, of being able to ‘hide’ your disability, and the consequences when this doesn’t happen.

During the fieldwork different members of the support group remarked that they could not tell that I had a brain injury. This was presented by them as a positive:

> Meeting 2: “you are one of the lucky ones cause you canny see you’ve had a brain injury” – Georgie.
>
> Meeting 6: “Ye canny tell way you that yiv hud wan, you look really well” - Rab.

A lack of obvious physical impairment is understandably viewed positively, as it suggests a better medical outcome and fewer societal barriers. When considered in the context of a hostile societal environment it is a measured and informed point made by peers who are aware that being able to hide or mask your disabled status or impairments makes navigating aspects of society easier. In that context it is not a denial of the difficulties faced, but an awareness of the reality of what the reduction of status that being visibly disabled can bring.

7.12 Confirming your status: the ritual of ‘what is your injury’

Status within the group was established through a clear observable ritual, that of ‘what is your injury?’. As a researcher with a brain injury, I disclosed that I had a brain injury prior to the commencement of the research. This led to a repeated, ritualistic process was that was central to what I perceived to be my early adoption of insider status. As shown below in Figure 7-1, this loosely followed a repeated structure based around a series of questions aimed at confirming and assessing the severity of a person’s injury.

> Meeting 1: A number of people (4-5) were keen to share story instantly. Insider status was well received. It felt like I was being sounded-out.

Figure 7-1: Ritual of peer assessment for brain-injured status - 'what is your injury'?

This ritual demonstrates a long-lasting, and ingrained impact of a process of medicalisation that usually begins at diagnosis and would appear to perpetuate long after people receive primary care for their injury. This ritual was not unique to me, and I observed it when people were getting to know each other, and when new people joined the group:

> Meeting 8: New person turned up from the brain tumour group. She sat with her husband. Made friends and conversations that I noticed were again based on listing the injury, how it affects her and the like. This sharing of information happens consistently.

Within this ritual, a conscious or unconscious interrogation or vetting process appeared to occur. I never experienced or felt that this was a process rooted in suspicion when I experienced it or observed others engaging in this ritual. This is a crucial distinction as it is in sharp contrast to other societal fields which people must navigate when interactions regarding these details occur. The sharing and description of impairment is a process that is commonplace for people with brain injury, as it is with other disabled people. Its successful performance is vital to navigate and receive treatment, rehabilitate, to gain an understanding of your injury, to access the welfare system (and in this to be able to feed, clothe and heat, yourself) and also at times to maintain relationships. For the individual, this can raise a question of “How can I feel authentic when I always have to play-act my credibility for others?” (Birk, 2013: 395). The support group appeared to offer a place where credibility was achieved by declaration of injury, which in turn ensured authenticity which was not subject to review.

However, in the group the conversations I took part in and witnessed were generally marked by the compassion and empathetic manner in which they were carried out:

> Meeting 10: From my perspective it is a real ‘safe-space’ for people to have these conversations without it dominating, the way that I thought it did when I went to the previous group I worked in. Not sure what the difference is. Perhaps that I am doing ‘better’.

This represents the sole space discussed during interviews or observed as part of the group where people confidently and safely disclosed detailed information regarding their injury and experience. It is possible that for people coming to the group this is the only space that exists for them to do this. The creation of a safe-space for this to take place offers potential for people to process their biographical disruption(s), and to then begin or continue the process of recovery on their own terms. This is in sharp contrast to the discussions in unsupportive medical settings where the more convincing performance of one’s condition “the greater the harm done to one’s own sense of self” (Birk, 2013: 395).

7.13 Chapter summary

The data presented illustrates the complex navigation of the social world, its structures and processes following brain injury. The experiences and possible sites of biographical disruption present as fluid - and specific - in its impact upon the individual. Emerging throughout this analysis chapter is the link between disruption and the role of participation, or lack thereof. Attempts to achieve biographical repair were routinely undermined by societal structures and processes - processes that were seen to emerge initially in medical settings. The accounts highlighted the complexity of the management of people’s injuries, a management that referred often not to impairment but rather of the negotiation of hostile social and cultural structures and norms. The peer-support group offered a space in which to exist without the need for resistance but was also an environment that would be augmented by a human rights-based approach. This would ensure that rhetoric meets reality, and provide a safer place for biographical repair and growth to occur. Brain injury, as articulated by participants, causes an upset and disruption to people’s lives, and their perception of their social space, as they experienced before. Habitus enables “a world of common sense, a world that seems self-evident" (Bourdieu, 1989: 19). The world to which participants emerged following injury was one which is fractured, and an environment through which biographical disruption was repeated, and repair and flow is undermined. A human rights-based approach, evidenced in participation, offers a framework to achieve a rights realisation absent in a range of stages and settings articulated by the participants of this research. To understand the barriers to this realisation, the following chapter will analyse the presence and absence of accountability, non-discrimination and empowerment.

Chapter 8 Theme 2: Accountability

8.1 Introduction

Accountability is a vital component of a rights-based society. In the field of health (and indeed more widely) accountability “provides rightsholders with an opportunity to understand how government has discharged its right to health obligations” (Potts and Hunt, 2008:13), and crucially shifts citizens from “passive beneficiaries” into rights-holders (Yamin, 2008: 1). Furthermore, accountability structures should provide a clear route to redress when rights are not realised and through monitoring ensure that the scale of rights violations are known, and that these violations are not repeated.

This chapter will explore how participants understood accountability and consider how a lack of accountability can contribute to the creation of an environment where biographical disruption, as opposed to repair, is facilitated. The chapter will focus on participants experience of healthcare, perspectives that are largely absent in academic literature (Panday et al., 2022). This will span from initial critical care to rehabilitation and the experience following discharge, and further the role of frontline staff, and other health diagnosis.

8.2 Critical Care

The experience of critical care was largely absent in participants’ accounts, and in general discussion at the support group. This is unsurprising considering the nature of the injury and the often-reduced levels of consciousness during this period. One explanation for the absence might be the nature of the injury. Further, an exception to this is the account provided by Sarah, who was interviewed alongside her partner John, and provided the perspective of someone who witnessed their partners experience of injury and critical care. Sarah detailed her concern following the process of her partners’ move from an intensive care ward:

> “it was such a culture shock, because you went from high tech ICU [Intensive Care Unit] to this, four-bedded ward, it was dark and dingy, and I just went, oh my god, they put him up here to die. It was just because it was such a, a change from the high- tech stuff to this.” – Sarah

This move at other times could have been seen as a sign of recovery, and a cause for optimism. The removal however of the ‘high-tech’ equipment in this case signalled to Sarah that her partner’s care had been reduced, and with it his chances of survival. Accountability processes could have ensured that Sarah clearly understood what the next stage of treatment entailed, and why John was being moved from that ward. Sarah highlighted further aspects of John's care where she believed participation, and consequently accountability was not present. When it came to further decisions on the course of future treatment and rehabilitation, Sarah critiqued the lack of a person-centred approach that would allow space for her partners personality and way of doing things:

> "I kept on saying, John's a thinker… he will be trying to process this, he, he is not ready, he is not ready for rehab, because that's not how he is. He, he was a total thinker, he needed to think things through before he did anything, that was, that is John." – Sarah

In this period of warped temporality, a denial of the time needed to process his new reality could represent a loss of, or failure to reinstate, his own autonomy. Person-centred care is, according to the NHS, a "strategic priority for NHS Scotland and the Scottish Government" (Scottish Government, 2019b: 1), where the encouragement and support of the presence of family members is one that carries an "ethical and human rights imperative" (ibid: 15). An acid test of accountability structures should therefore be a pathway for redress and the resumption of meaningful, empowered participation. Sarah's account did not highlight a clear and accessible accountability mechanism that recognised what she considered to be her partner's personality and holistic needs. A person-centred, human rights-based approach should encompass the impact of fundamental shifts in treatment to the individual, and any psychological impact on those affected. Healthcare settings where the holistic needs of patients are secondary to medicalised authority and process contradict this. Medicine-centred practices can also open further areas of biographical disruption, as fundamental decisions that would have been taken prior to injury, such as where a person will live and under what conditions, are no longer taken autonomously.

This is past the stage of initial diagnosis and where the limits of medical knowledge and solution are beginning to be met. Bury (1982) highlighted the difficult contrast between a medical diagnosis which provides a firm basis to relate to and share with others, whilst "the actual nature of the disease remains elusive and the treatments empirical" (Bury, 1982: 174). This unveiling of the limits of medical knowledge, Bury contends, pushes an individual back towards their own knowledge and experience, and the beginning of a search for more comprehensive knowledge to enable them to cope with their new-found reality. The management of this process, and routes for redress when required, would appear therefore to be potentially crucial for biographical repair. This is both in respect to the individual themselves and indeed their wider family and loved ones, whose often key role in the recovery process suggests biographical repair as a collective as opposed to an exclusively individual process (Panday et al, 2022: 5545). The role that dignity plays in this process will now be addressed.

8.3 Dignity, care and biographical disruption

The concept of dignity is a fundamental principal of human rights and a cornerstone of accountability mechanisms. It provides us with an analysis framework from which to interrogate and understand our relationship to social structures and how people are viewed and treated within them (Basser, 2011: 18). Furthermore, it is a concept from which people individually derive "a sense of self and of self-esteem, providing a foundation for self-determination" (ibid: 18). This is of relevance to our understanding of biographical disruption as if it is removed following an injury or diagnosis, a fertile ground for disruption is enabled.

Dignity in healthcare settings was discussed broadly by participants. There was a general sense that the staff in these settings were attentive and dedicated as summarised by Vaila "I have to say that I think the people at the hospital, they were amazing". The loss of dignity was conceptualised in different forms by participants. Sarah described a situation where John's dignity was not upheld by the duty-bearer:

> "I went to the hospital and I found John sitting in, in the dining room with a cup of soup in front of him, and he didn't even know how to pick up the cup, let alone eat."- Sarah

This represents a brutal and undignified example of the "disruption of taken for-granted assumptions and behaviours" (Bury, 1982: 169). That it was empowered by a failure on behalf of the duty-bearer, also represents a clear sign that dignity is no longer assured following injury. This institutional failure supports the general view of disabled people not being considered right-holders, but passive recipients of state benefits and charity (Basser, 2011). Accountability could be seen as crucial to our understanding of biographical disruption in this case as its absence enables the removal of dignity, which in turn encourages a development of self that is negative, and a person's sense of self prior to their injury. The lack of accountability structures therefore presents a significant barrier to biographical repair and the development of a positive sense of self.

Sarah was herself navigating an extreme and previously unknown experience, which may have included elements of ambiguous loss and biographical disruption. Dignity and accountability for Sarah was described through the context of the care of her partner, however accountability structures could have provided support for her during this time. This is important as those providing care, a group of hidden voices, are rights-holders also. To frame it from a more medicalised viewpoint, the establishment of dignified processes also serves an important purpose in relation to John and his ongoing care, as, with keeping with the general trend, his care was predominantly about to pass from the duty-bearer to Sarah herself. This suggests a need to widen considerations of accountability beyond in this case 'the patient' to loved ones, and consideration that more people fall through the net than the person who has sustained the injury.

Tommy described a life in rehabilitation and how basic aspects of his life that may have been previously taken for granted were now experienced in stark contrast:

> "I wasn't allowed to walk about, so I had to get hoisted everywhere, bit like Peter Pan, hoisted to the toilet, hoisted to everywhere… sometimes never made it, pooing all the way along the hallway and things and it was very embarrassing."
> – Tommy

The lack of provision of resources that would have enabled dignified care for Tommy and met his needs. Strong accountability mechanisms should have ensured at least not have redress, or a change in process that avoided repetition. Tommy's embarrassment illustrates that whilst he was resilient and maintained his own sense of dignity, it was damaging none the less. The management of disruption and construction of a new sense of self can be considered crucial to the maintenance of dignity and its recognition necessary to healthcare systems required to uphold it.

8.4 Frontline staff, duty bearing and rights-realising?

The person providing the patient care was the difference in whether a healthcare setting afforded accountability or not. Nursing staff represent a human-face amongst the de-personalised and medicalised healthcare system. Sarah, having witnessed her partner's treatment highlighted the tremendous effort that individual staff members made to keep John alive and in as much comfort as possible:

> "Claire [changed name] was amazing, she just, she never stopped, she would, she did a twelve-hour shift and they never, ever stopped. She just, just was astonishing how she worked, and the pressure to keep, keep him alive." – Sarah

The role of healthcare workers, often working under tremendous pressure and difficult conditions cannot be underestimated. The realisation of rights should be the responsibility of the duty-bearer, but in its absence the gap will be filled by people like Claire. Healthcare professionals are intrinsically linked to the duty-bearer, despite having little or no influence on the development or policy and practice, and often lack sufficient human-rights education themselves (Black et al., 2023). The engaging of these workers in processes that aim to decide how to realise the right to health brings a crucial expertise to the table, also offers the possibility of overcoming "conflicts between providers and users of health services" (London, 2008: 73). This also offers possibilities to grow an environment where their own right to health, which may be compromised from their own role in the healthcare system, is realised, or at the minimum the creation of a framework where their own rights-violations can be explored.

The complexity of the role staff play within this system was exemplified further by Tommy's description of the support he was provided for his incontinence issues:

> "luckily I had two nice people on night shift, I used to say can I have an emergency bedpan, basically just two carboard ones put together, so that it wouldn't concertina, so I wouldn't be sitting on the shit." - Tommy

Tommy's reliance of being lucky to have nice staff mirrored that of the staff member that Sarah described. However, the reliance on luck, or people being nice, suggests that autonomy, dignity, and accountability is severely limited or exists in small pockets. It further demonstrates an environment where participants did not consider themselves as rights-holders. This complexity was captured in previous research that engaged the perspectives of people with brain injury in in-patient rehabilitation settings. In this study participants reported that whilst most encounters with staff were positive, there was an awareness that staff remained gatekeepers to important information, had power to enforce changes in a patient's medical care, their daily routine, and eventual discharge (Panday et al, 2022). Autonomy following brain injury is clearly a fluid and multifaceted process, which in turn further underlines the need for meaningful participation as soon as possible (as discussed in the previous analysis chapter), and rigid and clear accountability structures for when it is not.

8.5 Falling through the net

The participants of this study sustained serious, and complex, injuries that were long-lasting in their impact. Sadie, who had suffered a subarachnoid haemorrhage, went into detail of her experience of support and provision of information following her discharge from hospital:

> "I got nothing, I got a letter from the GP, this woman has had a subarachnoid haemorrhage, but I never got anything. I never got, well if you want to talk to someone you could phone here, I didn't have a helpline, I didn't have an anything, you know, I had nobody to talk to about, should this not be gone by now or how long is this going to last for? So, I did feel very sort of isolated and on my own, and that didn't help with feeling quite fed up and depressed. If I had had some information from day one, that would help us with the support that I should have had, it would have made a great difference." - Sadie

Sadie's description illustrates the reinforcement of disruption by a lack of information and access to adequate healthcare. Accountability is understood here as being a source of information, and information is understood as a form of power. Resources in this area were absent, and this lack of access, and the impact this had on Sadie's mental health, raises questions regarding accountability, and whether this is occurring in systems where access is denied or heavily restricted. This builds evidence of the holistic impact of a lack of accountability, that its absence contributes to the creation or exacerbation of new health conditions beyond the primary diagnosed condition, in this case brain injury. Sadie further discussed a lack of community and outpatient care following discharge from the hospital:

> "I really kind of fell through the net because I didn't get any help at all once I got home, nothing, no OT [Occupational Therapist], no physio, nothing, and we just sort of slipped through the net." – Sadie

A rights-based approach to health with accountability embedded into its foundation and practice "empowers right-holders and takes health-related human rights from rhetoric to reality by requiring mechanisms to assure monitoring and review as a foundation for remedy and redress" (Bustreo and Doebbler, 2020: 99). This would ensure that Sadie had access to the services she required and, at a minimum, that a route to redress was available for anyone who had 'slipped through the net'. The absence of a human rights culture also contributes to a lack of a clear acknowledgement of others denial of their rights and makes it more difficult to ascertain whether people slip through the net or whether the net exists in any meaningful respect. The experiences of Sadie and Tommy are particularly stark, as both had worked in healthcare settings and did not highlight knowing of, or feeling able, to access any accountability processes and routes to remedy and redress.

Acceptance has been highlighted as a strategy of biographical repair (Locock et al., 2009). Sadie detailed her attempts to gain information and understanding about her injury and prognosis from the nearest available access point, her local GP:

> “my GP, she was lovely, but she didn’t have all the answers to questions that I had, whereas the neurosurgeon would have done. So things that I would say to her, well what about this, is this normal, am I supposed to be feeling like this, am I supposed to be feeling like that, and it was like, you know, it was kind of, she, she didn’t know because she said herself, I was the only patient she ever had that had survived to that extent.” - Sadie

In confronting her lack of access to information, Sadie demonstrated what could be considered an attempt to carry out her own biographical repair. The inconsistency of the information and access to services that Sadie experienced evidence an absence of rights realisation and a barrier to recovery and biographical repair. This demonstrates the focus from healthcare systems on “curing or improving [disabled people’s] impairments, rather than improving their health” (Rioux, 2019: 94). This process of seeking understanding of Sadie’s own injury is one that was clearly hindered by the healthcare system she encountered.

Whilst human rights incorporation into Scots Law remains unrealised, there are examples of Government moves towards a rights-based approaches already evident in policy in Scotland. The Scottish Government policy of ‘Self-directed support (SDS), is one example of a range of policies designed to “support, promote and protect people’s human rights and through access to independent living support people’s participation in Scotland’s social, political and civic life” (Scottish Government, 2022b: 3). Research that explored at the complaints process built into Self-directed Support (SDS) in Scotland found that people faced a range of barriers to redress. The weight of responsibility on the individual, knowledge barriers, the fear of negative impacts due to making a claim itself, and barriers to legal support and the legal process itself were highlighted by solicitors and advocacy and advice agency workers that took part in the research (Gittens et al., 2021). This highlights the complexity of accountability, that to change the experience of Sadie, identification of duty-bearers and a redress procedure must also bring with it the establishment of clear thresholds and processes where patients become and view themselves as rights-holders.

8.6 Control is absent in other diagnosis

Referencing Foucault's (1980) unpacking of the power dynamic within a courtroom, and the role of its judges, Rioux (2019) posed the question "how many people must feel like they are in front of such judges every time they need health care or every time they feel the influences of societies that do not provide justice in the context of the right to health?" (Rioux, 2019: 84). Each participant at some point in the interviews discussed experiences of healthcare that spoke to this power imbalance and was not limited to participants experience of brain injury. Andy described his experience and the long-lasting impact of his attempt to access medical support years prior to his eventual diagnosis of autism and dyspraxia. Andy was attending university at the time, and in need of a medical letter in order to access the additional support he required to continue his course and realise his right to education:

> "I spoke to a clinical psychologist, and he was the most unsympathetic doctor you ever met. His exact words were… 'Andy just suffers from excessive anxiety and immaturity'.... how am I supposed to give that to my, my lecturer'… to this day I have never got over that, never, never got over, I even dropped out of uni, the first time I went." - Andy

Andy's experience demonstrates how the lack of realisation of his right to health, in turn impacted on his rights and ability to take part in society. This highlights the importance of a medical diagnosis, from both the personal and social perspective, and the chasm that is left when this process is mismanaged. For Andy's 'condition' to be recognised socially, a medical diagnosis was required. The lack of a correct diagnosis or explanation had a profound effect on his health and led to Andy having what he described as a "breakdown" at this time. The initial denial of his right to health contributed to a worsening of his own health, and revealed the possibility to Andy that the healthcare space was no longer a place where he could confidently seek help for any existing and consequent health concerns:

> "I just dipped after, I didn't, I didn't get to, I didn't seek anymore help after that. I had a complete and utter identity crisis; I didn't know what was wrong with me… I became so obsessed with finding an answer to what was wrong with me."
> - Andy

This reveals both the profound impact of Andy's attempt to access health, and a hidden barrier as the process of presenting himself to be judged again was something he felt unable or unwilling to do. It is also symptomatic of a healthcare system, and society, where people are encouraged to focus on what is 'wrong' with them and not on which rights are being denied, and where individuals have no authority to challenge the power of the system. This denial also crucially impacted on Andy's right to education and brings with it a crucial learning in respect to accountability. For Andy to realise true redress, this wider impact must be recognised, as his life does not exist in a vacuum. This indicates that mapping of rights violations must include the relationship and impact on rights more widely. This mapping must, however, be backed by the State and duty-bearer in the form of human rights incorporation and the embedding of human rights-based approaches as "mapping accountability is useless if there are no consequences for failures to meet obligations" (Yamin, 2008: 5). Furthermore, it requires a shift from monitoring models which view disability as an issue that requires medical treatment and classification where head counts then determine services, to a human rights monitoring approach which "places access to rights (including rights to services) within a broad range of indivisible, interrelated and interconnected spheres of human life that span civil, political, social, economic and cultural dimensions" (Pinto, 2011: 455).

8.7 Chapter summary

Accountability in any meaningful form was a concept and process that was hidden in the accounts of the participants of this study. Participants' experiences illustrated an environment where accessing dignified care, services and information was inconsistent, and which led to participants 'falling through the net' without apparent routes to redress. This led to experiences where participants were at best beneficiaries of care navigating a range of settings and gatekeepers, as opposed to empowered rights-holders.

Participants' accounts highlighted the role that accountability in healthcare settings has to play in relation to biographical disruption and repair. As people begin their recovery, care that is undignified, inadequate or hard to reach following brain injury provides a fertile environment for disruption and a barrier to repair. This is long lasting as further negative experiences may encourage a negative reappraisal of the self and a questioning of one's new biography.

The experiences of the participants also suggest the need for a widening of what meaningful accountability structures should look like in practice. Rights denial in one area will naturally lead to impacts elsewhere in people’s lives. If the right to health is not realised and this results in a person then not being able to realise other rights, such as the right to education as was the case with Andy, then redress must encapsulate this. This highlights the need for holistic and maximalist approaches to human rights as “no right can be really achieved if all the others are not similarly guaranteed” (Pinto, 2011: 451). A key path to accountability in Scotland would therefore appear to be that of human rights incorporation, however questions remain as to whether in Scotland incorporation “rhetoric meets reality” (Black et al., 2023: 64). The growth of a rights-based society would remove key barriers to participants ability to navigate healthcare and create an environment where biographical repair is enabled. This also of course extends to all of society, which in turn could empower other key factors such as family members and healthcare professionals. Accountability can therefore be understood as both a safeguard and indeed an enabler for all to live dignified, rights-enabled lives.

