Seeking connectedness post-stroke: An existential perspective on lived experiences of working-age men using grounded theory

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Dedication

To the men who generously gave
their time to participate in this research
and courageously shared
their experiences and reflections.

Acknowledgements

My deepest gratitude is reserved for my participants. Their motivation to freely give their time was that others might benefit. I hope I have done this some justice.

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Statement of Authorship

This thesis is written by Barry Hannon and has research ethics approval from the New School of Psychotherapy and Counselling and Middlesex University. It is submitted in partial fulfilment of the requirements of the New School of Psychotherapy and Counselling and the School of Science and Technology at Middlesex University for the Degree of Doctorate in Counselling Psychology and Psychotherapy by Professional Studies. The author is solely responsible for the content and writing of the thesis, and there are no conflicts of interest.

Abstract

Stroke, or cerebral vascular accident (CVA), is a type of acquired brain injury (ABI). It is a leading cause of disability, with over 1.2 million survivors currently living in the UK. Age at onset has dropped over recent decades, with men at higher risk of having stroke at a younger age than women. The biomedical model is crucial for stroke survival. However, psychosocial factors in determining progress with rehabilitation have been increasingly recognised, along with stroke literature pointing towards the (less widely acknowledged) significance of existential factors. Ten male stroke survivors of working age with mild to moderate stroke-related impairments were recruited through noticeboard advertising at a branch of Headway (a leading ABI charity). Participant ages at onset of stroke ranged from 38 to 60 years, with time post-injury ranging from 1 to 10 years. Participants were individually interviewed using a semi-structured interview schedule. Analysis of the interview data was guided by grounded theory methods described by Corbin and Strauss. The theoretical model generated from the data outlines a process comprising three components: ‘experience’ of *enduring otherness*, which can lead to ‘outcome’ of *experiencing belongingness*, through ‘action’ of *seeking connectedness* (which was selected as the core category of the theoretical model). Furthermore, this process of seeking connectedness unfolds across four domains of lived experience; namely, the *physical*, *psychological*, *social*, and the *philosophical*, with each domain having dimensionality of *alienation vs. integration*; *acceptance-resignation vs. defiance*; *isolation vs. participation*; and *pointlessness vs. meaningfulness*, respectively. The model goes beyond the biopsychosocial perspective to include an existential viewpoint (under the philosophical domain). Rather than being diagnoses-focused, the model offers a framework for a formulation-based understanding of lived experiences and meaning-making for working-age male stroke survivors. Further work is required to ensure the validity of the model and its applicability to a wider stroke population.

Keywords: stroke, CVA, brain injury, ABI, grounded theory, GTM, lived experience, existential, counselling psychology, working age, men

Contents

List of tables and figures

Tables:

Figures:

Figures in appendices:

Acronyms and abbreviations

ABI:	Acquired brain injury
ACE-R:	Addenbrooke’s Cognitive Examination - Revised
BPS:	British Psychological Society
CVA:	Cerebral vascular accident (also known as stroke)
DCoP:	Division of Counselling Psychology
DoH:	Department of Health
GTM:	Grounded Theory Method
MoCA:	Montreal Cognitive Assessment
NAO:	National Audit Office
NHS:	National Health Service
NICE:	National Institute of Health and Clinical Excellence
RCP:	The Royal College of Physicians
SSNAP:	Sentinel Stroke National Audit Programme (run by RCP)
TIA:	Transient ischaemic attack (also known as ‘mini’ stroke)
UK:	United Kingdom
WHO:	World Health Organisation

Definition of terms

- *Stroke* refers to a 'brain attack' caused by a disturbance of the blood supply to the brain. See section *2.4 Aetiology and biological aspects of stroke* for a detailed review of the condition.
- *Working age* refers to adults under the age of 65 years.
- *Connectedness* is particularly associated herein with the pragmatic notion of continua of interwoven relatedness across four dimensions of lived experience; that is, the physical (*connectedness* with embodiment), psychological (*connectedness* with self), social (*connectedness* with others), and philosophical (*connectedness* with meaning).
- An *existential perspective* is a viewpoint underpinned by philosophical thinking about human existence, thus can draw upon a vast range of notions, concepts, and theories for understanding the human condition. It is based on fundamental assumptions that human beings need meaning and purpose; have capacity for freedom and taking responsibility for choices; inevitably face limitations and challenges in life; and that human experience is fundamentally embedded in relationships with others and the world.
- *Emotional difficulties* refers to lived experience of emotional responses to events or circumstances which, in turn, adversely affects levels of functioning.
- *Thrownness* is an existential concept that refers to the arbitrariness of circumstances that surround a person's existence in the world, which are beyond the person's control and are not of their choosing.
- The terms *patient* and *client* are used interchangeably, with the aim of reflecting the terminology originally used in the referenced material.

1. Introduction

> "*The emotional impact of stroke can be just as profound as the physical effects*" (Stroke Association, 2013, p. 10)

1.1 Overview

1.1.1 Locating the research focus

The manifestation of stroke is changing; with this change comes a need to reconsider approaches to rehabilitation after stroke. Over the last two decades advances in early stroke management have led to a marked decline in mortality, with most strokes being neurologically mild to moderate in nature (Cadihac, Purvis, Bernhardt & Korner-Bitensky, 2012). There has been a decrease in age at onset of stroke, and an associated increase in the number of stroke survivors who are alive long after stroke (ibid.). These changes in the stroke population have required a repositioning of stroke management, from the traditional thinking that stroke is an acute condition treated with a short intensive effort, towards rehabilitation over many years beyond the acute management which facilitates participation in work, family, and community life (Wolf, Baum & Connor, 2009). Moreover, it has been recognised that the traditional biomedical model commonly used in stroke management may contribute to frustration for both survivors of stroke and rehabilitation service providers (Siebens, 2011). Accordingly, support has grown for models of rehabilitation based on chronic disease management that incorporates outcomes meaningful to the stroke survivor, rather than assumed needs and outcomes as defined by rehabilitation professionals (Cadihac et al., 2012; Cott, Wiles & Devitt, 2007). This study argues that a revised approach on stroke survival, which recognises the stroke survivor as an important partner in the process of recovery, would benefit from an existential perspective. Towards that aim, this study uses an existential lens to construct a substantive theory to explain how male stroke survivors of working age deal with their emotional and psychological difficulties.

1.1.2 Structure of research report

The subsequent report of this research study is divided into a number of chapters as follows:

Chapter 1 - Introduction begins (with the previous section above) by familiarising the reader with the focus of the research project, before introducing and locating the researcher with respect to the topic under investigation, and clarifying the influence of counselling psychology within the project. The project is then further situated both with reference to current psychological treatment for stroke rehabilitation and regarding the profession of counselling psychology itself. Lastly, the case for an existential perspective on stroke rehabilitation is introduced and elaborated;

Chapter 2 - Literature Review draws upon the existing stroke-related body of knowledge to develop the arguments introduced in chapter one and to prompt questions pertinent to the current research project. The review outlines acquired brain injury, the aetiology and biology of stroke, and neuroplasticity and duration of organic recovery; before providing data on impact of stroke both globally and across the UK. Experience of stroke is considered in relation to age and gender, and effects of stroke on psychosocial functioning and social participation are reviewed along with the challenges of providing appropriate support for psychological issues and emotional difficulties. This is followed by a discussion of the emotional difficulties faced by working-age male stroke survivors, and a presentation of relevant male gender theories, some of which will be accordingly drawn into the analysis and findings of the current study, and the subsequent discussion. A critique of recent studies that shaped this current project is then presented followed by a rationale for adopting an existential lens for gaining additional understanding of experiences of stroke;

Chapter 3 - Aims and objectives further explicates the rationale for conducting the current study, highlighting questions that emerged from the review of the literature, and stating the research question and the aims and objectives of this project;

Chapter 4 - Methodology decribes the philosophical underpinnings to the research project, and provides a rationale for adopting a qualitative approach and the selection of each of the research methods used for answering the research question;

Chapter 5 - Research Procedures begins by presenting the considerations and adaptations for interviewing stroke survivors, then details the wider ethical considerations, outlines the sampling of the research population, and describes and discusses the procedures used in this study for recruitment, data collection, transcription, and data analysis;

Chapter 6 - Pilot Study provides initial findings from the data collected from a pilot interview with one research participant;

Chapter 7 - Analysis and Findings opens with a presentation of the participant demographics and characteristics. This chapter then goes on to introduce the substantive theoretical model which was generated from the analysis of the data. The components of the model are then reviewed in detail, alongside excerpts from participant interviews to illustrate how each component is grounded in and supported by concepts that emerged from the data;

Chapter 8 - Discussion is introduced with a brief overview of the chapter, which is immediately followed by an overview of the study findings, before the findings are discussed in the light of existing literature and wider bodies of knowledge, with particular reference to the grounded theory model that was developed. Next the significance of the study is considered, particularly with respect to the role of counselling psychology, the relevance of adopting an existential perspective, and the implications for clinical practice. The strengths and limitations of the study are then considered, leading to recommendations for future research. Finally, the author's response to the research is outlined, before presenting concluding remarks on the research project.

1.2 Introducing the researcher

This project has been conducted as partial fulfilment towards my qualification as a counselling psychologist. As required in the field of counselling psychology, I have trained in a variety of approaches for providing psychological treatment including cognitive behavioural methods, psychodynamic perspectives, and existential phenomenological theories and practices, among others. Naturally, I have sought to position this study in accordance with the philosophy and practice of counselling psychology, which in turn underpins my professional identity; as well as drawing upon my knowledge of different approaches to better understand implications for practice. Further discussion for locating this study within the current landscape of stroke rehabilitation, positioning the project with respect to the field of counselling psychology, and for introducing the need for an existential perspective on stroke rehabilitation is provided in the subsequent section: *1.4 Situating the study*.

With respect to the research design, the questions that arose from my reading of the literature relating to my chosen area of interest led me towards conducting a qualitative study. (Some additional reflections on this choice are provided within the next section that immediately follows: *1.3 Counselling psychology, qualitative research, and reflective practice*). Qualitative approaches demand an attitude towards research that is strongly underpinned by reflexivity. Indeed, Finlay (2009) further asserts that qualitative researchers recognise that they inescapably have an impact on the findings that are obtained; thus the aim is not to eliminate such impact, but instead to understand it and to explicitly acknowledge it. As the researcher of this project I had a pivotal role in the collection, selection, and interpretation of data, and undoubtedly I have had an unintended impact on all of these processes. For instance, my behaviour towards participants would have had some influence on their interview responses, and my prior life experiences and understandings will have affected how I observed and interpreted the data. In view of this, I have included a number of reflective sections in this thesis, providing some evidence of my reflexivity. These sections aim to help inform the reader about my own personal and professional experiences which might have influenced the choices that I made throughout this research project; and, more broadly, to assist with locating the researcher within each aspect of this project. With the aforementioned in mind, the rest of this section now concentrates on providing the reader with some context to my interest in the field of stroke survival.

My research focus in the area of lived experiences following stroke emerged out of a layering and coalescence of my own experiences over the last decade or so, which has culminated in this project aimed towards better understanding how men of working age deal with psychological and emotional difficulties post-stroke. These varied experiences relate to events in my personal life, my academic learning, and my voluntary activities during and since my time as an undergraduate psychology student; and most prominently, my clinical training across a variety of client groups and settings.

From the perspective of my personal life, I have observed consequences of stroke and traumatic brain injury following three unconnected tragic events that have befallen two unrelated family friends and one personal friend. When I was a teenager a family friend in his early thirties suffered a traumatic brain injury during a road traffic incident, which resulted in personality changes that I struggled to understand at the time. Then, approximately 10 years later, another family friend in his sixties who was seemingly the personification of health suffered a stroke which reduced his verbal communication to a few single words. I witnessed the consequences of brain injury for both these individuals, and personally found the impact it had on them deeply upsetting, and in different ways somewhat perplexing. However, I was most disturbed by the event of severe stroke suffered by one of my peers within a long-established social friends group. The stroke occurred in his late thirties, and the impact of his stroke resulted in a long recovery process which led to financial difficulties, marital breakdown, and disruption for his two school-aged children. It was this particular friendship that initially provided me with a greater insight into the utter confusion and sheer panic that can result from stroke, as well as the profound sadness of the circumstances that can often follow. Nevertheless, these experiences did not stimulate thoughts of pursing any related research at the time, but rather served to amplify my interest in this area at a later date once a focus had begun to emerge from my academic endeavours and clinical experiences.

My strong curiosity towards cognitive psychology and how brain functioning impacts on human experience truly began to surface while I was immersed in my studies and activities as an undergraduate psychology student. During this time, I was not only fortunate enough to secure work as a research assistant to Prof Alan Baddeley at the University of York, assisting with experiments investigating cognitive processes; but additionally, I was able to gain some rudimentary clinical experience while volunteering at The Retreat in York. The Retreat being a not-for-profit specialist mental health provider which works with the NHS to provide care for people with complex and challenging needs, including those arising from dementia and acquired brain injury.

However, it was much later, after gaining clinical experience in various settings and with different client groups that I became inspired to conduct my research in the area of psychological provision for stroke survivors. Indeed, I have worked in generalist settings with the general public, in a category ‘B’ men’s prison, in locked rehabilitation settings, and at a drug and alcohol service; but it has been my work with stroke survivors that at various times, I have found to be the most perplexing, the most challenging, the most haunting, the most humbling, and the most meaningful. Stroke strikes suddenly and without warning, and typically leaves the victims that survive with life changing injury. The challenges faced by survivors of stroke are immense. For me, Hinkebein and Stucky (2007) powerfully expressed the predicament of stroke survivors when they stated that “the very personal skills and resources necessary to cope with disability are the ones most undermined by their injury" (p. 389). And so, I have developed a passion for working with this vulnerable client group and have attempted to contribute something that might assist towards their psychological wellbeing, and recovery and rehabilitation.

Secondly, my experience of working with stroke survivors has highlighted for me how difficult and challenging it can be to facilitate psychotherapeutic gains for this client group. In the field of stroke rehabilitation within healthcare settings a strong emphasis is placed on assessing cognitive functioning and identifying deficits in the areas of memory, attention, motivation, language and perception. Outcomes from these assessments are routinely used to determine symptoms, diagnosis, and treatment plans (Wilson, Rous & Sopena, 2008). Yet, during my own clinical practice, I have noted that the difficulties resulting from stroke frequently involve more than just the functional aspects of recovery. Often my clients present with narratives of existential crisis relating to the *thrownness* of their post-stroke circumstances which are not readily addressed through the cognitive-behavioural approaches. Despite this, cognitive behavioural therapy is the established approach for addressing psychological difficulties in the field of neurorehabilitation. Hence, my clinical experiences have led me to wonder how an alternative approach to the cognitive-behavioural model may offer additional understandings into stroke survivors' difficulties, which in turn prompted me to contemplate whether an existential perspective would contribute to a more complete understanding for shaping therapeutic formulation, intervention, and outcome.

Consequently, I hoped that conducting this qualitative research project would further clinicians' understandings about the difficulties faced by stroke survivors throughout their recovery process, using an existential approach with a specific focus on males of working age. Indeed, I believed that the sudden, pervasive disruption to the life aspirations of working-age men, accompanied by unexpected impairments and disabilities, firmly warranted an existential perspective. As such, I hope that the findings from this research study will serve to further raise awareness of the existential issues encountered by this client group, and thus inform clinical practices.

1.3 Counselling psychology, qualitative research, and reflective practice

Counselling psychology espouses the principle of privileging the subjective experiences of clients over models of diagnosis, assessment and treatment; and advocates imaginative phenomenological methods for understanding human experience (Bury & Strauss, 2006). This research project, as with other studies underpinned by the philosophy of counselling psychology, not only considers the subjective meanings and impact of the research on the research participants, but explicitly includes reflections from myself as the researcher. Indeed, this reflexive attitude towards research is in accordance with my identity as a counselling psychologist engaging in reflective scientific enquiry. Additionally, Schwartz-Shea and Yanow (2012) remind us that “research design is about making choices and articulating a rationale for the choices one has made” (p. 2). Thus, as well as providing paradigmatic justifications for my decisions, I have sought to weave a reflective narrative within the fabric of this report to elucidate my impact on the research process and increase transparency about the subjective choices I made, which inevitably shaped the processes and outcomes of this research. Hence for clarity, sections of the report that are principally reflective have been written using the first person, whereas all other sections are written in the third person.

1.4 Situating the study

To elucidate intended contributions towards advancing existing knowledge a research project must be firmly situated within the current body of literature that relates to it; this contextualisation is provided in the next chapter, namely the *Literature Review*. However, prior to that, this section provides a broader context to the project in relation to the current landscape of post-stroke rehabilitation. It begins by highlighting a lack of provision for psychological treatment for stroke survivors, then considers the current role of counselling psychology in this domain, before introducing the notion that an existential perspective might have something to contribute towards clinical practice in this field, and ends with a tentative assertion that understanding stroke survivors’ difficulties from an existential perspective has benefits for informing clinical practice.

1.4.1 Psychological provision in stroke care

An obdurate lack of adequate provision for psychological support for stroke survivors persists in both acute and community settings, despite strategic policies and authoritative calls for action across the recent decades. It was back in December 2007 that the Department of Health published its ten-year *National Stroke Strategy* (DoH; 2007) for raising the quality of stroke prevention, treatment, care and support. The strategy recognised that “people who struggle to adjust to the longer-term effects [of stroke] . . . need access to emotional support services” (p. 43), and asserted that “services need to develop long-term psychological and emotional support, with co-ordinated programmes starting with psychological support in hospital and longer-term support involving the voluntary sector” (p. 43). Despite these aspirations, there was apparently little progress in the immediate years that followed, with the National Audit Office (NAO; 2010) reporting an ongoing widespread lack of provision of psychological care after stroke. This concern was echoed in Tony Rudd’s foreword for the National Sentinel Stroke Audit 2010, which highlighted the intractable nature of the problem: “we have written about the poor levels of psychology provision in nearly every report since the audit started [in 1998] with little effect” (Rudd, 2010, p. 4). Indeed, the audit went on to report that less than half of all stroke units have access to psychological support (Henssge et al., 2010). Fast forward a further seven years and, with the ten-year National Stroke Strategy nearing its end, there was no doubt acute stroke care comprises significantly better medical interventions; better staffed units; shorter length of stay with rapid transfer to early supported discharge (ESD); and better outcomes, certainly for ischaemic stroke, for 30-day mortality and disability (Tyrrell, 2016); yet the shortfall in psychological provision for stroke survivors still remained. Indeed, the fifth edition of the *National Clinical Guideline for Stroke* (2016; prepared by The Intercollegiate Stroke Working Party) reaffirmed the unresolved need to provide psychological care for stroke services across acute and community settings, even though “national audits continue to highlight inadequate service provision” (Bowen, James & Young, 2016, p .25). Additionally, the report further underlined the need for better provision beyond the acute phase of recovery, noting that “surveys of the long term needs of people with stroke echo the need for service improvement” (ibid.). Disappointingly, more recent auditing continues to expose a gaping hole in psychological provision, with only 6% of hospitals having access to sufficient clinical psychologists; coupled with dubious reporting which claims only around 6% of stroke patients need psychology, which is not consistent with published literature or the self-reported long-term unmet needs of stroke survivors (SSNAP, 2018).

1.4.2 Stroke rehabilitation and counselling psychology

With authoritative reporting highlighting a chronic lack of adequate psychological provision for stroke survivors, it might understandably prompt questions about the role played by counselling psychology in this field. However, it is difficult to accurately determine the current role played by counselling psychology across physical health settings (Davies, 2016), much less its contribution to stroke rehabilitation. Nevertheless, it does seem reasonable to assert that counselling psychologists are now well established in clinical roles across the NHS and in the private and third sectors across different services. Some years ago, a survey of employment of counselling psychologists in the UK (undertaken by the British Psychological Society's Division of Counselling Psychology) revealed that 58% of respondents were working in the NHS or NHS-funded organisations (DCoP, 2011 cited in Davies, 2016), which supports earlier estimates that between 40% and 50% of all counselling psychologists in the UK work in the NHS (Walsh, Frankland & Cross, 2004). Though, as Davies (2016) points out, it is likely that a substantial majority are working in mental health as oppose to physical health settings. With scant evidence of counselling psychology research and practice being undertaken in the field of stroke rehabilitation, this certainly appears to be one area where counselling psychology is yet to develop its influence. This situation has been highlighted by Cheng (2014) who suggested that a predominance of the biomedical model, psychopharmacological treatments, and functional assessment-led interventions may adversely influence counselling psychologists' decisions about entering this particular field. Equally, the principal focus on neurological assessment and physical and cognitive recovery lends itself to clinical approaches; such approaches do not readily align with the philosophy of counselling psychology which eschews the use of medical terms to pathologise human suffering, and instead seeks to emphasize human potential and wellbeing (Strawbridge, 2016). Nonetheless, as Cheng (2014) asserts, counselling psychologists can contribute an additional perspective to the medical model by foregrounding the benefits of a client-centred approach, individuality, and reflective practice, thus providing a different way to conceptualise clients' difficulties. This notion is reflective of both the ethos of counselling psychology and Walsh's et al. (2004) understanding of how counselling psychologists endeavour to influence the medical language and mechanistic approach of psychiatry and mental health by working from within an organisation.

1.4.3 Existential perspective on stroke survival

Indubitably, surviving stroke and minimising injury to the brain is reliant on the biomedical approach; and cognitive and functional assessments are imperative for directing rehabilitation and adaptations for supporting residue functioning. Nevertheless, in recent decades, focus has broadened from the traditional emphasis on physical recovery to include consideration of emotion and identity reconstruction, and attention given to how survivors of brain injury might return to meaningful activities despite cognitive and behavioural difficulties (Salas, 2012).

It follows that the nature of post-stroke experience, as such, can be described as a biopsychosocial phenomenon, with organic injury resulting in impairments of functioning and psychological difficulties, which in turn impact upon social participation, with changes in participation contributing to disrupted functioning and emotional disturbance. Indeed, the renowned *'Y-shaped' model of the rehabilitation process* (Wilson, Gracey, Mallery, Bateman & Evans, 2009) is itself predicated on a biopsychosocial perspective towards brain injury; so-called as the converging lines of the *V* at the top of the *Y* represent discrepancy and process of resolution between pre- and post-injury self. The model proposes a process of adaptation and reintegration following brain injury relating to intrapersonal, interpersonal, and societal relations. It emphasizes change with respect to resolving discrepancies in the psychological domain (including meaning, identity, understandings, and expectations) and in the social domain (including roles, activities, context, interactions, and relationships). Central to the model is the notion of experience of *self under threat* or discrepancy, and the application of the principles of behavioural experiments (Bennet-Levy et al., 2004) for goal attainment and achieving an updated, adaptive, realistic self-representation.

Pointedly, Gracey, Evans and Malley (2009) equally advise that experience of *self under threat* can lead brain injury survivors to adopt coping strategies that may moderate threat in the short term, but obstruct resolution of discrepancies and result in poor psychosocial outcomes. Certainly, during my own clinical practice, it is common for stroke patients to report engagement in maladaptive cognitions and behaviours, such as wishful thinking, increased alcohol use, and avoidance of social situations. Similarly, I have been struck by how often patients' narratives reflect the Y-shaped model's notion of *self under threat* with statements along the lines of: '*I just want the old me back*'; '*I don't know who I am anymore*'; and '*How can I have any goals if I don't know who I am?*' In my clinical experience, the frame of reference that emerges from these narratives inevitably hinders patients' engagement with goal-focused approaches. It is at this intersection in the rehabilitation process, between prevailing goal-focused CBT interventions and patients' experience of *self under threat*, that introducing and applying an existential lens to the phenomenon of life post-stroke seems particularly pertinent.

The existential perspective focuses on concerns rooted in every individual's existence, including death, freedom, existential isolation, and meaninglessness (Frankl, 1946/2004; Yalom, 1980). Threat of feared and actual catastrophic meanings associated with the post-injury circumstances can be readily conceptualised using theoretical constructs, such as freedom, meaning, choice, purpose, values, responsibility, and appreciation of the unique experiential world of each individual. Furthermore, the existential approach seeks to inspire clients to transform personal despair and suffering into meaningful fulfilment as better human beings (ibid.). In this regard, given the anguish and the uncertainty of their post-injury existence, especially with respect to the notion of *self under threat*, the relevance of applying an existential perspective to post-stroke difficulties starts to become apparent (Klonoff, 2010).

1.5 Summary

This chapter has provided an overview of the current research project and situated it with respect to the development of provisions for stroke recovery and rehabilitation. It established this study within the field of counselling psychology, and introduced the relevance of an existential perspective for providing an additional understanding about stroke survivors' experiences.

The next chapter goes on to further develop a rationale for conducting this study. Indeed, a review of existing literature and research was conducted, focused on relevant areas of interest discussed in this current chapter. The review aimed to build potential directions of enquiry, critically advance arguments for this research project, and further locate this study within the research area of stroke survival. The results of this review have been outlined in the chapter that now follows.

2. Literature Review

> *"The literature review is one of the most important parts of any piece of academic writing. It is rather like the foundations upon which the rest of the work is built."* (Oliver, 2012, p. 1)

2.1 Introduction

This chapter presents a review of the literature deemed most salient to the research area of this study, that is, psychological provision for stroke survivors. Based on an unbiased selection of sources, the review aimed to critically situate the nascent rationale for this study (which was introduced in the previous chapter) within the existing literature. Moreover, the review sought to perceptively and analytically develop this rationale, and lay the foundations for advancing research questions grounded on gaps in the existing body of knowledge (Jesson, Matheson & Lacey, 2011).

The review outlines the methodology used for searching the literature, what the broad literature on stroke currently comprises, and decisions about inclusion and exclusion of particular literature and specific studies. Key aspects that emerged from the literature are then discussed and evaluated under headed sections, outlined as follows: the first five sections provide an overview of acquired brain injury, aetiology and biological aspects of stroke, neuroplasticity and duration of organic recovery, prevalence and economic costs, and differing experiences of stroke due to the demographics of age and gender; having provided some background on the impact of stroke within the UK, the next four sections shift attention towards the negative consequences of stroke for psychosocial functioning and social participation, and complexities of providing support for psychological issues and emotional difficulties, with specific consideration of male stroke survivors of working age; following this, there are two sections that critique and summarise recent studies particularly relevant for contextualising and shaping this current project; lastly, there are two sections that provide rationales for adopting an existential lens for further understanding the experience of stroke, and utilising *The Four Worlds* model as a theoretical framework for achieving this. The subsequent chapter, *Aims and objectives*, then goes on to state the research questions for this current study.

2.2 Methodology for reviewing the literature

This section outlines the methodologies, methods, and criteria used for conducting the literature review, outlining the search strategy, the reading approach, and the criteria for selecting or excluding material.

The literature available at Middlesex University was searched using the *Summon* search engine; which provides a Google-type search facility with coverage across all the academic resources available to the university, such as journal articles, books, newspaper articles, and academic databases. At the time of the review, the university had access to 31 academic databases, including CINAHL, Cochrane, Index to Theses, PsychINFO, Medline, NICE Evidence, and OVID Full Text Journals. All academic resources were searched, however, a list of the 20 databases considered most relevant for this study is provided in *Appendix 1*.

To keep the search of the literature appropriately focused towards the current study, the inclusion criteria aimed to capture scholarly and peer-reviewed items, written in the English language, from 2005 onwards, identified as primary research directly related to stroke survivors' subjective experience of emotions. The basic strategy adopted for the search itself is commonly referred to as *building blocks*, which allows for each search set to be reused and facilitates development of themes, as opposed to the *successive fractions* approach which incrementally adds to the set to form the final search criteria potentially providing more focus but less flexibility (see Markey, 2015 for a comprehensive review of search strategies).

The literature was initially searched using the broad subject term of *stroke* which yielded 111,044 hits. A review of the retrieved terms revealed that the existing literature relating to stroke is predominately focused towards the medical model of risk assessment, prevention, diagnosis, neuroscience, and treatment. The subject areas included the following (reported with the number of related articles in brackets): risk factors (11,283), aetiology (10,905), prevention (5,107), clinical neurology (24,447), surgery (7,527), drug therapy (5,818), pharmacology & pharmacy (3,453), clinical trials (4,162), mortality (11,388), diagnosis (6,700), pathology (5,001), peripheral vascular disease (16,664), and thrombolysis (3,837). Whilst the subject areas relating to psychosocial factors and rehabilitation included: age (5,739), female (2,924), male (3,278), rehabilitation (11,303), psychology

(2,709), and therapy (5,468). Subsequent searches all included the subject term of *stroke*, constituting a *Most Specific Facet First* search strategy (Markey, 2015).

The next search narrowed the focus by adding the subject term of *emotion* which yielded 372 hits grouped under 28 disciplines, with 81 articles relating to psychology. These 81 articles were further narrowed down by reading the abstracts and assessing their relevance to the area of this study. Similarly, another search narrowed focus of the initial search term *stroke* by adding the subject term of *experience* which yielded 1,640 hits grouped under 34 disciplines, resulting in 94 articles relating to psychology, public health and nursing (when excluding terms relating to the medical model, such as cancer, cardiovascular disease, medical research, and diagnosis). These 94 articles were also reviewed for relevance to the current study. Relevance was evaluated using the researcher's tacit knowledge of the research area, the knowledge gained from the review of the literature, and supervisory guidance.

Hence, the initial strategy cast a wide net across the literature relating to stroke, before narrowing the focus of the search around theories, concepts, and findings relating to the specific research area. This focus was further developed by adopting strategies from the *snowball* approach (Ridley, 2012) and the *berry-picking* model of information retrieval (Bates, 1989), whereby other relevant literature was identified from the bibliographies of the retrieved material from the aforementioned online searches, as well as drawing on the researcher's prior knowledge to search for authors in the field.

To facilitate efficient reading of the vast quantity of literature identified the researcher adopted the *SQ3R* framework (*Survey*, *Question*, *Read*, *Recall*, *Review*), a procedure commonly recommended (e.g., Jesson et al., 2011; Ridley, 2012; Robinson, 1978). This approach encompasses three different types of reading: firstly, *survey* or skim read the text to gain an outline of what is being presented; secondly, *question* the content actively and look for answers; thirdly, actively *read* based on the previous background work to answer questions and make connections; then *recall/recite* from memory what has been learned; and finally *review* to ensure understanding and that nothing has been overlooked.