Chapter 9 Theme 3: Non-discrimination

9.1 Introduction

Despite the Equality Act, which offers legal protection from discrimination in the workplace and wider society (UK Government, 2015), and its forerunner the Disability Discrimination Act (1995), disabled people still face discrimination and barriers to participation across society. This is apparent and demonstrated in the Scottish labour market, where disabled people face significantly lower levels of employment (50.7% compared with 82.5% of non-disabled people). When in employment, disabled people face a median hourly pay gap of 16.2%, an increase from 12.8% between 2014 and 2019 (Scottish Government, 2023b: 2-3). Of further concern is the economic inactivity rate, defined by the duty bearer as "people not in employment and who do not meet the criteria for unemployment" (Scottish Government, 2023b: 24). This rate of economic inactivity could encompass many people with brain injury, who may not easily sit within traditional employed/unemployed categories. For disabled people, the rate of economic inactivity is 46.0%, in comparison to 15.1% for non-disabled people (Scottish Government, 2023b: 2). For people with brain injury who have re-entered the labour market, the return to work (RTW) is one which often requires them to navigate spaces where the legitimacy of their injury is liable to be questioned (Paniccia, 2018). For the participants of this study, returning to work was experienced as barrier-strewn, hostile and one where discrimination was layered and its impacts wide-ranging.

This chapter will focus primarily on participants' experience of the barriers they faced as they attempted to RTW following their injury, and focus specifically on interview data. To understand this, a lens of non-discrimination is applied to understand how this process was experience compared to a principle that demands that "all forms of discrimination must be prohibited, prevented and eliminated" (Scottish Government, 2015: 15), and whether those furthest from realising their rights were in any meaningful way prioritised. This chapter will include explorations of the circumstances and motivations which drove people back to work, and the impact that a return to a new environment of hostility and discrimination had. This will also consider the strategies employed and the cost of continued re-engagement with this process. In doing so, this chapter will provide insight into the potential offered, and the need for a change to a rights-based society. Furthermore, it will consider how these experiences contributed to biographical disruption, and the role played by "the timing, context and circumstances within which illnesses are ‘normalised’ or ‘problematised’, and the manner in which identities are threatened or affirmed” (Williams, 2000: 62).

9.2 Reasons to return

Returning to work following a brain injury represents a clear and observable marker of recovery and reintegration, and evidence of biographical repair. For each of the participants of this study, the return to work was one characterised by revelation of repeated barriers and discrimination. The need to return to work, as opposed to just the desire, which was also a driver, was present in accounts which signalled the structural failure of the social security system. There is also the clear evidence that being disabled increases the day-to-day cost of living. This was illustrated in the continuation or resumption of the role of ‘breadwinner’ within a household, previously highlighted as being important to both women and men following brain injury (Stergiou-Kita et al, 2016). Sadie described this responsibility and the pressure this placed on her:

> “that was a huge worry to me, was like, what are we going to do, what are we going to do, I need to go back to work because I need to get money, I have got a mortgage to pay, you know my kids need things, I need things, and the heating needs to be paid” – Sadie.

The lack of adequate financial support created an environment where Sadie’s recovery and health was likely to be compromised due to the need to provide for herself and her family. This represents a barrier to recovery but also to employment, as people recovering from brain injuries are pushed into a situation where the basic foundations of family life are at risk, which in turn may lead people to a return to work (RTW) before they are ready. Previous studies have explored motivations to return to work for men following brain injury, at times “driven by strongly gendered notions of what it meant for them to be men”, which included being the perceived providers and breadwinners of a household (D’Souza et al, 2022: 351). Sadie’s responsibilities as a mother and parent clearly influenced her need to return to work at this time, and the consequent success or failure of this could be considered to be crucial in attempts to achieve biographical repair. The State’s failure to provide adequate social security and healthcare illustrates an environment where the failure of a duty-bearer is discriminatory, as a premature RTW may impact on a person's physical and mental health, as well as their success in the labour market and in navigating wider society if this is not successful. The rights of their children are also threatened in this sense, which again suggests the need for a holistic understanding and responsibility for failures of human rights realisation. Previous studies have highlighted the gendered nature of the process of a return to work following a brain injury (Stergiou-Kita et al, 2016), and Sadie's description suggests the presence of this taking place to a backdrop of a triple-burden in brain injury where women are required to work, carry out domestic roles, whilst also being responsible for their own recovery when the right to health is not realised. For women, discriminatory attitudes in the workplace will often have been experienced prior to injury. Previous studies that looked at RTW following maternity leave reported that mothers returned to a field that was barrier-strewn environment that "devalues reproductive labour" (Huppatz et al 2019: 783). This highlights the need for intersectional considerations of where barriers to participation and discrimination lie when a return to work is attempted following injury.

9.3 The return to work

A lack of societal understanding of brain injury is reflected as a microcosm within the labour market. Employers, who in turn may hold "fears of the unknown" when they encounter employees, or potential employees, with brain injury (Sergiou-Kita et al, 2017: 254). This lack of awareness has been cited as a main contributor to inadequate workplace support and adaptions (Paniccia, 2018). Supportive workplaces have unsurprisingly been reported as an important environmental factor that facilitates a RTW following a brain injury, but this requires good communication between the employer and employee, and an understanding of the range of impairments and effects following a brain injury (Brakenridge et al, 2022). Both Tommy and Sadie discussed their attempts to return to work in medical settings, an environment that theoretically should have been a site for best practice in terms of the need and ability to understand their injuries. Tommy discussed his phased return to work, on reduced hours, which he considered had occurred "to say they [his employer] had done something right". Once back at work Tommy found himself struggling to adapt to the role he had been assigned and discussed a lack of available support to be able to do what was being asked of him. His return to work culminated in the termination of his contract:

> "the next thing, it was, your contract is terminated. So that was that. They were offering me jobs within the hospital, things like carrying x-rays about and shall we say, menial jobs as opposed to being the manager… I haven't been able to work since."- Tommy

The failure of Tommy's return to work is indicative of a process which was not fit for purpose for him, or society, as it contributed to his removal from the labour market. Return to work practices for people with brain injury are "still a long way from taking into account the full complexity of factors that contribute to increasing or decreasing the chance of individuals retaining work after ABI" (Alves et al, 2020: 129). The choice available to Tommy appeared to be to accept a reduction in job role and status, or to leave employment, rather than the employer making supportive and reasonable adjustments to support his return to work. Sadie underwent a protracted process of attempting to return to her workplace, beginning with optimism and an expectation that she would be supported to do so:

> "I just had it in my head that I would be able to go back to work and I would get supported to go back to work, but when I went back to work it was the dynamics of the profession is that, that, that you just can't, you get sort of like, railroaded into, into the ground, because you can't work with the rest of the machinery that is, that is that industry" – Sadie.

A return to work (RTW) that involves being 'railroaded into the ground' suggests an environment where the prospects for success were minimal. Stergiou-Kita et al (2016) reported that the RTW prospects were more positive for people with brain injury whose workplaces were characterised as nurturing (described by the authors as more feminine) and supportive. This highlights that Sadie's was not, despite the stereotypes of the nursing profession. Absent in all accounts was evidence of fluid processes that recognised the changing needs, abilities and personal understanding of the injury (Gourdeau et al, 2020). If brain injury is not adequately understood or encapsulated into these processes, then an environment of discrimination will flourish. Vaila, who was working in benefits support, experienced a similar end to the career she had enjoyed prior to her brain injury:

> "they just said, said they had to let me go because I was, well it was, it was affecting other people and you know, people that I was doing benefits for as well" – Vaila.

Such an abruption of employment disregards the ability and experience that Vaila, as with other participants, had accumulated through their careers, in addition to the experience and skills gathered during their illness and rehabilitation period. It also reflects an environment in which experiences away from the labour market from groups that are marginalised, such as disabled people and mothers, are deemed irrelevant and undervalued. Vaila, Tommy and Sadie's experience of being forced out of employment suggests that employers disregard the contribution that the disabled worker can provide. Employers appear to favour ‘functional’ people to fill roles rather than removing barriers to allow disabled people to adapt to their roles.

9.4 Workplace adjustments

Brain injury can cause impairments which can impact people’s ability to carry out specific tasks in the workplace, though assistive technologies that can support people with brain injuries in the workplace, even in basic forms such as customised calendars with reminders, are increasingly being used in the workplace (Sabatello, 2014). Common impairments highlighted as having adverse effects in the workplace include headaches, fatigue, sensitivity to noise and light, difficulty with concentration and memory, reading and writing (Paniccia, 2018). These do not preclude people from the labour market, and the failure to meaningfully reintegrate people mirrors economic practices and perspectives witnessed since the industrial revolution (Turner and Blackie, 2018; Finkelstein, 1993). Adaptations such as a phased RTW, flexibility in scheduling, recognition of the need to attend medical appointments and strategies that are self-directed have been recommended to better enable RTW following brain injury (Gourdeau et al, 2020).

Participants did not provide any details on adaptations that were provided that were meaningful to them, and in contrast voiced frustration as to the huge cost of impacts on small areas of their work:

> “There’s a small percentage of my job that I couldn’t do, but the majority of it I could, so it’s a pity.” – Sadie

By removing people’s jobs (and in Tommy’s case offering him one that he considered to be menial in comparison), employers enabled disruption. Indeed, continuing in employment (stable role and status) was a form of narrative continuation that could have stabilised people as they adjusted to life after an acquired brain injury (ABI). Their acquired status of ‘disabled’ was observable to employers and colleagues and represents the passing of a baton from the medical world to the social. In doing so, a revised status is stamped, and a barrier to participation erected. How this environment was experienced when in work, therefore, requires further exploration.

9.5 Office banter as normalised hate crime

How, when, and whether to disclose an injury has also been highlighted as an issue for people with brain injury who return to work (Sabatello, 2014, Stergiou-Kita et al, 2017). This was linked to fears of discrimination, and being viewed as different, as found in Linden and Boylan (2010) and stereotypical views of people with brain injury are underpinned by generalised notions of cognitive impairment and limitations on a person's ability to function independently. This includes a belief that they have suffered catastrophic outcomes which limit their ability in wide-ranging areas such as reading and writing, and the ability to recall childhood memories (Freeson et al, 2017). Further studies propose that negative appraisals of people with brain injury "are not necessarily underpinned by an automatic or deep-seated bias, but rather are due to an openly held belief that brain injuries result in personality changes or deficits that render a person as less desirable" (McLellan et al 2010: 708). It is this hostile societal backdrop to which participants described their return to work:

> "when I was struggling at work, they used to say to me, why don't you understand how to do, I was doing benefits at the time, why don't you understand how to add up and just simple things, but I couldn't, just couldn't make head nor tail of it" – Vaila.

Vaila's impairments were clearly viewed as her fault, and not the fault of her employer to provide adequate adaptions that enabled her to carry out her tasks. This reflects public ignorance of the recovery process and the hidden impairments, which can result in people with brain injury "being perceived as lazy and effortless and their symptoms as illegitimate" (Ralph and Derbyshire, 2013: 1488). The often invisible presentation of brain injury can lead to an environment where "surrounding people tend to minimize its symptoms, deny that they exist, or even shame others for believing they're still affected" (Paniccia et al, 2018: 1340). The toll of the hostility that such views enable was described by Sadie:

> "I had had quite a few problems in the workplace... I had taken such a lot to keep putting myself in that position of being sort of, criticised so much and picked on so much" – Sadie.

The hostility received from co-workers represents a significant barrier faced to peoples' return to work and participation in society. Return to work (RTW) was experienced by participants as a process where impairment, medical diagnosis, and bureaucratic processes interacted, where people were interpreted and judged by employers and co-workers alike. Andy discussed his long history of being the recipient of ‘office banter’ which included the description by colleagues in one job who were slow at a task as being termed “as slow as Andy”. Andy detailed similar abuse in a subsequent job:

> “I remember being in tears with something in the office with, one of the managers… one of them called me Space Cadet… it was just office, office banter” – Andy.

This pattern of abuse and hate crime illustrates workplace discrimination in its most visceral form, and is an obvious and dangerous barrier to employment and participation in society. Again, this reflects societal stereotypes which view people with brain injury as “warm but incompetent” (Freeson, 2017: 550), and as cited in one study on young adults with brain injury, “less mature, intelligent, flexible, polite, and employable” (McLellan et al, 2010: 708). This was mirrored in the repeated discrimination and the dehumanisation that Andy faced in his attempt to access healthcare, education and employment. Root causes of the hate speech also offer insight into the potential offered from a shift to a rights-based society. Hate speech has been theorised in times of austerity to be part of a process of a self-validation on the part of the perpetrator (Burch, 2018). This raises the possibility that rights-realisation may reduce the desire to self-validate in this manner as those carrying out this form of hate crime become rights-holders themselves, in addition to increased accountability when it occurs. These experiences of discrimination raise further questions as to what contributes to negative generalised societal views of people with brain injury. Previous studies have demonstrated how public opinion on disability is negatively shaped by media reporting and framing (Briant et al, 2011). In terms of brain injury, the media has been cited as a rich source of information that forms the general public’s perception of brain injury (Linden and Boylan, 2010; Chapman and Hudson, 2010). This has been criticised for the promotion of heart-warming portrayals where hard work is the key to overcoming challenges, and where a full recovery is common (Hux et al, 2006). This encourages the gaze of person who has had the injury to turn inward, in turn diminishing and absolving the responsibility of society.

9.6 Internalising the public issue

The experiences of participants contribute to our understanding of societal navigation following brain injury being one that is characterised by discrimination and rights-denial, as opposed to realisation. Navigating these hostile environments may in turn lead to a process of biographical confirmation, where a negative perception of self-following injury is confirmed by those around. That this occurs in official spaces such as hospitals, workplaces, and in wider society that is apparently subject to laws is revealing about the strength of such laws, and indeed the societal norms and conventions that undermine them. The internalising of the discrimination that Andy faced in the workplace, and possible biographical confirmation, was evident in the accounts of other participants. Whilst he was highly critical of his employer's treatment of him following his return to work, Tommy discussed feeling that he was partly responsible:

> "so I blame myself partly because I should have got help... I thought, no, I will be alright" – Tommy.

This is consistent in participants' accounts which recognise and articulate the clear barriers and discrimination that they face, but where the legacy of medicalisation and societal discrimination still looms large. Vaila similarly negatively described herself after starting her own food business following the loss of her previous job, where she had faced hostility:

> "After that… got my own business then, I got a takeaway, which again, stupid idiot I don't know why I done it" – Vaila.

Vaila launched and maintained a business that required the use of a range of skills, and some bravery, but despite this, she still framed her efforts as a personal failing. This may also have represented a conscious, or subconscious strategy to remove and protect herself from a labour market which undermined attempts at constructing a positive sense of self. Vaila's efforts to engage in a new area of employment mirrors the experience of Phineas Gage, who contrary to the framing of him as a simple passive recipient of medical curiosity, demonstrated repair by carrying out a complex job in a completely new environment. This suggests the need for environments where people can 'try out' work, with the continued support of social security if and when it is needed. This requires new approaches to employment, and workplace environments that are supportive and are aware and understanding of the consequences of any impairment a person now lives with (Sveen et al, 2016). One area in which a human rights-based approach could have been particularly effective for participants was in empowering them to view the human rights failures and discrimination they faced as rights-violations, and themselves as rights-holders. For people who have navigated systems where they lack agency and are dehumanised, this re-conceptualisation of self could be profound. This re-conceptualisation also offers possibilities for biographical repair, and a rejection of negative biographical confirmation. This, however, requires such systems to be in place, with frameworks and thresholds provided by duty-bearers such as the Government.

9.7 Duty bearers fail and disruption follows

The Scottish Government's 'Neurological Care and Support in Scotland: A Framework for Action 2020 – 2025', makes no space for employment, citing that this is addressed elsewhere in other Government policy (2019). The vision of this framework is that "everyone with a neurological condition will be able to access the care and support they need to live well, on their own terms" (Scottish Government, 2019c: 5). The absence of a focus on the care and support that people need to return to work, suggests a lack of awareness of how critical this can be for people following brain injury. The absence of consideration for the holistic needs and impacts was highlighted in the experience of Tommy, who discussed accessing support from a psychologist following his attempt to return to his previous career:

> "the psychologist… managed to sort of, stop me thinking well, obsessing about work or these people, he said, you would not want to work for these people, he said, you wouldn't want to work for these people anyway would you, so no, and just let it go, so I have, rather than sort of taking a baseball bat to them all" – Tommy.

People with a brain injury who are also experiencing mental illness are less likely to return to work (RTW) (Garrelfs et al, 2015), however Tommy's description illustrates the impact that his experience of RTW had on his health. This illustrates the longitudinal impact of returning to workplaces that are hostile and discriminatory and contribute to the development or worsening of health conditions that could be attributed in part at least to the social reception of brain injury. The significance that a person attributes to a role or activity is central in determining the extent to which its absence will impact on an individual's sense of self-identity (Villa et al, 2021). This was discussed by Sadie who discussed her love of her previous career, and how she grieved for the *"old me"*. Sadie also discussed the positive impact of the counselling she received:

> "I got some really good counselling and that helped a lot. So, I was, I think if I hadn't got any help those thoughts of just not being any use to anybody or being useless, or not being able to contribute or not being able to do anything, that would have that would just have [gotten] worse and worse and worse with me, I think." – Sadie

The need to contribute, and to be of ‘use’ was a major issue for participants adjusting to life following a brain injury, and symptomatic of social structures that did not prevent or offer redress to a discriminatory labour market. Attempts to RTW were in respect acts of compliance to the apparent social contract. This social contract was found to be unreciprocated, which in turn led to the disruption of “taken-for-granted assumptions and behaviours” (Bury, 1982: 169). Subsequently, “profound disruptions in explanatory systems” (Bury, 1982: 169), which was experienced as a realisation that “all that is solid melts into air, all that is holy is profaned, and man is at last compelled to face with sober senses his real conditions of life, and his relations with his kind" (Marx and Engels, 2020: 9). The accessing of psychological support in this case can be seen as an example of attempts to the third aspect of biographical disruption as outlined by Bury, “the mobilisation of resources, in facing an altered situation” (Bury, 1982: 169-170), and evidence of how biographical disruption may in itself be a cause or contributor to a chronic illness (Williams, 2000). A society that is rights-based offers the possibility of a reversal, or mitigation of this process, but this was clearly not a society that was experienced by the participants of this research. This underlines the inherently social aspect of brain injury and recovery, and of the potential offered to people with brain injury in legislative reform that reimagines them from passive recipients of state support and charity (Basser, 2011), to empowered rights-holders.

9.8 What for those still in work?

For participants who still attempted to navigate the labour market, the need to prove themselves to be of worth in the eyes of society was evident. Andy stated a wish to be *“be normal”* and how he wants *“to be part of society,”* where he contributes despite feeling that *“I don’t necessarily [contribute]”*. Vaila echoed the importance of paid work to her own sense of self in her continued engagement in the labour market and her desire to be seen to be “worthy” despite the toll that this search takes from her. She described being:

> “still determined to find work, had an interview on Monday, but I failed it miserably. I, I, I think, I think for me, even though I have not worked since 2018, I just feel I have to prove myself that you know, I can still do something, I’m doing voluntary work with homeless people just now and that, I think is just to prove to myself that I’m still worthy of work, so I keep applying for jobs and stressing myself out again because, and then going for the interview and making a mess, and you know, that, that part of me I think, stroke or no stroke, is ever going to change it, I think that’s me that has to work on that” – Vaila.

The blaming of herself echoes the experiences of other participants as they attempted a return to work. Navigating this process offers little hope for repair, and suggests that biographical confirmation of the new, less worthy, self occurs. Voluntary work with people who themselves are far from the realisation of rights is not valued in a capitalist labour market, and consequently was not enough to prove "worth". Vaila felt that she must present herself repeatedly to processes that were harmful to her sense of self and health, and further confirmation of a new self that was of less value than before. This required a resilience that Andy similarly described in what, for him, had been a repeated cycle of attempts to access education and the labour market:

> "every year I have nowhere to go and have that, have that breakdown, something comes up to save me, or I save myself, but I'm not sure, maybe both, but I do have this determination in me though, not to fail, I do have this determination to say to the world, to prove do feel determined to say to the world, prove to all look, Andy's not stupid, Andy is not retarded, Andy's normal, and I do have this drive in me, this, maybe too much, this complete and utter drive in me to, to say, look Andy's one of you, Andy's normal or average, whatever that means you know. I have this utter, complete utter drive in me." – Andy

The need to prove oneself as 'normal' and not 'retarded' is indicative of a society that has consistently in a range of fields discriminated Andy, and underlined that being disabled is deviant. Andy's response was one of at times resilience and resistance, which is further evidence of the lack of rights-realisation. Such a response requires labour that is emotional and draining. If this resource is not accessible or rewarded, then further disruption or confirmation is likely to occur, in turn further damaging a person's sense of self, and prospects of participating fully in society.

9.9 Early retirement as a route out

Examples in the data of routes out of this cycle, and away from discrimination, amounted to early retirement, which was the case for Colin, Tommy and Sadie. For Sadie, early retirement required the 'successful' navigation of a stressful bureaucratic system, but one which had removed stress from her life:

> "I think being retired means that I don't have that added worry of work. I don't have that added worry of you know, trying to do my job properly, or whether or not anybody is worrying about my brain injury, because that was what a lot of the tension is around, my brain injury." - Sadie

Her retirement ensured that her brain injury, in this area, was no longer privy to the scrutiny and evaluation and inverse accountability often expected by employers and her colleagues. Sadie's description here of her injury being an almost distinct character, which is judged by others, and represents the lens through which her ability to remain in the labour market is evaluated, mirrors earlier experiences where bodily autonomy is surrendered to healthcare professionals in earlier phases of brain injury. Sadie's navigation out of the labour market was in some regards successful as it removed her from a hostile environment. It was, however, a somewhat pyrrhic victory, given the loss of a career that she loved and had given most of her working life to, and the fact that she felt forced, as opposed to empowered, to begin a new phase of her life.

Once retired, Sadie described an increase in financial resources due in part to the ending of her mortgage. This underlined the role that access to financial resources plays following brain injury, and the inadequacy of social security to provide for people at different life stages:

> "I don't have a mortgage now and we don't have any financial worries, my hubby has just reduced his hours at work and he's quite happy, because he knows that I need a bit more help." – Sadie

Increased financial resources enabled an easing of the pressure to provide through paid employment for her family. It also enabled Sadie to be able to access increased support from her husband. This suggests a process of biographical repair "of relationships and material and practical affairs" (Bury, 1982: 175) was enabled by this increase in financial resources, and underlines the central role that financial resources can have in promoting biographical repair. Had Sadie's injury occurred years previously when her mortgage was further from the end, this may not have been possible. This reliance on wider resources and illustrates a labour market and society which has failed to adequately realise the principle of non-discrimination, and one in which radical restructuring is painfully overdue.

9.10 Chapter summary

Return to work (RTW) was highlighted as being central to participants' sense of self and backed by a need to return to provide for themselves and their families. Push factors such as the role of breadwinner were not gendered, and further underlines the need for intersectional considerations of why people return to work, and how family roles and responsibility are experienced when this happens. Participants returned to a labour market that was precarious and barrier-strewn, where the new emergent self faced discrimination and disruption. RTW processes were further experienced as inadequate and damaging to participants' sense of self, and indeed their health, and led participants to view themselves as partly to blame for the discrimination and hostility they faced. Reproduction of negative societal stereotypes appeared to contribute to this hostility, an environment that required resilience and resistance to navigate and remain in. It was an environment that was characterised by a lack of rights-realisation.

This provides insight into the role played by the labour market in our understanding of biographical disruption. These experiences took place at various points and lengths following injury, and highlight the key role that RTW plays in biographical disruption, as well as the potential role it has in repair. Structural discrimination was bureaucratic, but also experienced in the behaviours and words of colleagues. This was described as a focus on perceptions of what people could no longer do, but also in direct hate speech. These experiences contributed to biographical confirmation, conceptualised here as the confirmation of the new, reduced self where discrimination is internalised as evidence that the person experiencing discrimination is at least partly to blame. It is, therefore, distinct to the term used previously that was tied to previous identities as discussed by Williams (2000). The damaging impact of navigating RTW contributed to poor mental health and the need to access further medical support. This suggests the possibility of biographical disruption, and its mismanagement as being a contributing factor to the development of new chronic illness (Williams, 2000).

These experiences raise questions as to what non-discrimination currently means for people with brain injury attempting to reintegrate themselves into the labour market and wider society. In an equality sense, disabled people experience positive discrimination due to their protected characteristics under the Equality Act. However, even if this has been the case, and many examples of the participants suggest otherwise, a process of othering occurred that suggests that legislation alone has not adequately shifted wider damaging perceptions. This shift must be led by the Government and other duty-bearers, with maximalist incorporation of human rights acts, and education on rights. Participants' human rights disappeared when they acquired their injury, and they had neither the human rights language to articulate it, little evidence of duty-bearers' attempts to prevent repetition, nor the pathways to redress.

These insights on non-discrimination highlight the need for further exploration of the participants’ understanding of their rights, and the support structures that were in place, or not, for realisation to occur elsewhere.

Chapter 10 Theme 4: Empowerment

10.1 Introduction

People with brain injury clearly face a wide range of barriers and discrimination in society. This discrimination is not novel and suggests both a lack of and need for the empowerment of people with brain injury and other oppressed groups. Empowerment in a human rights sense relates to people both knowing and understanding their rights, and then being able to claim them (Cahill, 2018: 151-152). It has been described as a process where people "who belong to a stigmatised social category throughout their lives can be assisted to develop and increase skills in the exercise of personal influence and the performance of valued social roles" (Solomon, 1976: 9). Difficulties with re-assuming social roles such as those linked to relationships and employment have been identified as sites of disruption. Brain injury peer support groups potentially provide a space for people who may have felt alone in their "otherness" for a long time and have a need to practice "their new identities" within a supportive and safe space (Mead et al, 2001: 136).

This chapter aims to understand how empowerment was experienced or realised in the context of the brain injury support group. This chapter will additionally focus on where empowerment and disempowerment emerged, and the continued reach of societal discrimination in these processes. This will build on our knowledge of peer support groups, and the role that empowerment and disempowerment plays in both enabling disruption and repair.

The majority of the data is drawn from field notes recorded directly after each group meeting. These are distinct to interviews (which carry the person's name) and are referred to as 'Trip 1, trip 2' etc in the text. Empowerment is conceptualised in both the human rights sense, and in the more traditional sense referring to the firming of individual capabilities such as "the emotional, perceptive, intellectual, behavioural, informational aspects of a person's life" (Barbuto et al, 2011: 195). This is due to both a lack of data evidencing it (rights were not an initial focus of the study or the group itself) and the prevalence of a focus on individual capabilities in group activities.

The chapter will begin by considering what draws people with a brain injury to peer support groups, and how empowerment is enabled and experienced in this space. It will then consider the role of reciprocity following injury, and how this subtle yet vital social process illustrates and contributes to disruption. The second part of the chapter considers how empowerment is affected when the group interacts with wider society, duty-bearers and institutions, and what this tells us about the progress made, and continued need for rights-realisation.

10.2 Why do people come?

Evidence of the effectiveness of peer support groups for people with brain injury is limited (Hughes et al, 2020; Wobma et al 2016). Peer support groups are found in a range of settings (from inpatient groups in rehabilitation settings to non-medical community-based groups) and are facilitated at times by both peers and paid facilitators utilising different approaches and aims (Hughes et al 2020). Whilst the evidence is mixed, a systematic review on peer support groups following brain injury found four common themes "obtaining friendship and support, expression of feelings, sharing of coping strategies, and gaining information" (Hughes et al, 2020: 854), areas in which people with brain injury commonly report facing issues or barriers. Peer support provides a space for people who may "have felt alone in their "otherness" for a long time and need to practice "their new identities" within a context of safety and mutual support" (Mead et al, 2001: 136). In this regard they represent a possible rehabilitative space to continue a form of recovery, but also to repair from the experience of recovery and the societal barriers the acquired self has faced.

Participants in this study 'found' brain injury support groups at different points following their injury. For some such as Colin, this happened whilst still in hospital, though for some members such as Andy, this came decades after their injury. Colin described his introduction to a sister brain injury support group, and how this provided an environment outwith medicalised settings to carry out more holistic rehabilitation:

> "Initially it was sort of a couple of hours at a time, and then it became that I was there for two afternoons a week and then it becomes I was there for two days a week, and they used to come and collect me in the minibus, and we would trundle off. It meant it was a relatively early start, in that since they had lots of other people to pick up and it was a big route really that they were doing it from, but you know that was great because it got me out, it got me starting meeting people again. It got me doing more things, I started getting back on the computer because I hadn't really touched it since my aneurysm, I got back into cooking, which was something they were worried about, because I had done quite a lot of cooking previously, well I was cooking for myself, but… when I got back at first, I put on a, can't remember, it was some kind of meat… I went

> and left it on and forgot about it, and burnt the pot and set off the smoke alarms." – Colin

By attending the group Colin was able to meet new people and begin to resume previous activities such as using a computer and cooking. Being able to carry out these activities were important to Colin, and support to regain confidence and the ability to do so represents a form of empowerment. Furthermore, this early intervention may have provided an environment to carry out biographical repair; repair which also carried an important rehabilitation aspect giving the boost to independence and sense of self that being able to prepare meals may bring. The assumption of the patient role following injury encompasses a loss of choice and control, having navigated a healthcare environment which, whilst expert-led and often lifesaving, can be disempowering (Murray et al, 2022). By engaging in these practices repair and transition from this role may begin to occur. Choice in this respect is key as "the meaning of the experienced impairments lies in their impact on the individual's everyday occupations and their symbolic significance for the individual" (Sveen et al, 2016: 2303).

10.3 Reciprocity and its role in repair

Support or 'self-help groups' can enable disabled people, who will often experience isolation that leaves them with only themselves or immediate family for support, to gain the awareness that they are not alone in their experience, and that others before them have faced the same or similar barriers and challenges (Barbuto et al, 2011). The identity that is built of 'patient' is often forged under harsh conditions of pain, injustice, and disruption. This enables a strong connection with people who have similar experiences, which can lead to a belief that "the rest of the community can't understand us and creates an "us/them" split with others" (Mead et al, 2011: 135). Prior to injury, people will have been involved in daily processes where reciprocation occurs. Following injury these processes can be subject to disruption. Whilst these social practices differ across cultures and time, conceptions of reciprocity "are everywhere regarded as defining something fundamental to human life" (Becker, 2005: 18). It is described as an "equal or comparable exchange of tangible aid, emotional affection, advice, or information between individuals in return for benefits received" (Antonucci and Jackson, 1989: 84). The understanding of this 'social glue' that holds together groups and societies (Zhang and Epley, 2009: 786), in relation to people with an acquired disability is an under-researched area (Pound, 2011). This represents a possible hidden barrier to our understanding of disruptive processes, given that a lack of reciprocity has been linked to a range of negative outcomes, and is suggestive of a “basic psychological mechanism is at work that may be rooted in evolution” (Buunk and Schaufeli, 1999: 260). This is of particular interest to repair as the experiences of people following injury as “a deeply embedded motive to reciprocate is effective in reestablishing cooperative and reciprocal relationships that have been disrupted” (Becker, 2005: 32). Being able to draw on the experience and expertise of others, a form of accessing of resources, and to reciprocate was identified as a key by Sadie:

> “The things that we have done, the fact that everyone else understands, everyone gets it in the group and everyone has got their own different levels of abilities and disabilities, and nobody ever questions whether you can do it well or you can’t do it well, or whether you need a hand or you don’t need a hand, or, nobody every judges anybody and you don’t need to justify anything, and that’s what I like about it, and I think we are all really very supportive of each other, and if I was to ever not come back to the group, that’s what I would miss, miss is, that sort of guidance and support from everybody. So I would be very lost without it.” - Sadie

Following injury, autonomy and choice is removed. Alongside, processes of reciprocity are also disrupted. This may take direct forms in the removal of day-day practices and environments where reciprocity took place, but also due to a reduction of status and perceived value of what the acquired, brain injured self can contribute. Support groups offered a space where Sadie could both give and receive support and care. This enabled Sadie to positively resume a social process that would have previously been a major, if subconscious, part of social life. For someone who had been denied access to these processes, social groups where reciprocity occurs presents space for biographical repair, and a rejection of negative confirmation linked to no longer engaging in these exchanges as before. Sadie discussed how she accessed similar groups, and what she gained from doing so:

> “part of the group and the friendships and the extended sort of roles that I have, I just really enjoy it. I enjoy the things I do at the [local arts centre], I enjoy the things I do with [another support group centred around a different chronic health condition], I enjoy the group of people that we meet, we have a social life, we go and meet up and you know, it’s like in this little, like-minded people, we are all very supportive of each other... my friendships that I have made in the group, have meant a lot to me.” - Sadie

This offers insight into the motivations and benefits of peer support, and their role on the reconstruction of self. These spaces may offer respite from hostile social spaces such as medical settings and employment where people are disempowered. Furthermore, they can offer spaces to re-introduce daily social processes such as reciprocity that may have been. Empowerment in this sense is however reliant on the labour of peers to empower each other. This suggests that by providing a space to carry this out, support groups are sites of resistance to oppressive societies. In a society that is not rights-respecting this is more likely to focus on the building of resilience for the individual, as opposed to rights realisation. Empowerment offered in the human rights sense may remain unrealised despite the other benefits of the group and the assuming of a new, positive group identity. A new identity based on the new acquired label may also represent a type of dignity violation as the person becomes ‘seen’, but only as a member of a specific group (Mann, 1998). This is complex as it can occur even when the group identity is one in which the person draws pride from as “the dignity-injuring element remains because individual character is denied and subsumed entirely into a group identification” (Mann, 1998: 33). This may encourage a later negative reappraisal of self if the positive assumption of this identity, and the participatory, reciprocal behaviours experienced within are not replicated elsewhere.

10.4 Group activities – reflections from the field

A ‘drop-off’ in formal support over the longer term for people with brain injury has been reported as an issue for participants in longitudinal studies (Lefkovits et al, 2021; Strandberg, 2009). This contrasts with generally intensive (and often life-saving) support and rehabilitation in the early phase. The ‘changeover’ process is one theorised to be long-term and “probably never ending” (Strandberg, 2009: 294). The support group offered a form of informal support, of which group activities were central. The group offered a range of activities where members were generally encouraged to take part in actively doing something but could still comfortably sit out or observe if they did not want to. How the programme was designed was unclear, although there was an informal process of gathering ideas that I observed taking place. The first meeting that I attended as part of the study involved an interactive presentation on the sinking of the Titanic.

> Trip 1: Talk on the Titanic. Wasn’t to do with brain injury or disability. Felt progressive. Allowed the space for people to talk about brain injury (which people did) or their lives but there was another purpose to being there.

Throughout the presentation the historian passed round archival objects for people to touch and feel, which enabled more engagement than a traditional ‘lecture’ format. The topic being discussed was one that everyone in the room could reasonably be expected to have some familiarity with. This encouraged questions and did not demand much of the group if anyone was not feeling like taking an active part. The progressive element from my perspective was that the talk was not on brain injury, or matters related to it. Whilst this contradicts the need and benefit of awareness raising, it was borne from having attended many groups as a member and volunteer where this was the only topic of discussion. Had the talk taken place 10 years prior I would probably have been unhappy as at that point I wanted information and strategies, or recognition of what I was going through. This illustrates an issue with groups that come together under a banner but where individuals have different needs and desires and are at different point in recovery. Particularly in environments where resources and time is extremely limited.

A focus on what people were still able to do, as opposed to what they could not was a consistent theme within the group activities. This reflected a philosophy of ‘reablement’, where the aim is to empower the person to maximise their abilities and “takes cognizance of both the person’s deficits and strengths, life stories and biographies” (Cahill, 2018: 181). In this respect, the group space offered an alternative to the experiences of barriers to participation experienced outside of the group, and a space to tentatively begin or continue repair. Given the range of activities that took place, members would most likely have taken part in activities that they had not done previously, or perhaps for a long time. In this respect these activities represented more than ‘you can still do it’ to ‘you can do new things’.

> Trip 2: Seated exercises, yoga. Excellent exercise for people as everyone was able to take part. Enthusiastic instructor. Focus on what people can do as opposed to what they can’t. Our broken bodies not so broken. Felt empowering from my perspective as bits of it were tough (I’m not the most flexible) but still did it. Finished exercise session with yoga. Group seemed relaxed at the end. People smiling. Cuppie and biscuit afterwards felt well earned.

Participation in this activity required being able to move a part of your body, or to have someone with you who could support you to do this. This ensured everyone could take part and had what was perhaps for some (myself included) an introduction to new activities. Without the knowledge of how the programme was shaped in relation to member involvement and choice it is difficult to conclude that the activities were empowering in the human rights sense, but an approach of doing new things was apparent. Meetings sometimes consisted of two activities, as was the case at the second meeting where the group did yoga followed by craft making exercise that was led by a member.

> Trip 2: This involved people being given a sheet of paper with a print on it (tree in my case, art tutor suggested ‘tree of life’ other people butterfly, what looked like a Christmas tree). Given glue and a range of buttons and shiny things to stick on. Art tutor (Sadie) - a volunteer who has a brain injury. Focus again was on people being able to create something. At the end, everyone’s pieces were framed which made a huge difference. Picture taken of them all together. People left with theirs in a frame. Leaving with something physical felt special. Will give it to my partner when I get home who will be surprised. Interesting that a few people (including myself) said that they ‘were rubbish at art’ and yet produced something really good.

This activity took place in a relaxed fashion, in an environment where support was available if it was needed, and one in which the support came from someone with a brain injury. It felt powerful for me to leave the meeting having tried something such as yoga for the first time and been able to do it, and to have created a piece of art that was framed, signed, and in my hands:

> Trip 2: Hard to not conclude that people left feeling good. The exercise/yoga and then leaving with a piece of art that looked really good. The group seems to benefit from doing things that gently push people out of their comfort zone and encourages a focus on capabilities. They have created a safe space to do this.

Activities where people physically created something also worked as a catalyst for people to discuss themselves and their lives in an organic way and created opportunities to have fun and laugh. The group space was one where people were enabled to express themselves. This is particularly powerful for people with brain injury as those coming into the spaces will often have going through hostile, disempowering social processes, processes that offer little space for expression. Art therapy following brain injury offers a different method for people with brain injury to express thoughts and feelings (Guay, 2018). This is of particular value as it makes expression more accessible for people who have impairments that impact on their verbal communication, and for people who do not wish to or feel uncomfortable talking.

Previous studies that looked at art therapy as a form of neurorehabilitation treatment have highlighted the need for guidance for the therapist themselves, as they are working with a group “who are often misunderstood and devalued due to problem behaviours, impairments, and deficits in social skill” (Kline, 2016: 72). The art therapy at the group did not appear to set out with any premiss, and people's impairments or anxieties in their own ability to produce art were ignored beyond making sure that people were supported if they wanted (by the roving art tutor, or in my case the people around me) to produce something themselves.

This was empowering in the basic sense, as was the fact that the activity was being led by one of our own. This can be problematic as when ‘caring for’ others, disempowering relationship of dependency can emerge, particularly when people are used to relationships of dependency elsewhere in their lives (Scott and Doughty, 2012: 1021). However, this activity felt more akin to Sadie ‘caring about’ rather than ‘for’, where her care in this sense was “a gift rather than a vigil” and a space where the group were enabled to “establish his or her own subjectivity, to take responsibility for himself or herself” (Scott and Doughty, 2012: 1019).

The informality of the art approach which enabled space and time for discussions was again exemplified when the group took part in a card making workshop at a later meeting - again led by a member with a brain injury - around the time of Valentine’s Day:

> Trip 12: The Valentine’s card making was a laugh. Sat with Vaila and Anna (who it was great to see again). It prompted a conversation about getting married and the ladies told me about their weddings. Anna’s story was funny as it showed a side to her that me and Vaila found quite surprising, and was a reminder that people can surprise! I made a card for Anna’s [my partners] birthday and it just gave a natural platform to open up and chat away a bit. Really enjoyed it.”

Most people in the group made Valentines cards, which encouraged a space for people to talk about love and relationships. The issues facing relationships following injury are complex and often areas in which people are left to work out on their own (Godwin et al, 2014). These issues are often enduring over time (O’Keeffe, 2020), which again suggests their complexity and a lack of support which is reflective of a focus on the ‘curing’ of individual impairment. This activity, which referred, but was not restricted to Valentine’s Day (evidenced by people making different cards) provided myself and the people around me a nudge to talk about these very personal topics. This underlines a key benefit of the group, that activities that were accessible and achievable and were in themselves prompts for getting to know the people around you.

Members were also offered spaces to take an interest in creativity forward outwith the group. One regular attendee who worked in the local art space periodically appeared to inform people of new classes and groups that were starting:

> Trip 11: talk about the different art opportunities. He was really keen to push the possibilities that people can still do things. Offering courses in Japanese calligraphy, music, digital photography, creative writing. Been involved with

> people in the group for a while. Talk was straight to the point and didn't hang about.

This enabled a degree of continuation of activities that people found enjoyable, possibly therapeutic and empowering, in spaces which were not linked to brain injury. This form of signposting was carried out in person, which enabled greater understanding of what taking part would look and feel like. This approach offered a degree of choice for members who wanted to pursue such activities despite the groups, and possibly their own, limited resources. This supported a positive new environment of repair, where people had the option of "being able to choose to go further, to do other things; having the chance not to withdraw into a state that becomes totalising, absolute and without ways for escape" (Barbuto et al, 2011: 203).

10.5 A need and willingness to claim rights

Empowerment in the group emerged primarily in an individual sense, with a focus on individual capability, as opposed to the definition used in human rights-based approaches. A talk on energy suppliers from a representative of Citizens Advice, however provided evidence of a rights focus where this occurred, and also of people's willingness to engage in such an area:

> Trip 10: Was interesting the difference in engagement from the stroke talk. It was practical and useful, not everyone was interested but probably about a third of people asked a question as opposed to the one or two (from a full group) with the stroke talk. If you are going to make people sit and listen quietly then there needs to be a real reason. Also, the CAB guy gave information about where their service is run, what they offer (benefits advice). Also spoke about the process of attending them, how you can talk about any query etc which if you were a bit anxious about going would have gone some way to reassuring you that it was ok to go. In that respect even people who had no interest in the energy supplier info (changing supplier, government schemes to change boilers and the like) might have gotten something from it.

Discussing the process of attending was central to this being empowering in a rights sense, as this is central for participation. The lack of knowing how to behave in a space, of the habitus, is in itself a hidden barrier to participation. The need for this knowledge following brain injury is also symptomatic of a safety net that does not exist, as the advice and support related to the meeting of basic human needs. Attending such a talk may also bring with it the possibility of biographical repair as awareness of rights and of the barriers enable private troubles to be recast as public issues.

Taking part may also bring elements of disruption. Simply attending such a talk could represent the "disruption of taken-for-granted assumptions" (Bury, 1982: 169), as prior to the acquiring of the injury the ability to meet your basic needs may have never been in question. This possibility could be extended to attending the group itself, as attending brain injury support groups was not an activity that people ever considered as part of their future biography. Tensions relating to this new identity may build on a labelling process, which for disenfranchised people, is usually negative. This emerges at diagnosis, and "creates an entire tone about the person. It is set up to expect certain things from the labelled person, based on what is known or understood about the label" (Condeluci, 1992: 546).

To be labelled negatively is disempowering, especially when people understand, and potentially taken part in the process of 'othering' elsewhere in society. A rights-based approach presents a tool with which a support group can engage these difficult realisations and labelling by reconceptualising these private troubles as public issues and offering pathways to redress.

10.6 Disempowered at the King's House

People with brain injury "may make sense of themselves in terms of the meanings and felt experiences of activities in different places" (Meijering et al, 2019: 23). How the group functioned away from the usual meeting space provided a snapshot of navigating new spaces and provided insight into the functioning and value of the group. The group met outwith the confines of the arts centre on a fairly regular basis. These trips included full group outings where staff and volunteers would be present and involved social activities and awareness raising, and more informal outings where the group may have helped to organise an outing, but members would meet without any formal staff. The second meeting I attended as part of the group involved an organised trip to the Palace of Holyrood - an historic site and museum (and the King's official residence in Edinburgh):

> Trip 2: People seemed to enjoy getting away for the day even if they were indifferent about the tour, which some also loved. Getting a hired bus and away to a different city represents a change of scenery, folk said.

I met the group at the car park where the bus that the group had hired was parked. Once the tickets had been purchased for the tour, people split up into small informal groups and took in the site at their own pace. Entering the palace itself provided a case study of how accessibility is experienced:

> Trip 2: Royal Palace. Open for tours. Has accessibility (strictly speaking) but required people to take different routes. Still able to access the different levels but not in the route that everyone else did. Building is hundreds of years old but reminder of reality that even with 'adaptations' the physical space still segregates.