Once the pertinent literature had been found, the principles of thematic analysis (McLeod, 2011) were broadly applied for the purposes of identifying, drawing out, explaining, interpreting, and evaluating key areas that emerged from the literature. These areas were structured into a thick descriptive narrative that presented an account of the literature that related to the focus of the current study. This account is provided in the sections that follow.

2.3 Overview of acquired brain injury (ABI)

Acquired brain injury (ABI) is an ‘umbrella’ term for all situations where brain injury is not congenital and is not degenerative (Coetzer, 2006). ABI can be broadly divided into two categories, namely traumatic brain injury (TBI) and atraumatic or non-traumatic brain injury. TBI is caused by trauma to the head. Many possible causes can result in TBI such as road traffic incidents, assaults, falls, accidents at work or at home, and sports-related injury (Goldsmith, 2014). Other traumatic brain injuries can result from asphyxia, often referred to as hypoxic or anoxic injury, which can be caused by events such as hanging or strangulation, drowning, smoke inhalation, respiratory or heart failure, very severe asthma attack, carbon monoxide poisoning, among others (Silver, McAllister & Yudofsky, 2011). Brain injury can result from neurotoxins including carbon monoxide poisoning, poisoning by solvents, metals, drugs, and pesticides (Lowings & Wicks, 2016). Additionally, extreme chronic alcohol intake can cause deficiencies such as Korsakoff’s syndrome which results in severe loss of memory through lack of vitamin B or Thiamine (Freund, 1985; Lowings & Wicks, 2016). Atraumatic brain injuries can occur following infection or disease that affect the brain potentially causing lasting injury. Such illnesses include encephalitis, tumours, and stroke. Encephalitis results in inflammation throughout the brain destroying neurons and their networks. Early diagnosis is important to reduce long-term damage. Encephalitis can be caused by a virus, including the Herpes-Simplex virus, or alternatively by an erroneous attack by the immune system (Bloom & Morgan, 2006). Tumours, both malignant and benign, cysts, and abscesses can all restrict the flow of cerebrospinal fluids and the supply of oxygen, as well as damaging neural networks (Coetzer, 2006; Lowings & Wicks, 2016). Stroke is an interruption of blood flow to the brain due to either bleeding from a blood vessel or a clot in a blood vessel (Grader & Bateman, 2017).

Headway, the brain injury association, is one of the leading UK charity organisations for providing rehabilitation services to individuals with brain injury. Headway has led the way in compiling statistics on ABI-related admissions to hospital, using hospital admissions data (based on financial years, which run from 1st April to 31st March). Their most recent report for the financial year 2016-2017 indicated that there were 348,453 ABI-related hospital admissions across the UK, which equates to 531 admissions per 100,000 of the population (Headway, 2018). The report highlighted that since the financial year 2005-2006 there had been a 10% increase in admissions; that men are 1.5 times more likely than women to be admitted for head injury; and that in the financial year 2016-2017 there were 132,199 admissions for stroke, which equates to one stroke every four minutes.

2.4 Aetiology and biological aspects of stroke

Stroke or cerebral vascular accident (CVA) can be defined as the “sudden loss of blood supply to a region of the brain leading to permanent tissue damage” (Robinson, 1998, p. 3). An interruption of blood flow to the brain resulting in stroke can be caused due to either haemorrhage or thrombosis (Lowings & Wicks, 2016). Haemorrhagic stroke results when a weakened blood vessel bursts and bleeding occurs, either within the brain which is known as an intracerebral haemorrhage, or between the delicate layers of the brain referred to as subarachnoid haemorrhage (ibid.). The other main type of stroke, which accounts for 85% of all incidence, is thrombosis or ischaemic stroke where blood supply is blocked due to a blood clot forming either in the small vessels deep within brain or an artery leading to the brain (Meyer, 2016). Ischaemic strokes can be categorised as follows: large-artery atherosclerosis, referring to a clot from the arteries; cardioembolism, referring to a clot from the heart; small-vessel occlusion, referring to a narrowing and weakening of blood vessels; stroke of other determined aetiologies; and stroke of undetermined aetiologies (Warlow et al., 2008). Transient Ischaemic Attack (TIA) is a related condition whereby blood supply to the brain is temporarily interrupted causing a ‘mini stroke’, which can result in stroke-like symptoms which typically only present for a short duration of up to 24 hours (Pendlebury, Schulz, Malhotra, Rothwell, 2012). However, early assessment and treatment after onset of TIA is important as there is very high risk of full stroke in the weeks that follow; indeed, TIA is considered a prodromal syndrome of ischemic stroke, with between 15% to 30% of ischaemic stroke patients having a history of TIA (Lindley, 2017; Uchiyama, 2014; Warlow et al., 2008).

There are many known risk factors for stroke, such as prior stroke or TIA, heart disease, and carotid artery disease. Broadly, risk factors can be categorised into risks that can be addressed and those that cannot. Risk factors that can be reduced include medical conditions, such as hypertension, diabetes mellitus, atrial fibrillation, high plasma cholesterol; and lifestyle factors, including cigarette smoking, excessive alcohol intake, unhealthy foods, lack of exercise and obesity. Risk factors that cannot be addressed include age, ethnicity, family history of stroke, and genetic conditions (Lindley, 2017; Warlow et al., 2008).

When a stroke occurs, the neurons at the location of the injury die within minutes, releasing free radicals that destroy neurons in the surrounding area, thus any delay in treatment can result in an increasing rate of brain damage (Chan, 1994; Flamm, Demopoulos, Seligman, Poser & Ransohoff, 1978). The consequence of stroke depends on the areas of the brain affected and the extent of the damage. For instance, left-hemisphere stroke can result in problems with speech, with damage to one hemisphere often resulting in paralysis or weakness in the opposite side of the body, known as hemiplegia or hemiparesis respectively (Gillen, 2016). Other physical consequences can include reduced mobility, loss of sensation, hearing impairment, visual difficulties, loss of sense of smell and taste, balance problems, dizziness, headaches, fatigue, and sexual dysfunction, among others (Barton, 2007; Henshaw, 2007). In addition to physical difficulties, stroke can result in cognitive impairment of executive functioning such as multi-tasking, planning, organising, and problem solving (Merino & Hachinski, 2013). Other cognitive impairments can include memory deficit, speed of information processing, perceptual and visuospatial ability, receptive and/or expressive language difficulties, and reduced insight (Harvey, Stein, Winstein, Wittenberg & Zorowitz, 2015; Patel & Birns, 2015). Furthermore, the negative impact on emotional regulation can cause distress such as anger, frustration, low mood, depression and anxiety (Barton, 2007; Park, 2017).

2.5 Neuroplasticity and duration of organic recovery

Neuroplasticity refers to the brain’s potential ability to develop, modify, strengthen, and adjust neural pathways in response to internal and external stimuli (Grafman, 2000; Kolb & Whishaw, 1998; Mateer & Kerns, 2000). Although the capacity for neuroplasticity is most evident during development, the brain remains malleable throughout one’s lifetime; manifestly, we can learn and remember information long after maturation. And though at one time the field of neuropsychology assumed that the brain was hard-wired following development, it is now well-acknowledged that changes in neurons and their structural and functional networks continue to occur during lifespan in response to learning and experience (Pascual-Leone, Amedi, Fregni & Merabet, 2005). Notably, neuroplastic changes can be both adaptive (positive) or maladaptive (negative) for the individual (for a wider discussion on the typology of adaptive and maladaptive coping post-stroke, refer to section *2.10 Coping typology post-stroke*).

Following brain injury there is evident variability in patterns of cognitive recovery from one individual to another, depending on a number of factors; but most notably, the severity and location of injuries to the brain. Complete return to premorbid functioning is extremely rare; the vast majority of survivors of brain injury present with some form of lasting impairment for which they need to learn to compensate (Himanen et al., 2006; Hoofien, Vakil, Gilboa, Donovick & Barak, 2001; Ruttan, Martin, Liu, Colella & Green, 2008). The greatest rate of recovery tends to be in the first 5 months post-injury (Christensen et al., 2008; Chu, Millis, Arango-Lasprilla, Hanks, Novack & Hart, 2007; Dikmen, Reitan & Temkin, 1990). The point of plateau of cognitive recovery varies across studies and individuals, but cognitive recovery typically plateaus between 6 to 18 months post-injury for most individuals (Ruttan et al., 2008).

Some individuals continue to show improvements in cognitive functioning beyond the initial two years post-injury, albeit at a slower pace (Millis et al., 2001; Van Zomeren & Deelman, 1978); with improvements in functioning seen up to ten years post-injury (Sbordone & Long, 1996). Indeed, neuropsychological recovery may continue several years after injury with substantial recovery (Millis et al., 2001), and studies have shown very long term psychosocial outcome following serious head injury may be better than expected from data reported at earlier stages of recovery (Wood & Rutterford, 2006).

2.6 Prevalence and economic costs of stroke

Stroke led to 6.24 million deaths worldwide in 2015, equating to over 11% of all deaths globally (WHO, 2017a). As a leading cause of death, stroke was second only to ischaemic heart disease, which accounted for 15.5% of all fatalities across the globe (ibid.). In the UK itself, incidence rates of stroke exceeded 100,000 in

2015 (SSNAP, 2015a) and accounted for over 40,000 deaths (ONS, 2016), making stroke the third single leading cause of death in the UK (SSNAP, 2015a). However, whilst stroke still accounts for 7% of all deaths in the UK today, figures have shown a recent reduction in stroke-related fatalities by almost 26% (ONS, 2016; NRS, 2016; NISRA, 2016). This reduction reflects a trend from 1990 to 2010 where stroke mortality rates in the UK decreased by roughly 46%, whilst incidences of stroke only fell by approximately 19% (Feigin et al., 2014). The implication is the prevalence of stroke survivors has been increasing steadily over recent decades. Indeed, from 2005 to 2015 the total prevalence of the post-stroke population throughout the UK increased by 28%, such that there are now over 1.2 million stroke survivors living in the UK (NHS Digital, 2016; Welsh Government, 2016; ISD Scotland, 2016; DoH, 2016). With more people surviving stroke than ever before (Feigin et al., 2014), stroke remains a leading cause of disability in the UK, with almost two thirds of survivors leaving hospital with a disability (Adamson, Beswick & Ebrahim, 2004). Indeed, in England alone there are over 900,000 stroke survivors living with moderate to severe disabilities (NICE, 2013). What is more, the number of stroke survivors in the UK is expected to more than double in the next 20 years (Patel et al., 2018).

From an economic perspective, the cost of stroke is considerable; and, against the background of the UK’s ageing demographic, is certainly set to increase yet further. Back in 2009, the total annual cost of stroke to society was estimated at almost £9 billion across the UK as a whole (Saka, McGuire & Wolfe, 2009; National Audit Office, 2010). This estimate included the direct cost of £2.8 billion to fund NHS care for sufferers of stroke, which increased to approximately £4.38 billion when the total costs of health and care were factored in: with costs of the informal care for stroke survivors provided by their families, estimated at £2.42 billion; indirect costs to the wider economy, believed to amount to £1.33 billion in lost productivity (as a result of care, disability and death); and benefit payments which accounted for a further £841 million. A decade later, conservative estimates of total societal costs have ballooned to £18 billion, with expectations of costs doubling again by 2025 (Patel et al., 2018).

2.7 Age and gender relating to stroke

Just over one in four strokes in the UK now occur in people of working age (SSNAP, 2017; Stroke Association, 2018), suggesting the traditional view of stroke as predominately a disease of older adults is outmoded. Nevertheless, the bulk of the extant research concentrates attention towards incidence, effects, treatment, and outcomes for stroke in older adults. What is more, the studies that have focused on stroke in working-age adults underline the need to understand this experience in quite different terms to those applied to older sections of the population (Alaszewski & Wilkinson, 2015). For example, a Luxembourg study of 94 stroke survivors observed that retired survivors had better self-rated life satisfaction compared to survivors of working age (Baumann, Couffignal, Le Bihan & Chau, 2012). Indeed, younger stroke survivors face the prospect of managing post-stroke consequences for a greater proportion of their lives, and contend with difficulties that arise with their ability to engage in paid work, perform parental responsibilities, and plan for the future (Daniel, Wolfe, Busch & McKevitt, 2009; Kersten, Low, Ashburn, George & McLellan, 2002; Lawrence, 2010).

Similarly, gender differences in stroke prevalence and mortality seem equally complex. Figures from 2006 show incident rate of stroke across the UK was higher in women than men, with 1 in 5 women compared to only 1 in 6 men suffering stroke by the age of 75 (Seshadri et al., 2006). However, significantly more women than men suffered strokes after the age of 85 years (due to longer life expectancy in females), with stroke incidence rate higher for men than women in most other age groups (Reeves et al., 2008). Indeed, men tend to experience stroke at a younger age than women (Green & King, 2007). However, over a six-year period, from 2006 to 2012, incident rate of stroke in men increased by 9% compared with a 3% increase for women, and for the first time this century more men than women suffered stroke across the UK (Headway, 2015), with men at higher risk of stroke, as well as at a younger age, compared to women (SSNAP, 2016b; SSNAP, 2017; Townsend et al., 2012). In addition, epidemiological studies, mainly based on Western European surveys, indicated that stroke is more common in men than in women (Appelros, Stegmayr & Terént, 2009). However, national data has shown that more men than women survive stroke, with 23,060 cases of female mortality compared to 16,224 cases of male morality (ONS, 2015; GROS, 2014; NISRA, 2015). These circumstances indicate a greater number of men living with consequences of stroke at a younger age than women in the UK today. Indeed, NHS data show during 2014 there were 6,221 hospital admissions in England for men aged between 40 and 54 who had suffered stroke, representing a rise of 1,961 cases over the previous 14 years (Mundasad, 2015). Notably, this 46% increase in incidence rate of stroke in men of working age occurred against an overall increasing trend of only 9% in the total incidence rate of stroke across the UK from 2005 to 2014 (Headway, 2015). Given these findings, further investigation into the lived experiences of stroke survivors of working age seems justified for better informing practitioners in the field of neurorehabilitation about the difficulties, challenges, and choices that these individuals are faced with.

2.8 Psychosocial impact of stroke

The psychosocial consequences of stroke are multifaceted and wide-ranging, and include significant and ongoing implications for mood, identity, social relationships, return to work and quality of life (Kirkevold, Bronkena, Martinsen & Kvigne, 2012). Stroke is a leading cause of adult disability in the UK (Adamson et al., 2004; Bhatnagar, Scarborough, Smeeton & Allender, 2010), with almost two-thirds (65%) of survivors leaving hospital with some form of disability (Stroke Association, 2018). Indeed, stroke is the most common cause of severe adult neurological disability and impacts more individuals in terms of disability than any other chronic disease, as well as being the largest cause of complex disability (Adamson et al., 2004; SSNAP, 2015b). In cases of stroke, individuals can experience changes in their functional ability, such as impaired speech, cognitive deficits, and reduced mobility, as well as experiencing difficulties with emotional functioning, social participation, and community integration (Barton, 2007; Gillen, 2016; Henshaw, 2007; Park, 2017; Patel & Birns, 2015). Behavioural, emotional and cognitive difficulties are all very common following stroke, and these difficulties inevitably have a considerable bearing on everyday life functioning and quality of life (Hackett, Yapa, Parag & Anderson, 2005; Park, 2017).

Following stroke many individuals are left feeling emotionally and physically overwhelmed. Over half of the survivors suffer the effects of stroke-related fatigue for years afterwards (Glader, Stegmayr & Asplund, 2002; Michael, 2015), with 24% of survivors suffering extreme fatigue, and a further 33% of survivors having to deal with moderate levels of fatigue (Lerdal et al., 2011). Approximately 20% of survivors experience emotional lability during the first six months, with half this number still experiencing the symptoms one year post-stroke (Hackett, Yang, Anderson, Horrocks & House, 2010). Furthermore, many survivors have described some loss of identity (Anderson & Whitfield, 2013), and a growing body of research is establishing that brain injury can have negative consequences for self-concept (e.g., Cooper-Evans, Alderman, Knight & Oddy, 2008; Gracey et al., 2008; Howes, Benton & Edwards, 2005; Nochi, 2000; Shuttleworth, Wedgwood & Wilson, 2012; Vickery, Gontkovsky & Caroselli, 2005).

Additionally, the consequences of stroke are likely to adversely impact mental health, with a third of stroke survivors experiencing post-stroke depression and almost as many reporting symptoms of anxiety (Barker-Collo, 2007; Hackett et al., 2005). Indeed, a survey conducted by the Stroke Association (2013) found that 67% of respondents had experienced anxiety and 59% felt depressed following stroke. The survey, which yielded over 2,700 responses, aimed to better understand the emotional impact of stroke on survivors' lives. Findings highlighted that emotional impact of stroke was particularly evident for those aged between 30 to 59 years, with 76% of this age group reporting high levels of anxiety, 69% reporting depression, and 55% fear of another stroke. This age group also fared especially poorly with partner relationships, with 61% reporting difficulties; and 44% reporting breakdowns, or imminent breakdowns. Other findings underlined further psychosocial concerns experienced by stroke survivors, indicating 73% of all respondents lacked self-confidence, 55% felt unable to care for family in the manner as before, and 56% felt friends and family treated them differently. Moreover, 44% of stroke survivors reported that they found it difficult to talk about their stroke and its effect on their lives.

The aforementioned difficulties can negatively impact a stroke survivors' inclination or ability to participate in activities, social events, and interpersonal relationships. For instance, stroke survivors typically characterise their experience of emotional lability as not only distressing, but also socially disabling (House, Dennis, Molyneux, Warlow & Hawton, 1989). Indeed, stroke survivors often report difficulties with social participation and feelings of being socially isolated (Haun, Rittman & Sberna, 2008). The implications of this are significant for both emotional wellbeing and physical health. Social functioning is known to be an important determinant in patients' perceived quality of life (Lynch et al., 2008); and social isolation places stroke survivors under increased risk of subsequent strokes, myocardial infarction, and mortality compared with those more socially engaged (Robinson, Murata & Shimoda, 1999). Furthermore, social isolation, a lack of social support, and an inability to continue working are all linked to slower recovery of function from stroke injury, and an increased risk of depression (Ayerbe, Ayis, Rudd, Heuschmann & Wolfe, 2011).

The importance of considering stroke rehabilitation from a psychosocial vantage point has been underlined by the finding from Satink et al.’s (2013) synthesis of existing qualitative evidence on stroke survivors’ perspectives on the impact of stroke on themselves and their roles. The team searched the PubMed, CINAHL, Embase, PsycINFO, and Cochrane databases from inception up until September 2010 for studies reporting the views of individuals post-stroke, which initially yielded 494 studies. After excluding quantitative studies, studies that reported somatic functioning, and opinion articles, 33 studies were selected for thematic analysis. Among other findings, the researchers reported one notable area of incongruence between healthcare practitioners and stroke survivors. Stroke survivors described their recovery in relation to social and psychological functioning, whereas healthcare providers viewed recovery from a biomedical perspective. Indeed, Satink et al. claimed their study elucidates the need to address emotional management and identity issues to assist stroke survivors with regaining a sense of self and social functioning. Seemingly, these findings suggest that stroke survivors and healthcare practitioners do not have a shared understanding of what constitutes post-stroke recovery and rehabilitation. And specifically, this indicates that stroke survivors’ rehabilitation needs relating to psychosocial factors are not necessarily being met by their current rehabilitation programme. Although of paramount importance during the acute stage of recovery, the predominant focus on the biomedical model is apparently not adequate for fully addressing stroke survivors’ later ongoing rehabilitation needs. As previously advocated by others (e.g., Cadihac et al., 2012; Cott et al., 2007; Yeates, Gracey & McGrath, 2008), perhaps a revised approach that places an increased emphasis on psychosocial factors following the acute stages of recovery is warranted in the field of post-stroke rehabilitation.

2.9 Psychological issues

Stroke can leave the individual with many psychological issues that can potentially contribute to the development of mood disorders. Such issues include trying to make sense of cognitive, physical and psychological changes, dealing with losses and/or changes in identity, struggling with reduced independence, and dealing with the impact of the distress experienced during the brain injury incident itself (Ben-Yishay, 2000; Cantor et al., 2005; Nochi, 2000). The challenge of recognising and addressing psychological distress in the stroke population can be further compounded by various biopsychosocial factors that exist. Such factors might include pre-injury personal history, premorbid personality, pre- and post-injury coping strategies, ability to make life adjustments, the emotional impact of the brain injury event, the nature and severity of the acquired brain injury, the type of support available, and any post-injury issues such as divorce, disrupted sleep, and physical pain (Williams, Evans & Fleminger, 2003). The complexity of stroke individuals' presentations can also be exacerbated by either a limited ability to communicate, whereby anxieties and depressive issues are not adequately voiced, or by the individual's lack of awareness of their psychological difficulties and their underlying causes. A further level of complexity can arise where such limited ability to either communicate or be aware of emotional difficulties leads to the development of agitation, anger and aggression (ibid.). Additionally, Ownsworth and Oei (1998) highlighted that the relationship between depression and brain injury can be complicated, as depression may be experienced entirely as a result of the injury. Indeed, certain lesion-locations within the brain are more likely to cause depression (Gillen, 2016; Robinson & Szetela, 1981). Alternatively, depression may be a consequence of psychological responses to the effects of the injury (Eitan, 2009; Gillen, 2006). However, symptoms of depression following brain injury are most often interactively related to both physical aspects of the injury and psychological reaction to its consequences on everyday life functioning (Hinkebein & Stucky, 2007).

2.10 Coping typology post-stroke

Coping is a dynamic process, formed by a series of two-way responses between individual and environment, which can influence each other reciprocally. Hence, the type of strategies employed for coping are an important psychosocial factor that influences quality of post-stroke life (Buono, Corallo, Bramanti & Marino, 2017). Indeed, according to Lazarus and Folkman (1984), coping strategies are cognitive and behavioural modalities employed to manage the negative impact of stressful situations. Depending on the success or failure of this process, coping may be defined as functional, that is, adaptation, or dysfunctional, that is, maladaptation (Buono et al., 2017). Furthermore, several coping styles can be distinguished such as emotional-focused coping—which refers to the ability to regulate negative emotions; problem-focused coping—which includes strategies and actions to reduce the negative impact of the situation through an external change; active coping—which is directed to the source of stress; avoidant coping—which represents an escape of emotional and cognitive events; accommodative coping—which is directed to a change in the personal goal standards in accordance with perceived deficits; and assimilative coping—which involves active attempts to alter unsatisfactory life circumstances and situational constraints in accordance with personal preferences (Aspinwall & Taylor, 1992; Brandtstädter & Renner, 1990; Donnellan et al., 2006; Lazarus & Folkman, 1987; Suls & Flechter, 1985).

The general literature on coping suggests that adoption of a strategy type is determined by personal style and cognitive appraisal of the stressful event (Ferguson, 2001), with most negative life events seeming to elicit both problem-focused and emotion-focused coping strategies. And while it is noted that people with more personal and environmental resources may rely more on problem-focused and active coping, and less on emotional coping and avoidance (Holahan & Moos, 1987), both emotion-focused and problem-focused coping may be needed simultaneously when an individual is dealing with different aspects of post-stroke recovery (Brands, Wade, Stapert & Heugten, 2012).

Decisively, coping strategies are determinant on quality of life after stroke since they affect both recovery and adaptation to acquired disability. Indeed, a few specific types of coping, such as wishful thinking, avoidance, worry, self-blame, and using drugs and alcohol, are fairly consistently associated with poor adjustment (Park, 2017). And although the tendency to underestimate or deny post-injury deficits may initially protect individuals from emotional distress, persisting denial may also cause negative emotions or aversive reactions (Costa, Gullo & Caltagirone, 2017). Furthermore, avoidant coping has been implicated in reduced pace and extent of recovery post-stroke; for instance, avoidance in response to sequelae that restricts ability to engage with pre-injury schedule of activities, and activities that are increasingly challenging and frustrating due to acquired limitations. Such reduced activity can result in a negatively-reinforced cycle of behavioural inactivation and avoidance leading to inactivation of critical brain networks and associated loss of function (Blake, Heiser, Caywood, & Merzenich, 2006). Indeed, Doidge (2015) tells us that the plastic brain, capable of so much, still needs the help of mind and body to realise its possibilities; the brain's way of healing "requires the active involvement of the whole patient in his or her own care: mind, brain, and body" (p. xix; for further discussion on neuroplasticity, refer back to section *2.5 Neuroplasticity and duration of organic recovery*).

Correspondingly, as described by Brandtstädter and Renner (1990), accommodative coping involves flexibly adjusting of one's goals in response to a persistent problem; and active coping strategies, whether behavioural or emotional, could be good strategies to deal with stressful events. The use of these strategies can help adjust goals to accommodate constraints and impairments by revising values and priorities, constructing a new meaning from the situation, and potentially transforming personal identity. And thus, intimates another type of coping, which is meaning-focused. This type of coping has generally received little research attention even though it is highly useful in dealing with major life stressors that are not amenable to being solved but instead require major shifts of meaning to resolve (Park 2010). Indeed, research has shown the importance of meaning-focused coping for acquired brain injury (Park, 2017), including stroke; for instance, a study of stroke survivors revealed that their search for meaning was driven by greater distress, but those who reported finding meaning through their search had better long-term adjustment (Thompson, 1991). For a detailed review of meaning-focused coping and its application for adaptation in acquired brain injury, see Park (2017).

2.11 Emotional difficulties

Emotional difficulties following stroke are common and have important clinical consequences (Hackett et al., 2005; White, Attia, Sturm, Carter & Magin, 2014), as how such difficulties are dealt with will generally have some influence over long-term rehabilitation outcomes (Coetzer, 2009). Indeed, a large-scale study by Teasdale and Enberg (2001) highlighted the importance of addressing psychological distress after brain injury. Furthermore, within the stroke population emotional distress and psychological difficulties can often present atypically, and recognition of psychological distress can be further obscured by commonalities that exist between psychological and neurological symptoms (Khan-Borne & Brown, 2003; Lincoln & Flannaghan, 2003; Williams et al., 2003). For all these reasons, emotional distress might readily be misattributed to neurological sources, and thus remain unaddressed.

A recent two-part study investigating emotion regulation difficulties in relation to social participation further underlined the need for emotion support (Cooper, Phillips, Johnston, Whyte & MacLeod, 2015). Participations comprised 75 stroke survivors who completed assessment measures for social participation (Modified Functional Limitation Profile [mFLP], WHOQoL-Bref), activity limitations (mFLP), and emotion regulation (DERS). Study 1 was conducted for participants who were stroke survivors at the acute stage (63 days post-stroke), and Study 2 was conduct at 18 months post-stroke. The results of these two studies establish that following stroke, there are impairments of emotion regulation and that emotion regulation is associated with later social participation. This further suggests that understanding the emotional difficulties experienced by stroke survivors and how to better provide support for these difficulties can assist with promoting increased social engagement. Although this study suggests an important association between emotional difficulties and improved quality of life post-stroke, it raises the question of what underlies these emotional difficulties that hinder stroke survivors' social participation.

2.12 Psychological difficulties faced by men of working age post-stroke

Even though epidemiologically speaking stroke is not gender specific, it is clear that gender can play a significant role in shaping the experience of suffering from illness, and represents an influential factor in the recovery process. Both loss of strength and control are commonplace consequences of illness for both genders (Bendz, 2003); however, several studies underlined the significant threat to men's sense of masculinity and manhood that the loss of these characteristics can represent (Gibbs, 2005; Maliski, Rivera, Connor, Lopez & Litwin, 2008). Moreover, Connell (1995) highlights that where illness disrupts men's ability to meet societal norms of masculinity, there is a strong tendency to reflect on their gender roles prior to illness, and their taken-for-granted beliefs about gender. Accordingly, traditional male stereotypes and deep-rooted sociocultural expectations of men are discussed in the next section, *2.13 Masculinity as a social construct*, to elucidate the dilemma represented by traditional masculine ideology and its potential for detriment to men's overall mental health—not least when compounded by post-stroke sequelae.

Indeed, on a psychological level, dysfunction following stroke and the disruption to normal life results in distress and anxiety, with prevalence of post-stroke depression and anxiety reportedly around 33% and 28% respectively (Hackett et al., 2005; Barker-Collo, 2007). With respect to men's sense of their masculinity, these psychological difficulties are concerned with their physical strength, independence, practical abilities, sexual abilities, and personal control over life, as well as their capacity to be a provider and protector of their family (Green & King, 2007). Indeed, research has shown that men attempt to renegotiate and establish their masculinity with reference to the limitations that emerge from their own understandings of the personal and social consequences of their chronic impairment, as well as those limitations imposed by others' understandings (Green & King, 2007; Shuttleworth et al., 2012). Yet, as Guttman (2000) highlights, Western males may be culturally socialised to refrain from help-seeking when they are in crisis thus rendering males more susceptible than females to social isolation, and what Guttman refers to as gender role strain. In this context, gender role strain refers to the experience of men who are unable to rebuild a post-stroke lifestyle that is congruent with their perceptions of male adulthood. As such, these research findings have elucidated the role of psychological difficulties in relation to masculinity and gender roles; that these difficulties hinder male stroke survivors' life adjustment and recovery process; and this process is further hindered by male gender role strain. Nevertheless, there is seemingly limited focus in this respect on how these men face their everyday life circumstances post-stroke. Plausibly gaining a better understanding of how male stroke survivors deal with psychological and emotional difficulties may be an important area for investigation.

2.13 Masculinity as a social construct

Masculinity has been the subject of scholarly enquiry since the early twentieth century, with most studies focusing on differences in life satisfaction between men and women, or social issues attributed to masculinity (Pleck, 1975). Indeed, it was not until the late 1970s that a new construct evolved differentiating sex from gender (Sherif, 1980)—where sex indicates the biological traits that stem from being male or female, and gender represents the psychological and sociocultural qualities that are associated with biological sex, such as masculinity and femininity. Consequentially, this new framework permitted researchers to re-examine the concept of masculinity through a lens of social construction shaped by stereotypes and sociocultural expectations (Levant, Rankin, Williams, Hasan & Smalley, 2010). Thereafter, scholars specialising in gender studies agreed that speaking of masculinity in a singular form is incorrect, as masculinities are socially constructed, and therefore plural (Burke, 2016; Connell & Messerschmidt, 2005; Kimmel, 2010).