Consequently, members were split depending on their ability to use the stairs and a status was conferred by the physical space. Whilst social model approaches have helped to ensure greater accessibility of such buildings, these adaptations still reflect a medical model approach as while the physical impairments may have been mitigated access by the lift, the person using it is still segregated and does not experience the public space in the same way. In keeping with the history of disabled and other oppressed people, alternative access points are deemed adequate by those that are not required to use them. Being shown the back or side door is disempowering, and this was reflected in the overall mobility access of the building. The building, described as 'largely accessible' provides manual wheelchairs and walking aids, but these are provided on a "first come first served basis" (Royal Collection Trust, 2023). If you require 'step-free' access you are instructed to "speak to a Warden", which is problematic for people, including members of the group, who have communication impairments or feel uncomfortable asking for support. Engaging a warden for support is not in itself disempowering, but the lack of control and potential access is, as "independence is not about doing everything for yourself, but about having control over how help is provided" (Morris, 1997: 56).

Access to Mary Queen of Scots' Chambers, arguably the centre piece of the Palace and tour, is accessible only by a steep spiral staircase. The adaptation provided to mitigate the lack of access is film and audio content on "on Mary Queen of Scots" that does not specify if it refers generally to the subject's life or specifically the inaccessible space. Flooring and surfaces inside the State Apartments are either wooden, which is usually accessible for people using mobility aids, or thick pile carpets. In terms of accessibility, thick carpets should be avoided "if possible, since it makes it more difficult to circulate in wheelchairs" (Hammersley, 2021). Deep pile carpets, a term used interchangeably, are described by the

University of Oxfords Estates Department as “a barrier for wheelchair users” that are “very difficult for wheelchair users to travel across and should be avoided” (University of Oxford Estates Services, 2022: 35, 28). Outside of the Palace itself, but on the same site, is the ruins of Holyrood Abbey. This space is a mixture of paving and gravel chippings, which again may restrict wheelchair and mobility access, or enable only the partial enjoyment of the space, as you may be limited to the paving. Accessible toilets are not located in the main Palace building but away in the Café and Mews Courtyard, and not close to the Palace itself. This is the experience of a space which has huge resources and will (almost certainly) meet the requirements of any legislation relating to access. A negative experience of access at a place of such public prominence further risks biographical disruption or indeed confirmation if someone finds the space inaccessible. This may in turn lead to a shrinking of a person’s social world as they discover such places are no longer for them. This undermines empowering practices and experiences elsewhere and highlights the need to consider how empowerment is experienced beyond the environs of specific groups and their spaces. Without a wider network of empowering spaces, the work done by specific support and awareness groups is undermined, and then at risk of becoming “like Foucault’s brothels—heterotopias from which to reflect on the world but not to change it” (Kesby, 2005: 2059).

During this trip one of the members that I walked with - in a group of three - had numerous seizures:

> Trip 2: The severity of Anthony’s epilepsy which he discussed prior was really apparent. Had numerous what appeared to be (absence?) seizures as we walked round. Was really tough to support him without being imposing. Being in public makes it more difficult as people stare, and looked shocked both at someone having a seizure, but then continuing with the tour round the palace. Their emotional response became a source of stress in itself.

Whilst I have experience of epilepsy and have seen people having seizures before, watching it happen was a stark reminder of how people are “disabled both by social barriers and by their bodies” (Shakespeare and Watson, 2001: 17). However, the tour continued as we had intended due in part to our small groups comfort and familiarity with each other and a condition which is common following brain injury. The relationships built on trips was healing as it challenged “the need to hide and to use defensive, self-justifying explanations in social encounters.” and in doing so demonstrated that “peer support can and should contribute to the challenge, not foster collusion with roles that we have defined ourselves by in the past” (Mead et al, 2001:136). Epilepsy is a health condition that has historically carried with it stigma (Fernandes et al, 2011). The clash of Anthony's condition and the social world which stigmatises it, is important to our understanding of the disruption of friendship and community which "arises not only because of functional limitations (for example restrictions in mobility, problems of fatigue) but also because of the embarrassment which such disabilities create" (Bury, 1982: 175). This did not happen on the trip (to my very limited knowledge), and a precarious form of partial, and therefore inadequate, accessibility was experienced. This was in spite of the physical and social barriers face which was illustrated by the need for resistance and resilience, which in the absence of right-realisation appear to be essential to navigate society following brain injury.

10.7 The minister pays a visit, and power and control are lost

The support group was a place that I experienced as supportive, empowering and empathetic. On trip 8, the space changed quite dramatically with what was to me (and those around me) an unexpected appearance - and speech - from a government minister:

> Trip 8: Got the feeling from talking to folk that this visit was sprung on the group, everyone seemed unaware.

Central to empowering processes are "efforts to gain control, access to resources and a critical understanding of one's sociopolitical context" (Zimmerman, 1995: 583). This visit was significant as it offered access to a politician with direct power in areas in which the group faced discrimination. From a research perspective the meeting was of further interest as it offered an opportunity to understand the groups sociopolitical position and how power dynamics and control existed.

The meeting began with a period of time where it was unclear (to me at least) who the people in the suits were and what we would be doing, and also why members of the committee were similarly in attendance:

> Trip 8: Were there for a good bit (30 mins at least) before introduction. One is an MSP (and Minister) with an assistant or two and a camera person who is taking pictures. Gave a speech (had been speaking to a few folk prior) and then stood for a while during the stroke lecture before leaving...

Prior to the speech, the Minister spent time talking to some group members and members of the committee. The potential opportunity offered to the group was access to a government minister who represents the duty-bearer with most responsibility for the lack of rights realisation experienced by the members of the group. This in addition to the chance to raise awareness of the group and brain injury through the inevitable press coverage. It was however apparent that the event signalled a loss of control of both the group and the space:

> Trip 8: The space felt claustrophobic for the first time and very busy. From the first meeting it has felt like the space is 'ours' and today it didn't. The group wasn't in control, they sat and were spoken to.

Members were not made aware of the possible reasons as to why a Minister may make such a trip, or to decide if the transactional nature of it was satisfactory to them. Empowerment "means choice and control; it means that someone has the power to exert choice and therefore maximise control in their lives" (Morris, 1997: 54), when the group was public choice and control was surrendered (suggesting it was never fully there), and the acquired self was again subject to possible biographical disruption or confirmation. Shortly following the speech, the Minister left, leaving some of the people towards the back of the room annoyed that he had not spoken to them when they were under the impression that he would:

> Trip 8: Left and Sally complained that he had promised to come back to talk to her and hadn't.

This illustrates an act of resistance, and again the resilience that is required in social worlds where you are oppressed and subject to the imposition of power by those who perceive themselves to be in, or deserving of, authority. Where the power lay was also clear by the visual contrast in the space:

> Trip 8: Visual divide of people in suits and people with brain injury.
>
> […]
>
> The committee people were dressed totally different and stood apart from the rest of the group. Would be an idea to each take a seat amongst the members, power disparity was really apparent. If you come sit in amongst everyone or maybe don't come in?

Those wearing suits – the minister and committee members (who included two people with a brain injury, suggesting identities in the group were not fixed) - were generally standing up at the front of the room, or in the kitchen space (usually a functional and sanctuary space). Members were not formally dressed and mostly sitting. This visual and physical divide illustrated the emergent power dynamic and contributed to the members being disempowered.

The emergence of this classification is one is often subtle in nature but concerned with "questions of precedence on lists, in seating arrangements and in the distribution of material and symbolic rewards" which "are endowed with enormous significance because they are understood as measures of status" (Mann, 1998: 32). This also removed the possibility of clear exchanges of reciprocity to occur, as the role for members was passive. Repeated failed reciprocity when performing social roles that are important to a person negatively affects health and wellbeing (Siegrist et al, 2020: 1135). This is of particular relevance here as the support group may be one of the few spaces where this occurs positively, given the dehumanisation faced elsewhere in society.

The members, to my knowledge, were not given time to prepare any questions or supported to engage with a senior politician, or indeed their own board. Ultimately, this visit represented an opportunity to utilise participatory approaches and to empower members which was an opportunity lost:

> Trip 8: With member involvement prior, people could have had time to prepare questions. Could then have even been introduced by a member, allowed the group engagement and ownership. He is also the local MSP, more about how to access him perhaps? What can he do for them? Could do it with everyone sitting together with a 'cuppie' even, get him to make a few. The pictures that were taken for the paper still would have been taken, but more on equal terms. Felt like the minister was getting the better end of the bargain in a deal the members weren't aware they were part of.

If the group is viewed through a charity model, then the meeting was adequate. However, viewed through a rights-lens, this represented a crucial opportunity for an oppressed group to engage with a senior representative of the principal duty-bearer in the country. This is a complex engagement where the transaction between the parties was one that required at the minimum recognition, if not to be fully unpacked by the group prior. Engagement with the Government is risky as:

> "To get too close to the Government is to risk incorporation and end up carrying out their proposals rather than ours. To move too far away is to risk marginalisation and eventual demise. To collaborate too eagerly with the organisations for disabled people risks having our agendas taken over by them and having them presented both to us and to politicians as theirs. To remain aloof

> risks appearing unrealistic and/or unreasonable and denies possible access to much needed resources" (Barnes, 1995: 115).

This was considered 'for' the members rather than 'by' the members. Engagement with politicians and duty-bearers offers a test of empowerment, and whether change in society is occurring as "part of a process of political empowerment of disabled people as a group and through social policies and programmes delivered by establishment politicians and policy makers" (Oliver, 1995: 37). Tokenistic engagements where those furthest from rights realisation are not part of a transparent process, leads to outcomes which are disempowering and undignified, and relieve the duty-bearer of accountability. Furthermore, these processes are a barrier to rights-realisation as they offer visual publicised proof of the engagement of disabled people and contribute to a presentation of a duty bearer that cares and is engaged in participatory processes. People with brain injury already face multiple barriers to participation in democratic processes such as voting (Hammond et al, 2021), tokenistic engagement of support groups may be another.

10.8 The return of the medical

The disempowerment and power dynamic experienced because of the ministers' poorly handled appearance was compounded by the activity that followed, a lecture delivered by a visiting healthcare professional giving an overview of stroke:

> Trip 8: Lecture delivered on stroke. I was bored out my mind. Why did they have to sit for 45 minutes to listen to it? Felt really medical model. Was it necessary? Took up a large section of the meeting considering that we meet twice a month.

The talk focused on the causes, effects and prognosis of stroke, and offered little on any social barriers or social contributors to risk factors. It appeared to have been written for people with little or no knowledge of brain injury, and was a one-way street in respect to who was talking and sharing knowledge and perspective. My view of the talk being boring does not mean that other members shared this view, although it was notable that few questions or engagement occurred during the talk. This was in sharp contrast to other talks on the sinking of the Titanic and JFK. This lack of engagement, in combination with the visit of the minister ensured that members sat and were spoken to for the whole meeting. Medicalisation has been described as "the process by which some aspects of human life come to be considered as medical problems, whereas before they were not considered pathological" (Maturo, 2012: 123). This programme on this day revealed the distance left to travel to emerge from oppressed group to empowered rights holders. Members were denied meaningful participation by a lack of empowerment. This provided a prominent representative of the duty-bearer most responsible for rights-denial, the Government, the opportunity to commodify the members and their experiences and wider their cause. This lack of meaningful participation, and then returning the gaze to the condition and body, societal barriers remained unmentioned, accountability unrealised, and a process was engaged where the members "moral, social or legal problems become medical issues" (Pereira-Gray et al, 2016: 8) once more.

10.9 Chapter summary

Empowerment for group members was a complex process that was both realised and unrealised. It was realised, beneficial and evidenced in group activities that aimed to grow people's individual capabilities, in turn enabling repair and forms of rehabilitation. It was unrealised in the human rights sense, as there was only tentative evidence of the naming or claiming of rights, or involvement in taking decisions and shaping polices that impact on their own lives.

Observing the group highlighted the value that attending brings, and how much the members contribute to an environment that was largely caring, supportive and empathetic. The group provided a space to build new relationships, learn (or re-learn) new skills and express themselves. The group was in some respects a refuge from a hostile society, where emotional and practical support was available. This enabled a safe space where social processes such as reciprocity could be practiced again. This suggests that the group played a key role in being able to practise social processes that are essential to people's ability to navigate society successfully.

Despite the discrimination and lack of rights realisation they faced, members still empowered each other. Without access to processes and decision-making, this fell short of participation. When the group interacted with institutions and people in power, their voices and rights were again hidden. This required resources of resilience and resistance, and labour that is emotional and draining to participate, or the retreat into the acquired oppressed role of passive beneficiary. The experiences captured in this chapter once more underline that "much more than the CRPD [The Convention on the Rights of Persons with Disabilities] is needed to ensure that the individual's human rights are respected, promoted and fulfilled"

(Cahill, 2018: 183). The lack of empowerment and rights realisation evidenced is ultimately the responsibility of Government. Whether maximalist human rights incorporation is realised remains to be seen. It has been stated that “For people to be empowered to realise their rights, they first need to understand what their rights are” (Ferrie and Hosie, 2018: 17). This first step is crucial and one in which support groups themselves need support to achieve. This means more labour, resources, and the willingness of oppressed people to put faith in a concept that is familiar yet abstract. In this context, the empowerment that did occur is itself a testament to the members and volunteers of the brain injury support group.

Chapter 11 Discussion and conclusion

Drawn directly from the PANEL principles, there are four key themes which have been set out within the analysis of this research. The role of this chapter is to discuss the key findings which stem from these themes, develop understanding of the research questions and provide ideas for potential future research. Further to this, the chapter will discuss limitations of this study, and provide some recommendations for change.

11.1 Summary of key findings

The first analysis chapter explored the concept of participation with a focus on the private self. The chapter examined the extent to which people felt able to contribute to their own narrative of, and experience of care. Beginning at the point of injury the chapter captured the suspension of participation that effectively led to a denial of rights. The evidence presented showed that at a time where participants were unable to express their need for and right to dignity, to choice, and to information about their own health, medical professionals appeared unable or unwilling to bridge the gap and deliver a human rights-based approach. That is, the absence of their participation, led directly to the absence of rights. Healthcare settings that delivered acute care relied on healthcare professionals to deliver a human rights-based approach. Participants were unable due to extended periods of unconsciousness, which can be understood as having a bio-medical cause, and also by the inconsistency of, and limited access to information relating to diagnosis, which can be understood as having a socio-structural cause. Perhaps healthcare professionals having a period where their patients could not participate, 'infected' the periods of post-trauma consciousness exacerbated by declining investment in healthcare services and over-worked healthcare professionals, yet, if dignity were informing healthcare as it should, then participation should be the normative experience of participants in this research. The evidence presented found that following the trauma, healthcare settings were places where meaningful participation was absent, despite its centrality to a person's human rights. This began at the point of diagnosis, and continued through initial care, rehabilitation, and once an individual was back home. The subsequent difficulty in accessing information relating to the individual's injury and diagnosis illustrated a power dynamic between the healthcare professional and the person. The injury solidified a black hole in both memory and self-narrative that undermined attempts at repair. There was no recognition of this, or support to re-establish a biographical narrative from healthcare providers. This was symptomatic of experiences of healthcare which lacked dignity, had long-term negative impacts, and were in need of formally established thresholds for participation.

The analysis regarding participation began to unpack the interconnectedness of rights, and the experience of brain injury as a social phenomenon where power and participation fluctuate. The participants' experience also showed that in stark contrast to the disempowering medical field, they were capable of participation, and rejected the homogenous and disempowering label of a passive entity. The lens of participation consequently enabled an understanding of the social processes that people navigate post injury, and how these are damaging, promote disruption, and undermine repair. Supporting post-trauma patients to make sense of their biography, ensuring they are as informed as is necessary to begin participating in their own care and health experience and creating spaces where problems are shared and solutions co-produced by patients and healthcare providers would improve the experience of people with a brain injury. This highlights the potential that a human-rights based approach could have in the rebalancing of power and in rights-realisation, that would improve the lives of people with brain injury.

The second chapter focused on participation in a more public sense, as participants navigated wider society and sites of repair, and disruption continued to emerge. This section highlighted the need for a person's biography to be encapsulated in their care and support, and the potential for rights-based approaches to support holistic, rather than medical focused rehabilitation and recovery focused solely on impairment. Where participation was present, co-creation took place which helped to humanise participants and promote repair. However, when medical approaches were impairment-focused, solutions were not co-produced, underlining that the new self was not equivalent in rights to the old.

A dominant theme continued to emerge in this analysis, that highlighted the management of the injury, not as the 'management of symptoms', but of hostile and oppressive social environments, structures, and norms. This oppression was acquired and emergent following injury, and suggestive that what a person with a brain injury is required to survive both the injury and a hostile society. Themes of passivity and dependency were reinforced by employers, and by non-trauma health and social care providers. Had biographical recovery started in hospital and had participants had explicit opportunities to participate and co-deliver a dignified experience of healthcare, they may have been more able to cope and challenge other social barriers to being and doing. It is also likely true that change is needed outside of acute care and hospital wards.

The possibility of human rights-based approaches to promote repair was a prominent finding throughout. Participation, and by extension, rights-realisation, was inconsistently experienced. This ensured that any biographical work carried out was at constant risk of being undermined. Narratives highlighted a post-injury environment where driving licences are revoked, and bus passes issued, which required further navigation of spaces that are inaccessible and often hostile. This finding is key because it suggests that attempting to reintegrate the acquired self into society will lead to more biographical disruption and undermine attempts at repair.

The third chapter's analysis focused on accountability, which was a concept that remained hidden and unrealised for participants. This lack of accountability was explained as 'falling through the net'. This conceptualisation is a key finding, as whilst there was a strong awareness of the failure of the system, it demonstrates that participants did not view themselves as empowered rights holders. This offers insight into the processes of disruption, as a lack of accountability negatively impacts on the individual navigating the system and removes elements of their dignity. A key finding of this thesis is that all participants had fallen through the net which then allows the question: does the net even exist? If not in practice, the net exists conceptually as people imagine that their falling through is an exception to the norm. As a result, when they fall through the net, and they all did, they viewed it as a personal trouble (Mills, 1959), as an individual issue, as 'bad luck' rather than the failure of the duty-bearers. In turn a human rights-based approach allows us to consider duty-bearers as being at fault, again as a conceptual argument which can be helpful. It is helpful for us first to consider that 'this is not the way it should be' and that 'someone ought to do something'. In first naming this someone as a duty-bearer allows us to get it clear, hermeneutically, that someone other than an individual patient is responsible for dignity within health, social care and beyond: that needs establishing for people to then collectivise to determine what change is needed and examine who the duty bearer is.

Further to this was evidence which highlighted the interconnectedness of rights, and how failures in one can lead to impacts and negative outcomes elsewhere. Whilst the interconnectedness of rights is familiar, the tracing of the impact is less so. This chapter suggested the need for a rethinking of what redress means, and of the complexity of this, which may require a widening of responsibility on the part of the duty-bearer. These findings contribute to a call for maximalist incorporation of human rights law.

The fourth chapter focused on non-discrimination, and drew strongly on participants' experience of attempting to return to work. The labour market was experienced by participants as discriminatory and hostile in ways which they had not experienced pre-injury. Given the central role of work and employment to understandings of identity, this represented a crucial area of disruption to individuals' biography. The social barriers imposed contributed to people being unable to continue in employment. This removed the stable role and status previously experienced, and denied a form of narrative continuation that may have aided repair to occur and stabilised people after injury. This highlights employment as a key site of disruption that requires management regardless of whether a person returns to work. Inadequate legislation was key here, as social security - another safety net - was inadequate. Participants often found that their ability to access 'reasonable adjustments' to their work was barrier-strewn and ultimately, unrealised. The failure of the social contract again led to an internalising of societal oppression, that caused furthered disruption, but longitudinally led to a form of biographical confirmation. The social barriers were experienced bureaucratically and reproduced by colleagues who engaged processes of 'othering' in a system where repetition of rights violation occurred. This encouraged a process of partial, and damaging repair, where participants were able to either remove themselves from the labour market or strived to be simply 'normal' or average.

The final chapter focused on empowerment, and how this was experienced in the context of the brain injury support group. Attending support groups was found to enable people to carry out biographical repair, by resuming tasks that had been previously important to them and tasks that promoted independence. Within the data, this presents as a precursor to participation (which is in itself problematic as support groups may never be accessed or accessed years after diagnosis). The support group enabled biographical repair as it was a space where people were able to practice disrupted social customs such as reciprocity, establish new relationships, provide and receive forms of care, and engage in activities that were new and provided evidence of growth. Empowerment was, however, undermined when the group engaged with wider society. Public buildings were disempowering despite meeting legislation standards for accessibility, and spaces where access required a public reveal of personal information about their health condition required resilience. This highlighted the need for conceptualisations of biographical disruption to encapsulate the meanings and experiences people derive from the societal fields they navigate (Meijering et al, 2019). Support groups will have more impact if they start as close to the point of trauma as possible and could be considered as valuable during the post-trauma stay in hospital particularly as remote-access is possible.

An overall finding from the research regards the lack of choice and control that people experience from the point of the emergence of their injury. Their passivity was assumed by those in positions of authority. This was illustrated in this chapter through the exploration of the loss of control that was experienced when a government minister, and representative of a duty-bearer, came to a meeting of the group. The need to rebalance power illustrated in this chapter contributed to a key finding of the need of legislation that equalises power dynamics and re-conceptualises disempowered and oppressed people as rights-holders.

11.2 Discussion of key themes

11.2.1 Participation – personal perspective

The lens of participation enabled the unpacking of the social experience and processes, and the removal of choice. The first chapter focused on the initial critical phase of injury and disruption. In contrast with Bury's (1982) study, the data highlighted that the emergence of the injury was sudden. This led to an immediate surrendering of control and bodily autonomy, and due to the nature and seriousness of the injury, without space or time for processing what had happened. In this regard it is more a shattering rather than "disruption of taken-for-granted assumptions and behaviours" (Bury, 1982: 169). It could be considered as closer to Locock and colleagues (2009) concept of biographical abruption. What is concerning about this, is that participants in this study were facing end of life, where their anticipated biography could not be returned to. For people with brain injury prognosis cannot be determined and so abruption seems like an unnecessarily brutal experience.

Whilst the insidious onset described in Bury's study was largely absent, some participants did retrospectively link symptoms they had experienced prior to the full emergence of the injury. Whilst this retrospective return may be expected, it is suggestive of people returning to their own knowledge and biography to provide understanding of what had happened to them (Bury, 1982). Inadequate experiences of diagnosis were damaging, and this provides evidence of the value of the theory in enabling understanding of medical processes that had long-lasting and damaging impacts on participants, and a barrier to repair. This adds to the understanding of a process which already signals change and of “damage to the inner self” (Gelech and Desjardins, 2011: 67). The onset of injury, whilst viewed and discussed medically, carried a clear social component, and the disconnect between a factual diagnosis and the assimilation of information was one that was complex, longitudinal, and experienced traumatically. This was illustrative of a lack of “something firm to relate to” (Bury, 1982: 173). This was the first clear location where participation, decision making, and rights were removed.

A rights-based approach would have provided access to this information when required by the ‘patient’, as opposed to when the healthcare professional decided. Consequently, this key site of disruption could have been prevented, or managed. The inadequate diagnosis also emerges as key point of reference for comparison of the old and new self. For each person this experience may have been different as it may have been a continuation of rights-denial, or may have been in sharp contrast to their previous lives – or indeed in many cases somewhere in between. What is consistent, however, is that exposure to such social processes is likely to be negative in the reconstruction of self, where they could have in fact been positive. This underlines the value in Bury’s theory in enabling the tracing of where processes begin to go wrong, which is experienced longitudinally by the individual, whilst a HRBA lens locates the loss of involvement and choice as a cause in the beginning of this process, and consequently provides insights as to how this process could be improved.

These findings highlighted the need for the creation of clear thresholds where participation is formally ensured. Most of the participants discussed being unconscious for long periods following their injury. Being unconscious, and/or cognitively impaired places people at clear risk of rights violations and of being amongst the furthest from rights violations. The seriousness of the injury, and removal of bodily autonomy that is necessary often to save a person's life, underlines rather than excuses the need for participation. Whilst this is likely to be complex, if person-centred care is a goal and central to participation, then an unconscious person is still a person. Dignity in this setting has been equated by student nurses as ‘being heard’ (Macaden et al, 2017), and undignifying processes can be understood as a barrier to repair.

Participants (with one exception) were admitted to acute wards where the biomedical focus was dominant (Mäkelä et al, 2019: 8), and where a clear power dynamic was established. As this was the first stage in which participation was removed, its suspension set a standard which was continued, and set a standard which informed and mirrored the subsequent experiences of participants. What is particularly novel in the data is that two of the participants (one as a midwife, one in management) had considerable experience of working and navigating healthcare settings. Both discussed at length an overwhelmingly negative experience of care, highlighting that decades of experience were not able to circumvent these practices or limit their harm. This contrasts with previous research that highlighted, in cases of stroke, that increased knowledge of the condition may reduce impact of disruption (Nasr et al, 2016). Greater knowledge of systems and practices, which place the onus on the individual rather than the duty bearer appear inadequate, reiterating the need for thresholds of care to be introduced.

The lack of participation in this early critical phase was mirrored in consequent discharge processes that were not rights-respecting. The focus on treatment of impairment being the goal, did not enable rights-realisation in areas such as housing which in turn violated the right to an adequate standard of living once discharged. How this is experienced for each individual will again be dependent on their own biography, and access to resources. This highlights a basic flaw in medical model approaches as the lack of rights realisation will lead to poorer long-term outcomes for recovery. It also once more provides information to the individual of the confirmation of the reduced status, and thus encourages further disruption or confirmation. A human-rights based approach that defines and embeds participation redresses this power imbalance, providing security and space with which to begin repair. The findings suggest that biographical repair should be a treatment goal that operates in tandem with medical treatment. A rights-based approach appears to be a framework under which this can occur, and a "the route to ending the dehumanising, undignified and un-autonomous lives lived by many people in receipt of care" (Ferrie, 2010: 875). The lack of participation from health care providers throughout the process of diagnosis, recovery and discharge impacts on a number of rights including family life and adequate standard of living, which highlights the need for, and central role that dignity plays in repair.

11.2.2 Participation – public perspective

The second chapter focused on participation as participants moved from initial critical care to rehabilitation and back into wider society. Given the sudden and violent onset of the illness, rehabilitation settings provided a space where biographical comparisons emerge.

The findings were not consistent as to where people began to consciously consider the new self. For some this began at the bedside and was characterised in concerns over cultural pressures and responsibilities that, in one participant, required a positive presentation of self. What did emerge was that this was a place in which ‘the dust began to settle’, and where the disruption in routine temporality emerged. Medical recovery is focused on the individual illness or impairment, but this highlights previous research which uncovered how injury and disruption is conceptualised in the impact of others, and the intersection of roles such as being a mother (Wilson, 2007). Recovery itself is confusing as the adoption of the ‘sick’ role may be beneficial to access treatment and social security but can be damaging culturally and to the reconstruction of self.

Brain injury is often referred to as a ‘hidden injury’ due to the unseen nature of potential impairments. The data revealed that this was a complex process. Disclosure of injury was evidenced elsewhere in the navigation of society in areas such as work, where participants had to assess whether they should, and then commit to, disclosure. It is telling with regards to perceptions of how this would be received by society that the ‘default’ was not to disclose, and only to do so once a form of analysis of the risks versus the benefits was considered. Disclosure of a health condition can lead to disruption in itself (Campbell, 2021), and is a difficult decision and process which requires negotiation, and further symptomatic of a society that is hostile and not rights-respecting.

This suggests that it is a hidden injury because we can’t see it, society at times does not want to see it due to the need for social security and adaptions, and people themselves realise that by hiding their injury their navigation is, temporarily at least, better enabled. Repair in such contexts is precarious. This reveals the choices available and decisions that are being made feel partial, or experimental as people attempt repair without the support or information required. The support group promoted repair in this sense as it was a space in which disclosures of injuries were made in a space that was safe and without consequence to the navigation of society. The repair this enables may be considered precarious as the hostile society outside persists. The management of disruption was found to begin at the hospital bed, illustrated in Vaila's description of biographical attendance, where a social process of enquiry where pre-existing character or physical traits are sought in order to make a connection between the past and present self (Whiffin et al, 2017). In this case it was gendered cultural expectations that necessitated the presentation of this connection. This supports the view of brain injury as an intersectional, rather than homogenous experience (Harvey, 2018). Furthermore, it adds to the need to develop clear treatment guidelines that reject a one-size-fits-all approach (Mass et al, 2017) that fails to cater for the needs and biography of a patient.

The findings suggest that how people spend their free time is a key element to the understandings of biological disruption and repair. Routinised experiences of temporality were disrupted, as the previous routine of life is swapped for one which is crucially imposed. This was illustrated by examples of being placed in front of a television at night, to watch whatever happened to be on. Participation in this sense would enable people to engage in pastimes that were desired and familiar, as opposed to the most convenient and catch all. This was also discussed in terms of rehabilitation itself, that in the case of Tommy was not as rigorous. Tommy had spent much of his career as a soldier, and it is this understanding of his biography that appeared absent for him. For people who have surrendered their autonomy previously, and their liberty currently, a rights-based approach offers a crucial tool of repair, as returning choice would allow greater connection with the previous self, or a feeling that the path forward was more likely to reconnect past and present biography. This also allows for an intersectional approach to recovery which circumvents dominant medical and cultural norms. A rights-based approach would have encapsulated areas considered secondary to medical rehabilitation such as the right to cultural life within the process, and afforded space to address areas where rights-realisation may be threatened on discharge. This also presents a tool to redress the power imbalance that is illustrated in the role played by healthcare professionals in assessment and decision making in areas that are not medical and stray into other rights such as education, employment and housing (French and Swain, 2001). Without participation, the biographical work where a person can revise future goals on their terms is undermined (Morgan and Burholt, 2020). A holistic discharge process where these rights were understood and realised by patients, with continuing support to ensure they are realised, in addition to improving overall outcomes, may limit the need for retrospective redress, future disruption, and enable space and stability for repair to take place.

The navigation of society was highlighted in experiences of using public transport and availability of toilets, where strategies of planning and resilience were evidenced in the possible use of incontinence products. These processes are clearly key to societal participation, empowerment and ensuring access to dignity. Such evidence builds on a consistent theme of a society that no longer caters for the person following injury, and one in which resistance or acceptance is the choice available. The disruption in the meeting of basic needs is a clear barrier to repair, and provides symbolic reference points of disruption. Estrangement of body and self can be reinforced by societal perceptions of the body (Nasr et al, 2016), a society that perceives it as not worthy of adaption in fundamental areas such as transport and toilet access is one that adds great precarity to processes of repair. This adds to the emergence of possible biographical confirmation, where repeated rights-denial is no longer a disruption to the previous biography, but further evidence of the new, reduced citizen. Resources such as social workers may enable participation, however this was fluid in the data as it is not enshrined and thus inconsistent and precarious.

Data referring to the support group offered insight into its role in moving people out of a disruptive or ‘lost’ phase. Previous research discusses how a lack of choice increases disruption (Cutler, 2016). The support group attempted to support people's independent access to cultural life. However, this was not fully meaningful as, in the case of the trip to see an orchestra, choice extended to whether you attended or did not, as opposed to the choice in the music or cultural event you wished to see. This is not a criticism of the support group, but evidence of the failure of the State to respect these rights and empower people to claim their rights. Attending something cultural may have in itself provided an opportunity for repair, but a rights-based approach would have gone further by enabling choice in the activity itself. This highlights the need for an age and interest appropriate support groups, where the activities someone enjoyed before their injury are encapsulated in life post-injury.

11.2.3 Accountability

The third chapter examined the participants narratives for evidence of accountability. This chapter focused on participants experience of healthcare, and the central role of power in this experience. The account of Sarah provided an insight into the processes and management of care as viewed from a relative. Accountability processes were hidden, as was highlighted when her husband was moved hospital wards from intensive care. A lack of accountability meant that Sarah had to rely on symbols and environmental cues to make sense of what the shift of care meant. This caused distress as Sarah equated the shift in care to a downgrading in care, and reduction of the chances of survival, whether this was the case or not. Sarah fought for her partner to be humanised and to be understood as a participant, and even in absence of the use of human rights language. This required labour on the part of Sarah to position John as a rights-holder rather than a passive recipient of care.

The lack of discourse from medical staff following the making of a medical decision, removed the duty-bearer from any dialogue of accountability. The power dynamic here was stark and ensured that despite Sarah's attempts, John was dehumanised and mechanisms to resist or affect change were blocked. Next of kin will often be aware of the disruption prior to the person who has had the injury themselves, and this disruption was present and unmanaged in Sarah's account. The key role played by Sarah supports previous research that suggests biographical repair can be a collective process (Panday et al, 2022: 5545), and illuminate the power dynamics that play a clear role in this process.

This lack of accountability also adds to the "actual nature of the disease being elusive" (Bury, 1982: 174), which led to Sarah using symbols and environmental cues to assess what the move meant. Accountability structures will not in themselves provide a firm prognosis in brain injury, but a clarity that should limit the need to fall back on their own knowledge, which will likely be limited and developed in a situation of sustained stress. This is also crucial considering the family role in conveying of diagnosis and prognosis as it is to them that people will often look for deeper or repeated explanation, which could be merged with the experience to that date. A human rights-based approach to shifts in care would therefore be an opportunity to rectify damaging social processes too easily ignored due to the power dynamic and the seriousness of the situation.

The lack of accountability evidenced in Sarah's and Tommy's account of care echoed the loss of dignity that John endured. Sarah's perspective is informed and allowed her to see the indignity in her partner's experience. Others observing this, because of their medical roles, should also have recognised this as obviously dehumanising treatment. That Sarah needed to resist this treatment, demonstrates a lack of dignity in how her partner was treated, and if it was evident in such an obvious situation (food presented to a patient unable to eat it in the form given) then it may well pervade all forms of health care provided in Sarah's absence. Thus, in small ways, the medical practitioners were not providing dignified care, and this ultimately undermined his human rights. Such a lack of consideration prevents accountability in that healthcare practitioners do not appear to consider dignified care, or the delivery of human rights, to be part of their role. This suggests the need for further role out of human rights training in healthcare training such as the ‘dignispace’ programme, which is a module integrated into nursing course that allows for the application of dignity in professional practice (Black et al, 2023).

This chapter raised questions regarding the impact of the human rights of heath care staff. Trade Unions set out that the working conditions of staff are human rights, and that they are the conditions in which people are cared for (Black et al, 2023). The example for the intensive care nurse who ‘never stopped’ during 12-hour shifts, working under extreme pressure is telling. Healthcare structures in this respect are creating environments where dignity in care is, at times, only available if individual practitioners are willing to comprise their own human rights. Recognition of the role and rights of the staff should encapsulate the provision of psychological support (Harvey, 2018) to ensure the realisation of their right to health. This should be available alongside in adequate pay and conditions that ensure an adequate standard of living and right to family life which has been reported in recent research into human rights and nursing (Black et al, 2023). Staff hold a degree of power, but this power resides in their interactions with patients, as opposed to the system itself. This builds a situation where a lack of power equals a lack of human rights, with clear potential impacts on a person's health. The focus of curing or lessening disabled people's impairment rather than supporting their health and capabilities to flourish (Rioux, 2019: 94) can be seen as potentially damaging to all involved. The application of a human rights lens is therefore revealing for our understanding of a hierarchy of power, where patients and indeed staff lack access to accountability.

Narratives produced evidence a lack of flexibility in patient care and adjustments. In Tommy’s example of the use and adaption of bedpans, where Tommy exercised agency within the limited space that he was afforded to improvise a response and problem solve, an accountable system would ensure that Tommy had access to a tool that worked, and that was applied to future situations. Accountability structures would enable such instances to be the preserve of emergencies or one-off instances, and guarantee that this is a right, as opposed to dignity fluctuating depending on staffing levels and who is in role at any given time. This was not met and calls into question Government pronouncements of the strategic priority of patient centred care with a central “ethical and human rights imperative” (Scottish Government, 2019B: 15).

Participants discussed the feeling of a lack of access to information and additional treatment at discharge as being evidence of having ‘slipped through the net’. Systems of accountability carry the principle that everyone counts, and someone leaving hospital feeling this way is an indication that the duty-bearer either lacks the information to be willingly accountable, lacks the resources to be willingly accountable, or does not consider it their responsibility to have the information, or to use resources, and so are unwilling to be accountable. Healthcare professionals act as gatekeepers to crucial information and services which is common (Graff et al, 2018), a reconceptualization of passive patient as rights-holder could enable self-referral, and access to vital information and support that could support repair. A lack of transparency in accountability processes appears a method by which the State - in this case through its health institutions - avoids accountability. Powerlessness in healthcare and an absence of rights-realisation, which may have been a previous unconsidered space, is disruptive. It is therefore a socially imposed barrier to both recovery and repair. An NHS that is rights-respecting should therefore be a safety tarp rather than a net. Perhaps most gravely, this may help to address evidenced outcomes that show that people with brain injury are at significantly increased risk mortality from suicide (Teasdale and Engberg, 2001) and death than the general population (McMillan et al, 2014, Corrigan et al, 2014).

Accountability was found to be absent in other interactions with healthcare professionals as evidenced in Andy’s account of seeking support to enable his participation in education. Andy was powerless to challenge his inadequate care here, and his example provided insight into the lack of accountability for the wider impact on his right to education and the severe and long-lasting emotional impact. Accountability promotes repair as it should require a redress of the power dynamic, and act as a safeguard against violations, but also as an enabler for people to lead dignified lives.

11.2.4 Non-discrimination

Central to the theme of non-discrimination was the experience of the barriers that participants faced in attempts to return to work (RTW) following injury. This need was driven by two key pressures, the need to reconnect and repair the disruption to the sense of self, and to provide for themselves and their families.

The need to provide was illustrative of a failure on the part of the State to ensure the right to an adequate standard of living was realised. As the injury was not part of any biographical plan, participants would not have reasonably expected to have to cover set-up costs or to face significant and sustained income loss whilst still meeting pre-existing financial commitments such as mortgage payments. Social security is therefore experienced as a precarious form of insecurity, and itself a barrier to repair as living is replaced by a struggle to exist.

Re-entry into the labour market before a person feels ready as a means to achieve to redress the failure of the duty-bearer was a barrier that had consequences for participants' chances of returning and maintaining a RTW. This carried further risk to long-term adequate standard of life, health and indeed family life and disregarded the importance of RTW as a milestone in biographical repair or continuity (Whiffin et al, 2017). The State can choose to remove this initial barrier by legislating and ensuring that all citizens have an adequate standard of living as a human right.

The RTW experience was one that failed to meaningfully re-integrate participants into the labour market and supports recent reflections on the distance between current RTW processes for people with a brain injury (Alves et al, 2020). Particular focus was placed on what participants couldn't do, and impairments viewed in the workplace as being the fault of the individual, rather than a failure to provide adequate adaptations. Continuous employment provides a form of narrative continuation and a role and status that is stable. This could have helped to enable continuity and repair as people adjusted to their lives following brain injury. The feeling of being forced out is illustrative of a short-term approach to human capital. This focus on getting functional people back in post as quickly as possible instead of focusing on successful adaptation deprives the labour market of vital experience, knowledge and specific organisational memory. Discriminatory processes, such as those documented in this research, therefore also damage the labour market and economy.

Discrimination presents a barrier that is complex but was described as emergent in hostile bureaucratic processes and was reproduced in the workplace by colleagues who engaged in processes of othering, illustrated in criticism, and in hate crime, cloaked in the societal acceptable form of 'banter'. This represents a further barrier to the labour market and to refer back to an original push factor, to an adequate standard of living. Experiencing discrimination in spaces which are central to our sense of self when linked to the acquirement of the injury and disabled status presents a negative reference point of comparison. Discrimination in the workplace mirrors repeated discrimination and dehumanisation in other areas such as healthcare, and so builds on the thread of acquiring a brain injury leading to a loss of rights. This in turn promotes disruptions and hinders repair. Disruption, as well as repair, is a process therefore without a specific time limit, and investigation into it should encompass this. The learnings discussed also add to Williams's (2000) urging of the consideration of timing and context when considering disruption.

At what point discrimination no longer causes disruption, but confirmation, was a question raised in the analysis. Discrimination of disabled people is a clear structural and public issue. A process of internalising the discrimination emerged as a possible pathway to biographical confirmation, which is theorised here as the process where barriers and discrimination confirm rather than disrupt one's biography. The internalising of this public issue was reinforced by its occurrence in official spaces such as hospitals and workplaces. This led to a complex interpretation by participants where they recognised and articulated the clear barriers and discrimination, but where participants still apportioned partial blame to themselves for their experiences. These experiences provide insight into possible causes of disruption that contract and expand over time and contribute to a situation where "no final point of resolution was gained, only a sense of tentative equilibrium" (Muenchberger et al, 2008: 988).

The reconceptualization of the self as a rights-holder offers an opportunity to address this negative self-view, but it requires clear frameworks, thresholds, and accessible routes to redress. The navigation of the workplace and one's own sense of worth, and disruption to work and previous roles made people feel useless. The accessing of psychological support following injury that was described by participants suggests that biographical disruption may in itself be a central cause or contributor to chronic illness, as discussed by Williams (2000). It is difficult to disentangle the fallout from disruption to other factors such as impairment effects, but participants' accounts strongly suggest that it is the re-emergence into a social world that is hostile, and crucially where their new roles and status do not match their previous biography, that is the cause of turmoil. This contrasts with the actual impact of living with impairments, which did not figure prominently in the data and is suggestive of the prominence of damaging power dynamics, failures of duty-bearers and an oppressive and hostile society. This is not to suggest that impairment alone cannot be catastrophic for someone, but that the data in this research points to the longitudinal damage to self comes from the navigation of the social world.

The navigation of the labour market following injury is in itself an act of resistance and one which requires payment in the labour of resilience to simply exist. The structural oppression faced creates a desire, less the resources of resistance are endless, to be at best normal or average. The labour market is a useful space for exploration given its centrality to society and social life, and the narrative accounts in this research contribute to evidence that "discrimination against disabled people is institutionalised in the very fabric of British society" (Barnes, 1995: 114). The labour market doesn't work for people with brain injury, and current legislation appears an insufficient tool to redress the experiences of the participants of this study and disabled people more widely.

11.2.5 Empowerment

The theme of empowerment focused on data that related to the support group itself. This theme provided a backdrop from which to consider support groups and their role in repair. Providing a mix of activities that are likely to be a combination of things people have done before, and new appears a positive step to repair as it allows a reconnection with the old, and, in trying new things, opportunities for growth too.

The support provided a starting point for empowerment by providing a place where a person's brain injury was safe to reveal, making "visible a brain injury that is invisible to the public" (Schwartzberg, 1994: 303). The group provided an environment for people to engage with others who they felt understood what it was like to have a brain injury and to deal with its impact, in contrast to a society, as discussed elsewhere, that either didn't or didn't want to (Barbuto et al, 2011). Members were able to talk to others who shared their experiences that were not family or loved ones, cited as being a positive aspect that promoted self-value in previous research (Kersten et al, 2018). This also enabled a reference for comparison (Bakmann et al, 2019), though the data was unclear as to how this took place, or whether people drew solace from seeing others in a situation that was subjectively worse than their own (Harvey, 2018). The data suggests that these processes of repair enabled are deep and complex, highlighted in the role of reciprocity in repair. People were empowered by being part of the group to both provide and receive care and support, described as the social glue that binds people in society together (Zhang and Epley, 2009: 786). Given the reduced roles and status that members experienced following injury, an environment to safely practice this process is particularly powerful for a group whom society clearly signals are of reduced ability and worth. The group is a space for repair, but also of a form of social rehabilitation or respite, where routine processes prior to injury, can be resumed. This also represents the accessing of a resource, as a support group is in essence a collection of experts in the experience. Empowerment in this sense is reliant on the labour of peers, and suggestive of a group that is a site of resistance to an oppressive society. Whether the risk of the injuring of dignity due to the adoption of a group identity as discussed by Mann (1998), or if there was an impact on members of ‘negative labelling’ (Condeluci, 1992), was a barrier to repair was unclear in the data.

A rights-based society would enable participation elsewhere in society and would in theory reduce the need for the support group, and the group identity, to be front and centre. By linking in with other groups and services, people were empowered to have the choice to further pursue activities elsewhere. By doing so members were encouraged to carry out repair, and to repair or grow their post-injury identity. This extended into areas that aimed to tackle societal barriers, as seen in the session that included a talk from a representative of the Citizens Advice Bureau. This empowered members as they told what to expect in these new spaces, which increased the accessibility. Empowerment of members may therefore be evidenced further by what members chose to do outwith the group, a significant achievement for support groups that exist often on meagre budgets and resource constraints.