Indeed, Connell's (1987) seminal work on social theory of gender foregrounded plurality in masculinity. In its earliest form, this social theory centred around a hegemonic masculinity—implicating traditional masculine ideology, *which is described later in this section*—that compartmentalises a dominance over women and the devaluation of other males who eschewal or fall short of traditional masculine ideals; where shortcomings likely included emotional sensitivity, physical weakness, feminism, effeminateness, and even disability, among others. Later, scholarly critiques of this social model (e.g., Demetriou, 2001) and subsequent theoretical redevelopment (see Connell & Messerschmidt, 2005) led to a more complex model of gender hierarchy, which emphasizes agency of women; recognises the geography of masculinities—*and the interplay among local, regional, and global levels*; allows more consideration of embodiment in contexts of privilege and power; and places a stronger emphasis on the dynamics of hegemonic masculinity, recognising internal contradictions and the possibilities of movement toward gender democracy.

Arguably, however, in the eyes of the general public the prevailing characterisation of masculinity is still *traditional*. That is, the universal expression of biological maleness and manliness. And under these circumstances, from early childhood boys begin internalising traditional masculine ideology through social learning and processes of social influence. Moreover, their adherence to the socially-endorsed masculine gender role becomes increasingly associated with appreciable benefits, such as status and prestige; whereas failure to conform is linked with negative outcomes, such as loss of privileges and punishment (Levant, 2011; Pleck, 1995)—whilst girls encounter little consequence for failing to observe feminine norms, or at least not to the extent for boys transgressing masculine norms (Levant et al., 2019).

As such, cultural surroundings that advocate traditionally masculine ideology impose a singular lens through which boys view themselves, others, and the world; ultimately inculcating a range of gendered beliefs and expectations which shape their developing concept of manhood (Pleck, 1995). Among these traditional principles are the conviction that expressing emotion is a sign of weakness (e.g., crying or being warm and tender toward another person); the imperative to avoid anything that is seen as feminine (for an discussion on *fear of the feminine* see Blazina, 1997; and additionally, Kierski & Blazina, 2009); the resolve to be physically tough and aggressive; and the axiom: *do not rely on others for help* (Levant et al., 1992; Mahalik et al., 2003; O'Neil, 1981; O'Neil, Helms, Gable, David, & Wrightsman, 1986; Solomon & Levy, 1982).

Perhaps expectedly, the consequences associated with such affective constraints cover a number of inter- and intrapersonal spheres (see O'Neil & Denke, 2016 for a review). One of the problematic consequences being that men find themselves *between a rock and a hard place* whenever they presume that they are weak for either showing emotion—which will surely occur—or for seeking help when they are distressed. Moreover, with boys being taught from a young age to believe that emotional expression is weak and therefore unmanly, they are left with limited internal resources to accurately interpret and label their emotional and physiological experiences—which inevitably manifest (Levant, 1998; Levant et al., 2006). Accordingly, Levant and colleagues (2006) coined the term *Normative Male Alexithymia* (NMA) to describe the mild to moderate levels of restricted emotional expression and affective labelling difficulties proposed to exist among men who adopt traditional masculine ideals (Karakis & Levant, 2012; Levant, 1992).

Increasing our understanding of how gender socialisation impacts the health and wellbeing of men has been the focus of research spanning the last four decades. In the early days, Pleck (1981) proposed that, in most cases, men experience stress because of the contradiction between male-typed roles that society and culture demand (i.e., masculine attitudes, beliefs, and behaviours) and naturally occurring emotions, desires, and drives. Moreover, Pleck (1995) described three types of male gender role stress: *discrepancy-strain*, when a man fails to live up to internalised expectations of the ideal man; *dysfunctional strain*, occurring as an outcome of the negative consequences of living in accordance with potentially destructive gender norms; and *trauma-strain*, the consequence of extreme experiences that result from gender role stress, such as war.

Following on from Pleck's (1981, 1995) conceptualisations of gender role strain, the later model of Gender Role Conflict (GRC) has been used to empirically study and explain the various psychological and emotional consequences that come with being a man. GRC occurs when a person's socialised gender norms prevent him from acting in a certain way or leads him to feel negatively for doing so (O'Neil, 2015). In particular, GRC purports that socialisation unfavourably impacts men when certain male role norms are strictly followed or completely fulfilled. Furthermore, GRC discerns that gender roles are not biologically determined, but rather psychologically and socially constructed. Due to the discrepancy that men experience between the cultural demands of male-typed roles and their internal motivators, stress occurs which has shown to lead to risky behaviours (including drug and alcohol misuse, and unsafe sex practices; Levant, 2011). Indeed, through examining gender role conflict, gender role stress, gender role trauma, and overall conformity to traditional masculine norms, researchers have shown that conformity to male dominance is associated with depression, lack of help-seeking, educational problems, alcohol abuse, health and rehabilitation issues, poor dietary choices, and body ideal distress, among many other concerns (Addis & Mahalik, 2003; Harris & Harper, 2008; Kahn, 2009; Kierski & Blazina, 2009; Kimmel & Mahalik, 2004; Levi, Chan & Pence, 2006; Mahalik & Rochlen, 2006; Peralta, 2007; Schopp, Good, Mazurek, Barker & Stucky, 2007).

This current section has explored masculinity as a social construct and presented associated male gender theories and concepts which might readily pertain to the phenomenon under investigation. Indeed, sequelae of stroke can include consequences that lead to inadequacies with respect to the traditional masculine ideal, such as physical disability with accompanying bodily weakness or partial paralysis, cognitive impairment, and emotional lability, among other acquired deficits with negative implications for employment and traditional social standing. That being the case, it seems obvious that the challenge for men facing post-stroke existence intersects to some degree with their internalised sense of masculinity, and thus theories explored in this section might offer insights for new understandings of their lived experiences; particularly, perhaps, in terms of gender role conflict. Indeed, salient aspects of theories and concepts highlighted within this section are accordingly referenced later within the discussion chapter to draw links between extant male gender theories and the current research findings. Thus providing a wider context for understanding men's experiences of stroke survival, and situating the findings more broadly within the existing corpus of literature. In the meantime, the next section critiques some of the recent studies on stroke survival that served to shape and focus the current research project.

2.14 Critique of recent studies

One qualitative study conducted with the aim of describing the lived experience of stroke survivors suffering from depressive symptoms was conducted in Norway by Kouwenhoven, Kirkevold, Engedal and Kim (2011). The research team placed an emphasis on exploring what it is like to live with depressive symptoms and the nature of depression within the first weeks following stroke. The participant group comprised nine adults of mixed gender, ages ranging from 30 to 85 years, with four working-age participants. This study benefited from the inclusion of survivors of working age, and provided findings that support the notion that stroke survivors related their experiences of post-stroke depression to the losses they experienced. However, the study did not particularly explore subjective experience of other emotional difficulties such as anxiety or anger. Furthermore, the study focused on the acute phase of recovery, and thus does not provide insight into how symptoms of depression may develop and change during subsequent phases of recovery, and the longer term.

A more recent Italian-based phenomenological study by Simeone, Savini, Cohen, Alvaro and Vellone (2015) explored stroke experience during the three-month period following the acute phase. Fifteen stroke survivors (12 males and 3 females) were interviewed. The phenomenological analysis revealed that participants experienced a profound change in their lives, that their lives had been hindered, and that they felt a burden for their family members. And although participants felt relieved by their recovery, they also had a vivid memory of the acute phase of the stroke, which the researchers suggest might reflect posttraumatic stress. This study provided valuable understanding about lived experiences up to three months following the acute phase. However, with mean participant age over 70 years old (and only one participant under the age of 60), the findings cannot be readily generalised across the growing population of stroke survivors of working age.

Furthermore, the design of the study does not provide any insight beyond three months following the acute phase. Thus, this study does not provide any awareness on rehabilitation over the years beyond the acute management, and on what might facilitate or hinder participation in work, family, and community life (Wolf et al., 2009). Indeed, it is widely acknowledged that the recovery process from stroke is dynamic and unstable (Dixon, Thornton & Young, 2007; Patel, McKevitt, Lawrence, Rudd & Wolfe, 2007), and "psychological needs may change over time and in different settings" (NICE, 2013, p. 22). Accordingly, Klonoff (2010) suggested that there are seven different stages of recovery, namely: the time of brain injury; early adjustment, seeking help, starting outpatient therapy, retraining, therapy transition, and the future; and that each of these stages come with different challenges. Hence, it seems important to explore the experiences of stroke survivors over time to gain a better understanding of their difficulties and challenges at different stages of recovery and how survivors face these challenges.

A qualitative study conducted by Alaszewski and Wilkinson (2015) did specifically focus on individual stroke survivors of working age, with the aim of exploring the different ways in which this group made sense of what had happened and what was happening in their lives, and how they sought to manage these experiences. Participants comprised 43 adults (28 males and 15 females), 37 of whom were over the age of 40. Over an 18-month period participants were invited to attend four interviews, with the first interview typically taking place in hospital after completion of initial treatment, approximately one month after the stroke event. Transcripts of the interviews were analysed thematically using an approach which included both deductive and inductive elements. The inherently paradoxical experience of hope emerged as the main theme of the investigation, whereby any hope for the future was experienced as an unwelcome distraction, and even a source of distress, while survivors attempted to focus on living positively in the here and now. Whilst this study highlighted there are types of hope that are deemed useful for recovery, and others that might be unhelpful, its window on this phenomenon was limited to experiences within an 18-month period shortly following the stroke event. Although this study provides an important perspective on the potential trap of hoping for too much, it does not consider survivors' longer-term experiences and the other phases of recovery that generally occur. Furthermore, whilst the study aimed to explore how survivors sought to manage their post-stroke experiences, and as such described many unpleasant feelings and distressing emotions, there was no account of how survivors actually managed these psychological difficulties. Nevertheless, the findings of the study did serve to foreground how existential tensions arise surrounding the notion of commitment to *realistic* hopes and what might be hoped for over the longer term. Conceivably, further investigation into the experiences of stroke survivors of working age over a longer term could provide a better understanding of the complex role of hope, as well as aiming to focus more directly on how survivors manage their psychological difficulties.

Longer-term lived experience of stroke was the focus of a Norwegian study conducted by Brunborg and Ytrehus (2013), where data was collected using interview to capture the retrospective accounts of stroke survivors 10 years after their stroke. Participants were mixed gender older adult (61 to 93 years). This study provides some insight into how stroke survivors adapted and adjusted their life style after their stroke and how they dealt with challenges caused by the consequence of stroke, highlighting the roles of stamina, self-care, health literacy, positive thinking, and interaction with family and friends as factors in adaptation and wellbeing. Nevertheless, there was lack of exploration of how this group of survivors dealt with emotional needs and difficulties, even though this has been highlighted as an important factor for the rehabilitation process in the literature (e.g., Haley, Roth, Kissela, Perkins & Howard, 2006; Shimoda & Robinson, 1998). However, the researchers did advise that there is a need for further research attention towards working-age survivors, noting that impact on financial stability and resources (e.g., loss of income) present very different challenges to those faced by older adults. Indeed, the researchers stressed that realising gains and/or adapting to reduced functioning post-stroke is contingent on financial resources, and thus stroke survivors still of working age represent a particularly vulnerable group.

A recently conducted Canadian study by Maratos, Huynh, Tan, Lui and Jarus (2016) also aimed to explore the lived experience of high-functioning stroke survivors later in the recovery process. With participants 3 to 10 years post-stroke, the study focus was on identifying gaps in community and rehabilitation services. The participant group comprised five adults with ages ranging from 52 to 71 years, and were high-functioning based on a combination of criteria, which included evaluation of their cognitive level using the Montreal Cognitive Assessment (MoCA; Nasreddine, n.d.; Chiti & Pantoni, 2014). Data was gathered during four focus group sessions which employed the use of photographs taken by participants during the previous week to share their experiences. A modified inductive thematic analysis of the transcribed audio-recordings of sessions was conducted. Consistent with Brunborg and Ytrehus' (2013) findings, the research results provide further support for the importance of socioeconomic status, societal structures, attitudes, and available support for the trajectory of recovery. Although this study focused on the lived experiences of survivors over the longer term and included accounts of the emotional and behavioural impacts of stroke, it did not specifically seek to explore how survivors deal with these difficulties.

Another recent qualitative study (Leahy, Desmond, Coughlan, O'Neill & Collins, 2016) conducted in Ireland explored the lived experiences of 12 women of working age (20 to 48 years) who had survived a stroke, with time since stroke ranging from 10 to 29 months. Data collected from semi-structured interviews was analysed using interpretative phenomenological analysis (IPA). The findings revealed a problematic stereotype of stroke as a condition of old age, which negatively impacted on younger survivors' self-concept and identity, leaving them feeling old before their time. Further, the scarcity of younger role models with stroke, and the association with old age in terms of requirements to take stroke medication and experiences of stroke-related impairments, such as memory loss, reinforced perceptions of an aged self. Whilst this study highlighted experiences of age-related stigma faced by female stroke survivors of working age, the focus of the study was not towards an exploration of the psychological difficulties associated with these challenges, nor any attempt to explain how this minority group deal with their emotions post-stroke. Furthermore, the study does not consider post-stroke experience from the perspective of male stroke survivors of working age.

2.15 Rationale for present study

A review of the existing literature relating to stroke survivors' experiences, detailed in this chapter, revealed that the psychosocial components of post-stroke recovery are progressively being seen as important factors in the rehabilitation process, with instrumental components including emotional regulation, social participation, self-identity, recovery expectation, and acceptance (Anderson & Whitfield, 2013; Ayerbe et al., 2011; Cooper-Evans et al., 2008; Gracey et al., 2008; Haun et al., 2008; House et al., 1989; Howes et al., 2005; Lynch et al., 2008; Pallesen & Roenn-Smidt, 2015; Robinson et al., 1999; Shuttleworth et al., 2012, Yeates et al., 2008). Supporting evidence for an association between positive recovery outcomes and social participation is well established in the literature (Bendz, 2003; Berges, Seale & Ostir, 2012; Cowdell & Garrett, 2003; Peoples, Satink & Steultjens, 2011; Prigatano, 2011; Röding, Lindström, Malm & Ohman, 2003; Satink et al., 2013). What is more, stroke survivors themselves tend to think of their own post-acute recovery in terms of achieving social goals (Pajalic, Karlsson & Westergren, 2006). Given that emotions have been identified as important for successful social interaction and participation (Gross, 2002), one of the potential barriers to social participation and positive recovery outcomes is poor regulation of emotional difficulties (Robinson et al., 1999). Indeed, stroke survivors often experience a reduction in social participation which cannot be explained solely by activity limitations caused by physical impairments (Desrosiers et al., 2003; Drummond, 1990); and it has been widely accepted that post-stroke depression and anxiety, and other psychological symptoms affect everyday life functioning and social outcomes (Cooper et al., 2015; Crowe et al., 2015; Robinson et al., 1999). As such, the role of emotion regulation in both its influence over negative mood (Bogousslavsky, 2003; Ehring, Tuschen-Caffier, Schnulle, Fischer & Gross, 2010) and in successful social functioning (Kimhy et al., 2012) suggests that this may be an important area for exploration. Even so, the existing literature predominately focuses on the acute stage of recovery and the attainment of functional goals and discharge, using biomedical measures. And whilst the biomedical model is of paramount important for the survival of stroke victims and the early gains in the recovery process, this model inherently lacks the broader context associated with psychosocial factors. Indeed, the NICE guidelines (2013) have sought to address this by recommending the use of the World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF; WHO, 2017b), which provides a biopsychosocial model of disability, for supporting comprehensive assessment goal setting, treatment planning and monitoring as well as outcome measurement.

Moreover, the various psychological and behavioural difficulties that are often experienced after stroke are unlikely to be resolved with treatment based on psychopharmacology alone (Coetzer, 2009; NICE, 2013). Environmental, psychological, and social factors can all play an influential role in both the onset and maintenance of psychological difficulties in the stroke survivor client group. As such, the aetiology of these difficulties is probably biopsychosocial, and thus complex in nature, not least due to the interrelatedness of the psychological factors with the physiological causes resulting from stroke. Indeed, it is not uncommon for pronounced difficulties to be encountered when attempting to fully unravel, understand, and address the presenting issues (Coetzer, 2009). It follows that additional options to the medical model, and its psychopharmacology approach for achieving therapeutic outcomes, may have an important role to play in addressing psychological difficulties that present in this client group.

The review revealed gaps in the literature relating to stroke and emotional experience during post-stroke rehabilitation, which exist despite an innovative focus and movement in this direction noted some decade and a half ago (Dikmen, Bombardier, Machamer, Fann & Temkin, 2004; Scott, Phillips, Johnston, Whyte & MacLeod, 2012). Seemingly, there is still a need for research which aims to assist in addressing the aforementioned gaps with respect to the working-age population, gender, and how stroke survivors might deal with emotional difficulties post-stroke. Indeed, Robinson (1998) asserted that “there is little doubt that emotional disorders constitute one of the major obstacles to recovery and to achieving maximal quality of life following stroke” (p. 5). Accordingly, national clinical guidelines (NICE, 2003) previously recommended that stroke survivors “should be provided with access to individual and/or group psychological interventions for their emotional difficulties, adapted to take into account individual neuropsychological deficits” (p. 45). Furthermore, current guidelines continue to advocate assessment and interventions for emotional adjustment while acknowledging that “psychological needs may change over time and in different settings” (NICE, 2013, p. 22).

In particular, the review of the literature indicated that there is an increasing number of men of working age living with the consequence of stroke in the UK; and that this demographic of stroke survivors can face particular life predicaments and associated psychological difficulties due to multifactorial reasons relating to gender, age at onset of stroke, and societal expectations. Yet a specific focus on this particular demographic with respect to dealing with emotional difficulties post-stroke was not evident in the literature reviewed. “Research is guided by questions” (McLeod, 2003, p. 24), and the findings from this literature review have prompted questions, such as: ‘*What is it like for men of working age to encounter the actuality* *of stroke?*', '*What emotional and existential difficulties do these men face?*', and '*How do these men cope with such difficulties?*'

2.16 Rationale for existential perspective on stroke

Psychoeducational and cognitive behavioural therapeutic approaches have been widely recognised by practitioners within the field of brain injury rehabilitation as being appropriate and useful for many clients (Borgaro, Caples & Prigatano, 2003; Corrigan & Bach, 2005; Mateer & Sira, 2006; Persel & Persel, 2004; Rothwell, LaVigna & Willis, 1999; Yamagami, 1998; Ylvisaker, Jacobs & Feeney, 2003). Typically, these approaches involve the reiteration of such interventions due to the difficulties often experienced by many individuals when it comes to learning new skills and concepts, especially when the process involves challenging and changing well-established beliefs and/or behavioural patterns. The reasons underlying the current predominance of these approaches will include the need that brain injury clients often have for concrete and normative information about their condition, which in turn can serve to facilitate their rehabilitation process (Gillen, 2016). In addition, an individual who has suffered a brain injury will commonly need specific and concrete guidance about approaching particular situations, for instance interpersonal, social, and vocational, among many others. That is to say, psychoeducational and cognitive behavioural interventions can assist with the process of establishing and maintaining more accurate intrapersonal and interpersonal functioning, as well as other areas involving explanatory attributions, and thus provide an improved means for guiding clients' evaluations and behaviours (Hinkebein & Stucky, 2007).

However, it has been argued that the psychotherapeutic endeavour with this client group should not necessarily be limited to the aforementioned predominant cognitive behavioural perspective. Indeed, there is also the potential to assist this client group with the task of finding a new direction in life, while addressing some of the existential crises that can emerge following stroke, and as such assist them to define new meanings and purposes in life (Patterson & Staton, 2009). Confronting life following a stroke profoundly challenges an individual's very *being* and provokes existential questions about self (Nilsson, Jansson & Norberg, 1997), and raises existential threats concerning choice and freedom, loss, distortion, and fear about the existence they now face (Kaufman, 1988). Furthermore, as an existential turning point, consequences of stroke can lead to crisis phenomena such as emptiness, anxiety, discontinuity and despair (Nilsson, Jansson & Norberg, 1999). The existential predicament faced by individuals following stroke, underlined by biographical disruption and a process of self-reinterpretation, is likely to be extensive given the sheer scale of the challenges presented by recovery and rehabilitation. Indeed, stroke survivors often find “that the very personal skills and resources necessary to cope with disability are the ones most undermined by their injury” (Hinkebein & Stucky, 2007, p. 389), and where the consequences of stroke are experienced as persistent, then the implications for an individual’s purpose and direction in life orientation becomes profound (Williams, 1984).

Accordingly, whilst acknowledging the importance of addressing the cognitive behavioural component of the brain injury experience, Hinkebein and Stucky (2007) along with Prigatano (1999) and Goldstein (1959) place a strong emphasis on the need to explore the phenomenological and existential reality of the injury for the individual as the first step of the rehabilitation process. Indeed, Merleau-Ponty (1945/1962) advised that “phenomenology is also a philosophy that puts essences back into existence” (p. 298), and by existence he was referring to “the movement through which man is in the world and involves himself in a physical and social situation which then becomes his point of view on the world” (p. vii). Accordingly, drawing on phenomenology in this way could provide an existential lens for description of lived experience post-stroke that goes beyond the biomedical vantage point, and better captures rehabilitation issues that concern human existence and psychosocial circumstances.

Furthermore, an existential perspective opens up the potential to reference a broad range of philosophical ideas that might have useful application to the predicament of stroke survivors. Amongst others, these might include some aspects of the following: Kierkegaard’s (1844/1980) poignant observations on the human struggle and the acceptance of this struggle as the core of existence, or his thoughts on the fundamental role of anxiety in a well-lived life; Merleau-Ponty’s (1945/1962) views on embodiment and the primacy of body: “our body is our general medium for having a world” (p. 146); Heidegger’s (1926/1962) works on the significance of death, being-in-the-world, *thrownness* into a world not of our choosing, and readiness-to-hand; Frankl’s (1946/2004) emphasis on the importance of meaning; and Deurzen’s (1984; 1988; 2009) development of the Four Worlds model, among a wealth of other concepts and resources. Indeed, Hinkebein and Stucky (2007) imply it would probably be doing a disservice to a client not to incorporate an existential phenomenological approach into their therapy. Similarly, Klonoff (2010, pp. 5-6) asserts that for the brain injury client group “the relevance of existential psychotherapy . . . is enormous” given the suffering, distress, and uncertainty of post-injury existence.

2.17 The Four Worlds model

2.17.1 Introducing the Four Worlds Model

Systematic descriptions have delineated four dimensions to human experience (Strasser & Strasser, 1997). Inspired by Heidegger’s (1957) work, Binswanger (1946/2004) named the dimensions of Umwelt (physical world), Mitwelt (social world), and Eigenwelt (psychological and personal world), along with the inference of a spiritual dimension subsequently referred to as Überwelt (Deurzen-Smith, 1984, 1988; Deurzen, 2009). These four dimensions, or the Four Worlds model, recognise the complexity and multiplicity of human experience and provide an existential framework within which to explore and clarify an individual’s worldview. In a physical world of objects, there is the struggle between survival and death, and while aiming for security in this dimension through health and wealth, life brings a gradual disillusionment and realisation that such security can only be temporary. In the personal dimension there is the search for a sense of identity, a feeling of being substantial and having a self, and the tension between integrity and disintegration. Activity in a social world of others brings with it desires to belong and the possibility of isolation, pressures relating to cooperation and competition, and tensions between acceptance and rejection. On the spiritual dimension there is the anguish between purpose and absurdity, and hope and despair, where individuals create their values in search of something that matters enough to live or die for, seeking meaning against the threat of meaninglessness (Strasser & Strasser, 1997).

2.17.2 Applying the Four Worlds Model to stroke survival

Plausibly, it may be helpful to consider applying the framework of the Four Worlds model for gaining a better understanding of subjective experiences of stroke survivors. And, thus elucidate lived experiences of stroke event itself, acute recovery, the rehabilitation process, and discharge into the community; while aiming to gain a broader context for providing psychological interventions, promoting social participation, and supporting community integration. More on this later; in the meantime, some backstory will provide a fuller context to this proposal.

Not so long ago, the traditional biomedical model of disease and healthcare seemed peerlessly authoritative, whilst having little regard within its framework for the social and psychological dimensions of illness. Notwithstanding this, the biomedical model was vehemently challenge by the seminal notion of a biopsychosocial model (e.g., Engel, 1977, 1980), which was proposed for providing a blueprint for research, a framework for teaching, and a design for action in the real world of healthcare. Accordingly, over the last four decades or so, there has been widespread adoption of the biopsychosocial model, and not least within the field of stroke research (e.g., Hreha, Kirby, Molton, Nagata & Terrill, 2018; Kobylanska et al., 2018; Ormstad & Eilertsen, 2015; Poppleton, Watkins, Chauhan & Lightbody, 2018). But in any case, for better interpreting experience of stroke survival perhaps there is need to add yet a further dimension to the model. Indeed, within acquired brain injury literature there are calls for better foregrounding the existential and meaning-making facet of the human condition, which arguably remains undistinguished and underdeveloped within the ground-breaking biopsychosocial framework.

Certainly, in many instances brain injury is an existential and life-altering event (Butera-Prinzi, Charles & Story, 2014; Klonoff, 2010). The experience of brain injury can impact a person’s understanding of their own self at an existential level and shatter how their pre-injury understanding and story of self fits their post-injury self (Gelech & Desjardins, 2011; Mogerman, 2006; Morse & O’Brien, 1995; Muenchberger, Kendall & Neal, 2008). And all this, alongside negative post-injury consequences concerning aspects of physical health, cognition and psychological wellbeing, and social networks and vocational paths (Chen & Novakovic-Agopian, 2012), as well as complications with language and communication skills (Elbaum & Benson, 2007). Manifestly, the negative impact often wrought by stroke on physical, cognitive, and socio-emotional functioning can alter the “experience of self in the world” (Gracey et al., 2008, p. 639). More specifically, such impairments can reduce people’s sense of agency, independence, and participation in society, and increase sense of purposelessness and meaninglessness.

Undoubtedly, the subjective meaning of the abovementioned impairments, along with an individual's capacity to maintain valued activities and life roles and to make sense of one's post-stroke existence, is vital for stabilising or reconstructing one's sense of self (Ownsworth, 2014). But be that as it may, Tasker (2003) has very much foregrounded how, whilst brain injury "tears violently at the whole of individual mind, body, and spirit . . . sadly, the unification of body and *mind in spirit* [emphasis added] fails to be appreciated, and/or recognized, within . . . acute and rehabilitative medical practice and intervention" (p. 337). That is, "the brain and body are brilliantly yet objectively treated" (ibid.), with existential concerns being side-lined within the provision for stroke.

With all the above considerations in mind, the Four Worlds model with its inclusion of the spiritual feature of Überwelt can be seen as, to all intents and purposes, an existential extension of the biopsychosocial model. Indeed, the biological concerns are found in the physical world of Umwelt; psychological considerations are manifest in the personal domain of Eigenwelt; and social factors are reflected in Mitwelt (the relational dimension of being in the world with others). Arguably, this proposition adds the much needed fourth lens (that is, an existential perspective) to the well-established and widely applied triple lens of the biopsychosocial model; that is to say, much needed for further understanding the complexities of providing healthcare provision for survivors of stroke (and other acquired brain injuries).

Hence, given the aforesaid germaneness of the Four Worlds model for further understanding lived experience of stroke survivors, and in response to the above highlighted concernment with acute and rehabilitative medical practice and intervention, it not only seems decidedly appropriate but practically requisite for the lived experience of stroke to be clarified across the four domains of lived experience, as described hereinabove and conceptualised within the Four Worlds model.

2.17.3 Critique of Four Worlds model

It is acknowledged that the Four Worlds model has its limitations. It can provide a representation to facilitate our observations and understanding of where each individual is struggling. But it is a simple heuristic device and we should never mistake the map for the territory. Human existence is a lot more complex than this and we face challenges on every level at once, and all dimensions are woven and knotted together. As such, it is a pragmatic tool akin to a map of subjective experience that is never going to be completely accurate; providing only an abstract representation of something that is different for everyone, and is dynamically changing across time (Deurzen, 2015).

Nonetheless, applying the framework of the Four Worlds model to the experience of stroke may perhaps further expand and clarify understanding of the subjective experiences of survivors, and thus provide wider insight into how this vulnerable group might be better supported. Indeed, many other studies have gainfully applied the Four Worlds model as an analytic grid to provide a lens through which data is viewed and interpreted. Moreover, a remarkable range of topics have been explored in this manner, with more recent examples including research focused on meaning reconstruction following bereavement (Steffen, 2019); implicit meanings of challenges in daily life faced by individuals with type 2 diabetes (Inga-Britt & Kerstin, 2019); experiential-existential perspectives on posttraumatic growth during incarceration (Vanhooren, Leijssen, & Dezutter, 2018); and perspectives on encountering existential loneliness among older adults (Sundström, Edberg, Rämgård, Blomqvist, 2018), to name but a few. The heart of the matter herein is that the renowned biopsychosocial model has been widely applied to understand disease and healthcare issues, yet it does not emphasis the spiritual and existential aspect of the human condition, as called for within some areas of the acquired brain injury literature. Thus, this current study has drawn on the Four Worlds framework to address this well-documented yet somewhat neglected need for an existential viewpoint on the lived experience of stroke survival.

3. Aims and objectives

> *"There is an alarming increase in the numbers of people having a stroke in working age . . . figures show stroke can no longer be seen as a disease of older people."*
> (Jon Barrick CEO, Stroke Association cited in Mundasad, 2015)

The aim of the current study is to better understand how men of working age deal with psychological and emotional difficulties post-stroke, the circumstances and contexts that surround and underpin these difficulties, and to gain a better understanding about how this is impacting on their post-stroke recovery and rehabilitation process. It is hoped that the findings and the theory generated from this study provide a complementary framework for informing clinical practice in the field of stroke rehabilitation.

The research question of this study is:

- how do men of working age deal with psychological and emotional difficulties post-stroke?

The aims of this study are to:

- explore the psychological and emotional difficulties subjectively experienced by male stroke survivors of working age,
- explore how men of working age deal with their psychological and emotional difficulties post-stroke,
- consider this phenomenon of dealing with psychological and emotional difficulties from an existential perspective, and
- generate a theory which explains how men deal with psychological and emotional difficulties post-stroke with reference to existential concepts.