Empowerment and repair that takes place within groups does not exist in a vacuum, which was evidenced throughout the data and the activities that took place outside. The groups trip to the Royal Palace evidenced how public buildings and spaces themselves impose barriers and status and allowed for understandings of how people with brain injury “sense of themselves in terms of the meanings and felt experiences of activities in different places” (Meijering et al, 2019: 23). This highlights the need for considerations of biographical disruption to encapsulate the complexity of experiences people have in different spaces, and the possibility of parallel fields of disruption and repair (Meijering et al, 2019). Public buildings imposed a status and restrictions that promote disruption and possible confirmation by doing so, which require resources of resilience to navigate and is therefore precarious to repair. The navigation of society was experienced as disempowering, and spaces of public prominence provided symbolic evidence of the change of status, and disruption of old and new self. The experience of this trip is evidence of the change post-injury, where societal barriers ensure that “The erstwhile taken-for-granted world of everyday life becomes a burden of conscious and deliberate action” (Bury, 1982: 176).

A lack of the choice and control which is central to empowerment (Morris, 1997), was evident in the group meeting where a government minister attended. This was experienced by at least some members as disempowering, and a failed test of empowerment. This added to a powerful narrative of damaging engagement with duty-bearers, where power dynamics emerged and revealed hierarchical structures within the group’s organisation. Tokenistic engagement occurs when people are passive or viewed as passive. By denying members to prepare and engage with the duty-bearer, meaningful access to a resource was unrealised, and a barrier erected to what could have been an empowering process that supported “efforts to gain control, access to resources and a critical understanding of one’s sociopolitical context” (Zimmerman, 1995: 583). The failure of reciprocity on the part of the duty-bearer relieved the duty-bearer of accountability, and missed an opportunity for an empowering experience which could have been a marker of repair and growth, rather than one of disruption or confirmation.

The lens enabled an understanding of the complexity of empowerment, and the need for a societal re-conceptualisation of its citizens as rights-holders. The previous chapters highlighted the dire need for empowerment that is meaningful and leads to participation. The lack of power and hostile social environments ensured that this was a process that was precarious and mirrors the calls for radical action that was the foundation of the social model. The evidence presented in this chapter builds to the conclusion that the current landscape is one that is disempowering and still in need of radical reform. The damage that is done by an injury once more is rivalled by the disabling society experienced by people who have sustained a brain injury. Disempowerment is a hidden barrier to repair, and rights-based approaches are a defence that even without maximalist incorporation could enable oppressed groups such as people with a brain injury to understand that their private troubles are in fact public issues.

11.3 Limitations of the study

The following section will focus on a critical and reflexive evaluation of the limitations of this study. Firstly, it will focus on limitations relating to the design of the study, and secondly, it will focus on limitations that emerged during fieldwork.

11.3.1 Design

The research interviews took place with six members of the group. I had plans to speak to a further three members of the group that did not take place due to the COVID pandemic occurring during the interview phase. Whilst the intention was always for deep engagement with a limited number of people, these interviews would have provided further knowledge, experiences, and insights. This would have enabled a deeper exploration into the benefits of attending the group, providing greater insight into whether and in what ways support groups enable repair. Additionally, a greater understanding of socio-economic factors and pressures may have emerged than did so. The participants were all drawn from members of the support group. This is a specific group of people with brain injury, as there will be many people with a brain injury who lived in the area but did not want to, or were not able to, attend the group. This may have been due to preference but also due to not being physically able to attend due to impairment and/or social barriers. In this respect the design ensured that some ‘hidden voices’ remained hidden. Their inclusion would have enabled a deeper exploration of life with a brain injury, but would not have helped me explore the usefulness of group involvement.

I had intended to interview the sole paid employee of the group, who themselves had personal experience of brain injury. This did not take place again due to the pandemic and could have given me additional perspectives on the running, potential and limitations of the group, in addition to valuable information as to decision making, and the relationship between the committee and how the group was run.

I used the PANEL principles as an analytical tool despite a lack of knowledge of human rights amongst the population generally. Providing human rights training may have enabled participants to locate their experiences within this framework, and provide greater understanding of rights-realisation, or the lack of, to this study. Training could have provided a greater participatory aspect to the research as participants may have been empowered to ‘name’ their rights, and with support possibly claim them. I did not have the experience (my own rights ‘awakening’ took place during the research) or budget to carry this out.

11.3.2 Fieldwork

Follow up semi-structured interviews did not take place as intended. By using a biographical method, I asked few questions beyond ‘can you tell me about your life’. Once again this was due to the pandemic, and whilst single interviews eventually enabled a deeper analytical focus on the participants’ experience as described by them, it prevented me from focusing on some areas that had emerged from the literature, which were of interest. A follow-up interview may also have given participants time to reflect on their initial interviews, and to subsequently further explore existing or new aspects of their experience that they felt were important. No technologies were used to ensure access to the study of people with communication or memory impairments. Whilst this did not prevent anyone taking part to my knowledge, and time and space was given to each potential participant to consider additional accessibility requirements, it may have itself have been a hidden barrier. This could have been mitigated by presenting examples of potential technological solutions to further enable access.

My insider status may have led to people not discussing in depth specific points as they may have assumed that I knew what it was that they were talking about. My own experience of being a member and volunteering with another brain injury support group may have meant that my observations overlooked aspects of the group that a non-insider may have picked up on, due to my familiarity with the concept and workings of such groups. The pandemic did afford me time to engage reflexively with this issue and I believe that the richness of the data, and my use of extended quotes that provide depth and context, mitigate against this. My own injury may have at times limited my ability to record fieldnotes. By the end of each session, I was generally exhausted and often in pain, and it was under these circumstances that my fieldnotes were written. On reflection, I believe that this was the most effective way to proceed, as I wanted to minimise any disruption that having a ‘researcher’ at the group may have brought, be part of the group for the duration of the session, and to avoid emotional impact that people visibly seeing me take notes, or leaving to do so, may have brought. Further, pushing myself to write up notes as soon as I could, ensured that the notes were valid reflections of the experience.

11.4 Future research directions

This section will consider areas for future research arising from the findings of the present study. This will unpack the following main areas: research relating to the hidden voices that remain, biographical disruption, human rights, and the potential of rights-based approaches in healthcare and support groups.

11.4.1 Understanding and reaching the hidden voices

Research that engages people who are not part of a support group or rehabilitation service (the places from which research on brain injury generally draws participants) would enable a deeper understanding of disruption, identity, and the barriers faced. Furthermore, this may in turn inform our understanding of the benefits or costs of attending a support group. This could also provide important learnings of biographical repair following brain injury.

The understanding of who has, or may have, a brain injury is growing. Recent research has uncovered new at-risk groups such as the asylum seeker/refugee population, people in the criminal justice system, victims of domestic violence. People who are part of these groups are likely to face barriers to accessing treatment, support and information relating to their injury. Efforts to include people who have historically faced barriers to healthcare and wider participation, such as the LGBTQIA+ community, must be included in future research. These existing (for it is society and non-inclusive research practices that ensure these voices remain hidden) and emerging at-risk groups can be expected to be furthest from rights realisation, and research could generate much needed knowledge on the intersection of brain injury and rights realisation. This research did not engage with these groups knowingly, or with other hidden voices such as people living specifically in rural areas, suggesting a need for future research in these areas. This need extends to research that engages people living in the Global South, whose voices similarly remain largely hidden.

This research highlighted negative experiences of access to healthcare, it would be of value to explore how this impacted on future engagement with healthcare services generally following injury, and whether these experiences led to barriers and hidden voices in healthcare.

11.4.2 Human rights and rights-based approaches

Although human rights informed this study, further research is needed to explore gaps relating to several areas. From a policy perspective, how the incorporation of human rights treaties impacts the subsequent holistic navigation of society for people with brain injury would generate important learning on its potential to impact on the poor outcomes faced by people with brain injury. This could offer crucial knowledge of participation, disruption and repair by investigating involvement in the shaping of new legislation, and if it is incorporated, whether people were able to claim their rights, and re-conceptualise themselves as rights-holders.

Considering the potential of human rights-based approaches, future studies could apply this model to a range of areas discussed by participants. How a rights based-approach impacts on the experiences of people disempowered in the early recovery phase could transform the experiences described in this study. The potential of rights-based approaches in support groups as a method to empower the members to name and claim their rights, gain full ownership of the space, and shape the direction of the group (and parent organisation) itself is a further valuable area of study.

This research did reveal rights-violations, but the design could not uncover the scale of rights-violations faced by people with brain injury. Given the lack of available information on this, research that develops methods of gathering this information is much needed. The possibility of using ‘human rights’ databases where rights-holders submit evidence of violations that are accessible is further of interest. These offer potential to increase participation of those whose rights are violated, increase accountability of duty-bearers, reduce discrimination, and empower citizens to claim their legal rights. This would provide further learning as to the interconnection of rights including and beyond those highlighted in this study. This would then provide information for research that encompasses intersectionality, and areas such as the impact of poverty to be explored, understood, and actioned. This is more pressing giving the research took place prior to the pandemic and ‘cost of living crises’, and the likelihood that rights realisation is further following these events and the impact, and lack, of subsequent policy interventions.

11.4.3 Biographical disruption

This research has highlighted further areas of potential enquiry relating to the theory of biographical disruption. Research that further identifies sites of disruption and explores how this knowledge can be influence policy, both in respect to accessing forms of support and societal navigation longitudinally, is recommended. This research uncovered a gap in the role of access to information following injury and its role in biographical disruption. Research that further explores this could produce vital recommendations to inform practice and reverse medical processes that are undignified and are a barrier to recovery.

This research demonstrated the fluidity of disruption and repair in the midst of often hostile social environments. How this is experienced over the life course remains largely hidden as it has been since the time of Phineas Gage and before. Longitudinal research is needed to understand how these processes occur as different phases of life are reached. This could encompass areas such as policy interventions and the growing understanding of the long-term effects of brain injury.

The role of support groups in this process further requires additional research. Whether and how people are empowered to move on from the group and construct new identities outwith that of their injury was unclear. Research that explored this topic could provide learning on how this could be carried out and re-conceptualise the group as a part of the journey as opposed to the final destination following injury.

11.5 Recommendations for researchers exploring brain injury

The following recommendations are specifically targeted to researchers exploring brain injury.

11.5.1 Immersion in the field

I would recommend that any researcher carrying out similar research spend as much time as possible with people with brain injury. My prior experience, and the time I spent as part of the group, enabled me to build an understanding of both the general environment people faced, but also of the individual nuances of people’s experience. This encouraged me to not view brain injury as a monolithic experience, which is crucial to aid intersectional exploration of people’s experience. It also helped to build trust and relationships with the members of the group. I believe that this aided recruitment of interviews, and the use of a biographical method that required people to feel comfortable with sharing personal, traumatic, and emotional experiences without much input or direction from the researcher.

If possible, I would suggest that the immersion develops during the fieldwork itself. I attended a social event, a classical music recital which the support group had gotten free tickets for. This took place outside the group itself and was a great opportunity to get to know people, and for people to get to know me. It was an environment that I wasn’t used to and represented a shared experience. I also attended a meeting of a brain tumour support group that took place in the area, to share information about the group and parent organisation alongside the group leader. This served as both a valuable knowledge gathering exercise, and as a reminder of the vastness of conditions and experiences encapsulated under the umbrella term of brain injury.

I would further recommend that this immersion takes place in relation to the literature in the field. I drew heavily on research from fields outside of disability studies and sociology, which grew my own understanding of the nature of brain injury, particularly in respect to neuropathology, and helped to prepare me for the field.

11.5.2 Wider relationships

I carried out interviews at the same location as the group took place in. Booking the rooms was made easier because I had gotten to know the staff at the centre and was on good terms with them. I also utilised prior relationships to help gain initial access to the group, as people knew me from wider work in the field. I would recommend that this begins as soon as possible within the research cycle in order to build positive relationships.

11.5.3 Flexibility

Be flexible in terms of your approach to data collection. Making interviews accessible is standard practice, but it may take you into unsure waters when in the field. One participant requested to have their partner take part in the interview to improve comfort and accessibility. In practice their partner spoke for most of the interview. This meant that my interview data was not purely from the words of people with a brain injury, which is what I intended prior to fieldwork. Flexibility ensured that the person could take part in a way that was accessible and comfortable for them. I would recommend that you are led by the participant and not your own desire to achieve a certain form, or perceived standard, of data.

This also extends to the use of biographical methods. Participants may choose to focus on other areas of their life that does not perhaps cover a specific area of your academic interest. The holistic experience all connects in analysis, and I would recommend that you trust in the process, even if you leave an interview concerned that you are not getting the data you want or think you require.

If your research involves attending a support group, be aware that you need to make sure that new, or returning members, need to be informed as to why you are there. Again, this is standard practice, but within this process also consider the possibility that it is potentially daunting for a person to be attending a group for the first time (or the first time in a while). It was for me when I first attended a brain injury group, so make sure to give the person space and not to overload them with information or requests for interviews.

11.5.4 Do not replicate the medicalised environments that people are likely to have been exposed to

People with brain injury are likely to have been subject to historic and/or continuous forms of assessment that are often themselves traumatic and disempowering. I would recommend consideration of approaches to ensure that this is not replicated. One method I employed (as discussed elsewhere in the thesis) was avoiding taking notes during the group session and during interviews, as this is often what takes place in medicalised and bureaucratic environments. I also booked a room for the interview that had sofas and coffee tables, as opposed to the layout that someone would traditionally experience at medical appointments, work or benefit assessments.

11.5.5 Take part in activities and challenge yourself

As discussed elsewhere in this thesis, I carried out tasks in the group such as setting up chairs, doing the dishes, and helping make tea. I would recommend that where possible asking the people who are running the session how you can help in practical terms. Doing so helped me to break down the role of (and possible status and power dynamic applied to) researcher, in addition to just making yourself useful.

I took part in activities that I would have naturally avoided, such as art or reiki due to feeling incapable or awkward, and taking the tea orders, as I have impairments relating to memory. Taking part in these activities, I believe, integrated me further into the group, and, furthermore, challenged potential power dynamics as the group witnessed my anxiety or struggles, and created a space where I was offered support. Had I hidden from these tasks like part of me wanted to, this wouldn't have taken place.

11.5.6 Your own wellbeing

I would strongly recommend building in time following fieldwork to decompress. After each group meeting, I recorded fieldnotes before getting on the train. I was fortunate, in this sense, that my train journey home was long, which I believe helped to build a degree of separation from the field.

11.5.7 Avoiding the tragedy/inspiration dichotomy

I would recommend that researchers be mindful of falling into a trap of viewing people with brain injury as either tragic cases or as inspirations. This may seem obvious, but you are likely to hear details about people's lives that are tragic, or distressing given the seriousness of the condition, often sudden onset, and societal oppression faced after. Similarly, people's recovery and lives are likely to have elements that are inspirational. This dichotomy is hard to avoid as it is often replicated in media depictions of disabled people, as a fundraising tool by charities themselves, and can even be reflected in materials produced by support organisations. A method to mitigate this, beyond awareness, is again related to immersion in the field, and to spending time in getting to know participants holistically.

11.6 Recommendations related to the ongoing debates and legislation in the Scottish Parliament.

11.6.1 Human Rights Bill

The Scottish Government has previously signalled its intention to introduce a Bill which would incorporate a range of human rights treaties, including the Convention on the Rights of Persons with Disabilities CRPD into Scots Law. However, there is growing concern within civil society as to the lack of clear commitment to introducing the Bill (Human Rights Consortium, 2024). A primary recommendation, therefore, is that the Government commit to full incorporation. This should include the incorporation of rights that are not included in the International Covenant on Economic, Social and Cultural Rights (ICESCR) to be fully incorporated in the Bill, including: the right of disabled people to equal recognition before the law (Article 12); the right to independent living (Article 19); the right to personal mobility (Article 20); the right to education (Article 24); and, the right to the highest attainable standard of health (Article 25) (Scottish Government, 2024). The need to ensure access to justice for rights holders through adequate funding of accessible advocacy and advice services, and legal aid where necessary, is a further recommendation. The final recommendation is that the Bill includes clear minimum core obligations (MCOs). These should be defined in collaboration with groups furthest from rights realisation, and that participation of rights-holders is embedded within monitoring carried out by the Scottish Human Rights Commission.

11.6.2 Classification of brain injury in football as an industrial injury

One area of specific campaigning and debate regarding brain injury in the Scottish Parliament currently is the campaign to have brain injuries in football classified as an industrial injury (Injury Time Campaign, 2023).

With football being the national sport of Scotland, this campaign and the legislation that is being called for is a crucial tool in raising general awareness of brain injury amongst the general population. As the link between football and brain injury has been established through research, the lack of government action reflects the lack of accountability of duty-bearers that was also evidenced in this thesis. The need for this lack of accountability to be rectified in the form of legislation is therefore a clear recommendation.

11.7 My academic growth and changing views on brain injury

My own growth as an academic was, in my opinion, quite vast during the course of my PhD. The standard of my own writing has improved significantly, as has my confidence in following the data and my ability as a researcher. This confidence enabled me to draw on a wider range of academic disciplines than I had previously. Brain injury is of course a multifaceted, complex injury and subject that stretches beyond any one academic discipline, and the wider consideration of sources and disciplines enabled me to produce a thesis which, whilst sociological, is more inter-disciplinary than my previous research, and consequently richer.

A fundamental shift has occurred in how I view brain injury itself. Previously I had considered a brain injury to be static in nature, particularly when its onset is sudden. By 'static' I mean that a person's journey would be an acquirement of injury that does not shift, beyond an emerging awareness of impairment that stretches from initial injury to reintegration into society and beyond. I now have a greater understanding of aspects such as neurodegeneration that can take place parallel. This has led me to a greater awareness of the holistic experience of brain injury and reiterated the need to view and engage with the subject of brain injury as a fluid, complex process, and to be aware of the developments of wider research.

Integrating human rights into my thesis represented another significant area of growth. The use of the PANEL principles as a framework enabled me to identify systemic injustice through the narratives and experiences of the participants. This contributed further to my understanding of biographical disruption, and of the role of duty-bearers in this process. Finally, human rights represent the first theory or framework that I have encountered since the social model that has the potential to be transformative on a wide societal level, and thus aided my understanding in how things can change, as opposed to my previous work where my conclusions were more focused on the singular need for change. By engaging with the story of Phineas Gage, I have developed a deeper understanding of the roots, and misconceptions, of how people with brain injury are studied, pathologised and viewed in society. Furthermore, I now recognise this case to be one of rights-denial, providing a clear observable case long before that of the literature I have previously engaged with.

My understanding of the structures under which the support groups operate developed during the thesis. By undertaking research with a group with whom I had no prior personal involvement (unlike my previous research), my own critical engagement with the structures governing support groups as a sociological unit of analysis was clearer and more robust. Central to this critical engagement was my interaction with literature around the emergence of charities in the UK. which challenged my own experience (having been a member and board member of a similar support group) and encouraged me to consider the role of parent organisations and structures which can disempower and add to the conditions under which repair is promoted.

11.8 Conclusion

The thesis has provided a nuanced and rich exploration of the experiences of people with a brain injury and how they navigate life following injury. The concept of biographical disruption provided a useful tool in understanding recovery following injury. Medical research into brain injury is responsible for saving many lives (including almost everyone involved in this study) and limiting the impact of brain injury, but it speaks little to the experiences and host of negative outcomes that people often face following injury. The theory of biographical disruption enabled the gaining of a deeper understanding of the complexity of recovery and repair, a process that is ongoing and the subject of negotiation and navigation long after the medical world's treatment and involvement lessens. The use of this lens builds our understanding of brain injury as a 'social' injury, where the difference between past and present self is one that may be processed privately, but is very much lived socially in environments that are often hostile. In doing so it offers us vital information as to how outcomes, and ultimately the lives of people with brain injury, can be improved. The focus on a person's own biography, rather than viewing the experience through the medical lens, is empowering and dignified, and suggests its suitability to be used in conjunction with rights-based approaches.

This research provided evidence that face-face support groups can contribute to adults moving out of a disruptive phase. The group provided a safe space to practice being 'yourself', of critical importance to people who went through dehumanising experiences. The support group furthermore provided a space to access resources in the form of information and peer support. This enabled the resumption of fundamental and empowering social processes such as reciprocity to occur. Brain injury is both a private and public experience, and the group allowed a bridge between the two and a space where people could engage in activities that were both familiar and new. The study furthermore provided evidence, through the use of a human-rights lens, of how processes of empowerment and participation could enhance the experience of attending a support group, which in turn could further enable the moving out of a disruptive phase.

A central contribution of the thesis is the knowledge gained from the use of PANEL as an analytical lens. Whilst support groups can play a role in the moving from a disruption phase, this lens enabled an uncovering of a range of social barriers that persist, barriers that are potential sites of disruption. It also uncovered a process where participation was removed, and never fully returned. By using this lens, the failure of duty-bearers to be accountable for the lack of rights realisation was revealed. Brain injury is a serious medical condition which can lead to impairments that can be life changing. The analytical lens of PANEL principles, however, revealed that many of the key issues people face have solutions to be found not in medical treatment, but in the realising of rights. People with brain injury should and can lead dignified lives following injury. A human rights-based approach emerged as a clear means to redress the dehumanising treatment of people with brain injury. This provides the opportunity to replace the need for resilience and resistance, with the means of empowerment and participation, and in doing so rebalance the power dynamic present in societies that are disabling.

Chapter 12 The wounded storyteller in the field: an autoethnographic chaos narrative

12.1 Introduction

The following autoethnographic paper begins with the personal account outlining how I became the ‘insider’ and is intersubjective in nature as it details both my own experience of sustaining a brain injury, and my pre-existing understanding of what living with a brain injury was like. The production of the following paper was emotionally challenging and difficult to write. The key messages are clinical (how I sustained a brain injury) and intersubjective, positioning the experience of becoming ‘brain injured’ within the story of becoming a researcher. This autoethnography uses Frank’s (1995) illness narratives as an analytical framework to analyse my self-recorded account of field work, building evidence of a dominant ‘chaos narrative’, and of my growth as a researcher with insider knowledge of, and embodied challenges associated with, brain injury.

12.2 The injury

The Royal Wedding of Prince William and Kate Middleton, later Princess Catherine, took place on the 29th of April 2011. This was also arguably the most significant day in my life, as it was the day that I sustained a brain injury.

I was at that time a 26-year-old, a week away from sitting exams as part of a university Access Course that would hopefully lead me to a place on an undergraduate Sociology degree. Whilst more than 5,500 royal wedding street parties were planned around the UK, none were held in Glasgow (The Guardian, 2011) due to a lack of interest. The people of Glasgow had other ideas, and it was in this spirit that I attended an unofficial ‘royal wedding celebration’ that was held in Kelvingrove Park - a major park in the city’s west-end. The event ended shortly after I left, with what was described by a pro-royal family newspaper as a ‘boozy riot’, which had, according to the same paper, ‘marred the occasion’ (Borland, 2022). Occasion suitably marred, I went back to my apartment to meet my brother and friend, as we had tickets to a gig by the German electronic group, Modeselektor. I was last to leave and so locked the door, which I remember clearly. After that, my next memory is a vague one of being in a hospital waiting room around 24 hours later.