4. Methodology

> *Empathic or appreciative accuracy is attained when . . . we can adequately grasp the emotional context in which the action took place*.
>
> (Weber, 1914/2012, p. 281)

4.1 Research design overview

This study adopted a qualitative research approach using individual semi-structured interviews to capture rich and in-depth accounts of subjective experiences of men who faced a range of mild to moderate post-stroke difficulties. Ten adult males of working age were interviewed. The interviews were audio recorded and transcribed verbatim by the researcher. The data was analysed using Straussian Grounded Theory Method (GTM; Corbin & Strauss, 2015) for the purposes of developing a substantive theoretical model which provides an existential phenomenological perspective on how psychological and emotional difficulties are faced by the post-stroke male population. Reflective research practices were used throughout the process of designing this study to help ensure that the design was cohesive and fit for purpose. To this end, considerations encompassed: the aims of the research, the ontological and epistemological standpoints, the appropriateness of selected methodologies for answering the research question, alignment with the philosophy of counselling psychology, and the development of a theoretically compatible methodological framework. The rationale for adopting this research design is discussed in detail in the sections that follow.

4.2 Philosophical underpinnings

4.2.1 Counselling psychology research

This study approaches the chosen area of research from a counselling psychology perspective. As such, this research adopts a pluralistic approach which embraces theoretical and methodological differences. This stance is clearly underpinned by the stated mission of counselling psychology “to elucidate, interpret and negotiate between perceptions and worldviews but not to assume the automatic superiority of any one way of experiencing, feeling, valuing and knowing” (British Psychological Society, 2005, pp. 1-2).

4.2.2 Ontological and epistemological positions

Ontology and epistemology are fundamental considerations when conducting research, as choices of standpoint inevitably shape decisions about methodology and method; and thus determine the design of the study, the quality of findings, and consequently, the suitability of the design for answering the research questions (Hesse-Biber & Leavy, 2011).

Epistemology and methodology are driven by ontological beliefs (Killam, 2013). Ontology is concerned with the philosophical question of what constitutes the nature of reality (Blanche & Durrheim, 2006). The debate is between the *realist* position and the *relativist* position, with critical realists occupying the middle ground. The realists assert that there is an objective real world *out there*, made up of structures and objects that share cause and effect relationships. Hence, research seeks to discover, objectively describe, and measure phenomena generated by the structures and objects of that real world. In contrast, the relativist position assumes that there is no objective truth or fixed reality, and instead considers reality to be socially constructed, or interpreted. It asserts that all experiences are relative, and are constructed through language. As such, reality is subjective, pluralistic and mutable (Sarantakos, 2013; Williams, 2016).

Epistemology is the branch of philosophy that relates to the theory of knowledge, that is, what knowledge is, and how it can be established (Blaikie, 2007). The debate relates to the opposing *positivist* and *interpretivist* positions. Positivist epistemology asserts that an objective researcher can gain objective knowledge of objects and events in the world. As such, it assumes there is a reasonably direct relationship between the world and our perceptions and understandings of it. In contrast, interpretivist epistemology emphasizes how experiences and perceptions are constructed through language, and rooted in linguistic, social, cultural, and historical material. It asserts that it is not possible to be objective, as researchers are part of the world, not external impartial observers, and therefore inescapably influence the process and the findings of a study. Hence, findings will always be incomplete, provisional, and mediated by context (Jonker & Pennink, 2010; Sarantakos, 2013; Williams, 2016).

This study adopts a relativist ontological standpoint and an interpretivist epistemological stance; and more specifically, it takes a social constructivist perspective towards reality, whereby knowledge is understood as being constructed rather than discovered. Constructivism focuses on exploring subjective accounts of how people make sense of a situation in a particular context (Blaxter, Hughes & Tight, 2006). As such, both the ontological and epistemological standpoints of the current study are compatible with the philosophy of counselling psychology, which values subjective experience in and of itself, and aligns practice with a fundamental commitment to understanding the clients' subjective experiences (Woolfe, Strawbridge, Douglas & Dryden, 2010).

4.3 Qualitative and quantitative methodologies

Qualitative and quantitative approaches are rooted in philosophical traditions with different epistemological and ontological assumptions. Quantitative research adopts a positivist paradigm, whereby the deductive principle is applied to establish an objective truth by means of theory-driven hypothesis testing, using methods such as controlled experiments and statistical analysis (Ashworth, 2003). Study design based on a positivist paradigm, with an epistemological emphasis on objective and universal truth, seems particularly applicable for research conducted in the field of the nature sciences such as physics, chemistry, and biology. In contrast, qualitative research methodologies are strongly associated with the interpretivist epistemological assumptions (although there are some that lean much closer towards positivism, such as Glaserian Grounded Theory Method which is typically depicted from a post-positivist standpoint). All qualitative research draws on the phenomenological tradition (Moustakas, 1994), and aims for an authentic, detailed description of how an individual or small group of people experience a particular phenomenon, focusing on "the individual as a socially constructed being, and on the processes of social interaction by which individuals make sense of the world" (Stanley, 2009, p. 64). As such, qualitative methodologies broadly assert that there is not an absolute fixed truth to reality, but that truth is relative and therefore there are different realities which depend on our perspectives. Furthermore, although both qualitative and quantitative methodologies are concerned with detail, what constitutes detail differs between these contrasting approaches (Silverman, 2005). Indeed, quantitative research seeks detail in numeric values and correlations between variables, whilst qualitative research focuses on detail concerning people's understandings and interactions (Williams, 2016).

4.4 Rationale for selecting a qualitative approach

A quantitative design would not be able to elicit the type of data necessary to answer the research question in this study due to the restrictions of its hypothesis driven framework. In contrast, a qualitative design has the means to capture the required detail, as its focus is on "exploring, describing and interpreting personal and social experiences" (Smith, 2003, p. 2). Qualitative approaches allow for a rich and in depth understanding of subjective experiences. Furthermore, the inductive nature of qualitative methodologies has been identified as particularly valuable when investigating complex and under-researched areas (Denzin & Lincoln, 2011), such as subjective experiences of stroke survival. Additionally, inductive approaches can provide a basis for later deductive inquiry (Williams, 2016).

4.5 Methodology for data analysis

Straussian Grounded Theory Method (GTM) was selected as the methodology for conducting data analysis to provide answers to the research question in this current study. To be explicit and transparent about the methodology used for this research, the data analysis for this study was informed and guided by Corbin and Strauss' (2015) book, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. The constructionist underpinnings are clearly stated in this fourth edition of their book which acknowledges that "concepts and theories are *constructed* by researchers out of stories that are constructed by research participants who are trying to explain and make sense out of their experiences and lives, both to the researcher and themselves" (p. 26). Moreover, this assertion of a constructionist standpoint is not new, but a restatement of the self-same declaration in the third edition of their book (see Corbin & Strauss, 2008, p. 10). How these guidelines were applied for performing such data analysis is detailed within the next chapter (namely, *Research Procedures*). But beforehand, the sections that now follow will provide a rationale for the selection of the methodology; the role played by literature review; and the historic development of, and philosophical underpinnings for Straussian GTM.

4.5.1 Rationale for using Straussian Grounded Theory Method

Grounded theory method (GTM) is an appropriate approach for studying social problems and, as in the case of the current study, where people may need to adapt to a long-term health condition (Schreiber, 2001; Corbin & Strauss, 2015). Holloway and Todres (2005) note that GTM is most suited to studying the process of human action and interaction, which makes it relevant for better understanding lived experiences of male stroke survivors. Furthermore, unlike other qualitative research approaches, GTM facilitates a transition from merely reporting descriptions of a phenomenon to a better understanding of the process underlying its occurrence (Corbin & Strauss, 2015; Cooney, 2010). Indeed, GTM seeks to develop explanatory theoretical conceptualisations of findings, and thus GTM can provide the means for fully answering the research question of this study. Moreover, grounded theory method promotes openness to potential theoretical understandings by using the data to tentatively formulate interpretations about a phenomenon using a process of coding and the elaboration of emergent categories. This is an iterative process, whereby each successive collection of data is used to test and enhance nascent categories (Corbin & Strauss, 2015; Charmaz & Henwood, 2007), often where existing theories or areas of research are under defined (Henwood & Pidgeon, 2003). Hence, this further supports the selection of this method as appropriate for providing an explanation for the phenomenon under investigation and answering the research question.

Notably, in addition to the Straussian approach there are various other options for conducting grounded theory research, including the *Glaserian* approach (Glaser, 1992) and the so-called *Constructivist* approach (Charmaz, 2000)—that is to say, Straussian grounded theory is itself underpinned by a constructionist perspective. After considering grounded theory options with respect to the research design, the basis for selecting the Straussian became apparent to the researcher, predicated on the philosophical underpinnings and methodological considerations of the study design. Deliberation was focused towards ontological and epistemological standpoints; theoretical outcome (e.g., Straussian full-description versus Glaserian abstract-conceptualisation); and methodical practices (e.g., Strauss and Corbin's use of axial coding versus the Constructivist approach which advocates a coding and writing style that is more literary than scientific in intent; Charmaz, 2001). Indeed, Corbin advises that "while rich and thick description provides concepts and tells an interesting story, it is not theory. What makes theory different from descriptive qualitative research is the overarching structure—the skeleton or framework that explains why things happen" (Corbin & Strauss, 2015, p. 12). And, jumping ahead slightly, it was this emphasis on theory generation that primarily led to the adoption of the Straussian approach for this current study, over the less methodological structured Constructivist approach.

That mentioned, attention now turns to the rationale behind adopting the Straussian approach over the Glaserian option, which comprises the four considerations that now follow. Firstly, the Straussian approach aligns with a constructionist perspective, which resonates with the relativist ontological standpoint of this study, especially compared with the more realist position connected with the Glaserian approach. Secondly, and interrelatedly, the epistemological assumptions within this study relate to an interpretivist position, which again can be readily associated with the constructionist nuances of the Straussian approach, but jar with the typically positivist position of the Glaserian approach. Thirdly, this study benefits from the methodical structure of the Straussian approach which provides clear guidance for data analysis based on abductive reasoning with some reference to extant literature at the outset of the enquiry. In contrast, the flexible Glaserian approach is an inductive based method that has less methodical structure, and relies on the vagaries of an emergent theoretical framework. Lastly, the Glaserian approach has strong focus on abstract conceptualisations that readily relate to organisational, political, and technical issues intertwined with the substantive area of inquiry, rather than being concerned with people and time. This study was more interested in the lived experiences of participants and thus better suited the "full conceptual description" (Glaser, 1992, p. 132) of Strauss and Corbin. Nevertheless, this project's author acknowledges the strengths of Glaserian grounded theory for pursuing knowledge within different research contexts, and directs the reader to Glaser's (1978) book *Theoretical Sensitivity* for further understanding of this seminal research methodology. Additionally, there is further discussion on the Glaserian–Straussian debate in section *4.5.3 Development of Straussian ground theory method*, which follows later.

Having laid out the reasoning for selecting the Straussian approach for this particular study, rather than adopting a Glaserian approach, discussion now moves onto defending the choice of the Straussian approach over the option of the Constructivist approach. To assist discussion, the term *Constructivist* is reserved to reference the grounded theory method of that name, whilst the similar term *constructionist* is used to refer to the ideologies of social constructionism itself.

At this juncture, it seems pertinent to foreground the social constructionist underpinnings of Straussian grounded theory. The reasons being threefold. Firstly, the current research design practically dictates the need for a constructionist methodology, given its relativist ontological standpoint and interpretivist epistemological assumptions. Secondly, with its centrality towards lived experience—that is, lived experience of male stroke survivors—the phenomenon under investigation warrants a constructionist approach in and of itself. And more so, as this topic implicates the social constructs of gender and masculinity which additionally invites a constructionist approach (for a review, refer to section *2.13 Masculinity as a social construct*). Thirdly and lastly, corroboration of the veracity of Straussian methodology as a constructionist approach in the face of the long-contested terrain of constructionist grounded theory. Indeed, over the recent decades competing theorists and authors have jostled for prominence in this field, leaving qualitative researchers (novice and experienced alike) with a responsibility to avoid uncritical acceptance of these theorists' asserted viewpoints.

With the above in mind, this project's author contends that Straussian grounded theory provides the appropriate means to engage with enquiry into lived experience, gender, and masculinity from a constructionist perspective. And further, that Straussian grounded theory provides a sound methodological framework for facilitating the generation of substantive theory, which is grounded in research data.

However, the status of Straussian grounded theory as a constructionist approach has historically been questioned by proponents of the Constructivist approach, and not least by Charmaz (2008). Hence, the following brief review focuses on Charmaz's (2008) book chapter (written over a decade ago), that critically calls into question the robustness of Straussian grounded theory as a constructionist approach. Moreover, having critically adopted the Straussian approach for the current study—because of its constructionist underpinnings—this project's author offers an expository counterresponse, accordingly.

It is noted that Charmaz (2008) vacillated between tacitly acknowledging Straussian constructionist logic and critically questioning the vigour of its constructionist underpinnings. With that said, this short review begins by highlighting Charmaz's pejorative assertion that the Straussian approach "gave grounded theory an objectivist cast" (p. 401) due to its "prescribed" (p. 399) methodological procedures—an emphatic response to this is provided in the next paragraph. Charmaz then followed up by espousing Constructivist grounded theory, stating that "rather than assuming that theory emerges from data, constructionists assume that researchers construct categories of the data" (p. 402)—yet Charmaz failed to mention that constructing categories of the data is central to Straussian axial coding (see section *5.8.3 Axial coding*). Charmaz then continued by saying: "instead of aiming to achieve parsimonious explanations and generalizations devoid of context, constructionists aim for an interpretive understanding of the studied phenomenon that accounts for context" (p. 402)—again, referring exclusively to the Constructivist approach, whilst remaining silent on how this statement reflects the constructionist intents of Straussian grounded theory. Indeed, the Straussian approach seeks to better understand a particular social phenomenon within a specific context, and generate a substantive theory to provide some explanation of the associated actions and interactions, which is grounded in the research data.

Returning to the earlier assertion that Straussian methodology comprised "prescribed" procedures which "gave grounded theory an objectivist cast" (pp. 339, 401). Arguably, this characterisation is wholly unfounded, given that Strauss and Corbin had been consistently stating—in response to earlier critics (e.g., Melia, 1996)—that their procedures are offered as "guidelines, suggested techniques but not commandments" (Strauss & Corbin, 1998, p. 4); and later, Corbin further encouraged researchers to flexibly "use the procedures in their own way" (2008, p. x). Furthermore, Charmaz's tone appears to minimise the contribution of Strauss and Corbin seminal book. After firstly acknowledging *Basics of Qualitative Research* (1990, 1998, 2008, 2015) as being a path to qualitative success, and that the book "became something of a bible for novices" (p. 399); Charmaz seems to then lose interest on the basis that these self-same novice researchers "often interpreted the method in concrete ways that muted the social constructionist elements in the method" (p. 399). This remark is puzzling. The phenomenon of concrete thinking by novices as a precursor to later expertise and abstract thinking is widely understood by educators and academics alike (for further reading, see Dewey, 1997). Charmaz's shallow observation has no bearing on the legitimacy of the methodology itself, yet seemingly has been ostensibly presented as a weakness of Straussian grounded theory. For the enquiring reader, this might even be mistaken for fallacious rhetoric—and, indeed, active reading unearths more. Buried in the final pages of Charmaz's (2008) book chapter (under the *Notes*), we find the concession that "paradoxically, the social constructionist logic of Corbin and Strauss's (1988) empirical work often is apparent" (p. 409). And furthermore—coming to the most salient point—there seems to be nothing "paradoxical" about a set of procedural guidelines that fundamentally facilitate the very thing that they were devised to facilitate.

Having reviewed and countered historic *Constructivist questioning* of Straussian grounded theory as a credible constructionist approach, there is now a final look at the evident constructionist intent within the Straussian approach. Perhaps ironically, Constructivist grounded theory itself can be traced back to the earliest works of Strauss (1987), and Strauss and Corbin (1990, 1994, 1998). These works were underpinned by Strauss and Corbin's relativist position, and demonstrated their conviction that the researcher constructs theory as an outcome of their interpretation of the participants' stories. Arguably, Strauss and Corbin's focus on the provision of procedures and techniques for this process further confirms their constructionist intent. The central point of a grounded theory, the core category, integrates all of that theory's various aspects. Strauss and Corbin (1998) developed the process by which the core category is identified to acknowledge the role of the researcher as the author of a theoretical reconstruction. This occurs during the process of theoretical integration (see *5.8.4 Theoretical integration*). In particular, Strauss and Corbin achieved this through their exploration of the centrality of the story—their narrative rendering of the analysis—through to the eventual development of the core category. In writing a story about the analysis, Strauss and Corbin (1998) advocated that researchers describe their "gut sense" about the subject matter of the research (p. 150). The story line is the final conceptualisation of the core category, and as such, this "conceptual label" must fit the stories and data it represents (Strauss & Corbin, 1990, p. 121). This process acknowledges the reconstruction of the participants' stories by the researcher and the fulfilment of their obligation to "give voice—albeit in the context of their own inevitable interpretations" (Strauss & Corbin, 1994, p. 281).

This concludes the discussion of the rationale for using Straussian grounded theory method for the current study, which necessitated a constructionist standpoint. The next section now goes on to clarify the role of literature within this methodology.

4.5.2 Role of literature review

Across the different approaches to grounded theory method, there is some disagreement about the role that literature should play. Theorists who conduct an early review of the literature are seeking theoretical sensitivity and theory comparisons, as well as a background to and justification for the study. Indeed, theoretical sensitivity facilitates an awareness and understanding of the data, allowing researchers to approach the field of study better prepared for isolating the appropriate from the inappropriate information (McCann & Clark, 2003). Strauss and Corbin (1990) endorsed reviewing literature prior to and during the grounded theory process to establish areas requiring research (pp. 35, 56), to determine possible concepts and relationships for later verification against data (p. 50), and for suggesting possible ways to interpret the data collected (p. 51).

4.5.3 Development of Straussian ground theory method

Grounded theory method (GTM) was the innovation of Glaser and Strauss (1967) who developed the approach while studying the experience of dying patients. The GTM approach draws upon two conflicting notions, the philosophical standpoint of positivism and the sociological perspective of symbolic interactionism. Glaser's background in positivism provided a focus concerned with coding qualitative responses, whilst Strauss' training directed attention towards the active role of the people within the phenomenon under investigation. Thus, Strauss highlighted the perspicacity and richness of the qualitative approach to social processes and the intricacies of social life, whereas Glaser emphasized the systematic analysis integral to quantitative research through line-by-line analysis to generate codes, categories, and properties.

In their original book, The Discovery of Grounded Theory: Strategies for Qualitative Research, Glaser and Strauss (1967) only described the process of data analysis in loose terms. In view of this, Strauss (with Corbin) went on to publish a book (Strauss & Corbin, 1990) which specifically aimed at providing more guidance for data analysis. However, Glaser (1992) fiercely criticised the approach offered by Strauss as being incompatible with the original concept and purpose of GTM, and asserted that Strauss was in fact proposing an entirely new method characterised by "forced, full, conceptual description" (Glaser, 1992, p. 5). The central thrust of Glaser's rebuke was that the use of coding paradigms such as axial coding will force categories onto the data rather that allowing them to emerge; and to this end, Glaser further insisted that “there is a need not to review any of the literature in the substantive area under study” (Glaser, 1992, p. 31). This resulted in the now notorious split in grounded theory method, and the establishment of the ‘Straussian’ and ‘Glaserian’ models (Stern, 1994).

Seemingly, the divergence between Strauss and Glaser is rooted in their conflicting interpretations of their original work together. Glaser and Strauss (1967, p. 28) wrote: “generation of theory through comparative analysis both subsumes and assumes verification and accurate description, but only to the extent that the latter are in the services of generation.” Heath and Cowley (2004) argue that Glaser adhered to this original concept by focusing on induction and theory emergence. However, Strauss (1987; Strauss & Corbin, 1990) suggested that the importance of induction had been overstated, and instead emphasized the role of deduction and verification (Bryant & Charmaz, 2007; Heath & Cowley, 2004). Later, Strauss and Corbin (1998) indicate a shift in their thinking whereby they talk about deduction followed by validation and elaboration, but cease reference to verification. They define validation as “a process of comparing concepts and their relationships against data during the research act to determine how well they stand up to such scrutiny” (ibid., p. 24). Hence, researcher’s interpretations are to be checked out against the data, and where appropriate with participants, as the study proceeds (Corbin & Strauss, 2008). As such, the later presentation of Straussian GTM employs abductive reasoning (Bryant & Charmaz, 2007; Reichertz, 2007). Abduction is a form of logical inference that seeks the most plausible interpretation of observed data by first examining data, considering possible explanations for the observed data, looking for confirmation or disconfirmation until a credible explanation is reached (Bryant & Charmaz, 2007, p. 603).

Furthermore, the second edition of Strauss and Corbin’s (1998) book (published two years after Strauss’ death in 1996) responded to criticisms about their method being excessively prescriptive, “programmatic and overformulaic” (Melia, 1996, p. 370). It clarified their approach to data analysis and emphasized that their outlined procedures are offered as “guidelines, suggested techniques but not commandments” (1998, p. 4), and insisted that there had never been any intention to impose or encourage rigidity. In a third edition, Corbin (with Strauss) encourages even more flexibility, directing researchers to “use the procedures in their own way”

(2008, p. x). Whereas in a fourth edition, Corbin emphatically states that "analytic strategies are to be used flexibly, with understanding and with purpose" as a necessity for generating new knowledge of substance, asserting that thoughtful use of these strategies facilitate the required "sensitivity to the multilayers of meaning that are possible in the data" (2015, p. 102).

Indeed—whilst Glaser (1998, 2003), resolute that grounded theory should have remained unaltered, claims that the Glaserian approach stands alone as a conceptualisation method, with its roots in inductive quantitative analysis and theory construction—a review of the four editions of Basics of Qualitative Research (Strauss & Corbin, 1990, 1998; Corbin & Strauss, 2008, 2015) reveals that the representation of Straussian grounded theory has been progressively refined. Corbin (with Strauss, 2008, 2015) further acknowledges that their position on grounded theory has been shaped by current methodological debates.

4.5.4 Philosophical underpinnings of Straussian ground theory method

The philosophical underpinnings for grounded theory methods relate to symbolic interactionism. Symbolic interactionism is a social psychological theoretical perspective, introduced to American sociology in the 1920s by Philosopher George Herbert Mead (1934/2012; Blumer, 2004), that traces its origins back to Max Weber's (1914/2012) assertion that individuals act according to their interpretation of the meaning and purpose of their world. Interaction is at the core of symbolic interactionism, whereby an individual's circumstances are established through a shared understanding gained by interaction with others (Reynolds, 1990). These interactions are seen as symbolic, simply because some means (i.e., language, words, or symbols) is required to express meaning and enable interaction (Denzin, 2001). Moreover, the symbolic interaction perspective is concerned with subjective meanings that people impose on objects, events, and behaviours. Subjective meanings are privileged on the premise that behaviour is driven by what individuals believe, rather than just by what is objectively true. Hence, society is viewed as being socially constructed through human interpretation, whereby people interpret each other's behaviour, and these interpretations form social reality. Thus, symbolic interactionism contends that a symbolic world of learned meanings allows us to act and behave based on shared understandings (Charon, 1979; Herman & Reynolds, 1994). From this perspective, social reality is seen as a complex network of interactions between meaning-making people, whereby individuals’ self-definitions are shaped by others. We are seen to act on the basis of how we perceive others think and feel about us.

Hence, researchers who acknowledge symbolic interactionism as a philosophical underpinning for grounded theory method studies seek to comprehend how behaviours emerge from social interaction in a particular context. The aim being to discover the basic psychosocial processes underlying the behaviours and the meanings individuals give to their experiences of particular circumstances (Glaser, 1978). Accordingly, Straussian Grounded Theory Method (GTM) emphasizes the need to discover what is really going on in the symbolic world of participants by obtaining primary data, and that theory about the symbolic world, that is meanings, is generated from the data (Strauss & Corbin, 1998). Furthermore, commensurate with symbolic interactionism assumption that human beings act toward things on the basis of meanings that things have for them (Blumer, 1969), Straussian GTM assumes that people act on the basis of meanings (Strauss & Corbin, 1998). Moreover, the Straussian GTM notion that perspectives and social perceptions are defined, developed, negotiated, and contested through interaction (ibid.), resounds with the symbolic interactionism position that meanings emerge from interaction between people (Blumer, 1969), and that humans and society have a relationship of freedom and constraints (LaRossa & Reitzes, 1993). In addition, symbolic interactionism emphasizes that meanings are handled and modified through the interpretive process used by the person dealing with things he or she encounters (Blumer, 1969). Aligned with this, Straussian GTM reflects the complexity and variability of phenomena and of human action. It involves understanding and explaining how participants develop meanings, and how those meanings are influenced by other things, such as organisational factors, psychological factors, and social factors (Strauss & Corbin, 1998). Symbolic interactionism views the self as a social construct which is shaped by social interaction with others (Blumer, 1969), and that behaviour can be driven by self-concept (LaRossa & Reitzes, 1993). In keeping with this notion, Straussian GTM assumes that we are actors who take an active role in responding to problematic situations (Strauss & Corbin, 1998). In summary, as symbolic interactionism is a branch of interpretivism, grounded theory methods are underpinned by a philosophical position based on the assumption that people develop meanings to an event through experience and social interaction.

Thus, the meanings that people assign to these events eventually build their behaviour. Grounded theory methods therefore seek to explain psychosocial processes; and not only develop theory, but also modify and further develop existing theories (McCann & Clark, 2003).

4.6 Alternative data analysis approaches

Qualitative research methods enable researchers in the field of the health sciences to explore questions of meaning, investigate institutional and social practices and processes, ascertain obstacles to and enablers for change, and determine the causes of success and/or failure of interventions. The rationale for adopting a qualitative design, rather than using a quantitative approach, for this study was previously discussed in sections *4.3 Qualitative and quantitative methodologies* and *4.4 Rationale for selecting a qualitative approach*. However, there are many qualitative methods available, and choosing the most appropriate for answering research questions is crucial for achieving applicable research outcomes. Indeed, judicious choice of method directs the research toward the proposed aims and the production of creditable and useful findings. Accordingly, section *4.5.1 Rationale for using Straussian Grounded Theory Method* previously discussed the appropriateness of using Straussian Grounded Theory Method for this study. Nevertheless, there are various methodologies for conducting qualitative research, which as Smith (2004) explains, “have different and overlapping epistemological underpinnings and theoretical and methodological emphases” (p. 40). Two alternative approaches that were considered for data analysis are now reviewed with respect to the reasons that they were not selected for this particular study. These approaches are Interpretative Phenomenological Analysis and Foucauldian Discourse Analysis.

4.6.1 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is phenomenological in the sense that it aims to explore personal accounts of situations and circumstances rather than generate objective findings. Furthermore, IPA acknowledges understandings are contingent on the researcher’s own perceptions of another’s personal world through a process of interpretative activity. Therefore, two important theoretical underpinnings for IPA are phenomenology (which originated with Husserl’s (1929/1999) work to construct a philosophical science of consciousness) and the field of hermeneutics (which is concerned with theory of interpretation). Lastly, IPA takes an idiographic approach, with its focus on detailed analysis of a case either as an end in itself or before moving to similarly detailed analyses of other cases. Whilst IPA offers a means for exploring and better understanding the lived experiences of research participants, and indeed, goes beyond merely description to provide an interpretation of lived experience, IPA does not seek to explain a phenomenon nor generate a related theory. Thus, IPA was deemed inappropriate for answering the research question of the current study, whereas Straussian Grounded Theory Method is particularly focused towards explaining how and why particular circumstances occur (Lyons, 2007).

4.6.2 Foucauldian Discourse Analysis

Foucauldian Discourse Analysis (FDA) is concerned with how discourse constructs both people’s lives and the world they live in. Discourse is seen as a representation that reflects and perpetuates socially and culturally specific power relations (Willig, 2003). Thus, the nature and perceptions of experiences of the world are dependent on the discourses that are available to an individual (ibid.). This standpoint seems potentially relevant for better understanding stroke survivors’ experiences of living in a society where there is a predominant emphasis on the medical model of stroke recovery, and some lack of professional and public awareness about the psychological and emotional consequences of living life post-stroke. Furthermore, consistent with the epistemological position of this study, FDA is underpinned by a social constructivist perspective whereby knowledge is understood as being constructed rather than discovered. However, FDA emphasizes the role of discourse, asserting that discourses facilitate and limit, enable and constrain what can be said by whom, where and when (Willig, 2003). Although both FDA and Straussian Grounded Theory Method (GTM) approaches aim to produce research that can be used to guide action and improve the situation of the particular groups under investigation, the focus of FDA tends to be more abstract and more political than those of Straussian GTM. Indeed, Straussian GTM primarily aims to expound theories which remain located in the data, and are attuned to the lived experiences and understandings of the research participants, as well as having potential to guide action. Thus, Straussian GTM approach was deemed to be more appropriate than FDA for data analysis in this current study.

4.7 Data collection methods

4.7.1 Semi-structured interview

This study gathered data using semi-structured interviews. There are many ways to collect data for a grounded theory study, and naturally the researcher reviewed a number of different approaches for gaining insights into the lived worlds of the research participants, including unstructured interviews, personal diaries, focus groups, and semi-structured interviewing. A review of these approaches revealed that semi-structured interviewing is regarded as a particularly useful data collection method across a variety of qualitative research methods. Often semi-structured interviews are conducted face-to-face between the researcher and the research participant, on a one-to-one basis. The interview schedules are recognised for facilitating rich verbal accounts, whereby the researcher can pursue salient and significant issues. Questions are typically open-ended and structured to elicit in-depth responses. Indeed, the semi-structured interview is the most recognised interview classification in phenomenological research (Langdridge, 2007, p. 65).

For phenomenological research the interviewer will ask research participants to describe and reflect upon their subjective lived experiences in a manner that is rarely encountered in the course of their everyday life. Accordingly, Charmaz (2006) advises that semi-structured interviewing allows for “an in-depth exploration of a particular topic with a person who has had the relevant experiences” (p. 25), and provides a means to draw out each participant’s own interpretation of these experiences. Furthermore, Charmaz contends that “qualitative interviewing fits grounded theory methods particularly well . . . [as both] . . . are open-ended but directed, shaped yet emergent, and paced yet flexible approaches” (2006, p. 28).

Indeed, semi-structured interview schedules can be used in a highly flexible manner. Often in depth interviewing for qualitative studies does not dictate the direction of the interview. However, such is the flexibility of using semi-structured interview schedules that the focus of interviewing for grounded theory studies can be purposefully shifted as data gathering proceeds from one interview to another. This allows the researcher to narrow the areas of exploration and collect data for developing theoretical frameworks.

The semi-structured interview schedule (*see Appendix 2*) for this research was devised using the guidelines provided by Corbin and Strauss (2015) and Charmaz (2006) for conducting grounded theory studies.

4.7.2 Interview transcription

The semi-structured interviews conducted for this study were audio recorded and transcribed by the researcher to capture some of the idiosyncratic aspects of speech, but without attempting to transcribe every utterance and event in as much detail as possible. It is acknowledged that the transcriptions of the interviews form the foundation of the study, not only for the research analysis itself, but also for demonstrating evidence of that analysis (Duranti, 2007). A corollary of this is that the quality and trustworthiness of the transcriptions is fundamental for the validity of this study.

The quality and trustworthiness of qualitative research is enhanced by reflective practice (Fontana, 2004) and transparency (Yardley, 2000), amongst other means. Consistent with this notion, the literature on transcription for qualitative studies advises the researcher to engage with reflexive transcription practice, and to detail the transcription process in the written accounts of the study. Thus, the researcher needs to be aware of their interpretative effect on the development of the transcripts, and the effect of the transcribing process as a whole on the representation of participants' accounts. Indeed, Oliver, Serovich and Mason (2005) advise that "transcription is a powerful act of representation . . . [thus] this representation can affect how data are conceptualized" (p. 14). Accordingly, for this current study the researcher has sought to clearly and transparently articulate the reflective process and the choices made with respect to the transcription process (Bucholtz, 2000, 2007; Lapadat, 2000). Hence, these reflections are reviewed in the section that now follows.

4.7.3 Reflections on transcription style

Oliver, Serovich and Mason (2005) warn researchers against transcribing recorded data without first considering transcription style, lest the resulting work fails to match the design of the study. They noted that transcription styles can be viewed on a spectrum, with naturalism (aiming to capture as much detail as possible) at one extreme, and denaturalism (disregarding any idiosyncratic elements of speech such as stutters, pauses, nonverbals, and involuntary vocalizations) at the other.

Grounded theory method studies tend to employ denaturalised transcription styles (Oliver, et al., 2005), where data collection is approached with an interest in meanings and perceptions rather than focus on *how* speech is used or ideas are conveyed. Hence, there is curiosity about meanings within, rather than the mechanics of, language. That is, focus is on the experiences and perceptions themselves, not *how* they are communicated.

However, Schegloff (1997) advises that when transcription attempts to closely reflect actual speech then the participants' words are privileged, and a priori assumptions are reduced. And this has particularly relevance for this study, as "the essence of counselling psychology is its belief in the value of subjective accounts of experience" (Woolfe et al., 2010, p. xxii). Moreover, attending to how participants communicate their experiences and perceptions can actually be useful for capturing meanings (cf. Mehan, 1999). Indeed, elements of speech that are not actual words are nevertheless language. Research has shown that certain mono- or bi-syllabic vocalizations sounds such as *Hm*, *Okay*, *Ah*, *Yeah*, *Um*, *Er*, can provide important insight into not only how someone converses, but also provide fundamental informational content for understanding meaning (Gardner, 2001).

Therefore, although denaturalised transcription seemed most compatible with the constructivist stance of this grounded theory study (Oliver et al., 2005), it does not privilege the participants' voices. Equally, naturalised transcription which aims to capture every intricacy of spoken language seemed inappropriate, as the study was neither focused on conversational analysis, nor aligned with the interpretive notion that language represents the real world.

With these considerations in mind, it was decided to aim for the middle ground, where transcription would include an essence of idiosyncratic elements of speech information (limited to: mono- and bi-syllabic vocalizations, stutters, irregular grammar, laughter, and any significant periods of silence) without pursuing a systematic capture of every intricacy. In this way the participants' voices would not be overly-filtered, whilst primary focus fell on a curiosity about meanings and perceptions.

4.7.4 Sampling for Straussian Grounded Theory Method

Straussian Grounded Theory Method (GTM) employs two types of sampling, purposive and theoretical sampling. Initially purposive sampling is used to find participants for whom the research question will be significant, and initial data is collected. Straussian GTM employs a cyclic approach of data collection and analysis, hence the initial data collected is analysed and further decisions about the sampling is made based on the emerging theory. This later sampling is known as theoretical sampling, and the new data collected facilitates comparison of the emerging categories.

4.7.5 Sample size considerations

The aim of a qualitative study is to generate concentrated, genuine descriptive accounts of experience and behaviour. Usually qualitative research involves the transcription of audio recordings of interviews, and every hour of recording can require around four hours of transcribing, and therefore this approach can become very time consuming. Consequently, when too many participants are recruited, it becomes impractical to fully utilise their contributions in the research report. Furthermore, it is important to acknowledge that large numbers are not essential for valid research (McLeod, 2003, p. 30). Indeed, where the purpose is to understand common perceptions and experiences among a group of relatively homogeneous individuals, twelve interviews have been sufficient for most research studies (ibid.).

Non-probabilistic sampling often takes the form of purposive samples where size is typically determined by the point at which no new information or themes are observed in the data, known as the concept of saturation. Despite being a useful conceptual notion, using saturation to determine sample size does not readily allow for estimating sample size prior to data collection. That said, the research domain and corresponding recruitment criteria for participants can provide some indication of required sample size, as greater sample homogeneity is likely to yield similar accounts of experiences, and thus achieve saturation more readily than a research sample of lower homogeneity. The current study recruited a participant sample that was homogeneous in terms of the participants being adult male stroke survivors of working age who are at least one year post-injury. Based on the likely similarities in experience due to the recruitment criteria, and the sampling outcomes of other studies, it was expected that the current study would generate an empirically exhaustive dataset within twelve interviews (Guest, Bunce & Johnson, 2006).

Nevertheless, opinions about sample size have varied widely between leading theorists. For instance, Glaser (1998) and Stern (1994) have contended that small samples and limited data need not necessarily restrict the development of conceptual categories and the links between such categories. In contrast, Charmaz (2006) advocates larger sample sizes, suggesting that “a study of 25 interviews may suffice for certain small projects” (p. 114).

However, Steward (2006a) advises that “more does not mean better” (p. 42), as it is deemed to be unethical to involve participants whose contributions are not needed. This latter consideration seems particularly applicable to this current study in terms of avoiding surplus recruitment, as heightened ethical sensitivity seems warranted when recruiting from a vulnerable population, such as individuals who have suffered brain injury due to stroke.

Returning to the question of sample size and conceptual saturation for grounded theory methods, Thomson (2011) conducted a literature review of 100 grounded theory methods studies (selected from the period between 2002 and 2008). The findings revealed that conceptual saturation usually occurs between 10 and 30 interviews, although it was also noted that 12 of the 100 studies reached this point after less than 10 interviews (ibid.).

4.8 Validity

In terms of the validity of a qualitative study, Langdridge reminds us that “it is absolutely vital that qualitative research is conducted in a systematic and rigorous manner” (2007, p. 80). And correspondingly, Corbin and Strauss (2015) emphasize the importance of evaluating the quality of a qualitative study, and the plausibility of the explanation it provides about the phenomenon under investigation.

Validity implies that there is trustworthiness to the findings established through evidence that the research was conducted under conditions of rigour (Meadows & Morse, 2001). However, Finlay (2009) highlights that qualitative findings are inevitably “partial, tentative, ambiguous, fluid and open to multiple interpretations and emergent meanings” (p. 7). Nevertheless, although the researcher will inevitably have some influence over the findings of a qualitative study, there are a variety of procedures that have been designed to enhance the validity of such studies. Indeed, this current study utilises a series of procedures that have been proposed by Yardley (2000) to reduce the extent of conflation between the worldviews of the researcher and the participant, in order to obtain a more accurate and less biased observation of the participant’s reality, and thus improve the validity of this study. These procedures comprise five aspects, namely, *Sensitivity to Context*, *Commitment and Rigour*, *Coherence and Transparency*, *Impact and Importance*, and *Triangulation*. Details of how validity was accounted for in this study are provided under section *5.8.11 Validity* within the next chapter, *Research Procedures*, which follows next.

5. Research Procedures

5.1 Introduction

The previous chapter outlined the research design and discussed the methodologies and methods selected for answering the research question of this current study. This chapter goes on to provide a detailed account of what research procedures were performed, how these procedures were conducted, and the underlying ethical and theoretical considerations. But firstly, in the section that now follows, consideration is given to challenges that may arise and appropriate adaptations when specifically interviewing survivors of stroke.

5.2 Considerations and adaptations for interviewing

Undoubtedly, preparation for interviewing research participants is important for ensuring that ethical standards for research practice are met, and that the data collection is of an appropriate quality for permitting analysis that could answer the research question itself. Moreover, such preparation is especially important when investigating the lived experiences of vulnerable groups such as survivors of stroke. Indeed, qualitative inquiry acknowledges the effect of the researcher on all aspects of the process (Cheek, Onslow & Cream, 2004); and when interviewing stroke survivors (who will likely suffer sequelae impairing cognitive, emotional, and communicational functioning), the onus on the researcher to provide a safe and supportive environment for the participant is correspondingly intensified. Certainly, communication impairment is common following stroke (O'Halloran, Worrall & Hickson, 2009), both at the micro-linguistic level (e.g., lexical errors, word-finding difficulties, or difficulties with syntactic organization), as well as at the macro-linguistic level (e.g., difficulties with cohesion and coherence, including topic management and accuracy), and when responding to or comprehending auditory information (Galetto, Andreetta, Zettin & Marini, 2013). Additionally, communication difficulties can be associated with cognitive impairments due to negative impact on learning, memory, problem solving, and speech, and/or altered perceptions (McDougall, 2000). Such changes can often be subtle, difficult to assess, and certainly affect individuals in differing ways. For the current study, with the aforementioned concerns in mind, consideration and preparation for the interview process particularly focused on three main areas; namely, shaping and facilitating the interview process, designing a debrief procedure, and planning for distress management. Each of these areas are now reviewed in turn.

5.2.1 Shaping and facilitating the interview process

Smith, Flowers and Larkin (2009) are clear and emphatic that the most important task when beginning an interview is to establish rapport with the participant. They advise that a participant "need[s] to be comfortable with you, to know what you want and to trust you" (p. 64). And they caution that "unless you succeed in establishing this rapport, you are unlikely to obtain good data from your participant" (p. 64). Accordingly, it follows that when interviewing individuals with cognitive and/or communication impairments the researcher should have sufficient knowledge about these impairments and their potential impact on all areas of the interview process; including, not least, the task of building rapport. Regarding the current study, the researcher's competencies for interviewing stroke survivors were developed and honed over the course of a decade, with caseloads which often comprised clients with cognitive difficulties, behavioural issues, and acquired brain injuries; indeed, the impetus for this current study stemmed from contemplating this work experience (for further details, see *1.2 Introducing the researcher*).

The recruitment process for this study included a preliminary meeting with each participant prior to the research interview (see *5.4 Recruitment*). Not only did this meeting allow the researcher to apprise participants of the interview procedures in advance (as advocated by Paterson & Bramadat, 1992), but it also created a valuable opportunity for the researcher to start developing rapport with the participants. Particularly regarding participants with brain injury, Lynch and Kosciulek (1995) pointed out that a pre-interview meeting can serve various purposes for supporting the research interview. Accordingly, the current study used the opportunity afforded by the pre-interview for the following aims: to familiarise participants with the environment where the research interview would take place (as it would be in the self-same room); to discuss any preference for a particular weekday, or time of day to be interviewed (e.g., to take into account any patterns of fatigue); to gauge participants' tolerance of extraneous stimuli related to the interview room (e.g., the lighting conditions, ambient noise levels, etc.); and informally assess participants' recall and attention span, to gain insights about supporting the interview process.

Indeed, concerning informal assessment, depending on post-stroke sequelae, participants may misinterpret or forget questions, offer incomplete answers, loose focus, or use speech that is difficult to follow and comprehend (Carlsson, Paterson, Scott-Findlay, Ehnfors & Ehrenberg, 2007). Thus, interviewing individuals with cognitive and/or communicative difficulties can lead to fatigue, not only for participants, but also for the researcher. Hence, to remain responsive and reflective throughout the interview, the researcher was mindful of the need to remain attentive during the interview, and be willing to possibly experience some level of fatigue. Importantly, the researcher was watchful for signs of any fatigue in the participant, and facilitated breaks accordingly. The researcher was also prepared for the expected “long stretches of silence, false starts and the fact that information may not seem obviously intelligible or relevant to the interests of the researchers” (Kirkevold & Bergland, 2007, p. 74); and ready to assist participants with sustaining their train of thought, for instance, with use of prompts or brief summaries (Bronken & Kirkevold, 2013).

5.2.2 Designing a debrief procedure

Arguably, ethical considerations demand that a debriefing session should be part of designing any research project involving human participants; but that said, Paterson and Scott-Findlay (2002) have been especially insistent about this requirement when survivors of brain injury are involved. Indeed, debriefing after an interview provides the participant with an opportunity to give feedback about their experience of the research process and to further discuss matters of personal interest or need. In the current study, debriefing gave participants the opportunity to discuss their reactions to, and thoughts and feelings about, the interview experience (as advocated by others, e.g., Meyer, 2013). Thus, debriefing provided a space for participants to voice any emotional impact and facilitate a dialogue about how the participant might deal with the emotional effects of the interview. As espoused by others in the field of brain injury research (e.g., Carlsson et al., 2007; Paterson & Scott-Findlay, 2002), the consent form clearly stated that a debriefing session would be offered and that the researcher would be available to discuss possible resources and/or strategies for mitigating any negative emotional impact due to their participation (for fuller details, see *5.3.3 Briefing, informed consent, debriefing*).

5.2.3 Planning for distress management

Participants can respond both positively and negatively to an interview focused on exploring their life events and lived experiences (Cowles, 1988). Hence, particularly when focus is on sensitive phenomenon (e.g., stroke survival and post-stroke sequelae), a principal concern is the potential for provoking emotional responses that are distressing for the participant (McCosker, Barnard & Gerber, 2001). Consequently, clear protocols need to be included in research proposals and submissions to Ethics Committees that outline how risk is minimised for participants. The protocol for this current study contains guidelines about recruiting participants (see *5.4 Recruitment*), arranging and conducting interviews, protecting the physical safety of the participant and researcher, terminating the interview, and debriefing (see *5.3.3 Briefing, informed consent, debriefing*).

However, as Paterson and Scott-Findlay (2002) highlighted, despite such thorough preparation, events might occur prior to or during the interview that diminish a brain injured participant's ability to reply to questions (see preparations for interviewing in *5.2.1 Shaping and facilitating the interview process*) and/or result in emotional distress. In response to risk of incidences of emotion distress, a Distress Protocol was established to ensure the researcher was well placed to deal with any distress that participants may experience during their involvement in the interview process (see *5.3.4 Distress Protocol*).

Following on from the design considerations explored in this section, the next section now goes on to specifically provide more detail about the study's ethical considerations.

5.3 Ethical considerations

5.3.1 Ethical awareness

This research was conducted with practice informed by the British Psychological Society (2009) Code of Ethics and Conduct.

5.3.2 Ethical approval

Ethical approval for this study was granted by the Ethics Committee at the New School of Psychotherapy and Counselling (*see Appendix 3 for Ethics Approval Letter*).

5.3.3 Briefing, informed consent, debriefing

Potential participants were provided with a detailed *Participant Information Sheet* (*see Appendix 4*) and a *Written Informed Consent* form (*see Appendix 5*) at least one week prior to the interview to provide adequate time for making a decision about whether to provide consent and take part in this study. The *Participant Information Sheet* provided participants with a summary of the study, along with contact details for both the research supervisor and the academic principal in the event they wanted to raise any concerns about the conduct of the study. Potential participants were advised that they could decline to answer any question that they did not want to answer; and furthermore, that they could withdraw from the study at any time without any obligation to explain their reasons for doing so, and that any information and data that they had provided would be destroyed.

Participants were advised that the research project was being conducted as part of a doctoral qualification, and that papers based on the study may be published at some point in the future. Accordingly, this information was provided in the Participant Information Sheet; and the Written Informed Consent form, and specifically requested consent to allow use of data in any subsequent publication.

The audio recorded interviews were conducted at Headway premises. To ensure the personal safety of both the researcher and participants, the interviews were arranged with the participants' keyworkers, and other healthcare professionals at the premises were aware of the time of interviews and the meeting room in which they were being held.

It was acknowledged that sensitive issues may arise for participants during the interview. Therefore participants were advised that they would be offered a debrief after the interview, and presented with details of local organisations that could provide advice and support (*see Appendix 6 for details of the Debrief Sheet*). Further, participants were advised that there would be an opportunity to voice their thoughts and feelings about their interview experience, to explore any related concerns they may have, and to discuss resources and/or strategies for mitigating any resulting adverse emotional effects. Additionally, participants were advised that the researcher reserved the right to end the interview if the participant appeared to be experiencing undue distress or discomfort.

5.3.4 Distress Protocol

Before potential participants decided whether or not to take part, the researcher ensured they were made fully aware of the possibility of them experiencing emotional distress due to their involvement in the study. To support participants with any emotional difficulties they might experience, a distress protocol (*see Appendix* 7) was developed to monitor and manage this possibility.

5.3.5 Confidentiality and anonymity

Participants were advised of the steps that had been taken to ensure confidentiality and to preserve anonymity. This was made explicit in the Participant Information Sheet and the Written Informed Consent form, which specified how the information provided by the participant would be handled. Accordingly, following an interview the digital files were deleted from the recorder after being transferred to an encrypted USB stick, and during the transcription process the researcher either removed or changed any information that could result in the identification of the participant. During the analysis stage each participant was given a pseudonym to allow ease of discussion while still maintaining anonymity. Information to link a participant with their interview data was held separately and securely. Participants were informed that if the research is published then excerpts from their data may be used verbatim as anonymous examples, that is, without using any identifying details such as people's names, place names, and organisations' names.

A risk assessment for the interview process was completed by the researcher to identify potential hazards. Precautions and control measures were devised to reduce the identified risks to an acceptable level. The focus of this process was on safeguarding the wellbeing of the researcher and research participants, and concerned participants becoming distressed or aggressive, or experiencing physical health issues. Refer to *Appendix 8* for the completed *Risk Assessment form - FRA1*.

5.4 Recruitment

Headway is a leading organisation for supporting people with brain injury. To recruit participants for this study *Participant Recruitment Posters* (*see Appendix 9*) were displayed in a branch of Headway, after obtaining permission from the branch service manager. Over a three-week period, the recruitment poster yielded responses from three potential participants. The researcher initially met with all three respondents individually at the Headway premises in a quiet office space, and provided them with a copy of the *Participant Information Sheet* (*refer to Appendix 4*) and the *Written Informed Consent* form (*see Appendix 5*). The researcher verbally went through the information sheet and consent form with each respondent to apprise them of the aims and purpose of the study, their potential role in the research process, and their rights and the researcher's responsibilities towards them. For further details on the key points of the information sheet and the consent form refer to the previous section *5.3.3 Briefing, informed consent, debriefing*. During the initial meeting the researcher ensured that the participants understood and met the participation criteria, and provided opportunities for the potential participants to ask any questions about the study and their potential participation. The researcher informally assessed the respondents' understanding of the information that was being provided, and sought to ensure that the respondents did not feel coerced to take part. At that time, all three respondents expressed a willingness to participate. The respondents were asked to take the information sheet and consent form away with them and consider whether they would still like to participate after giving it some more thought over the next week or so. Within two weeks of these initial meetings all three respondents had confirmed their decisions to participate. The first respondent to confirm their participation was recruited for a pilot study, while the other two potential participants were advised that their participation would be appreciated following the completion of a pilot interview. The researcher established the availability of the self-same quiet office space used for the initial meeting, and arranged the pilot interview for a time most convenient for the participant. To comply with the risk assessment and management plan (*see Appendix 8*), the Headway branch service manager and the participant's keyworker were informed of the interview arrangements. After conducting the pilot interview, the data was analysed using Straussian Grounded Theory Method; see *Chapter 6 - Pilot study* for the results of the initial data analysis. The results from the pilot study indicated to the researcher that the interview schedule was appropriate for eliciting rich data that was potentially relevant for answering the research questions of this study, and thus further recruitment was conducted.

5.5 Participants

5.5.1 Sample size

The tentatively proposed sample size for this study was ten to twelve participants. However, grounded theory studies should aim for *conceptual saturation*. Simply put, the point of conceptual saturation is reached when new data does not change the emerging theory. As such, researchers cannot make any definitive decision about sample size until they are engaged in data collection and analysis (Corbin & Strauss, 2008, 2015; Strauss & Corbin, 1998; Glaser & Strauss, 1967), that is, researchers must allow the data to determine the sample size. For a full review of the researcher's consideration of sampling and sample size refer to the previous sections: *4.7.4 Sampling for Straussian Grounded Theory Method* and *4.7.5 Sample size considerations*. In the current study conceptual saturation was deemed to have been achieved after interviewing ten participants.

5.5.2 Inclusion and exclusion criteria

The inclusion criteria for participants in this study were as follows:

- adult men of working age who have survived a stroke,
- an adult (18 years and older) at the time of the stroke event,
- aged between 18 and 65 years old at the time of interview,
- minimum of one year post-stroke,
- proficient in the use of the English language,
- accessed neuropsychological rehabilitation services at a branch of Headway,
- high-level cognitive functioning (measured by neuropsychology assessment conducted by practitioners at Headway), and
- self-reporting as willing and able to share their personal experiences of emotional difficulties since their stroke.

The exclusion criteria for participants in this study were as follows:

- individuals with a severe and enduring mental health diagnosis currently under the care of a psychiatrist.

5.5.2.1 Inclusion criterion re: upper age limit

This study is concerned with men of working age, where the cut-off point for the purposes of this study is the UK state pension age. At the time of this study the state pension age for males was 65. For a discussion on age and gender relating to stroke refer to previous section *2.7 Age and gender relating to stroke*.

5.5.2.2 Rationale for inclusion criterion re: time post-stroke

Headway (2017) advises that “after a year or so one can be reasonably certain about the eventual degree of physical recovery. However, psychological recovery can take considerably longer and it is usually these more subtle psychological problems that cause longer-term difficulties” (para. 6). With this in mind, side by side with the contemporary neuroscientific views in relation to duration of organic recovery (for a review, refer back to section *2.5 Neuroplasticity and duration of organic recovery*), it was reasoned that recruiting participants who are at least one year post-injury would plausibly comprise a group that is more likely to be facing a particular set of existential issues and emotional difficulties.

5.5.2.3 Neuropsychological assessment

Cognitive functioning was assessed by practitioners at Headway. Neuropsychological assessment was performed by an occupational therapist or an experienced ABI rehabilitation worker. The assessment process considers subjectively reported information, including that provided by the referrer, key worker, carers, and/or close relatives, as well as the following clinical measures for determining the client’s level of functioning:

- Montreal Cognitive Assessment (MoCA; Nasreddine, n.d.).
- The Addenbrooke’s Cognitive Examination Revised (ACE-R; Mioshi, Dawson, Mitchell, Arnold & Hodges, 2006).

(*See Appendix 10 for further details of these assessments*).

5.5.2.4 Medical information about participant’s brain injury

This research does not seek to necessarily include detailed information about the participants’ brain injuries in terms of the specific sites of organic damage. As the research is concerned with the subjective experiences of the participants, details of the brain injury itself are not the focus of this existential-phenomenological research. Incidentally, such specialist information about the participants would not be routinely available as this study is recruiting from a social healthcare ABI rehabilitation setting where clients do not typically have neuropsychological assessments that include neuroimaging.

5.6 Materials

5.6.1 List of materials and documents

Participants were interviewed at Headway premises, in a quiet office space which was free from disturbance. The materials used before, during and after the interview included the following:

- Digital audio recorder
- Interview Schedule (*see Appendix 2*)
- Participant Information Sheet (*see Appendix 4*)
- Written Informed Consent form (*see Appendix 5*)
- Debrief Sheet (*see Appendix 6*)
- Distress Protocol Sheet (*see Appendix 7*)
- Participant Recruitment Poster (*see Appendix 9*)

5.6.2 Overview of materials and documents

The semi-structured interview schedule (*see Appendix 2*) for this research was devised using the guidelines provided by Corbin and Strauss (2015) and Charmaz (2006) for conducting grounded theory studies. It was noted that Corbin and Morse (2003) advise that unstructured interviews yield dense data, and accordingly the key questions were worded in a broad, open-ended style facilitating the capture of rich original data (Gomm, 2008; Langdridge, 2007; Smith, Flowers & Larkin, 2009). Indeed, Smith et al. (2009) assert that an interview schedule should be designed to promote circumstances whereby the participant feels more able to speak freely, with little or no prompting. Furthermore, the schedule should include both general and specific questions with the interview proceeding seamlessly between the two, where specific questions are only used as prompts, if necessary.

For further information on the Participant Information Sheet, Written Informed Consent form, and Debrief Sheet refer to previous section *5.3.3 Briefing, informed consent, debriefing*. For details on the Distress Protocol document see *Appendix 7*; and for the Participant Recruitment Poster see *Appendix 9*, while referring to the previous section *5.4 Recruitment*.

5.7 Data collection and preparation

5.7.1 Data collection process

Before an interview began the participant was asked if any questions had arisen for them as a result of reading and considering the *Participant Information Sheet* (refer to *Appendix 4*) and the *Written Informed Consent* form (*see Appendix 5*) that had been provided to them at least one week previously. Accordingly, any questions that had arisen were addressed. The participant was then asked to re-read and sign the *Written Informed Consent* form.

The interview itself was recorded using a digital audio recorder. The interview schedule (*see Appendix 2*) was used to assist with directing the interview and providing prompts, where necessary. Interviews lasted for approximately one hour (mean duration was 53 minutes). At the end of an interview the researcher thanked the participant for his involvement, before providing the participant with a debrief sheet (*see Appendix 6*). The debrief sheet covered several points: firstly, it thanked the participant for taking part; secondly, it invited the participant to contact the researcher with any concerns and queries, or any requests for a summary of the findings of the study; thirdly, it provided contacts for making a complaint about the research process; and finally, it offered suggestions for accessing support in the event the interview process had raised any sensitive issues for the participant that the interviewer was unaware of, or was unable to address. The researcher went through the debrief sheet with the participant to ensure the participant was aware of its content and purpose, and encouraged the participant to take the debrief sheet away with him.

After each interview additional notes were made to capture immediate personal observations and reflections concerning the interview, which may not have been captured by audio recorder (*please refer to Appendix 13 for an example of post-interview notes*). As Wengraf (2001, p. 47) states, “there is so much more to speech interaction . . . than just words of transcript”. By making notes immediately after an interview it was hoped that any thoughts, ideas and questions experienced by the researcher as a result of the interview process could be captured and then later used to inform the analysis; along with notes about any non-verbal whole body language communications that took place to ensure congruence across the verbal and non-verbal experiences.

5.7.2 Transcription

The transcriptions of the audio recordings was completed by the researcher. This process contributed towards the analysis of the data as the researcher became thoroughly familiar with the interviews. The first stage of the transcription process was to listen to the interview and make notes. Wengraf (2001) suggests that during the first listen memories flood back and thoughts are provoked, and this information was captured in memo writing (*for an example see Appendix 14: Memo Writing – First Listen*). The interview was then transcribed verbatim, including the interviewer’s speech, in a *Microsoft Word* document. As previously mentioned, during the transcription process the researcher was mindful to remove any information that could result in identification of a participant. Each line of the transcript was assigned a number for reference purposes.

5.8 Data analysis process

Data analysis was performed using guidelines offered by Corbin and Strauss (2015) for conducting Straussian Grounded Theory Method (GTM). These guidelines outline the stages of analysis and the recommended procedures for each stage. The stages of analysis include the *first reading*, *open coding*, *axial coding*, and *theoretical integration*, which in turn leads to formulation of theory. Other related activities include *memo writing*, *theoretical sampling*, and determining *conceptual saturation*. How each of these stages of the data analysis process were performed is detailed under this section.

5.8.1 First reading

The first step taken towards analysing a transcript involved reading it from beginning to end, often referred to as the *first reading*. The purpose was to gain further insight into the participant’s subjective lived experiences. As such, this reading did not involve making notes, or marking the transcription in any way (e.g., writing in the margins, or underlining text).

5.8.2 Open coding

The next stage of analysis involved breaking down the data and establishing concepts that represented chunks of raw data, referred to as *open coding*. The transcription was typed up on a Microsoft Word document, and the subsequent analysis of the transcription was conducted using Microsoft Word processing. Firstly, each line of the transcription was assigned a line number, effectively breaking apart the data and numbering it so that later coding could easily be traced back to the original data, and therefore readily be evidenced as being grounded in the raw data. The process of open coding was conducted by re-reading the transcription and typing codes against relevant lines or blocks of the data to delineate concepts that represent those blocks of data. Often the natural breaks in the transcript were used as delimiters for breaking the data into manageable pieces. These blocks of data were read in search of the answer to the repeated questions: ‘*What is this about?*’ and ‘*What is being referenced here?*’ to explore, seek out and interpret any ideas that they might support. These ideas were given conceptual names that characterised the identified essence or meaning within the block of data.

The Microsoft Word document used for the open coding comprised four columns: the first column contained the incremental line number of the transcript; the second column indicated whether the line of transcription related to the spoken word of the interviewer or the respondent, denoted by a letter ‘I’ for the interviewer and a ‘R’ for respondent (i.e., the research participant). The source of speech was further delineated by light grey shading on the lines of transcription relating to the interviewer; this was added to facilitate the re-reading and coding process. The third column of the Microsoft Word document contained the lines of transcript itself, and the fourth column allowed for codes to be typed against a line, or block of lines, of transcript. Refer to *Appendix 11: Sample of open coding*, for an example page of transcription and opening coding.