As I found out later, after locking my front door I had slipped on my top step and fell. I got up straight away and took the taxi to the venue. I then fell again outside the venue, was assessed by a first aider, who put my condition down to alcohol consumption and advised my brother to take me home and make sure I got into bed. When nobody could reach me the following day, my brother and sister came to my apartment and found me disorientated in bed and clearly ill. I was taken to a local hospital nearby, and once assessed, sent for a brain scan, which revealed that I had bleeding and bruising in the right frontal lobe of my brain. I was transferred that night by ambulance to a specialist neurosurgical ward at the city's then Southern General Hospital (now the Queen Elizabeth University Hospital).

I was discharged eight days later to the care of my parents and back to the family home where I would largely remain for the following years. I was left to contend with a range of cognitive impairments, which affected my ability to carry out previously simple tasks such as reading, writing, communicating with others, and walking (for which I now used a walking stick). I also developed chronic headaches and neuro-fatigue, both of which have continued to this day. I spent a short period of time as an in-patient of what was then called the Physically Disabled Rehabilitation Unit, now known as the Neurorehabilitation Unit, and in the months and years that followed, I was an outpatient of various medical departments, most notably the Community Treatment Centre for Brain Injury, who carried out neuropsychological testing and supported me to return to the university access course 16 months later.

I returned to the university access a year later, which was probably still too soon from a recovery perspective, as I was struggling with previously considered basic tasks such as reading and writing and was often in pain and exhausted. I did, however, pass and then went on to complete my undergraduate degree and master's degree. I then embarked on my PhD in the field of brain injury. It is the embodied experience of carrying out the fieldwork, whilst still living with the effects of my brain injury that is the subject of this autoethnographic study. This chapter aims to provide insight and recognition to a space in research and knowledge production that is poorly recorded, in this case the embodied experience of a 'wounded storyteller'. In doing so, I also attempt to position myself alongside my peers in an 'ethic of solidarity and commitment' which "is expressed when the storyteller offers his voice to others, not to speak for them, but to speak *with* them as a fellow-sufferer who, for whatever reasons of talent or opportunity, has a chance to speak while others do not" (Frank, 2013: 132).

This was not, however, my introduction to brain injury. A decade prior, my sibling had sustained a serious brain injury, and following surgery had spent time in the same department that I was admitted to. I therefore had experience of the impact that such an injury can have, and the barriers that people face long after discharge. I privately held the view, following my sibling's experience, that brain injury was amongst the worst things that could happen to a person, and that I was lucky it wasn't me. The lens through which I have viewed my own injury has therefore been intersubjective from the outset and underpinned by the fact that whilst my injury was serious and life-changing, the injury that my sibling sustained was more severe.

12.3 Literature review - Autoethnography

Autoethnography is a method that contains and joins elements of both autobiography and ethnography (Ellis et al, 2011). The autoethnographic approach, whilst gaining popularity more in the last two decades (Chang, 2016), has its roots in early sociological practice (Anderson, 2006). It is a contested term and one which encapsulates "interesting, boring, and revealing memoirs, recollections, personal journals, stories, and ethnographic accounts under the same name" (Charmaz, 2006: 397). It goes beyond mere recollection by placing the experience of the researcher within specific social contexts and using this to generate enquiry into areas of social agency (Naidu, 2014). This connection between the personal experience and the social is key, as is an understanding of the social context of the phenomenon beyond the researcher's own experience (Chang, 2016). The narratives produced can "...(potentially) offer embodied details, celebrate the author's position, problematize the production of knowledge, and reveal the profane in the sacred processes of research" (Ellingson, 2006: 304). It is an approach, that in narratives that explore illness, are "uniquely suited to acknowledge the role of one's own body in knowledge production and reflexivity" (Birk, 2013: 391), providing insight into the embodied experience of qualitative research, and in doing so produce insight into shifting power dynamics and researcher/participant shared vulnerabilities (Humphrey, 2023). It can enable the voice of the 'patient', often silenced, to become prominent, and be utilised to explore the experience of injury and disability (Shankar, 2018).

The form of autoethnography that is employed is dependent on the level of focus that the researcher decides to place “on the study of others, the researcher’s self and interaction with others, traditional analysis, and the interview context, as well as on power relationships” (Ellis et al, 2011: 278). What constitutes autoethnography, and the analytical approach required, has been the subject of debate. This is exemplified by the debate surrounding the two main approaches: evocative autoethnography and analytic autoethnography. Evocative autoethnography, has received critique to what is perceived to be a lack of traditional social science analytical approaches (Anderson, 2006; Charmaz, 2006; Learmonth and Humphreys, 2012). Autoethnographic approaches where personal narratives do not contain these traditional analytical approaches, have been considered particularly controversial (Ellis et al, 2011). The method has been critiqued for a lack of clarity in terms of the extent to which auto-ethnographers claim to speak “for the described experience” (Charmaz, 2006: 398). This suggests the need for caution, and reflexivity (layered as it is within an approach that aims to embed it), when attempting to combine an evocative approach, with research that aims to project the voices of research participants that have previously remained hidden.

12.3.1 Autoethnographic accounts of brain injury

Autoethnography has been employed by researchers to unpack aspects of personal experiences of brain injury. This has involved the challenging of medical perceptions around the lack of awareness and stigma (Shankar, 2018), identity transformation, posttraumatic growth following brain injury and post-traumatic stress disorder (Genetti, 2023). Its selection as a method in research carried out by someone with a brain injury has also been documented (Smith, 2005). It has been utilised to unpack the need for awareness of intersectional experiences and culture (Miffin et al, 2019), and to explore and illuminate areas of little academic understanding such as higher education participation of people with brain injury (Shiels et al, 2022). Autoethnography has also been employed to examine the lives of two brothers who had both sustained traumatic brain injuries, written from the perspective of one of the brothers who sustained a brain injury almost 22 years after his sibling (Kidd, 2021).

12.3.2 Frank’s Illness narratives

Arthur Frank’s work on illness narratives, and in particular “The Wounded Storyteller: Body Illness and Ethics (Frank 1995)”, are amongst the most influential and cited works in medical sociology. Frank’s work was deeply rooted in lived experience, having himself experienced serious illness and recovery as a result of both cancer and a heart attack.

Frank (1995) proposed three illness narratives - restitution, chaos, and quest - to understand the lived experience, and the stories told by people living with illness. Restitution narratives place the focus on the individual following a path from illness to recovery, and with it a return to the person’s previous life. Restitution and its narratives can be limited in cases where the medical world is not able to provide a full recovery (Frank, 2013), such as many cases of brain injury. Stories told in this way “bear witness not to the struggles of the self but to the expertise of others; their competence and their caring that effect the cure” (Frank, 2013: 92). As Frank (2013) pointed out, people who are sick, want to recover their health. The desire for restitution is not purely individualistic, and “is compounded by the expectation that other people want to hear restitution stories” (ibid: 77). Brain injury does not lend itself easily to this narrative, beyond the initial stage of medical recovery (which can last years), as it is unlikely to lead to a full recovery, or to be cured by medical procedures or treatment. Frank describes a brochure produced by an American hospital that describes the stories of three cancer patients in a restitution narrative that describes the positive recovery, but not the experience of the patient during treatment, or of the impact of the effect of the treatment (ibid: 78-79). Such narratives, as Frank points out, present the patient with a framing through which their own stories should therefore be told. Thus, in cases such as my own, where little or no medical involvement continues but the impact and uncertainty of the condition persists, it is unlikely to be an enduring narrative. It is, however, “a stage in the embodied process of illness that every body passes through” (Frank, 2013: 84).

Chaos narratives do not follow this linear path, and Frank contends, a chaos narrative “is the opposite of restitution: its plot imagines life never getting better. Stories are chaotic in their absence of narrative order. Events are told as the storyteller experiences life: without sequence or discernible causality” (Frank, 2013: 97). It is a narrative that “is rarely encountered by audiences because the chaos narrative is usually erased or silenced” (Donnelly, 2024: 3). Quest narratives communicate the experience of illness as a journey through which the individual gains insights and purpose despite their illness and are the most commonly published health stories (Frank, 2013: 115). It is a narrative that is reflected often in communications published by charities and support organisations, but a narrative that carries with it a risk that the experience of illness becomes romanticised (Frank, 2013).

Restitution and quest narratives fit into the traditional storytelling structure starting with the onset of illness, a middle where illness develops and is progressed, and finishing with an ending which provides "a resolution that resolves ambiguities and questions and conclusion" (Donnelly, 2024: 6). Donnelly highlights that for many disabled and chronically ill people, an insistence that their experience and narrative conform with these types "denies them the ability to authentically voice their experience" (Donnelly, 2024: 8). Engman (2019) contends that in order to understand the illness experience, consideration of an individual's "particular embodied orientations towards the world is paramount" (Engman, 2019: 126). The interrogation of the chaos narrative is crucial as it is in this fragmented space that orientation is being attempted, and often failed. If a narrative "is essentially a performance that reveals how we interact and *react* to the structures with we live" (Pearce, 2008: 132), it similarly stands to reason that the interplay of the body and its relationship and reaction to the structures and fields within which it exists is a vital area of sociological inquiry. Given the centrality of brain injury in this autoethnography, it is therefore valuable to unpack the umbrella term of brain injury as it relates to me.

12.4 Methodology

The data is drawn from the thirteen fieldnotes that I completed immediately following each session I attended at a brain injury support group, which was the site of my PhD fieldwork. The fieldnotes were initially not intended for analysis but as a tool to be reflexive and capture any aspects of my insider status. As will be outlined, the fieldnotes captured the embodied challenges that I faced. The fieldnotes were recorded using a proforma developed by Chiseri-Strater and Sustein (1997). This was selected as I wanted to use a simple proforma and had trialled it prior to entering the field, finding it to be accessible to me, especially as I was likely to be writing my fieldnotes when fatigued and in pain.

By practising reflexivity in the field, I became more aware that the embodied experience of injury was impacting on how I was recording my fieldnotes, and indeed the wider knowledge generation I was attempting. Pillow (2003) describes reflexivity as being a tool that highlights “one’s awareness of the research problematics and is often used to potentially validate and legitimize the research precisely by raising questions about the research process” (2003: 179). The questions raised led to me adding a section title ‘embodiment’ to my participant observation proforma. I became aware early on that whilst I was considering my impact on the group through my presence in the space as a researcher, I was negating how my own body impacted on the production of knowledge in my research. The initial aim of the addition was simple, to aid my reflexive practice by recording specifically the impact that carrying out the fieldwork had on my role as a researcher, and in doing so, insights on my own health and wellbeing during the process. I had not planned to capture data relating to this, primarily because the research wasn’t about me or my experience, and I was by this point accustomed to putting my health and wellbeing on the line (often with some cost) when I thought it was worth it. I am also guilty of pride, and don’t like to accept that I have limitations due to my injury. There was also a sense of injustice, that I was carrying out disability studies research in a system that didn’t recognise or offer much support for me as a disabled person, and that I had a responsibility to at least have the possibility to at some point highlight it. Whilst not initially the intention, this addition served in time in its own way as an act of resistance to “the erasure of researchers’ bodies from conventional accounts of research” which “obscures the complexities of knowledge production and yields deceptively tidy accounts of research” (Ellingson, 2006: 299). It does, however, raise a troubling insight for a disabled, Disability Studies researcher, that I viewed my own body through a medical model lens and as being ‘problematic’ and in need of strategies to address its perceived threat to the research process.

The autoethnographic method was selected as it enabled me to critically engage with, and further acknowledge, the role of my body in the research process. I recognised that any knowledge my research aims to produce, “is profoundly related to the conditions of its own production” (Thomas, 1999: 81). By drawing on this specific facet of knowledge production, it further traces the role of the body, and accepts and reflects that “All ideas arise from within the walls of the body. All thoughts are shaped by the contours of our ultimate material condition. No idea or experience is free from the constraints of the absolute structures of skin, muscle, and bone” (Birk, 2013: 396).

This process began with a series of three interviews, each around an hour in length, held by one of my supervisors, that aimed to explore my possible use of this method, consider bias, and augment my reflexive practice. Employing the autoethnographic method enabled me to "strive in some way to collapse the conventional distinction between researchers as agents of signification and a separate category of research subjects as objects of signification" (Butz and Besio, 2009: 1671). For me this was important as I was both a researcher and a peer of my research participants, in addition to being a previous member, group worker, and Chair of a similar support group in the years following my injury. The autoethnographic method is appropriate as a 'wounded storyteller', a role that this autoethnography enables me to share with my research participants, all people who have "suffered and lived to tell the tale" (Frank, 2013: xi). Furthermore, this method further challenges the power dynamic between the researcher and the researched, as by acknowledging the limitations of the body, it "reaffirms researchers' common humanity with patients by keeping researchers on the same (messy, imperfectly controlled) level where patients must live" (Ellingson, 2006: 307). In bearing witness to my own experience, this chapter "offers testimony to a truth that is generally unrecognized or suppressed" (Frank, 2013: 137). It is important to note that the fieldnotes from which the data is drawn were written primarily as a reflexive tool. They were written candidly, usually whilst feeling fatigued, ill and in pain, and not necessarily with the intention of publication. The data is presented as it was written, and without consideration of grammar, reception (I think, although I cannot say this conclusively), and at times in the Glaswegian dialect that I speak.

12.4.1 What's it like to have a brain injury?

The following section uses fairly clinical and descriptive language. This language is adopted to establish, with as much clarity as I can, what it is like to have a brain injury (for me), and how my life is different from before the injury. I have no catch-all term that adequately encapsulates or explains the impact that my brain injury has on my day-to-day or working life. Using the term 'brain injury' is useful as a basic explanatory term that denotes a level of seriousness. It is, however, an umbrella term and does little to describe to another person what I experience. Donnelly (2024) remarked that "Explaining disability often feels like you are navigating two languages, trying to translate yourself for the able-bodied world" (Donnelly, 2024: 12). I will attempt briefly to translate myself as best as I can in terms of impairment or symptoms, before interrogating the embodied experience of fieldwork and laying bare my own ‘chaos narrative’ (Frank, 1995).

The most translatable aspect of my injury is the chronic pain I experience. This is in the form of headaches which range from manageable to at times pain I would describe as extreme. Most people have had headaches of some form in their lives, and so this aspect of my injury is relatable and understandable. The pain is exacerbated when I work, particularly when I work long hours. I therefore often work in constant pain, and apart from taking over-the-counter painkillers, which is very limited on the advice of a pain consultant, and I suspect mostly placebo, have little relief. I previously took what I would consider to be a strong pain medication daily but stopped after a few years as I suspected (and found out) that it did little for my pain.

Another symptom is a form of neuro-fatigue, which slows me cognitively, by this I mean my ability to process information and concentrate, and where my senses feel overloaded. An example would be if I am in a café or busy space. If I am tired, I will pick a seat that faces a wall where the stimulus of the busy environment becomes less challenging for my brain to process. This neuro-fatigue, I think (though do not conclusively know) is a contributor to another symptom, that is my sense of balance being affected and feeling unsteady on my feet. At its most severe, I feel like I might pass out. Every time I feel like this I am scared, despite its familiarity.

Ever since my injury, I sleep poorly. I can fall asleep, but I wake up regularly throughout the night, and often in pain from a headache. My workload also exacerbates this symptom. From the extensive neuropsychological testing that I underwent following my injury, I know of specific areas in which I am cognitively impaired, but I am fortunate that the areas in which this is the case are areas that (broadly speaking) impact tasks I previously had little aptitude in. Growing up I would regularly help my father, who was an electrician, with various building work. Due to my disinterest and general ineptitude, I would be the person holding the ladder, lifting the heavy things, or going for our lunch. I was never good at the tasks that required skill, and now it doesn’t really matter if I can’t build Lego well or find an instruction manual overwhelming; or so I like to tell myself as was shown in a fieldnote towards the end of my fieldwork: *Trip 13 - “Found the bingo very frustrating as I struggled to follow it a bit after a while.”* What is revealing from those 16 words is that whilst I was comfortable recording my frustration, I attempt to qualify that I struggled to participate only ‘a bit’ and only ‘after a while’. I recognised my struggle with taking part in the bingo not as a relatively inconsequential matter but as “an identification of the situation as a “betrayal,” a failure of the body to live up to the role it historically played in the daily life of the subject (Engman, 2019: 123).

My injury was in the frontal lobe of my brain, which is linked to changes in personality such as social disinhibition (Chow, 2000, Filipčíková et al, 2021). How much my personality changed, and how much of this was due to the damage to my brain or other factors such as the impact of the traumatic event, biographical disruption or navigating society as a disabled person, is hard to disentangle. One description I heard in an interview with another person who had sustained a frontal lobe brain injury that resonated with me was their perception that their injury hadn’t changed them as such, but it had sharpened the edges of their pre-injury personality. I feel this has been the case with me. I have found following societal rules and hierarchies that I consider arbitrary to be challenging, and at times a personal afront. I think that since my injury that I mask or camouflage my behaviour in professional settings, which can make me feel frustrated and unhappy. I can become fixated on what I consider to be problems that are often trivial, and I suspect I am now a very difficult person to care for when I am ill. That said, my life post-injury has been successful by most societal measures, and meaningful and fulfilling by my own. I am surrounded by family and people that I love, get to do work that I consider to be important and is challenging, laugh every day and earn enough money to have a good standard of living. Whilst I often feel privately full of self-doubt, I also have a confidence in what I am capable of that is far greater than prior to my injury. My injury now is largely hidden, which has both positive and negative aspects, but it allows me, on the most part, to keep private that what I don’t wish to share or be judged on.

This explanation doesn’t really capture the full experience though. It is a roughly assembled translation for the reader that might have been written quite differently at another time. It also doesn’t unpack much of the social element. It doesn’t tell you how it feels to experience hate crime (in my case verbal abuse in the street due to my use at the time of a walking stick), the chronic loneliness of the years following my injury, or the impact of navigating hostile bureaucratic systems such as social security, experiences which all of which have been part of my journey and have also shaped the person I am, good and bad. Lara Birk, reflecting on her experience of living with chronic pain wrote that “pain is at base a phenomenon that is inherently resistant to language” (Birk, 2013: 392). So, it is the case for me with my brain injury - a condition and state of embodied being for which I have no comprehensive or neat descriptor that captures its multi-faceted impact.

12.5 Findings

12.5.1 The embodied experience

The embodied experience of my brain injury, and its relationship with my ability to carry out fieldwork, is consistent throughout my fieldnotes. This began with me recording my surprise by the impact on my health of attending the support group that served as the research site: *Trip 1* - "*Surprised a bit by how wiped out afterwards, reminder of my own injury*." In terms of treating this impact, the best approach I have found is lying in a dark room, and ideally sleeping, and not working until I feel better. It is important to point out that throughout this fieldwork and my PhD I had the most supportive and empathetic supervisory team I could have wished for, was limited to carrying out fieldwork fortnightly, and was producing my work in collaboration with a brain injury organisation. I also had access to the university disability service and a support officer who has been excellent throughout my academic journey. This was in addition to the love and encouragement from my loved ones that I received throughout. Finally, I was supported by the members of the support group that I attended. They were welcoming, patient, and generous. Access to these resources went a long way to mitigating the PhD funding structure which made no consideration of the fact that it might take me longer to carry out the research or that I should have extra-time to recover due to my brain injury. I am still grateful for the funding and opportunity, and would do it all over again, but it is a system that without review will prevent knowledge production from marginalised people and cause harm.

By the second trip, the impact on the research process and knowledge production of my injury, and of working elsewhere (in this case my teaching role at my university), was starker: *Trip 2 - "I think I am depressed because I was so ill after teaching for the first time yesterday… Feel tired writing these notes."* My notes were generally written immediately after each session. However, I added the following note the morning after this session, as I thought it important to record the impact that carrying out fieldwork was having on my health and life away from the field. *"Trip 2 (Next day note) - I felt terrible on the way home. That night was scary as I thought I was on the verge of passing out at times or was experiencing an 'aura'. Horrendous*."

Given that this note was written more than 8 years post injury, it is difficult to analyse this illness narrative as either restitution (as the medical world didn't solve my illness), or quest. The quest narrative could have been fitting, I had reached a significant milestone, doing fieldwork on a PhD, and teaching at a university had been a dream since I studied on the access course. However, "narratives are continuously made and remade as episodes happen" (Whitehead, 2006: 2243), and the impact of my health negated the triumph of the milestone, forming a chaos narrative. Writing on the impact of relapse on people with chronic fatigue syndrome/ME, Whitehead (2006) observed that "If a relapse was experienced the narrative reflected elements of a chaos narrative (Whitehead, 2006: 2243). At this stage of my own form of relapse, it is also interesting to note that I do not situate my experience as resultant of socially imposed restrictions, as in the social model, or as a public issue (for I am one of many people with a brain injury). Thomas (1999) discussed the need to analytically distinguish the strands of experience such as limitations caused by disability, the psycho-emotional consequences of disablism, and the experiences of disabled people living with both impairment and impairment effects (Thomas, 1999: 81). The fieldnotes are from the perspective of a person not thinking ahead, but required to very much be in the present, and redolent of Thomas' contention that "from the point of view of the reality of lived experience, this necessary analytical distinction tends to dissolve" leading to a "melding of the accumulated consequences" (Thomas, 1999: 81). So, it was the case here, the veneer of idealised researcher slipping to reveal the individual dealing with the 'accumulated consequences'.

The notes from the next trip tell a similar story of the precarious balance of my life as a researcher alongside the other roles and responsibilities I carried out more widely, and the impact this had on my health. *Trip 3* - "*Stupidly tried to work on the train on the way up and therefore felt a bit rough when I arrived. Discipline needs to be total on this, even if I feel fine*." My inability to carry out tasks without consequence, in this case working on a long train journey in the morning, was not recorded with much empathy. It is also evidence of what Frank (2013) termed 'the disciplined body-self' which "defines itself primarily in actions of *self-regimentation*; its most important action problems are those of control" (Frank, 2013: 41). At this early stage in the fieldwork, the disruption to what I considered or desired to be routine behaviours, is clear. When "stripped of one's ability to enact routine behaviours, the future is necessarily uncertain" (Engman, 2019: 126). The embodied experience of my injury produced this further level of uncertainty which provides insight into the environment under which knowledge production took place.

12.5.2 Embodiment as a specific area of research interest

I added the embodiment section to my fieldnotes prior to the fourth trip. In doing so, I established or at least categorised embodiment as a specific area of research interest. My first recording in the 'embodiment' section of my notes illustrates the impact of writing notes when feeling ill and fatigued:

> Trip 4 - "Feel a bit zonked after teaching yesterday on my way up. Writing notes is important as things are fresh but compromised because I am tired and today I quickly want to finish. Resisting the urge to listen to the voice saying, 'that'll do'."