5.8.3 Axial coding

Axial coding is the process of linking concepts or categories, via a combination of inductive and deductive thinking. Once the open coding process was completed for the first interview, in terms of assigning initial codes to blocks of raw data, a copy of the Microsoft Word document was made to preserve a record of the open codes against the transcription. The original Microsoft Word document was then used to facilitate the development of axial codes, which involved grouping open codes together under a related concept to form a more abstract category. This process began by deleting two columns in the document: the second column which indicated whether the line of transcription relates to the interviewer or respondent, and the third column which held the transcription data. This resulted in a document that contained only the open codes and their associated transcript line number. For ease of processing, these two pieces of information where amalgamated, whereby the transcript line numbers were placed within parenthesis and then prefixed to the open codes they had been associated with. The first column that originally held the line numbers was then deleted. This left a list of open codes which could readily be linked back to the line of transcription data that they originated from.

Additionally, as the open codes from different participant interviews would be clustered together, a unique reference number for each participant was prefixed to the line number. For example, the interview with Ryan (pseudonym) yielded the open code: *'Not wanting anyone to see me as I am'* which was derived from transcription line 106, and was therefore represented as follows: *(106) Not wanting anyone to see me as I am*. Ryan's interview data was assigned a reference of P01, which was therefore added to the open code as follows: *(P01.106) Not wanting anyone to see me as I am*; thus allowing every open code to be traced back to both the participant it originated from and the transcription line that generated it.

Even though the first interview alone yielded as many as 391 open codes, after formatting these open codes as detailed above, the codes could be easily moved within the Word document (using the cut and paste function), which allowed the researcher to start readily clustering open codes together. Codes were clustered where similar properties and characteristics were identified, or when properties and characteristics across codes could be meaningfully related together in response to persistent questioning by the researcher concerning the data, such as: '*What is this about?*' and '*What is being referenced to here?*'

During this stage, as groups of codes began to emerge, group properties and group characteristics for each cluster were developed and documented. As this process progressed for the first participant, all the original open codes were finally clustered across 56 groups. Following further analysis, each group was assigned a name that reflected an overarching concept for that group. These groups of concepts were documented as memos, which comprised the conceptual name, the raw data, and the analysis. The analysis included characteristics that defined and described the concept, which are often referred to as properties of the concept. Indeed, it was the variations within these properties that provided specificity and range to the concept, often referred to as dimensions. Next these groups of concepts where further explored and reviewed and organised to identify any links between them that allowed further clustering at this level. This process resulted in 22 higher level groupings, or categories, with each group assigned a conceptually higher level group name.

Throughout the coding process, memo writing continued to illustrate the links between the categories that were developed and the raw data. For an example of a category that emerged from the raw data, refer to *Appendix 12: Sample of axial coding*, which shows repeated axial analysis resulted in the clustering of six groups under one category which was given the concept name: *Feeling like a failure*. The example illustrates that the open codes from the raw data were clustered together under the following six groups, or properties: *Pre-stroke relationships*, *Role as a father*, *Self-critical voice*, *Employment*, *Struggling with acceptance of failure*, and *What is or is not a failure*.

These procedures for axial coding were repeated for each additional interview that was conducted, analysing the open codes with reference to extant axial codes. As more interviews were completed and the axial coding progressed, it facilitated greater abstraction. Thus, this process reduced the number of units to work on, whilst increasing density, dimensionality, and analytic power of the higher-order categories.

For an illustrative example of how the researcher engaged with the axial coding process to organise, structure, and manage the open codes, and provide evidence to support the emergence of increasingly abstract and higher level categories (using the functions and approaches detailed a little later in section *5.8.5 Use of Microsoft Word functions*), refer to *Appendix 17: Axial coding – categories/ concepts grounded in data*.

5.8.4 Theoretical integration

Theoretical integration involves choosing one category to be the core category, and relating all other categories to that category. The essential idea is to develop a single storyline around which everything else is linked, and also involves refining the resulting theoretical construction. Hence, this process is performed towards the end of the data analysis process after completing data sampling and achieving conceptual saturation (see section *5.8.10 Theoretical sampling and conceptual saturation*). Although a theory that comes from data is *grounded*, it is nevertheless constructed by the researcher through the organisation and interpretation of the data which in turn leads to the selection of a core category, often facilitated by a sudden moment of insight (Corbin & Strauss, 2015). This stage of analysis is not concerned with narratives or descriptive stories, but instead is focused on how the selected core category, central categories, and main categories can all be linked together. The theory can then be elaborated using the main categories and their subcategories to create a final theoretical storyline that completes the process of integration. It is a time to “create novel explanations” (Corbin & Strauss, 2015, p.309) based on the data which add new insight into the phenomenon, whilst being able to recognise when the nascent theory does not reconcile the data, and being prepared to rework the analytic story again and again until it falls into place and feels right.

Early on in this process of integration, Strauss and Corbin’s model of interaction coding paradigm (1998, p. 127) was applied to the axial coding analysis and adapted for structuring and presenting the preliminary results (*see Appendix 18: Theoretical integration – Model of interaction*). This exercise assisted with identifying categories involved in the causal conditions and problem areas that foster the phenomenon, and categories relating to the context in which the phenomenon is embedded. Furthermore, it provided some clarity on responding actions and interaction strategies, and the associated consequences. This further facilitated the process of relating high-level categories to subcategories through statements indicating the interconnections. Alongside this, considerations were made about how high-level categories might relate to each other, often initiated by cues from rereading the data.

As more focus fell on responding actions and interactions, consideration of process began to come to the fore, which in turn directed effort towards elucidating interrelations between experience, action, and outcome. This prompted further restructuring of category hierarchies, and led to what was to become the final draft list of categories (*refer to Appendix 20: Theoretical integration – Categories: central, main, and sub*). Furthermore, this work helped towards facilitating the emergence of the three central categories and the core category itself. However, what really provided the means for integrating concepts and categories around the core category was “integrative diagramming” (Corbin & Strauss, 2015, p. 300), as it was during the diagramming process that eventually an analytic story began to *fall into place and feel right*. And certainly, it is at this stage of integration that writing an *analytic story* gives way to the construction of theory (ibid.). Finally, through referencing back to the original participant narratives the validity of the theory was checked, refined, and established. Indeed, the final version of the integrative diagram went on to form the theoretical model that is depicted in *figure 1. Model of ‘seeking connectedness’ post-stroke*, under section *7.3.1 Introduction to seeking connectedness: a substantive theory* in the *Findings and Analysis* chapter that follows later.

5.8.5 Use of Microsoft Word functions

As previous mentioned, Microsoft Word was used to format, organise and cluster open codes using the *cut and paste* function. However, as further interviews began to generate more and more open codes, several other functions of Microsoft Word were used to help manage the increasing volume of data and to facilitate analysis and the coding process. These included the use of font colour, font size, the zoom function, the find function, and the style function (for assigning hierarchical headings which can be collapsed and expanded).

A different *font colour* was assigned to each participants’ set of open codes, which provided a visual aid for readily noticing which concepts were widely supported by data from across the participant group, and which concepts were more narrowly supported by data generated from only one or two participants.

Font size was used to help manage the volume of open codes by using a relatively small font size for open codes which simply assisted with data handling, as less scrolling was required. Coupled with this the *zoom* function was occasionally used for reading the open code due to the small font size.

The *style* function allowed hierarchical headings to be assigned to the data. All axial codes were formatted with a *heading*. This allowed use of the *collapse heading* and *expand heading* functions, whereby headings could be collapsed so that all content under them was hidden, or conversely expanded to display the content. Thus, all headings could be collapsed except for those with codes that were currently being worked with. This greatly assisted with managing the analysis process as handling the sizeable document became much easier.

The *find* function was used to search across the open codes to find common concepts, properties, and characteristics. Importantly, the find function retrieved matches across the whole document even where there were headings that had been collapsed (see paragraph above for details on use of headings).

5.8.6 Memo writing

Memo writing was an integral part of the analysis. Memos are theoretical notes about the data and the conceptual connections between emerging categories, and therefore memo writing began following the first interview and spanned the entire analytic process. For an example of a post-interview memo see *Appendix 13*. This ongoing process helped establish properties for each category, and facilitated the evolvement of data to a conceptual level. Indeed, notions about grouping open codes, establishing properties and characteristics, developing axial clusters, and assigning meaningful axial code names were facilitated by memo writing throughout the transcription and analysis processes. For examples, see *Appendix 15: Memo Writing - Open Coding*, and *Appendix 16: Memo Writing – Axial Coding*. Memo writing served to shape coding and analysis, along with hypotheses about connections between categories and their properties, and thus the integration of these connections with clusters of other categories to generate a theory. As such, memos are elementary representations of the researcher’s thoughts that relate to the research, and are central to the process of generating grounded theory.

5.8.7 Flip-Flop technique

The term *flip-flop* refers to a different process of comparison within the constructivist approach to that described in the Straussian approach; thus some account of how this term has been understood and used within this current grounded theory study seems warranted. The clarification herein begins with a review of the constructivist usage of the term. Principally, constructivist grounded theory uses the term *flip-flop* to convey a process of constant interplay between data and the researcher's developing conceptualisations, a *flip-flop* between ideas and research experience (Bulmer, 1984; Henwood & Pidgeon, 1992, 1995). In turn, this process aims to generate theory with the flip-flop facilitating "the active and constitutive analytic process of inserting new discourses within old systems of meaning" (Pidgeon & Henwood, 1997, p. 255). Accordingly, theoretical comparison between emerging analysis and any pre-existing theories or concepts (that might relate with the phenomenon under investigation) are often encouraged. Such departure from the philosophy of grounded theory—which ordinarily seeks to reduce and delay engagement with extant literature until after data collection and analysis to reduce risk of obscuring researchers' openness to the emergence of new core categories (Holton, 2007)—is based on the premise that such comparison, especially during later stages of analysis, will likely enrich the analysis. This process would usually include asking such questions as: "*Do the key concepts of the existing theory fit the current data*; *Do the supposed existing relationships hold up*; and *What is present in the current set of concepts but missing in existing theory?* [emphasis added]" (Pidgeon & Henwood, 1997, pp. 268).

It is important to note that in the Straussian world of grounded theory the term flip-flop is used differently, in that it specifically refers to a technique for generating and developing categories. The principal idea is to look for and think about the opposite to a particular category, and then make comparisons at the extremes of one dimension (see *Appendix 19: Evolution of proposed theoretical model*, for working examples of the flip-flop technique—and examples of other Straussian methods for increasing sensitivity to the data and progressing analysis, including *negative case analysis*, and *waving the red flag*). Indeed, the aim is to increase sensitivity to possible germane dimensions of the phenomenon under investigation, and consequently be stimulated to find additional categories of relevance. Strauss and Corbin have consistently advocated use of the flip-flop technique to enhance researcher sensitivity during analysis (Strauss, 1987; Strauss & Corbin, 1990, 1998, 2015); while emphatically insisting that ideas generated from use of the flip-flop technique do not constitute more data, but instead “stimulate reflection about the data at hand” (Corbin, 1998, p. 122). As such, the flip-flop technique forces the researcher to think about the data analytically rather than descriptively, helps to generate provisional categories and to find their properties and dimensions, and thus provides different ways of knowing and understanding the data.

To be clear, the constructivist usage of extant literature and its own take on the *flip-flop* for supporting analysis is not advocated by the Straussian approach, which strongly cautions against it. The concern being that, as previously stated, turning to existing theories and concepts during the analysis stage carries with it a potential risk for suppressing grounded theory construction; that is to say, thwarting theory development that could otherwise have been more fully grounded in all that the research material might have to reveal. Moreover, Corbin is categorical in her assertion that “most of the literature review comes after the research has been completed . . . [stating that] it is better to do a thorough search once the theory is formulated and then bring the literature into the findings (as support for your concepts) and into the discussion chapter as appropriate” (Corbin & Strauss, 2015, p. 371).

5.8.8 Negative case analysis

The negative case is a case that does not fit an emerging conceptual structure. Looking for the negative case, even when the researcher does not find one, can be invaluable because this serves as a device both for challenging initial assumptions and categories (hence guarding against premature closure of theorising), and for modifying and elaborating theory where necessary. Thus, negative case analysis adds richness to findings and highlights that “life is not exact, that there are always exceptions to almost any explanation” (Corbin & Strauss, 2015, p. 101).

5.8.9 Waving the red flag

The purpose behind the technique of *waving the red flag* is to help the researcher to see beyond the obvious in the data (Strauss & Corbin, 1990). Whenever a respondent uses absolute qualifiers such as *always*, *never*, *impossible*, *all*, *none*, and so on, then the researcher should flag these responses for closer inspection.

This inspection again involves asking questions of the data, such as: *what is meant by these absolutes?*; *Why are they used?*; *What are the consequences of their use?*; *Under what conditions does it apply?*; and, *Are there strategies to overcome these absolutes?* The strategy for success in this field is to never take anything for granted, but rather to be sensitive to how reality is constructed in the data. Indeed, Corbin tell us that “to simply accept what we are told and never question or explore issues forecloses on opportunities to develop more encompassing and varied interpretations” (Corbin & Strauss, 2015, p. 99); and reminds us that both researcher and participants bring their biases, beliefs, and assumptions to the investigation; hence, it is essential that researchers recognise this happens and stay watchful for instances of these aforementioned impositions on the analysis.

5.8.10 Theoretical sampling and conceptual saturation

Theoretical sampling is where the researcher allows the nascent findings from the analysis of the data collected so far to determine the source of subsequent data collection such that it can best further the analysis process (Glaser & Strauss, 1967; Strauss & Corbin, 1998; Corbin & Strauss, 2015). For purposes of transparency, it should be acknowledged that theoretical sampling, as such, did not play a role in this grounded theory study. However, the purpose of theoretical sampling was considered and accounted for, and thus an adequate level of conceptual saturation was nevertheless achieved. The researcher argues that necessity for theoretical sampling was alleviated by the homogeneity of the target group under investigation (refer to section *5.5.2 Inclusion and exclusion criteria*), which at the outset signalled conceptual saturation would likely be reached with a relatively low sample size. Refer to section *4.7.5 Sample size considerations* for further discussion.

Conceptual saturation, itself can be understood as the point when sufficient data has been acquired to develop categories and themes well enough to account for variation, and there are diminishing returns from any new data collection and analysis (Corbin & Strauss, 2008, 2015; Charmaz, 2006). As already mentioned, saturation was deemed to have been adequately achieved with the recruitment of ten participants.

5.8.11 Validity

“Validity is one of the outcome goals of a [research] project” (Meadows & Morse, 2001, p. 187). In terms of ensuring and demonstrating the validity of this study the following five principles have been incorporated into the research approach.

5.8.11.1 Sensitivity to context

Sensitivity to context was demonstrated for the duration of the research process. This began with an exploration of the relevant theoretical and empirical literature relating to acquired brain injury, and particularly the sub-type of brain injury resulting from stroke, in the context of neuropsychological rehabilitation. This process was crucial for gaining a wider perspective on the current knowledge and understanding of the research topic, and for subsequently being in a position to formulate a research question, which can potentially address some aspects of the gaps in the current literature. Secondly, the study attempted to show sensitivity to the context of the research topic and worldviews of the participants by applying open-ended questions which allowed the participants to express their opinions freely and discuss a topic which is important to them rather than “being constrained by the preoccupations of the researcher” (Yardley, 2008, p. 247). Lastly, the analysis showed sensitivity to data since the analysis was open to the participants’ interpretations. An attempt was made to recognise the participants’ inconsistencies and complexities of the speech by ensuring that the emergent codes were grounded in, and supported by the data. Each transcript was re-examined to ensure that the codes were truly representative of the data collected (c.f. Yardley, 2008).

5.8.11.2 Commitment and rigour

Commitment and rigour were demonstrated during the interviews through the researcher’s attentiveness to what participants were saying, through the use of active listening skills and an empathic attitude towards participants throughout the data collection process. The researcher ensured that participants were comfortable about taking part in the study. Rigour was demonstrated by the robustness of the research in terms of the appropriateness of study design, including the philosophical framework, the methodology selected, the data collection process, and the appropriateness of the selected method for data analysis to answer the research questions (c.f. Yardley, 2008).

5.8.11.3 Coherence and transparency

Coherence and transparency were demonstrated throughout the study by clearly outlining every stage of the research process, including the study's research questions, the theoretical approach adopted, the recruitment process, interview procedures, and data analysis method; and then presenting the findings in a concise and coherence manner. It is believed that this endeavour has facilitated transparency for assessing the trustworthiness and validity of the findings presented by the researcher (c.f. Yardley, 2008).

5.8.11.4 Impact and importance

Impact and importance refers to the fact that the study "may have direct and practical implications, which will be immediately useful for practitioners, policymakers, or general community" (Yardley, 2008, p. 250). It is hoped that this study will contribute value through offering a theoretical framework for informing information gathering which will contribute towards an individualised formulation-based understanding of factors, and their interactions, that underpin subjective experience of psychological and emotional difficulties (see section *8.4.3 Implications for clinical practice* for further details); and that it will facilitate additional understanding for the various practitioners working in the context of neurorehabilitation healthcare.

5.8.11.5 Triangulation

Finally, emergent themes from the research were reviewed with a fellow counselling psychologist in training who became familiar with the anonymised transcripts. This procedure was performed to help ensure that the analysis makes sense to others and is not unhelpfully limited by the researcher‘s perspective (Yardley, 2008). This method helped the researcher to clarify, modify or identify potential concepts which were not captured by the researcher originally and contributed to the coherence of the analysis (c.f. Yardley, 2008).

6. Pilot Study

A pilot study was conducted for this research project primarily to ensure the research procedures and materials were appropriate for meeting the demands of this study in terms of ethics, safety, and wellbeing of the participants, and that they were adequate for collecting the required depth and breadth of data to answer the research questions. Indeed, the literature on research methods commonly advocates conducting pilot projects or pilot studies prior to performing a full study, and highlights various reasons for doing so; for instance, where a researcher has an interest in a particular area but no precise focus, conducting several pilot interviews or pilot observations can be a means for establishing and clarifying a problem area. Other reasons given for conducting a pilot study include generating ideas about the topic under investigation; gaining information about the viability and practicalities of conducting a full study; and checking whether there are any issues with the research procedures and materials (e.g., Corbin & Strauss, 2015; Howitt & Cramer, 2017; Steward, 2006b).

A participant was recruited for the pilot study as detailed in the previous section *5.4 Recruitment*. The pilot interview was conducted, and the data collected was analysed in accordance with the methods and procedures outlined in the previous two chapters. The participant was given a pseudonym: *Ryan*, and Ryan's data was assigned the reference: *P01*. The analysis yielded 391 open codes which were organised and clustered under 24 axial codes, or categories, and each were assigned meaningful names that reflected the overarching concept of the clustered open codes, properties, and characteristics that emerged from the analysis process.

Five of these categories were assigned names that were taken from the raw data, known as *in vivo* codes. These *in vivo* codes were prefixed with an asterisk for identification purposes. Additionally, for reference purposes, each category was assigned an incremental reference number. These category names and references are presented in *table 1*. below:

Ref.	**Category** (Axial code name)
P01.01	Becoming aware of stroke: event and consequences
P01.02	* Having a brain that doesn't shut down
P01.03	Spiralling into depression
P01.04	* Asking 'Why me?'
P01.05	* It's not me in control of me
P01.06	* Feeling like a failure
P01.07	Loss of manliness
P01.08	Using Alcohol
P01.09	Struggling with memory
P01.10	Misjudging speeds and distances
P01.11	Avoiding pre-stroke relationships
P01.12	Relating to others
P01.13	(Looking the same, but) Being a different person
P01.14	Reflecting on pre-injury abilities
P01.15	Experiencing emotional difficulties
P01.16	Coping and adapting
P01.17	Experiencing professional services
P01.18	Reclaiming some control
P01.19	Looking at spirituality
P01.20	* Doing a U-turn
P01.21	Engaging with new people (post-injury)
P01.22	Noticing sensations (bodily / emotional)

Table 1. Axial codes for analysis of Ryan's interview data

A sample of the raw transcribed data from Ryan's interview and the open coding that was conducted is documented in *Appendix 11*. Furthermore, an example of an *in vivo* axial code with its underpinning cluster of open codes, properties, and characteristics (from whence the axial code itself emerged) is presented in *Appendix 12*.

The findings from the initial analysis of the data provided by Ryan yielded an insight into his lived experiences of surviving stroke. Many of the categories that emerged suggest that Ryan was confronted by an assortment of adversities as a consequence of stroke; while other categories reflect coping strategies, or indicate areas of new exploration and positive engagement. Across the emergent categories there were aspects that could be related to biological, intrapersonal, interpersonal, and transpersonal perspectives. Indeed, the categories encompassed a broad range of features, including predicaments with a clear temporality, such as the category of *Becoming aware of stroke: event and consequences*; issues with cognitive functioning such as *Having a brain that doesn't shut down* and *Struggling with memory*; dealing with emotional difficulties such as *Use of alcohol* and *Coping and adapting*; interpersonal difficulties such as *Avoiding pre-stroke relationships* and *Relating to others*; contending with intrapersonal issues such as *Loss of manliness* and *Feeling like a failure*; as well as adaptive themes such as *Engaging with new people (post-injury)* and *Reclaiming some control*.

At this early stage in the project it would not have been appropriate to conduct work with respect to theoretical integration (see section *5.8.4 Theoretical integration*). Rather, theoretical integration occurs towards the end of the data analysis process, often after completing data sampling and achieving conceptual saturation (see section *5.8.10 Theoretical sampling and conceptual saturation*). Indeed, further levels of abstraction within the analysis was deemed unconstructive for the pilot study due to the directive of grounded theory method to first engage with theoretical sampling, which should later facilitate layering of analysis from the particular to the general. With this in mind, consideration was given to further participant recruitment both with respect to the initial analysis and the participant's personal characteristics. It was noted that Ryan's experiences related to a relatively short period of time post-stroke, that is less than 18 months. Noting this temporal aspect assisted with directing the researcher's attention while interviewing participants that had experienced a longer period of life post-stroke in terms of exploring aspects such as: how their difficulties may have either persisted, improved or worsened; what new problems might have arisen for them; and what coping strategies or adaptations they have engaged with to deal with their emotional difficulties over time.

Importantly, conducting the pilot study allowed the researcher to establish the appropriateness of the research procedures and materials, and the data from the study indicated to the researcher that the interview schedule was appropriate for eliciting rich data that was potentially relevant for answering the research questions of this study. Furthermore, as no issues with the procedures or problems with the materials emerged from conducting the pilot study, the researcher concluded that it was appropriate to include the resultant data and analysis in the full study that followed. The next chapter presents the findings and the analysis of the full study.

7. Findings and Analysis

7.1 Overview

In this chapter the final results from the data analysis are presented. The data was collected, processed and analysed (as described in *Chapter 5 - Research Procedures*) in response to the research questions that were posed (see *Chapter 3 - Aims and Objectives*) following a critical review of the literature (detailed in *Chapter 2*). This chapter begins by describing and discussing the participants' demographic data and shows self-ratings for post-stroke difficulties relating to mobility, fatigue, cognitive functioning, and depression. This is then followed by the main section: *Substantive grounded theory*, which presents the proposed substantive grounded theory that was constructed from, and is grounded in, the collected data, and comprises several subsections as follows: *Introduction to seeking connectedness: a substantive theory*; *Causal conditions and problem areas*; and *Experience*, *action, and outcome*. Where quotes, excerpts, and key information are presented from participant interviews, they have been referenced back to the transcript of the interview using an identifier comprising the participant number and the line number from the transcript. For example, if a quote were taken from line 237 of the transcript of Ryan's interview, who is participant #1, then it would be referenced using the notation: (P01.237).

7.2 Participant demographics and characteristics

Dean, Smith and Payne (2006) recommend providing a clear description of the participant group, even if some aspects might not be explicitly linked to the analysis, allowing specific statements to be more readily made about a particular group of people. Additionally, this could be beneficial for providing a wider contextual understanding of the sample group. In this study, it was decided that in addition to capturing the participants' age at the time of the stroke event and the number of years post-injury, it would be potentially informative to record the participants' ethnicity, marital and parental status, employment status, and self-rated (none, mild, moderate, severe) stroke-related difficulties/disabilities. This information potentially relates to social support networks, participation in the community, and engagement with workplace setting, all of which have relevance to the focus of this research project. Accordingly, the participants' demographics and characteristics have been detailed in *table 2*. below:

pseudonym / participant reference	age at stroke event	years post-injury	relationship / parental status	employment status / job sector	self-rated difficulties at time of interview (mild/moderate/severe)
Ryan (P01)	48	1.5	married young children	**long-term sick** business owner	mobility: mild fatigue: mild cognitive: mild depression: mild
Gary (P02)	46	2	single no children	**long-term sick** safety inspector	mobility: mild fatigue: mild cognitive: mild depression: mild
Liam (P03)	49	7	divorced adult children	**unemployed** business owner	mobility: moderate fatigue: mild cognitive: mild depression: mild
Russell (P04)	58	1	separated adult children	**unemployed** accountancy	mobility: moderate fatigue: mild cognitive: mild depression: moderate
Terry (P05)	52	2	married adult children	**unemployed** sales	mobility: mild fatigue: mild cognitive: moderate depression: none
Thomas (P06)	60	6	married adult children	**early retired** management	mobility: none fatigue: none cognitive: mild depression: none
Dave (P07)	38	10	single no children	**unemployed** construction	mobility: mild fatigue: moderate cognitive: mild depression: moderate
Peter (P08)	49	6	married adult children	**unemployed** construction	mobility: mild fatigue: moderate cognitive: mild depression: moderate
Danny (P09)	50	6	married adult children	**early retired** policing	mobility: moderate fatigue: moderate cognitive: mild depression: moderate
Mark (P10)	41	5	separated young child	**unemployed** marketing	mobility: moderate fatigue: mild cognitive: mild depression: none

Table 2. Participants' demographics and characteristics

All participants reported being born in the UK and self-defined as being of white British ethnicity. Age at stroke onset ranged from 38 to 60 (with a mean of 49.9).

7.3 Substantive grounded theory

The results of the data analysis are fully described within this section, and the subsections therein; and are covered in thorough detail with the aim of conveying a clear understanding of the emergent theory. As previously stated, this research project is underpinned by the proposition that, by following Straussian grounded theory method guidelines, analysis of the qualitative data captured during semi-structured interviews will permit development of a theory about how men of working age deal with emotional difficulties post-stroke. Indeed, after following the analytical methods laid out in the previous chapter, a core category of *seeking connectedness* was selected as the main theme of the research. As such, this category was deemed to be sufficiently abstract and broad enough to be representative of all participants' accounts. Moreover, the category summarises in two words what the substantive theory is all about, whilst still providing a means to integrate other emergent concepts around it; and as Corbin and Strauss (2015) advised, it is the process of linking concepts and filling them with detail that constructs a dense and explanatory theory. For a review of the evolution of the proposed theoretical model—following the selection of *seeking connectedness* as the core category—see *Appendix 19: Evolution of proposed theoretical model*. The substantive theory that was constructed from the process of integration is now presented and reviewed in detail.

As explained earlier, the constructed theory was developed through identifying and clustering concepts grounded in the data and raising the emergent categories to a more abstract level (with the purpose of generating a theory general enough to encompass all of the participant data). As such, the task of both presenting and conveying the theory in all its density, while simultaneously providing supporting evidence for its legitimacy as a grounded theory, necessitates presentation of comprehensive detail within a layered structure. To this end, the presentation of the theory is laid out across several sections that now follow, beginning with an introductory overview of the theory in terms of its structure and constituent parts, along with a diagrammatic model to assist understanding. Following this, two further sections cover the two main components of the theory. The first section reviews the *causal conditions and problem areas*, and the second section covers the components that relate to subsequent areas of *experience, action, and outcome*.

7.3.1 Introduction to seeking connectedness: a substantive theory

The theory of seeking connectedness as a response to psychological and emotional difficulties following stroke is diagrammatically represented through the model illustrated below in *figure 1*.

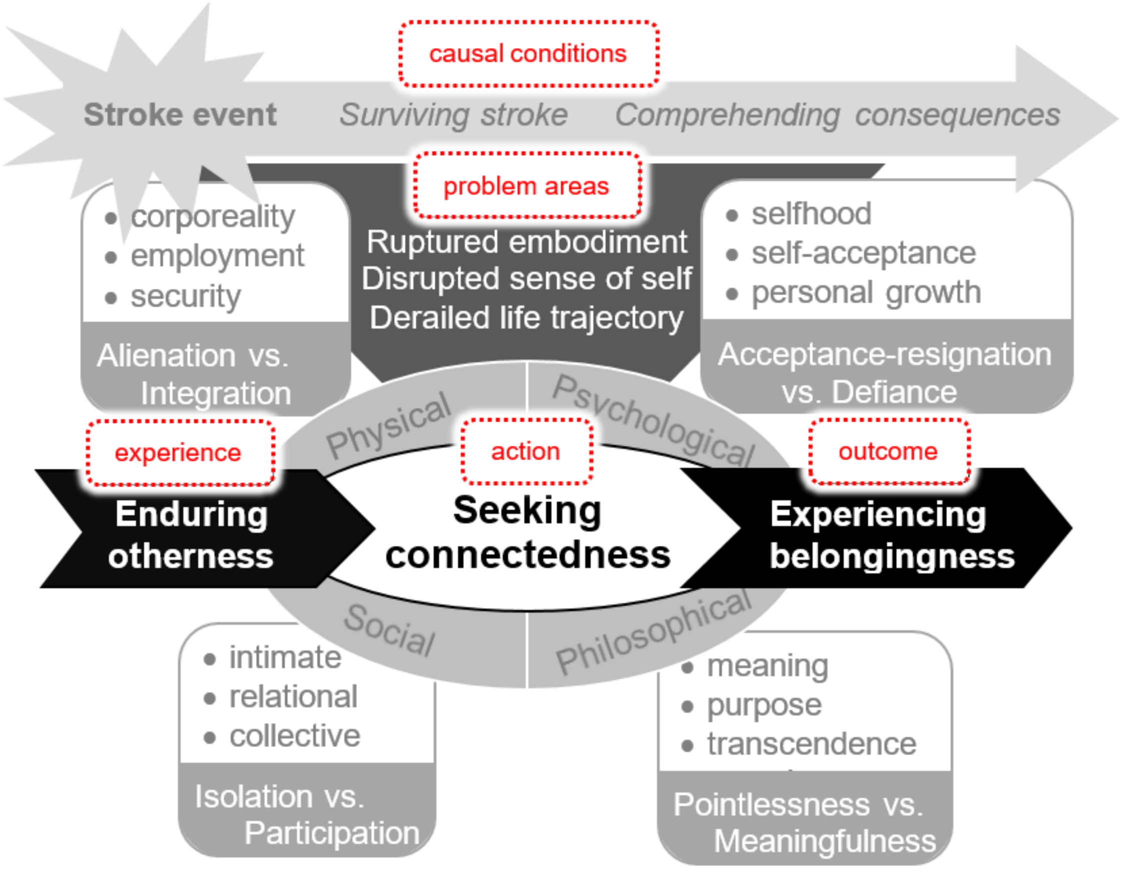

Figure 1. Model of ‘seeking connectedness’ post-stroke

The model can be broadly divided into two component parts; the first being the *causal conditions* and *problem areas* component, and the second being the *experience*, *action*, and *outcome* component.

The first component of the theory is bound up with lived experiences of stroke event, survival of stroke, and comprehension of the consequences. The consequences themselves are categorised under three areas, namely ruptured embodiment, disrupted sense of self, and derailed life trajectory. These features constituting the first component of the model are reviewed in detail in section *7.3.2. Causal conditions and problem areas* which follows next.

The second component is driven by the temporal aspect of the theory that asserts the phenomenon of *enduring otherness* emerges from the lived experiences described in the first component and becomes intertwined with an endeavour of *seeking connectedness*, which in turn can facilitate a sense of *experiencing belongingness*. This temporal process unfolds across four domains of lived experience (namely: the *physical*, the *psychological*, the *social*, and the *philosophical*), and is expressed across a particular dimension within each domain (namely: *alienation vs. integration*; *acceptance-resignation vs. defiance*; *isolation vs. participation*; and *pointlessness vs. meaningfulness*, respectively). These elements of the theory form the second component of the model, and are explained in detail under section *7.3.3. Experience, action, and outcome*.

7.3.2 Causal conditions and problem areas

This section specifically considers underlying *causal conditions* and the presenting *problem areas* that emerged from the participant data and subsequently became conceptualised under the categories illustrated below, in *figure 2*. Self-evidently, the originating causal condition is the event of stroke itself; and accordingly, this is prominently indicated in the top left-hand corner of the diagrammatic model.

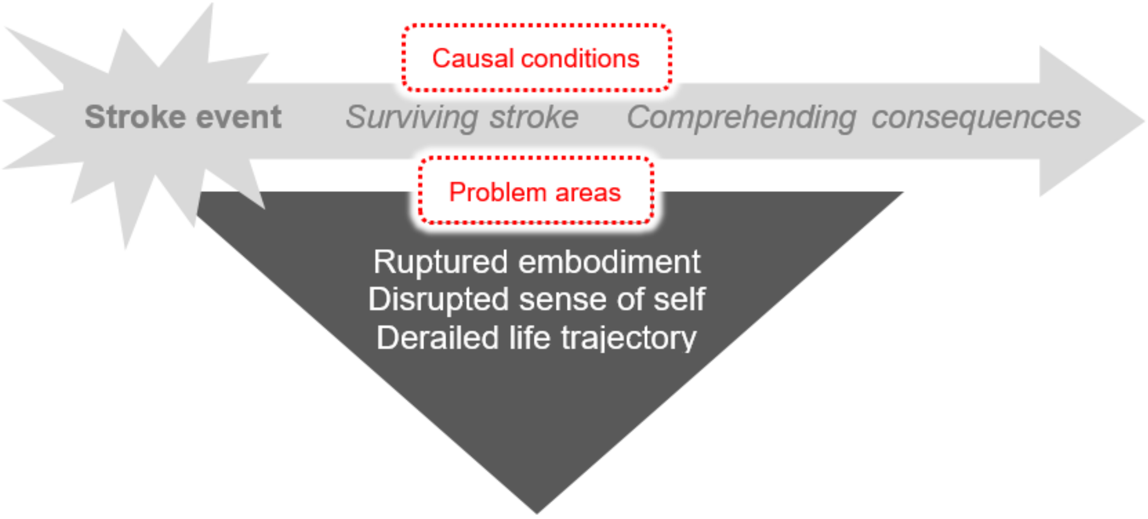

Figure 2. Components of causal conditions and problem areas

However, there is an overarching temporal aspect to participant accounts (depicted in *figure 2*. by an arrow representing passage of time after *stroke event*); and, as with other areas of the theory, temporality of experience was fundamental in shaping the conceptual development of the categories which encompassed the causal conditions and problem areas. The outcome being that the categories of *surviving stroke* (which includes the stroke event) and *comprehending consequences* emerged as being broadly representative of causal conditions, with the problem areas being encompassed by the categories of *ruptured embodiment*, *disrupted sense of self*, and *derailed life trajectory*. Indeed, despite diversity in circumstance and lived experience, as participants described how their post-stroke predicaments unfolded, commonalities across accounts became increasingly apparent; and this convergent aspect has been represented diagrammatically in *figure 2*. through the use of an inverted triangle.

Each category representative of the causal conditions and problem areas are now discussed in the subsections that follow, along with the inclusion of quotes taken from participant accounts to demonstrate that each category is grounded in the data.

7.3.2.1 Surviving stroke event

Participants' narratives relating to the stroke event itself reflect onset as sudden and unexpected, and occurring during the course of their everyday living. Indeed, Russell (P04.008,094) recounts how he was getting ready for work on a Monday morning having just finished showering; Danny (P09.004) described how he was walking his dogs; and Thomas (P06.004-5) highlighted that he was attending a Sunday church service. And Peter (P08.235-6), who was working on a motorbike on a Sunday afternoon, conveys the abruptness of his stroke event by contrasting the normality of ending his working week with the unexpected event of stroke that Sunday afternoon:

> *I mean I was, I was at work on the Friday, plastering a landing c-c-ceiling, um, working with my, my brother, radio go-going on the Friday afternoon. Everything was normal. On the Sunday afternoon I was in [a] hos-, hospital stroke ward . . . . That's how suddenly it came*. (Peter, P08.022-7)

Indeed, stroke typically occurs suddenly and without warning, leaving many survivors in a state of confusion as they often inexplicably find themselves in unfamiliar surroundings, unsure what is happening to them, frequently while trying to contend with the impact of cognitive difficulties due to organic consequences of their injury. Participant experiences of the early events surrounding their stroke survival broadly separated out under two groupings: those who regained consciousness in hospital with no knowledge of why or how they came to be there; and those who remained conscious throughout the stroke event and their consequent hospitalisation. Ryan (P08), Terry (P05), and Gary (P02) all report being unware of events immediately surrounding their stroke:

> *I was unconscious for four hours and, erm, w-when I came round, my wife was by the bedside and a couple of nurses, and I really hadn't got a clue what had happened to me.* (Ryan, P01.004-6)
>
> *I don't remember getting in the ambulance. Uh, I don't remember going to the hospital. Um, they said that I was at, um, [hospital name], I don't remember any of that.* (Terry, P05.291-3)
>
> *I was in a really bad way and I was sort of in a sort of coma-type phase, wasn't communicating at all, um, just out of it for a month and I didn't know what the hell was going on*. (Gary, P02.048-050)

In contrast, both Thomas (P06) and Peter (P08) describe being conscious and aware of what occurred while they were suffering the stroke event and their hospitalisation and interventions that followed:

> *I was fully conscious and so on, and so, so forth, and I knew exactly what, er, was, um, going on.* (Thomas, P06.021-2)
>
> *I mean even when I had the stroke I wasn't unconscious. I was conscious through the whole thing*. (Peter, P08.511-2)

Nevertheless, whether conscious or unconscious during hospitalisation, participant predicaments began to slowly converge as they began to gain a clearer understanding of the immediate consequences of their stroke, and contemplate the implications for their future life.

7.3.2.2 Comprehending consequences

The participant accounts highlighted that, following survival of stroke, being able to wholly comprehend the breadth and depth of the immediate, short- and long-term consequences of the sequelae is generally a layered and unfolding process; which can span years. Indeed, within this temporal aspect there are a raft of contributory factors at play, including stroke severity; pace and extent of recovery; acute and early post-stroke experiences; accessibility of, and extent of engagement with rehabilitation and community services; quality and availability of support from family and friends; impact on financial circumstances and employment prospects; and responses from social networks; among others. Furthermore, all this is set against a background of fundamental *unknowing* about the definitive sequelae—especially during the recovery and rehabilitation process.

It was as participants began attempting basic physical activities that most recall becoming increasingly aware of difficulties with mobility and weaknesses in their body. Russell explained that *"initially after the stroke I couldn't even sit up*" (P06.086-7), and Ryan described how *"I got out of bed and, er, I had to support myself, so I realised with my left leg then wasn't taking my weight properly*" (P01.032-3). Most poignantly, as previously mentioned, these early experiences of impairment were accompanied by a deep-rooted uncertainty surrounding prognosis for recovery of physical functioning. The profundity of this uncertainty was particularly elucidated by Liam (P03) and Gary (P02), who both now mobilise with the aid of a walking stick or cane, but recounted how they were told that they would probably spend the rest of their life as wheelchair users: *"the first week I was in there, they'd say I, I would never walk*" (Liam, P03.028); *"when I had my first sort of family consultation with my neurologist to be told that I would probably spend the rest of my life in a wheelchair"* (Gary, P02.006-9). However, it was probably Peter (P08) who most succinctly captured the intense uncertainty associated with any potential for recovery and the outcomes which inevitably shape one's life possibilities: *"No one knew if you were going to end up walking . . . no one can call it but the stroke"* (P08.522-3).

In contrast, despite the inherent uncertainties associated with the possibilities for recovery outcomes, Dave's (P07) recollection of his attitude towards his recovery from stroke conveys something of single-minded determination. He expressed his circumstances in terms of *a battle that had to be won*, where the objective was to *"get back to normal again"* (P07.009-10). Dave's account further suggests that his resolute stance was bolstered by heightened expectations of a progressive trajectory towards premorbid recovery, fuelled by early functional gains, such as regaining ability to walk. And Dave's optimism for achieving full recovery was further buoyed by emotional highs that naturally accompany such major advances. This defiant attitude in the face of impairment persisted for about 18 months, until his recovery trajectory plateaued short of his expectations. This tailing-off of recovery gains was accompanied by the realisation that his life had *"changed completely"* (P07.018), and he faced the task of adjusting to his post-stroke predicament and accommodating the *recovery gap*; that is, the gap between a full recovery and the actual recovery achieved (Ruff & Chester, 2014):

> *It was a battle . . . I had to win, get, get back on my feet, you know, and get back as, to, to normal again . . . I'd say 18 months was like that. Then after that it's the realisation that, uh, um, you're not going to see any, after the first changes, especially physically, like if you can start walking again, you know, that's a big step and you can, oh, yeah, you feel really good about that. Um, but after that when, when all the big changes cease, the realisation that you, your life has changed completely. And you're gonna have to get used to the fact that, um, well you're just gonna have to get used to the way that you are.* (Dave, P07.008-18)

In accordance with Dave's (P07) experience of recovery, it is widely accepted within the field of neurorehabilitation that the nature of *spontaneous* brain healing (or recovery) has a temporal aspect, and essentially takes place during the first year following brain injury, with some further less marked gains possibly extending into the second year, after which improvements due to healing become less apparent (Ruff & Chester, 2014; for more details refer back to section *2.5 Neuroplasticity and duration of organic recovery*). Nonetheless, expectations of achieving a premorbid recovery are not uncommon among stroke survivors while they are experiencing steady advancements, especially during the early phase of recovery. Hence, there is often considerable risk for a mismatch between recovery expectations and realised outcomes, culminating in substantial disappointment that triggers anger, frustration, and/or depressed mood, all of which can impede further rehabilitation and adjustment (ibid., 2014).

However, in contrast to participants with expectations of full recovery, other participants reported an earlier understanding of the enduring impact that the consequences of stroke would likely have in different areas of their lives. Indeed, Peter's (P08) earliest concerns echoed the limitations survivors often encounter relating to employment, driving, and sports; an increased dependency on family;

changes in social roles and relationships; and financial strain (Karlovits & McColl, 1999; Turner, Ownsworth, Cornwell & Fleming, 2009):

> *Since I had the stroke I've, I've known what it's meant for the rest of my life. I've, I've realised what I've going to have to give up, where I'm, where I'm going to be at in life, you know, um. I laid in hospital thinking through, thinking everything through; my relationship, um, work, um, being, um, how I feel about, I mean I've always been against, against benefits. My dad was one of these guys, "you get out there and work, son". And I'd been working since I was 15, and my work ethic is, um, don't take handouts. So to be on benefits is horrible*. (Peter, P08.513-9)

Conversely, Liam's (P03) account particularly foregrounded a case of sheer determination towards returning to managing his business, which was gradually undermined by a protracted process of gaining more insight about the impact of his stroke. Indeed, Liam describes how *"it took another couple of years"* (P03.434) to realise that post-stroke he was no longer capable of making strategic decisions to keep his business running:

> *my first focus was get out of hospital, and once I was out of hospital, my next focus was, 'right, how can I run my business?' . . . and that was my focus then, on, run, running business, um, and clearly, I couldn't do that, although it took another couple of years for that to actually be apparent. Um, every day was a real hard slog, it really was, because I couldn't make strategic decisions in business, where I could do it in my sleep before. Um, and I, I couldn't understand that . . . I had a business that, in my mind, naively thought, "Well, I can still do that", but I couldn't*. (Liam, P03.430-8, 083-4)

As extracts from participant accounts illustrate, fully comprehending the consequences of stroke is often bound up with a temporal dimension, which can be protracted and tends to develop as a process of overlapping insights. Indeed, given the sudden onset of stroke, survivors need time to process their losses (Ruff & Chester, 2014), as well as form a better understanding of changes in their abilities and how their everyday functioning has been affected. This process is often accelerated as the survivor leaves hospital or treatment settings and attempts to return to typical pre-injury activities (Turner, Fleming, Ownsworth & Cornwell, 2011).

Having reviewed the underlying casual conditions that shaped the landscape of post-stroke experiences of psychological and emotional difficulties, the broad problem areas that emerged out of the analysis of the participants' accounts are now reviewed in the subsections that follow next.

7.3.2.3 Ruptured embodiment

All participants experienced some level of hemiplegia (one-sided paralysis) and/or hemiparesis (one-sided weakness), speech difficulties, and cognitive impairment as a result of their stroke. Accordingly, one of the main threads that ran through the participant accounts was their lived experience of their corporeality. Common features relate to the sudden disruption to the relationship with their own body, how that damaged relationship was experienced and confronted, and how their expectations of their body shifted over time. This aspect of participants' narrated experiences can be understood in terms of the notion of embodiment, where embodiment encompasses the felt sense of one's self being located in the body (Feinberg, 2011; Neisser, 1998) along with a felt sense of having ownership of one's body (Gallagher, 2000; Ward, 2012). For instance, Peter (P08) expressed a disconnection with his body, describing how he felt like "*I was a spirit living inside my body*" (P08.061-2). Similarly, Ryan (P01) conveyed a sense of bodily disconnect when describing how he woke up in a hospital bed, unaware that he had suffered a stroke, but soon realised that his left arm was not functioning normally; Ryan's experience elicited a sense of disconnection from his own arm, as though it did not belong to him:

> *I felt there was something wrong, something different and, and, er, you know, as, … within a few minutes, I think, you realised that left arm was not working as it wanted to. In fact, it almost looked like someone else's arm, 'cos the brain just didn't seem to connect with the arm*. (Ryan, P01.007-011)

Furthermore, Peter (P08) tells how, while still in hospital, he literally confronted his own arm for not working, and asserted his intention to regain ownership of it:

> *I actually looked at my arm, this sounds silly, and I said to it "if you think I've finished with you at the age of 49, I haven't". So I give my arm a good stiff, stiff talking to [laughs]. That may sound stupid, I know*. (Peter, P08.062-065)

This experience of being disconnected from parts of one's own body was echoed in terms of participants relating to parts of their body as being *dead*: "*there's parts of your body that you completely, that they just seem dead*" (P02.271); "*My whole left side was dead*" (P08.025). Similarly, Russell (P04) talked about parts of his body in terms of loss. He explained his experience using the notion of having a *stroke line*, conveying a sense of a body divided, where one part is functional and owned, and the other *lost* to its owner:

> *I've lost the use of, uh, I... the, I, I describe it as a stroke line. If, it comes all the way up my left body . . . . it's all the loss, of all of that side.* (Russell, P04.127-8,132)

Russell further reported particular frustration with his left arm as "*sometimes it knocks things off the table . . . other times it unbalances one*" (Russell, P04.169-70), and expressed an understanding for someone who might contemplate having their arm amputated (P04.169-70).

These accounts indicate that the participants tended to experience a rupture to their embodiment post-stroke. This finding corresponds with the notion of a post-stroke *self-body split* identified by Ellis-Hill, Payne and Ward (2000). Ellis-Hill et al. found that stroke survivors perceived their body as a separate, precarious and perplexing entity in hospital, and continued to perceive their bodies as unreliable at one year post-stroke. Indeed, Peter (P08) poignantly encapsulated much of this common experience when he simply expressed that "*I felt my body had let me down*" (P08.062). Nevertheless, these accounts of rupture embodiment clearly did not extend to the rare presentation of post-stroke misoplegia—hatred towards hemiparetic limbs, often accompanied by verbal or physical abuse towards the affect part of the body—(see Pearce, 2007, for a review).

7.3.2.4 Disrupted sense of self

A stroke can negatively influence an individual's sense of self (Hole, Stubbs, Roskell & Soundy, 2014), with survivors commonly viewing themselves as less capable, less independent, and less in control (Ellis-Hill & Horn, 2000). Moreover, despite improvements in functional status, survivors do not typically experience less sense of discontinuity (e.g., loss of aspects of self, sense of control, independence and connection with others) over the six month period post-stroke (Secrest & Zeller, 2007). Similarly, the majority of the participant accounts include descriptions of experiences that reflect a disruption to their sense of self. And perhaps it was Ryan's (P01) statement that most succinctly conveys something of this experience when he shared that: *"it's weird, I look at myself in the mirror and I'm still the same person to look at, but it's the inside bit that's changed"* (Ryan, P01.453-7). Furthermore, Ryan's narrative seemed, at times, to communicate a sense of being somewhat emasculated as a consequence of stroke: "*the man inside me has, has gone, yeah. Although I'm still a man … I'm not, the man I was*" (Ryan, P01.474-5). Indeed, this notion of feeling less of a man post-stroke resonated within Danny's (P09) account, especially in terms of not being able to do what a man should be doing:

> *[I feel] almost a bit emasculated not to, not to be the bloke who does all the, I should be driving off, towing my caravan, that sort of thing, you know . . . I feel as though I've lost a lot of things that I should be doing. Like decorating and that . . . But I'm not physically able to do it . . . I'm not doing what I should be doing*. (P09.565-84)

Similarly, Ryan (P01) linked his feelings of personal failure firmly with his experience of discrepancies between his pre- and post-stroke abilities to do things: "*The feeling of failure. Er … well, the, it's, it's the difference to what you could do before and what you can do now*" (Ryan, P01.474-5). As well as undermining sense of self, such self-realisations of post-stroke deficiencies typically lead to emotional distress, which commonly involves feelings of being overwhelmed. Intolerance of one's acquired limitations might present itself in various forms, including anger, frustration, sadness, tearfulness, and anxiety. Due to the strong emotional reaction when confronted by post-stroke reality, such responses are commonly referred to as catastrophic reaction. Less pronounced but equally concerning reactions include avoidance, shutting down, minimisation, denial, and concealment (Klonoff, Lage & Chiapello, 1993; Riley, Brennan & Powell, 2004). Responses of this type were evident across most of the participants' narratives. For instances, Liam (P03) described his self-loathing in response to an altered sense of self, deeply dissatisfied with how he experienced himself post-stroke:

> *my self-esteem and confidence has taken a battering . . . I really, really didn't like myself . . . in fact, I'd go stronger than that, I probably hated myself. Um,*

> *you know, I, I would be verbally, um, I would verbally abuse myself, um, if I'm going to be honest . . . I'd look at myself in the mirror and just insult myself. Uh, my, the way I looked, why I couldn't do certain things, and things like that*. (Liam, P03.244-54)

In addition to strong reactions following increased insight into acquired impairments, participants reported experiences of responding emotionally to circumstances in a manner that was unfamiliar to their pre-stroke sense of self. For example, Ryan (P01) related an incident where he struggled to contain his anger towards his wife after arriving at a supermarket car park that was full (P01.624-630). Ryan reported that he misattributed the outcome of not getting a parking space to his wife taking time to smoke a cigarette before they left home. It was only through later reflection that Ryan realised he had conflated his disappointment with his wife's inability to give up smoking with the inconvenience of not finding an available parking space when they arrived at the supermarket; his assumption was that if his wife had not smoked they would have left slightly earlier and there *certainly* would have been an available parking space. Such misassumptions accompanied by disproportionate emotional responses left Ryan *feeling stupid again* (P01.663), and unsure whether a full emotional outburst was only prevented by his medication. Ryan reflected on these events as being *"little things that really meant a lot to me, when it shouldn't do"* (P01.633-4). And in the midst of this perplexity, the only thing Ryan can be sure of is that such emotional reactions do not fit with his pre-stroke sense of self:

> *I contained it and coped with it, but I, you see, you come back to the: "Is, is the doctor absolutely right? If I wasn't on my happy tablets, would I have gone back to [being extremely angry like] The Incredible Hulk?* . . . *I know it wasn't me before the stroke, though. That's one thing that is absolutely clear in my mind*. (Ryan, P01.667-72)

Similarly, although 10-years post-stroke, Dave (P07) reported struggling with his temper outbursts, and despite acknowledging that it is *"just me now, that's part of me"* (P07.057-8), his narrative conveys hints of some ongoing disconnect from his sense of self with respect to his emotional responses: *"I can't seem to stop it"* (P07.043), *"it's distressing really"* (P07.077), *"you feel stupid* (P07.083), *I should have walked away"* (P07.083-4):

> *the main thing is, is my temper now, is that when, when, if I think people aren't listening or . . . I can't believe they're so stupid they don't understand, I lose my temper . . . it's just a very sharp quick outburst . . . I can't seem to stop it . . . it's just, just me now, that's part of me. All my friends realise that is just me . . . a stranger would think what the hell is going on . . . it's distressing really, 'cos I think well they didn't really deserve that outburst . . . then you've lost all respect really because you've lost your temper . . . you feel stupid for allowing it to happen in the first place. I should have walked away before that happened*. (Dave, P07.038-84)

In stark contrast to other participants, Terry (P05) explained that it was now very rare for him to get angry, and this was a *"weird"* (P05.114) and somewhat lamentable change to how he had previously experienced himself:

> *I very rarely get angry at anything. I think that's one of my traits is that I've lost, lost my anger. Um, it's weird . . . sometimes I wish I had it, 'cos, um, take as for example when we go out, if someone, and we're in a queue, if someone barges you in front, uh, I just accept it. My wife, will go, get irate, but I'd say to her, just let, just let the person go in front, 'cos it, it's not worth getting angry. I don't get angry, yeah. Well, I, I wish I could get angry, but, uh, I just don't, not anymore*. (Terry, P05.113-20)

Terry went on to describe that although he does not easily get angry since his stroke he does get upset and cry more readily: *"I don't get angry but I get upset. Um, uh, I, uh, I can't watch, uh, a stupid film anymore without crying"* (Terry, P05.127-8). This area of change in emotional response was also experienced by other participants including Dave (P07) who found it difficult to reconcile his crying behaviour with his sense of self as a manly man:

> *you cry a lot . . . It's just one of those [things]. I can't stop myself. I'll just be sitting there and I could be watching a TV programme that would never have affected me before, and now I'll be uncontrollably just crying. Not sobbing, just, just tears running down, uh, yeah, just, just crying, yeah, and the emotion would be really hard, which was really difficult for me 'cos I've been, up until ... I've been quite, yeah, you'd say a manly man and all the rest of it, never show emotions, never let anybody get under your skin . . . normally I'll just bottle it up.* (Dave, P07.029-38)

Another area of uncomfortable change was foregrounded by Liam (P03) in his account of his experience of self at social gatherings. Liam expressed how he felt different, abnormal, and intimidated by other people at social events; whereas pre-stroke he was a confident person who could *"hold my own"* (P03.339) in any meeting, or under any social circumstances:

> *actually being at a social event, I, I didn't like doing that because, uh, I just felt different . . . I felt abnormal. I think if there was a room full of dressed, people dressed, I was the all-naked one . . . I just was severely uncomfortable with, uh, those, that type of situation . . . it was awful . . . going from a very confident person . . . able to be at any event whatsoever; whether that [be] through work or, or social, private social, I could hold my own, hold my own in a meeting and things like that. I couldn't do any of that. It was, it was absolutely soul-destroying . . . I would be intimidated - I think that's a good word - by any situation or by any person. I would feel intimidation, and even though there was no reason . . . I would feel intimidated. I would go within my shell and put the sign out: 'Not at home'*. (Liam, P03.326-46)

These negative feelings about being different as a consequence of stroke, and feeling intimidated by the prospect of meeting other people and engaging with social situations is echoed by Terry (P05), who described wanting to avoid crowded places, unfamiliar locations, and new people:

> *I can't handle crowds. Um, if I walked into a room of crowded people . . . if I go into somewhere strange, uh, it's unnerving . . . Yeah, I tend to, um, sorry, lost the word I'm looking for, I, you know, [hide] myself away from people 'cos I can't get on with, um, meeting new faces that I don't trust . . . I don't know how they're going to, uh, accept me.* (Terry, P05.013-26)

However, Ryan (P01) particularly talked about his concerns related to engaging with people who knew him prior to his stroke, and the difficulties managing their expectations of him post-stroke:

> *I'm sure they will look at me and see the same person that they used to look at and they probably won't understand how I've changed. And I'm not sure how to overcome that problem*. (Ryan, P01.453-7)

Commensurate with the experiences articulated in the participant accounts, Nochi (1997) found that loss of sense of self after injury was accompanied by a reduction in the individual's social activity. And the implications are worrying, as research suggests that withdrawal from social groups can deprive stroke survivors of a buffer against negative effects of brain injury (Haslam et al., 2008). Furthermore, according to social identity theory (Tajfel & Turner, 1979) and the theory of self-categorisation (Jetten, Haslam & Haslam, 2012) group memberships themselves are integral to our sense of self and are not easily separable. For instance, being unable to return to work following stroke results in loss of professional identity and potentially leads to reduced self-esteem. Hence, when stroke survivors experience disruption to sense of self which impedes continuity of group memberships (whether through self-withdrawal or rejection by others), this can further threaten an already disrupted sense of self, potentially creating a downward spiral into isolative behaviour.

7.3.2.5 Derailed life trajectory

Evans (2011) tells us that brain injury "throws people off the life-course they had anticipated" (p. 117). In accordance with this, imagery of life trajectory thwarted by consequences of stroke prominently featured across many of the participants' narratives. Areas negatively affected included roles within family, employment and financial security, long-imagined holidays, and lifelong hobbies and interests. Furthermore, Ruff and Chester (2014) assert that having one's expected life trajectory derailed is likely to be a primary source of psychological and emotional pain. And, although improvements in stroke sequelae can be extremely influential at times, "the permanent residuals that interfere with the expected future often lead individuals to feel stuck and even to despair, since they have little or no hope of achieving what they had planned" (Ruff & Chester, 2014, p.190). Indeed, many of the participants described a sense of despair related to their inability to utilise work skills they had built up throughout life, no longer *"earning good money"* (P08.013) and being able to look forward to *"everything that comes with it"* (P08.13-4):

> *I've spent most of my working life trying to perfect my, my trade. I was a good tradesman. Um, you could ask what you wanted, work where you wanted. You was in total control of your working life. Suddenly that has gone from you. Um, your skills are no use to, to you. Effectively you've gone from being*

> *a skilled man earning good money, paying a mortgage etc., good holidays, everything that comes with it; you go from being there to being what I refer to as being on the scrapheap, um, going on benefits, feeling like you're a burden upon your f- partner and the state through no fault of your own, um, and I'm, I'm unable to do anything about it. A feeling of helplessness really*. (Peter, P08.009-17)

Along similar lines, Ryan (P01) reflected on his inability to continue as a leader and director of the company he ran with his brother prior to his stroke, which evoked a deep sense of failure:

> *I still avoid going to, to, to the yard . . . because I still don't want the team to see me as I am now. Er, and I've got to face up to it someday, when I, when I get back to work. But at the moment it's, when I have popped back just to pick up post and things … within minutes I'm being asked questions about future bits of the company, and how we're going to do this, that and the other . . . but I'm struggling to think about what I'm going to cook for supper, let alone how the company's going . . . [and] you're failing, you've failed as a, as a, as a leader of the company, as a director. Er. You've got to take some sort of back seat and, yeah, it's a very powerful and broad word, isn't it, failure.* (P01.434-41, 468-70)

Often inextricably linked with employment difficulties, another key area concerning disrupted life trajectory related to participants' goals for family life. Liam (P03) explained how his primary goal in life was to look after his family, and that following his stroke he was no longer able to achieve this: *"It was extremely scary. Um, my one goal was to be able to continue life and look after the family. That I always wanted to do. Um, and I couldn't see a way of doing that"* (Liam, P03.068-70). Similarly, Russell (P04) explained how prior to his stroke he had worked up to 60 hours a week to provide a comfortable lifestyle for his family, but following his stroke his expected life trajectory began to unravel, whereby he was no longer able to earn money and enjoy financial stability, and his family life steadily fell apart:

> *I'm still of working age and suffered the stroke . . . in that time, my wife has indicated she's filing for divorce, my business partner has refuted the amount that he owes me and won't pay me. I've lost the occupation of my home; my*

> *wife lives there. I live in a sheltered accommodation . . . I'm ostracised from the rest of my family. I have three children, all adult.* (Russell, P04.007-017)

Unlike Liam and Russell, Danny's (P09) marital relationship survived the burden placed on his wife as she adopted the role of his carer. However, Danny related how he felt *"really bad"* (P09.122) and *"terribly guilty"* (P09.143) that *"all the plans we've made were just suddenly kicked into touch"* (P09.127-8), as their future plans for caravanning holidays across Northern Europe were no longer viable having lost his driving licence as a consequence of stroke:

> *we had been married for about 10 of 15 years when this [stroke] happened. And I really didn't want her to become a full-time carer for the rest of her life . . . who I was hoping to spend the rest of my life with . . . I thought, oh, we can do this, we can do that. Then all of a sudden I can't do all that. And all the plans we've made were just suddenly kicked into touch. And that really did feel, make me feel really bad* . . . *Before I had my stroke I used to drive regularly. We had a lovely caravan that we used to go all round the bloody country in, including into northern Europe . . . we used to have some really good holidays with [our two kids] . . . and we were looking forward to more of those. Then all of a sudden they take my driving licence away because I've had the stroke . . . so our caravanning holidays went awry . . . And I felt terribly guilty about that. And I think guilt was the main feeling at that time*. (Danny, P09.115-44)

Similarly, Mark's (P10) stroke seemingly ended immediate hopes of future family holidays. Mark suffered a stroke shortly before he *"was due to go on a nice family holiday to Florida"* (P10.399-400) with his girlfriend and their young son. Due to his stroke event the holiday did not happen, and shortly after his recovery from his stroke he and his girlfriend separated:

> *when I had the stroke I was due to go on a, a nice family holiday to Florida . . . And, um, I guess that it was quite negative that we couldn't go-go, because we was all looking forward to it, so it was a one-off holiday. But on, on the positive side, my, my ex-girlfriend couldn't have coped, probably, if I'd had the stroke in the States*. (Mark, P10.399-405)

Additionally, participants lamented the loss of ability to continue engagement with their lifelong hobbies and interests. For instance, Terry (P05) explained that: *“I can't go back to skiing 'cos once I fall over I can't get back up, but I haven't got the strength in my arms”* (P05.084-5); whereas Mark (P10) had been a skilful golfer having played since his teenage years, and described the negative impact his stroke had on his ability to play golf to a standard meaningful to him and the loss he felt:

> *I used to play a lot of golf and I can't, because I can't grip with my left hand. I think, because I was a good standard of golf . . . I was a s-, a six handicap. But um, I've got adaptive gloves and stuff but because I can't hit the ball like I used to, it frustrates me . . . I've had to accept that I can't do any more, which is difficult, 'cos I, I've played from, from a teenager, so it's been most of my life . . . That, that's been difficult, knowing that I can't do that again.* (Mark, P10.131-153)

Similarly, Peter (P08) described his passion for motorbikes and how he had been *“riding motorbikes all my life”* (P08.037), along with conveying something of the despair he feels being confronted by a future devoid of further experiences of riding bikes:

> *I can’t ride a motorbike. What am I going to do without motorbikes in my life? (P08.073-4) . . . I was a biker. I rode big motorbikes. I went to rallies (P08.197-8) . . . I might keep coming back to motorbikes because they meant so much to me. And suddenly when you can’t ride a motorbike, and it’s a big part of your life is taken away from er, you, what do you do? You know; that was your hobby, that was your life.* (Peter, P08.238-43)

Having reviewed the underlying casual conditions and problems areas that featured in the accounts of participants’ lived experience post-stroke, attention now turns to experience, action, and outcome associated with the core category of *seeking connectedness*, and the supporting central categories of *enduring otherness*, and *experiencing belongingness*.