I considered this data to be important for my reflexive practice and for my PhD as a whole, and so felt that I had to write them up regardless of how I was feeling, providing insight into the knowledge production process. The embodiment section also provided insight into the embodied impact of the research process as the fieldwork continued:

> Trip 7 - "Had very bad night before going. Got quite lucky (lived reality?) as it wasn't a normal group so didn't have to do very much. Usually, I would have had to perform more, this time got away with a few well-timed jokes and some chat about the research. Was really warmly received. Feel like a zombie again on way home. Feel quite low again after leaving despite it going really well."

A quest narrative may have in this instance been evidenced in a positive framing, 'I was ill but still got the job done'. Feeling that I had been 'lucky', 'like a zombie', and 'low', without resolution is an environment more redolent of chaos, and of a person who is keeping their head just above the water and knows it.

Frank (2013) highlights that chaos narratives are "overwhelmed" by the threat of disintegration (2013: 171). This was evident in later notes, where I negatively compared my ability to record fieldnotes, itself simply a measure of quantity rather than quality: *Trip 10* – "*Absolutely shattered… 200 words [recorded in my fieldnotes] instead of the usual 5-800. Harsh reality and data lost.*" This trip took place following a Christmas party which, it should be pointed out, I had really enjoyed. My wider fieldnotes discussed having a laugh and hanging out with people I really liked. The negativity returned when I was required to engage in knowledge production and measured myself against an idealised role of researcher. Following this trip, I had a few weeks off over Christmas. When I am not working, I generally feel much better, and I am able to manage my condition better. As in the first trip when I recorded my surprise at feeling ‘wiped out’, my return to the field evidenced a similar process of forgetting:

> Trip 11 - “Felt like shit this morning. The difference between Christmas and now is really stark. I live with minimal symptoms when I am off for a period of time. As soon as I start having to concentrate again, I start to get fairly significant headaches, sleep becomes awful, and everything becomes more tough. It’s amazing [surprising] that you manage to forget. Just as I become used to it being normal it goes back to the usual, which in itself is always a bit of a shock.”

The process of readjustment and illness disrupted my physical interaction with the world, which in turn threatened “the foundation on which day-to-day life is built” (Engman, 2019: 126). In their autoethnographic account of spinal cord injury, Clifton (2014) highlighted the need for greater “investigation into the ambiguity of adjustment – the negative experiences and failures that accompany the positive virtues and strengths,” which in turn would “provide a more realistic understanding of rehabilitation and the longer-term journey” (2014: 1828). My embodied experience captured in these notes illustrated that my adjustment was similarly ambiguous, and one that without the use of the autoethnographic method would have been lost.

My own biography became a resource which I drew on to reassert control, and to address what I was experiencing as a private trouble, and which, at the most vulnerable times represented a ‘monadic body’, that is “understanding itself as essentially separate and alone” (Frank, 2013: 36). Whilst I view the collective experience of disabled people through the lens of the political and social, I view my own embodied experience less so. I know that my experience was made more difficult and precarious by the social barriers placed by a disabling society, but it isn’t what I think about when I am struggling. The following section provides detail of my own strategising and attempt to control the chaos, drawing on my own biography and self to mitigate the embodied experience.

12.5.3 The system and the disciplined body-self

The precariousness of managing my condition with my responsibility and desire to carry out my fieldwork to the best of my ability was present throughout my fieldnotes. My identification of my own body's role in knowledge production called for action which came in the form of what I termed 'The System'. This was an attempt to reassert control and reflects what Frank termed 'the disciplined body-type' (Frank, 2013).

My use of 'the system' came from a term used to describe the style of play deployed by the successful Donegal Gaelic Football team (whom I support) who had achieved great success under a revered and radical coach, Jim McGuinness (RTE, 2014). During my initial recovery following injury I decided to refer to my own engagement with, and largely self-directed attempt at rehabilitation as 'The System'. This was borne from my experience of a rehabilitation process where I, in keeping with the experience I had observed in my sibling and others, fell through the cracks (a common experience that I discuss more widely in my PhD thesis). I felt desperate at the time, and thought that by creating a structure, I would achieve better results, i.e. recovery, and remove or reduce the daily cycle of negative thoughts. I also then had something tangible to place my faith in. An embracing of faith by those predisposed to it can be triggered by the chaos narrative (Frank, 1995). I was raised as a Roman Catholic, and the concept of faith in a higher power was one that was familiar to me. It would be easy to linger on my loss or questioning of faith following my injury, but 'The System' is evidence of the consistent need for disabled people to "resist – an ever-present requirement to reforge resistance strategies" (Thomas, 1999: 47). The need for 'the system' pre-dated my academic journey, but its re-emergence is evidence of a working environment into which my condition was required to fit to exist similarly to others. My notes begin to be in part a conversation with this 'framework', as is evident in a fieldnote from trip 5:

> Trip 5 - "did zero work this morning [prior to the train journey]. Answered emails on way to [research site] but kept it light. Feel drained going home but managing it. Would prefer to go home and not talk to anyone. I am lucky to have the significant number of trips to work out the knack."

The reference to not talking to anyone was referring to the fact that I had arranged to go to a restaurant with my partner that evening, and that I was aware that it was probably too much and contradicted ‘The System’. Following this, I again made an add-on note the following day.

> Trip 5 (next day note) – “After trip home met [my partner] to go for dinner and it was a disaster. Was really not feeling good brain-wise. Truly bleak and I am still feeling rough today. Don’t really know what to do with this beyond attempting to refine the approach and stick with it. Would hate people [not loved ones] to see me like that. Bleak.”

When in the chaos narrative, “the individual makes attempts to reassert predictability, but these generally fail and efforts have a cost for the individual (Whitehead, 2006: 2238). Despite the failure of my efforts, my notes suggest that I believed that I would still be able to reassert predictability if I successfully ‘refined the approach’. Elsewhere in the data, this process was repeated:

> “Trip 8 - Stupidly spent an hour on the way up reading stuff for a student that was totally beyond the call, and now not feeling great before the start [of the group]. Need to stick to the system.”

The data evidence Frank’s (2013) conceptualising of the disciplined body facing “its gravest crises” when it loses control (2013: 41). To cope, attempts are made to reassert control and “predictability through therapeutic regimens, which can be orthodox medical compliance or alternative treatment. In these regimens the body seeks to compensate for contingencies it cannot accept” (Frank, 2013: 41). For me this raises the question of whether I have accepted my injury. During one discussion on personal acceptance of brain injury (a common discussion topic in brain injury support groups) a group member suggested that - *Trip 5 - “I had [found acceptance] as I was doing the research”,* before asking me if *“I was ok now, which I said it depends how you look at it.”* An insight that this autoethnography has generated is that acceptance of my injury is itself complex and fluid. I have long since accepted that the injury happened, and I accept its impacts, seeing it as part of the deal under which I didn’t lose my life and was still able to live the life that I had wished for prior to my injury. It doesn’t feel so straight forward when I am struggling, and I find it hard to say that it has been worth it. Acceptance in my mind is literal, that I accept that it happened and that I have done my best since. In writing this autoethnography, I have also considered why I don’t frame my own recovery as a quest narrative. My response is that I find the quest-laden type of narrative and acceptance problematic as it leaves little space for critical engagement with a society that is disabling. I also believe that it would silence what endures. My fieldnotes were, however, written without any conscious framing. What is clear is that the data was produced in harsh reference to the essential qualities that I aspired to and the social roles that I was inhabiting. Engman (2019) provides an explanation as to why this was the case:

> "When we attend, consciously, to our own existence, we do not often linger on the capacities of the body. We simply see, we do not experience our eyes seeing; we simply walk, we do not experience our legs walking. When we do ponder ourselves, we think of ourselves in terms of essential qualities (honest, hard working, generous, etc.) or with reference to the social roles we inhabit (mother, teacher, friend, etc.)" (Engman, 2019: 122).

When I first employed 'the system', I aspired to be a hard-working patient who was recovering. During my research, I aspired to be a hard-working researcher. The chaos narrative, and harshness towards myself and my efforts emerged when I was ill, and/or failed to meet my perception of the idealised qualities and social roles.

Frank (2013) shared a view which I would strongly echo, that "the disciplined body is not a pleasant way to live" (Frank, 2013: 43). On my final fieldwork visit before the COVID-19 abruptly ended my data collection, I recorded the following fieldnote: *Trip 13 - "Did nothing on the way up [to the research site], felt better for it and much sharper… THE SYSTEM."* The counterpoint to the obvious problematic adoption of the disciplined body-type is that in my case it did produce a form of, however precarious, certainty and control, and led to some of the results (particularly in the rehabilitation phase following my injury) that I desired. I had been quoted a rough figure of a recovery window of two years by healthcare professionals and peers. I had difficulty accessing a physio, and so designed my own series of mostly self-appointed tasks to 'recover'. I struggled to read more than a few sentences at a time, as I got tired and struggled to remember what I had read. So, I set myself the task of daily reading of academic journals to aid my return to the access course. My sense of balance was poor so I decided that I would do keepy-ups (juggling with your feet) with a balloon as I could no longer do it with a football as I had before. I practiced (almost daily for over a year) touching the tips of my fingers with my thumb, repeating a neurological test I had been asked to do at a hospital appointment. I still do this when I am thinking or stressed to this day. In lieu of being able to lift weights I lifted tins of soup or equivalent to build muscle strength (an act of vanity in all likelihood). I carried out these tasks repetitively, despite seeing little progress and wanting to quit. Without this structure, I would have stopped, which in turn would have increased the cycle of negative thoughts that were prominent at the time. I returned to a form of the framework during my fieldwork as I thought I needed to, and in all likelihood, I would return to it again. It was my way of attempting to control the chaos, and, certainly in respect to my rehabilitation, I am proud of myself for finding a structure and largely sticking to it when I really struggling.

I follow in the footsteps of other disabled people who have embarked on an academic journey as disabled people, including as mentioned, people with a brain injury. Genetti (2023), described their own academic journey following brain injury and remarked that:

> "My dissertation became my journey of recovery – from the aftermath of a TBI and PTSD, which resulted in further disability, but also in posttraumatic growth. My journey of recovery became my dissertation. My new goals and my purpose became to finish my dissertation, not even understanding what that would entail" (Genetti, 2023: 220).

What my own journey from injury to this point entailed was messy, difficult, interesting, rewarding, and without pause since my return to the university access course 16 months post-injury. Identifying that my fieldwork and its embodied experience was a chaos narrative is one part of that journey and the process of understanding myself and what I have been through. My experience echoes Genetti (2023) in that the academic journey became my goal, and that I didn't understand what it would entail. My academic journey has similarly been the foundation of huge post-traumatic growth. What I have attempted to do in this chapter is by focusing on one specific area of my 'story' is to provide insight into my experience, which whilst specific to me, speaks to wider challenges faced by other 'wounded storytellers'. By focusing on that which I have tried to mitigate and hide - my embodied experience - I have aimed to provide insight into the conditions under which the production of knowledge within my thesis took place. My hope is that by being transparent, I now stand closer to my peers and participants. Furthermore, I hope that my work, in its own small way, is an act of resistance to the disabling society and its structures into which we are expected to fit in, and in doing so keep our voices and holistic experiences hidden.

12.6 Reflections and conclusion

Autoethnography is a method that brings with it unique issues for the researcher to consider, issues that stretch beyond matters that are methodological. Lawlor (2003) proposes that "the ethnographer must learn to be open to vulnerability and to negotiate the often ambiguous implications of a vulnerable stance" (Lawlor, 2003: 33). I would recommend that researchers consider the emotional impact of producing autoethnographic work. The use of the autoethnographic method has required the lowering of a mask to "reveal inner thoughts and experience" (Shiels et al 2022: 323). In my case it has realised "the possibility of seeing more of what we ignore in both ourselves and others," and encouraged me to question "why it is ignored, and what we might need to do about it" (Dauphinee, 2010: 818). The lowering of the mask has been emotionally challenging, and this chapter has probably been the most difficult piece of academic writing I have produced. Birk remarked that "While I can write with relative fluidity in the active voice when I discuss pain in abstract terms, I tend to shrink back into the passive voice and mangle my words wherever I speak about and from my body" (Birk, 2013: 397). My experience is similar as the relative comfort I have in academic writing disappeared when I began to mangle my own words and interrogate my own experience more deeply.

Adding in a specific section of 'embodiment' to my fieldnotes proforma and engaging critically with my embodied experience has brought a greater depth of reflexivity to my research practice. By going into this space, I have been able to see with more clarity how I engaged emotionally and subjectively to both my own self and a social environment (Ferrie and Greenwood, 2023: 5) increasing, as Ferrie and Greenwood (2023) point out, my confidence in my knowledge production and my work in the field. I also consider it important to share my story as evidence of the need to recognise and support disabled researchers, and indeed other researchers who face challenges and barriers to their work. In that respect my own experience can be useful to others and become dyadic rather than monadic, "part of a larger whole; each suffering person is called to that whole, as a witness to other sufferings" (Frank, 2013: 179). It has, therefore, been a transformative practice, as my injury, experienced as a private trouble, is now situated more as a public issue, and I contribute something of my own experience to the discourse.

By sharing and interrogating my embodied experience, I am providing some "insight into the messiness and complexity involved in qualitative research" (Ferrie and Greenwood, 2023: 2). By employing an autoethnographic approach, I add to the literature that engages with illness as "an experience of the ways that the features of illness interact with a subject's embodied orientation towards the world and with the life narrative that orientation gives rise to" (Engman, 2019: 127). Finally, by utilising Frank's conceptual framework of illness narrative, and laying bare my own chaos narrative, I have challenged conventional norms and narratives of illness, disability, and the researcher in the field. In doing so the:

> "Chaos narrative emerges as a challenge to the prescribed norm for illness and conventional narrative, refusing to conform to traditional forms that demand a narrative end with restitution or with the narrator-hero's transformation and delivery of the inspirational or educational boon-message to the audience" (Donnelly, 2024: 7).

Producing this work has led me to consider how I have changed and what I have learned about myself since undertaking the research, and what the future holds. The experience of carrying out the fieldwork, and the PhD more widely, has shaped my identity as a researcher. I am more confident in my ability as a researcher, feel a freedom in writing that wasn't there before, and believe that I have a bright future ahead. Alongside this, there persists an enduring uncertainty. This stems in large part from the precarity of managing the tensions that emerge from pain, fatigue and the demands of my work, and the reality that I continue to work often when ill and in pain. My ambition and pride contribute to this, but to be able to do things in life I want to like start a family and buy a house, I need to make money. It's possible that as I emerge from the PhD, my working environment becomes healthier, and I can balance the tensions better. Time will tell. I accept this, due in no small part to the increased agency I now enjoy due to the skills, experience and qualifications I am fortunate to have. Similarly to my acceptance of my own injury, I also accept that navigating my own chaos narrative was a price I have had to pay to get to where I am. Writing this on a Sunday morning where I am in relatively little pain and have an afternoon off to recover and do what I like, there is a troubling reality that undermines my neatly packaged conclusion. My private trouble is a public issue faced by many, and if funding cycles and working environments in fields such as academia (despite its claims to accessibility and inclusivity) maintain the status quo, chaos narratives will continue to be formed and ignored at some cost to the individual, and the knowledge that is consequently produced.

I conclude with a call to deepen sociological engagement with our bodies and our chaos narratives, and in doing so, to challenge societal erasure of our fluid and holistic experiences. Chaos narratives offer the promise of revealing hidden voices and engaging with, amongst other aspects, "what can rarely be heard: the unmaking of a person's world" (Frank, 2013: 103). By embracing these narratives and the people who tell them, we can build a more inclusive understanding of the diversity of experience of illness and reveal the spaces where our bodies become ‘square pegs’ in society’s disabling ‘round holes’.

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Appendices

Appendix 1 – Aims and objectives of the group

Our Aim is:

to promote understanding of all aspects of brain injury and provide information, support and services to survivors, their families and carers (in the [location] area)

Our objectives are:

- To support acquired brain injury (ABI) survivors in their recovery from cognitive, physical and emotional issues.
- To assist people with brain injury to lead as independent a life as possible
- To promote better assessment, rehabilitation and community socialisation
- To provide information and support for people with brain injuries, their relatives, carers and professionals
- To help promote partnership working with health services, social work and third sector organisations
- To increase awareness and understanding of brain injury to general public and its consequences through education
- To actively campaign to help reduce the number of people suffering brain injury

Appendix 2 – Consent form for participant observation

University
of Glasgow

College of Social
Sciences

Consent Form

Title of Project: Biographical Recovery: Recognising Multiple Barriers for Adults with an Acquired Brain Injury

Name of Researcher: Paul Pearson

1. I confirm that I have read and understand the Plain Language Statement for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I understand that my name will not appear in the thesis arising from this research.
4. The material will be treated as confidential and kept in secure storage at all times.
5. I am aware that the observations recorded and field notes will be retained by the researcher. These may be used in future research and publications.
6. I agree to take part in the above study.

Name of Participant Signature

Date

Name of Researcher Signature

Date

Appendix 3 - Plain language statement for participant observation

University of Glasgow

College of Social Sciences

Plain Language Statement

Project Title: Biographical Recovery: Recognising Multiple Barriers for Adults with an Acquired Brain Injury

Researcher: Paul Pearson

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

This study is being carried out to expand the understanding of how adults in Scotland with an acquired brain injury (ABI) experience, are informed of, and are supported in relation to their ABI in rural and under-served areas of Scotland. You are being asked to take part in this study as you have experience of this and currently attend a brain injury support group.

Over the next twelve months I will come along to the group and observe how the group functions. I will take notes based on this which will then be used as data for my research study. Whilst I would appreciate you taking part in the study, you are not required to. If you do participate but at any time you do not feel comfortable being part of the research, you are free to withdraw. I would still be present at the group, but would not write about anything that directly involves you.

After having collected all the necessary data, I will write my thesis, which will then be viewed by the staff at my university and potentially the wider academic and ABI community. Please note that confidentiality will be maintained as far as it possible, unless during my time with the group I observe anything which makes me worried that someone might be in danger of harm, I might have to inform relevant agencies of this.

I will retain all my notes in a secure location for possible use in the future. This would mean that the content could be published in the future in a separate publication. Your anonymity would be ensured as it is in the current research.

If you have any questions, do not hesitate to email me at p.pearson.1@research.gla.ac.uk. You can also contact my Supervisor from the University of Glasgow, Dr Jo Ferrie by email on Jo.Ferrie@glasgow.ac.uk or by telephone on 01413303175.

If you have any concerns regarding the conduct of this research project you can contact the College of Social Sciences Ethics Officer, Dr Muir Houston by email on Muir.Houston@glasgow.ac.uk

If you have issues with the research and would feel more comfortable contacting someone from [support group], please get in touch with [name], who is the Chair of the Board of Directors. His email address is XXXXX@XXXXX.com.

Thank you for taking the time to read this sheet.

Appendix 4 – Plain language statement for interviews

University of Glasgow

College of Social Sciences

Plain Language Statement

Project Title: Biographical Recovery: Recognising Multiple Barriers for Adults with an Acquired Brain Injury

Researcher: Paul Pearson

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

This study is being carried out to expand the understanding of how adults in Scotland with an acquired brain injury (ABI) experience, are informed of, and are supported in relation to their ABI in rural and under-served areas of Scotland. You are being asked to take part in this study as you have experience of this. If you agree to take part, I will ask you to attend 3-4 interviews that will aim to last around 60 minutes. These interviews will be held at the [research site]. I will also ask you to bring along any item that you feel would help you to talk about your life. This could be something like a photograph, or an old gig ticket. There is no requirement to do this and you can still take part in the interview without it.

Whilst I would appreciate you taking part in the study, you are not required to. If you do participate but at any time you do not feel comfortable being part of the research, you are free to withdraw. If you agree to take part, I will ask you to select a name that isn't your own to be used for when I write my thesis. This should help to ensure that anyone who takes part in the research will remain anonymous. This should also ensure that the reader will not be able to identify you.

After having collected all the necessary data, I will write my thesis, which will then be viewed by the staff at my university and potentially the wider academic and ABI community. Please note that confidentiality will be maintained as far as it possible, unless during our conversation I hear anything which makes me worried that someone might be in danger of harm, I might have to inform relevant agencies of this.

I will retain the transcripts (the word for word record of our interviews) in a secure location for possible use in the future. This would mean that the content could be published in the future in a separate publication. Your anonymity would be ensured as it is in the current research.

If you have any questions, do not hesitate to email me at p.pearson.1@research.gla.ac.uk. You can also contact my Supervisor from the University of Glasgow, Dr Jo Ferrie by email on Jo.Ferrie@glasgow.ac.uk or by telephone on 01413303175.

If you have any concerns regarding the conduct of this research project you can contact the College of Social Sciences Ethics Officer, Dr Muir Houston by email on Muir.Houston@glasgow.ac.uk

If you have issues with the research and would feel more comfortable contacting someone from [support group], please get in touch with [name], who is the Chair of the Board of Directors. His email address is XXXXX@XXXXX.com.

Thank you for taking the time to read this sheet.

Appendix 5 - Consent form for interviews

University of Glasgow

College of Social Sciences

Consent Form

Title of Project: Biographical Recovery: Recognising Multiple Barriers for Adults with an Acquired Brain Injury

Name of Researcher: Paul Pearson

1. I confirm that I have read and understand the Plain Language Statement for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I agree to the interview being audio recorded.
4. I understand that my name will not appear in the thesis arising from this research.
5. The material will be treated as confidential and kept in secure storage at all times.
6. I am aware that the data transcripts (the word for word record of our interviews) and the field notes will be retained by the researcher. These may be used in future research and publications.
7. I agree to take part in the above study.

Name of Participant Signature

Date

Name of Researcher Signature

Date

Appendix 6 - Participant observation proforma

1. Date, time, and place of observation

2. Specific facts, numbers, details of what happens at the site

3. Sensory impressions: sights, sounds, textures, smells, taste

4. Personal responses to the fact of recording fieldnotes

5. Specific words, phrases, summaries of conversations, and insider language

6. Questions about people or behaviours at the site for future investigation

7. Page numbers to help keep observations in order

8. Embodiment

Guide taken (and adapted to include embodiment) from Chiseri-Strater and Sunstein (1997).

Appendix 7 – Topic guide for interviews

Topic guide for interviews with participants with acquired brain injury (ABI)

It is my intention that the initial interview will contain a single question:

“Can you tell me about your life?”

Following analysis of the initial interview, following interviews will focus on the dominant themes that emerge from the first interview.