7.3.3 Experience, action, and outcome

The second component of the model incorporates relevant elements of *experience*, *action*, and *outcome*, and constitutes the major substance of the theory. It is correspondingly more layered and denser than the first component (which was covered in the preceding section). With this in mind, this current section aims to continue peeling away at the high-level presentation of the model to reveal the underlying concepts and workings of the second component, and further demonstrate that the entire model is truly grounded in the participant data. This endeavour first begins by looking at the central categories that lie at the very centre of the model.

The core social process that surfaced during the culminating stages of the data analysis was *seeking connectedness*; and accordingly, as mentioned previously, this process was selected as the core category of the substantive theory. And, as this section goes on to illustrate, the category of *seeking connectedness* provides an explanatory concept for linking all the other major categories that were developed from the analysis. In addition to *seeking connectedness*, two other categories emerged as particularly prominent during axial coding and were later further developed during the integration and theory construction process. These two high-level categories are *enduring otherness* and *experiencing belongingness*. As such, both these categories feature in the theoretical model (see *figure 3.* below), providing a fuller context for experience, action, and outcome expressed by the model; as well as further situating the theory within a temporal dimension.

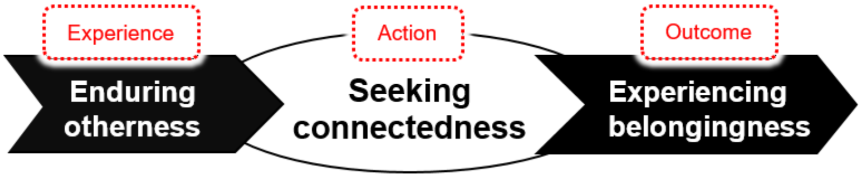

Figure 3. Central categories of seeking connectedness

Broadly speaking, the category of *enduring otherness* encapsulates the experiences that precede and motivate action relating to the category of *seeking connectedness*, with outcome associated with the category of *experiencing belongingness*.

Essentially, these three central categories form the hub of the second component of the theory, which is concerned with aspects of experience, action, and outcome. Support for the development and the elevation of these central categories emerged from the participant data during the axial coding process as relevant concepts and subcategories began to coalesce, and were subsequently grouped under higher-level categories. As each of these higher-level categories were further developed, four salient groupings of germane experience, action, and outcome emerged from the process, with each grouping encompassing a particular set of interrelated contexts. These four groupings were later refined at a conceptual level as main categories relating to domains of lived experience, representing aspects of the *physical*, the *psychological*, the *social*, and the *philosophical*. Furthermore, with respect to experiences of emotional difficulties, data analysis revealed different contexts and intervening conditions within each of these four domain-based categories that contribute to the density and dimensionality of the theory. For instance, within the physical-domain there are challenges, expressed across the dimension of *alienation vs. integration*, which encompass issues of corporeality (in terms of ruptured embodiment), continued employment, and securing sufficient resources and satisfactory living environment. Whereas within the psychological-domain there are difficulties encountered across the dimension of *acceptance-resignation vs. defiance*, with issues of disrupted sense of self which threaten selfhood, stifle self-acceptance, and obstruct personal growth. In contrast, the social-domain represents engagement with (or detachment from) others, with relationships categorised as either intimate (family and close friends), relational (social groups and associates), or collective (community and wider society), and are characterised along the dimension of *isolation vs. participation*. Lastly, the philosophical-domain is concerned with meaning and purpose in life, along with possible engagement with higher meaning and transcendence; this domain relates to encounter with existential crisis and is clarified through the dimension of *pointlessness vs. meaningfulness*. For ease of reference, *figure 4*. below diagrammatically shows the abovementioned elements of the *experience*, *action,* and *outcome* component.

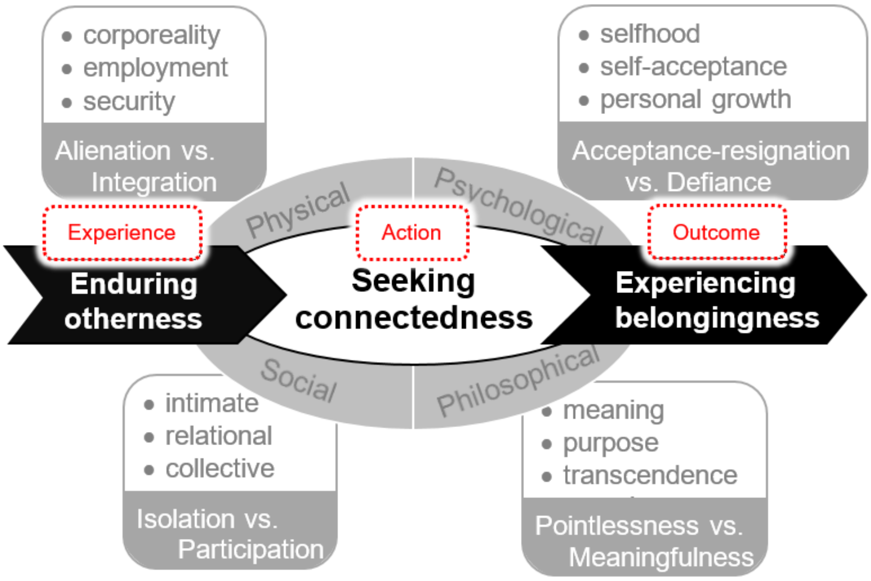

Figure 4. Components of experience, action, and outcome

To further assist with the task of unpacking the *experience*, *action, and outcome* component of the theory and effectively explaining its workings, a matrix is presented in *figure 5*. below:

		Central categories		
		Experience	*Action*	*Outcome*
		Enduring otherness	**Seeking connectedness**	**Experiencing belongingness**
Domains of lived experience	Physical - *corporeality* - *employment* - *security*	*Alienation vs. Integration*		
		Suffering ruptured embodiment	Meeting limits and adapting	Salvaging bodily ownership
	Psychological - *selfhood* - *self-acceptance* - *personal growth*	*Acceptance-Resignation vs. Defiance*		
		Encountering being less	Struggling for sense of normality	Confronting who I am
	Social - *intimate* - *relational* - *collective*	*Isolation vs. Participation*		
		Seeing relationships fracture	Shifting relations and associations	Engaging meaningfully with others
	Philosophical - *meaning* - *purpose* - *transcendence*	*Pointlessness vs. Meaningfulness*		
		Perceiving life as pointless	Valuing something before self	Feeling part of something beyond oneself

Figure 5. Matrix of central categories and domains of lived experience

This matrix is arranged with the three *central categories* set against the four *domains of lived experience*, while incorporating all the features presented in *figure 4*. Additionally, the matrix highlights twelve main categories that were influential for inducing the construction of the model as it now stands. Those main categories listed under *enduring otherness* relate to *experience*, those under *seeking connectedness* relate to *action*, and those under *experiencing belongingness* relate to *outcome*.

As previously emphasized, each of the three central categories, namely *enduring otherness*, *seeking connectedness*, and *experiencing belongingness*, are intrinsically related to each other through temporality. Temporally speaking, the first of the central categories is *enduring otherness*, which is associated with the first component of the theory (see section *7.3.2 Causal conditions and problem areas*) in that *otherness* manifests as a consequence of the *causal conditions* and *problem areas*. In relation to this theoretical model, the term *otherness* is adopted to broadly convey the overarching experience of encountering *being different* across the four domains of lived experience.

Within the physical domain of the model, *otherness* is related to the realm of embodiment, and encompasses the experience of an altered relationship with one's body, experiencing functional deficits and labelling and *othering* parts of one's own body as something alien; with salient concepts coalescing under the main category of *suffering ruptured embodiment*. Within the psychological domain, relatable concepts are grouped under the main category of *encountering being less*. Here, *otherness* manifests following comparison of current self with pre-stroke self, foregrounding shortcomings that lead to *self-othering* and self-hatred. Generally speaking, the concept of *otherness* is predicated on notions of binary oppositions between self and other, the foregrounding of distinctions through labelling, and the creation of in-group and out-group, facilitating marginalisation and exclusion (Hewstone, Rubin & Willis, 2002). This process is often referred to as *othering* and has been useful for highlighting the plight of many vulnerable groups, including those with acquired disabilities. Accordingly, this notion of otherness has been applied to the social domain of the model, where emergent concepts align under the main category of *seeing relationships fracture*. Within the philosophical-domain relevant concepts aligned under the main category of *perceiving life as pointless*; now stripped of once familiar references for purpose and meaning, there is existential encounter with *otherness*, where life is something *other* than what had been envisaged.

At the heart of the model is the assertion that experiences of *enduring otherness* provoke responses and actions related to human motivation for *seeking connectedness*. Within the physical domain, *seeking connectedness* is primarily focused on physical and functional recovery, exploring the limitations of current embodiment, and considering the possibility of future functional gains. Bound up with this comes a process of adjusting and adapting to life circumstances in terms of physical impairment, reduced employability, and uncertain life security; and accordingly, the concepts relating to this burden were grouped under the main category of *meeting limits and adapting*. Within the psychological domain, *seeking connectedness* refers to an endeavour towards reconstructing and identifying with a coherence sense of self following assault on selfhood from consequences of stroke. The main category that encapsulates the emergent concepts in this area is *struggling for sense of normality*. Within the social domain category of the model, seeking connectedness manifests in accordance with the social psychology principle that people attempt to create and maintain feelings of mutual support, liking, and acceptance from the people and groups they care about and value (Smith & Mackie, 2007; Smith, Mackie & Claypool, 2014). However, the model reflects that this endeavour becomes particularly perplexing when one's memberships of social and societal groups are threatened by the consequences of stroke. With this in mind, concepts were grouped and coalesced under the category of *shifting relations and associations*. Lastly, within the philosophical domain, *seeking connectedness* relates to relevant concepts that aligned under the main category of *valuing something before self*, where action is taken in response to confrontation with notions of life as pointless.

Finally, the model states that endeavours of *seeking connectedness* lead to outcomes of *experiencing belongingness*. Within the physical domain, the notion of experiencing belongingness is intertwined with concepts of reclaiming ownership of one's body, doing what one physically can, and beginning to experience an adjusted and adapted embodiment that is part of post-stroke living. These concepts are captured under the category of *salvaging bodily ownership*. Within the psychological domain, *experiencing belongingness* manifests under concepts relating to identifying with current self, having positive emotions, and discovering better aspects of self, which all group under the category of *confronting who I am*. Within the social domain, concepts coalesced under the category of *engaging meaningfully with others*, reflecting the notion that individuals need a quantity of satisfying social interactions (Baumeister & Leary, 1995). And lastly, under the philosophical domain *experiencing belongingness* presented under the guise of *feeling part of something beyond oneself*.

Having provided an overview of the central categories with respect to each domain of lived experience (as illustrated in the matrix in *figure 5.*), the subsections that now follow go on to review each of the four domain-based categories in turn (i.e., the *physical*, *psychological*, *social*, and the *philosophical*) in more detail with specific respect to each of the central categories (of *enduring otherness*, *seeking connectedness,* and *experiencing belongingness*). Importantly, the comprehensive review that follows aims to justify the construction of the second component of the model, and to this end the review references every element featured in the matrix above. In addition to this, pertinent excerpts from participant accounts are provided to evidence that the model is essentially grounded in the data itself. In this way, the following subsections illustrate how the central categories encapsulate the participant data and unfold temporally across the individual domains of lived experience.

Finally, to further convey the density of the model, defend its construction, and provide clarity, whenever the review draws upon a subcategory that has not previously been mentioned, that subcategory is denoted by *underlined italics*. Furthermore, where a subcategory has been assigned a name taken from the raw data (in other words, quoted directly from participant narrative - technically referred to as *in vivo* coding), it is denoted by double quotes along with a reference to the originating data. For further reference, a hierarchical list of all the salient categories (central, main, and subcategories) that fundamentally supported the generation of the theoretical model are provided in *Appendix 20*.

7.3.3.1 Physical domain

The central reference point within the physical domain is the body. Associated motivations relate to survival and safety, and implicate the risks of *not being employable* and *struggling to securing resources*. With particular respect to corporeality, lived experience in this domain is expressed across the dimension of *alienation vs. integration*, which is influenced by the temporal dimension within and across the central categories of enduring otherness, seeking connectedness, and experiencing belongingness. Analysis revealed that the extent to which participants reported *suffering ruptured embodiment* varied. Thomas (P06) located at one end of the range, or continuum, reporting that "*nothing has actually changed, to be honest . . . there is no change physically to me, apart from these minor ailments, nothing has changed*" (P06.116-8); although later in Thomas' interview he does acknowledge that *"I knew from that point that I had some limitations"* (P06.106-7). Whilst other participants located at the opposite end, reporting times of severe difficulty with physical functioning. For instance Russell (P04) stated that *"I can't wash myself, I cannot dress myself"* (P04.068), and the majority of participants reported times when they found themselves being barely able to walk. (Further interview excerpts relating to these experiences are provided in section *7.3.2.3 Ruptured embodiment*). During analysis, related concepts and codes grouped under categories such as having an unfamiliar body and experiencing an unresponsive body. Accordingly, the notion of *enduring otherness* at an embodied level is expressed in the model across the dimension of *alienation vs. integration*; where *otherness* is prominent at the *alienation* end of the dimension, when parts of one's body feel unowned and *alien*; and where *otherness* is obscure at the *integrated* end of the dimension, when one's body feels familiar and owned.

Perhaps unsurprisingly, participants reported motivation to regain their premorbid physical functioning through pursing physical recovery and rehabilitation, which the model conceptualises as *seeking connectedness* with embodiment. Dave's (P07) determination was clear: *"I had to win, get, get back on my feet, you know, and get back as, to, to normal again"* (P07.009-10). Similarly, Peter's (P08) narrative foregrounds his determination to walk again, but also implicates fearing ongoing dependency and having lack of agency as one of the underlying contributory drives behind his motivation:

> *if you couldn't get out that chair now, you'd be stuck. You'd have to wait for someone to come in and do something with you, and to suddenly find yourself in that situation is really s-scary, you know. And it makes you determined, if you can walk, to walk*. (Peter, P08.054-7)

Additionally, within this process of *seeking connectedness* there is often action under the category of *meeting limits and adapting*, where participants found themselves coming up against limitations of physical recovery and began seeking ways to adapt to their predicament. For instance, Ryan (P01) describes how, although he had *"got better about walking further and faster"* (P01.093-4) while walking his dog, he remained perplexed about regularly falling over:

> *I was falling over a lot. Erm, er, always onto my left side and once again it's the left leg, but I couldn't work out why, you know, I'm making all of the, the right movements with the leg, but sometimes I'd just topple over.* (Ryan, P01.084-6)

Only later, after Ryan engaged with a rehabilitation service, was he advised that he was not always fully planting his left foot. This information allowed Ryan to adapt to the limits of his recovery by monitoring his left foot while walking:

> *they noticed that I was, erm, erm, dropping my left foot. It has a term, 'drop foot'. And, of course as soon as that happened, your foot's not planted properly before you put the weight on it, you just topple over. And once that was pointed out, then I could keep an eye on my left foot, make sure it was getting planted properly and the problem went away then. So that's how I overcome that one.* (Ryan, P01.096-100)

In this way, Ryan's relationship with his body can be seen as becoming more *integrated*. Despite ongoing limits to the embodied coordination of his left foot, Ryan's watchful eye constitutes an adaptation that addresses this issue and thereby facilitates a deeper sense of ownership of his body, working with and within his body's functioning limits. Similarly, Liam (P03) reported how impairment to his body meant he could not fully undress himself: *"I used to go to bed with my shirt on . . . it just wasn't right, but it was something that, that happened . . . I was living on its terms"* (P03.382-3, 389, 391). However, Liam *"learned to put strategies in place"* (P03.362) and make adaptations to the manner in which he approaches his difficulties in order to leverage his residual physical functioning:

> *If I'm going out and I want to wear a shirt and look nice . . . at the end of the evening, before I'm going to retire, I know that I've got to make sure that I've got this cuff undone [by someone] . . . all I've got to think about is one button*

> *and the rest I can do . . . So it's just really putting strategies into place for certain situations that help me cope.* (Liam, P03.362-75)

Accordingly, the concepts and codes that emerged from participant accounts in response to the action of *meeting limits and adapting* were grouped under the category of *salvaging bodily ownership*. This in turn evoked the notion that, through both physical recovery and adaptations, there was an increasing sense of one's body belonging to oneself; and, in terms of developing abstract concepts, this finding supported the central category of *experiencing belongingness* within the physical domain.

With respect to the central focus on embodiment, analysis across the participant accounts revealed something of an overarching tendency for movement along the dimension of *alienation vs. integration* in a direction towards integration, although this was often a protracted and multifarious process. Conversely, with regard to the implications for employability and securing resources any progression towards *integration* was less apparent. Indeed, there was a strong sense of participants continued experience of *otherness* in this regard. For example, Peter (P08) explained that *"my work ethic is, um, don't take hands-outs. So to be on benefits is horrible"* (P08.518-9), and Mark (P10) told how *"I never thought I'd be on benefits, and I am. And that's probably quite hard to, to cope with"* (P10.523-4). Additionally, Peter (P08) went on to talk about the stuck-ness of his situation, where five and a half years post-stroke he was left *"<u>feeling helpless to go out and earn a living</u>"* (P08.520); and to illustrate his plight he shared one example of how he was unable to take up an offer of work:

> *a guy I know is, is a window cleaner and he said to me: 'Peter . . . when you get walking, when you get better, you can come on my round and do some windows with me.' But five and a half years on, I, I, I simply couldn't do it. I, I couldn't carry a buck-, bucket of water with a walking stick. I couldn't spend three hours on my feet walking around, round and round houses, um. So, er, you realise your limitations.* (Peter, P08.520-7)

Not only did participants experience the helplessness of not being able to work following recovery from stroke, but they were also <u>facing prospects of financial hardship</u>. As Russell (P04) explained: *"[Before my stroke] maybe I was arrogant, I'd got money in my pocket . . . I have to now think about every expense I incur,* *whether it's really worthwhile, whether I'm going to have more money to come in*" (P04.058-61). Added to this, participants often experienced frustration when their predicament was <u>not being understood or acknowledged by social services</u>, and further threatened their financial security from access to social benefits:

> *they're like: 'well, why can't you work two or three days a week?' I say, ideally yes, I'd like to be able to do that, but I can't tell you which days or . . . if I feel good in the morning whether I'm gonna feel the same by 11 o'clock, 12 o'clock . . . it is basically just frustration that they, they've ignored what I'm sure near enough every stroke sufferer has told them, is that you, you, you can't, um, predict when and how severe the, my, I call it downtime. . . it's just frustration, it's just having to deal with people who do, don't understand and aren't willing to, to maybe look and find out is this normal for people that have suffered a stroke*. (Dave, P07.122-38)

Having reviewed the physical domain with respect to temporality and movement through the central categories of the model, and illustrating how these circumstances can be viewed across an overarching dimension of *alienation vs. integration*, attention now turns to the psychological domain. The next subsection (as done in this subsection) denotes any subcategory that has not previously been mentioned with <u>underlined italics</u>, with evidence provided in *Appendix 20* for these subcategories being grounded in the data.

7.3.3.2 Psychological domain

The psychological domain is concerned with areas of selfhood, self-acceptance, and personal growth. Within this domain, lived experience, action, and outcome are expressed across the dimension of *acceptance-resignation vs. defiance* as post-stroke life unfolds (through the central categories of enduring otherness, seeking connectedness, and experiencing belongingness). Under the central category of *enduring otherness* nascent subcategories reflected participants' experiences of current self in comparison with their pre-stroke self, and clustered around the main category of *encountering being less*. Supporting subcategories include <u>*reflecting on pre-injury abilities*</u>; <u>*"feeling of failure"*</u> (P01.474); <u>*struggling with memory*</u>; and <u>*loss of manliness*</u>, among others. An excerpt from Russell's (P04) narrative broadly sums up the negative sentiments commonly expressed as participants evaluated how life has changed since stroke: *"it's eroded my self-worth . . . I don't feel as manly* *as I used to . . . I've lost self-respect"* (P04.064-8). These findings support the notion that along with increased awareness and comprehension of stroke-related losses, survivors can succumb to feelings of worthlessness, shame, and disillusionment (Gans, 1983; Klonoff et al., 1993), and with this can come experiences of sorrow, gloominess, emptiness, and despair. In terms of dimensionality within this domain, these experiences align with the *acceptance-resignation* end of the continuum, with more emphasis on a sense of *resignation* towards one's dilemma, even to the point where the individual effectively identifies themselves with the role of a victim. Indeed, Liam (P03) described a period where his despairing attitude became particularly resigned and unconstructive: *"I was living on its terms, not its on my terms . . . I'd create a prison for myself, but also I was a prisoner to my illness . . . I suppose, looking back on it in that respect"* (P03.382-93). Nevertheless, Liam's narrative additionally illustrates how his attitude of resignation to *being a prisoner to my illness* shifted towards one of greater acceptance as his experience of post-stroke life improved *"after putting strategies into place for certain situations"* (P03.370):

> *I accept my hemiplegia, um, for what it is, but it's going to be on my terms, not its terms. I go to the gym, uh, and I, I go, I get good things out, out, out of doing things like that. I'm far more independent now than I, I've ever been, absolutely, which is brilliant, and it just, uh, it's just a, a feel good factor, and it helps your wellbeing every day.* (Liam, P03.371-5)

Similarly, aspects of Ryan's (P01) account convey the notion of *encountering being less*, and reflect a resigned position towards the acceptance-resignation end of the continuum. Ryan expressed disappointment that he could no longer analyse work-related objectives in the way he could prior to stroke; and having noticed his recovery plateauing, realised that he needs to reluctantly accept this acquired limitation:

> *Almost all my life is looking at objectives from different angles to see the most efficient, cheapest, best way of doing something . . . I couldn't see things anymore. I couldn't see that step ahead . . . on just that one aspect, erm, I still feel disappointed in myself, 'cos out of all of the things that I've managed to achieve, erm, you know, whether it was the physical thing by carry on walking until you get better . . . I've got to the point where it's levelled out and*

> *I have to accept that I can't work things out like that anymore*. (Ryan, P01.378-81, 396-400)

Moreover, when an acquired impairment adversely impacts men's ability to work psychological and emotional difficulties can arise concerning their capacity to be a provider and protector of their family. Together with other difficulties relating to physical strength, independence, practical abilities, sexual abilities, and personal control over life, men can experience threat to their sense of masculinity (Green & King, 2007), sometimes referred to as gender strain (Guttman, 2000). And certainly, Ryan's narrative conveyed many aspects that contribute to gender strain and a sense of *"not feeling manliness"* (P01.719) in terms of no longer being able to fulfil his role as a provider and decision-maker for his family, and the perplexing shift in his sexual relations with his wife:

> *Everything got turned on its head from me being the provider of the family to making majority of decisions to, erm, the wife, having to look after me. And I think it's that transition from me being the dominant one to being looked after. Somehow in that switchover also is the [coughs] the, erm, the male aspect of, of, of life, the, erm, er, yeah, I don't see her now as a, as a, as a sexual partner and lover, as more of a friend and a carer*. (Ryan, P01.502-7)

Indeed, features of gender strain and the sensitive subject of sexual ability echoed across the participant accounts. This reduced sense of masculinity was captured under various subcategories including <u>*feeling emasculated*</u> and <u>*loss of manliness*</u>. Without going into detail, Peter (P08) disclosed that having sexual problems was embarrassing and left him feeling less of a man: *"I mean, [it's] embarrassing, you know, sex has been a problem . . . it makes you feel less of a man. I mean sex, sex is a problem after a stroke"* (P08.257-9). Similarly, Terry's (P05) narrative equally resonated with a shift in marital relations: *"as a married couple is okay, but as lovers as such, I can't remember the last time we went to bed together"* (P05.405-6). And in terms of his role as a husband Terry characterised himself as *"bad"* (P05.403) and *"inadequate"* (P05.408), explaining that: *"I feel that I'm not providing my side of the partnership"* (P05.419).

Another common aspect of gender strain and *encountering being less* reported across participant accounts was an increased dependency on their partner. Ryan talked about *"the wife having to look after me"* (P01.503-4) and conceded that *"I'd* *generally be lost without her"* (Ryan, P01.696). Similarly, Terry (P05) explained that: *"I couldn't do without her . . . I'll be lost without her"* (P05.427-8).

Difficulties with practical abilities and physical strength further compounded participants' experience of *encountering being less* and added to gender strain. Danny (P09) talked about feeling *"almost a bit emasculated"* (P09.565) because he was no longer able to drive, let alone tow his caravan. And he was distressed because he could not even do the decorating, resulting in the belief that: *"I'm not doing what I should be doing"* (P09.584). Whereas Russell (P04) felt belittled by his daughter repeatedly telling him to *"man up"*, which led him to feel that his efforts towards physical improvement were being minimised. Seemingly, this misguided attempt at encouragement only served to undermining Russell's self-esteem and potentially contribute towards his experience of gender strain:

> *My daughter had a pet phrase: "Man up, dad". Well, to be honest with you, that crushed me, because the physical attempt at trying to maintain dignity and try to, uh, continue a physical improvement was a big task*. (Russell, P04.301-3)

Returning to the notion of dimensionality within the psychological domain, described across the continuum of *acceptance-resignation vs. defiance*, variation across participants was apparent. Many participant narratives expressed a tension between resignation and acceptance in the face of *experiencing being less* that tended towards acceptance over time. More than five years post-stroke, Peter (P08) particularly captured something of the longer-term process when he asserted that: *"you just got to learn to live with it, and that's probably the bottom line. You got to learn to live with it, what you've got left"* (P08.104-6). Whereas Ryan (P01), who had experienced his stroke much more recently, conveyed a strong sense of conflict between hoping for a full recovery and letting go of that hope to accept himself as he now is: *"There's failure of wanting to be back where I was and trying to accept that I'm not, and in the middle there's failure"* (P01.518-9). Indeed, stroke survivors often respond critically to the idea of accepting shortfalls in recovery, maintaining that an act of acceptance amounts to giving up the fight for regaining their pre-stroke normality (Ruff & Chester, 2014), which in terms of the *acceptance-resignation vs. defiance* continuum relates to positioning at the *defiance* end. Aspects of this category of response were evident in many participants' narratives. For instance, at times Dave's (P07) account conveyed a strong attitude of defiance towards his post-stroke predicament and his experience of *encountering being less*, especially during the first 18 months post-stroke:

> *it was just literally . . . a fight to get, uh, movement and, uh, speech and basically coherence back into my life . . . it was a battle . . . I had to win, get, get back on my feet, you know, and get back . . . to normal again*. (Dave, P07.006-10)

Accordingly, the defiant and determined attitudes and actions expressed throughout the participant accounts in response to *encountering being less* were captured under subcategories such as <u>being stubborn</u>, <u>deciding this isn't going to be it</u>, <u>finding my determination</u>, and <u>fighting to get back to normal</u>. In turn, these emergent subcategories coalesced to support the main category of *struggling for sense of normality*, which itself aligned under the central category of *seeking connectedness*. A sense of determination and defiance towards the endeavour to recover and regain some sense of normality was evident in Dave (P07) narrative, and reportedly began from *"day one"* (P07.339) in hospital post-stroke:

> *I'd still say I'm really stubborn and . . . for me, it's a good thing 'cos otherwise I'd still be sitting in a chair, not pushing myself to start walking properly . . . from day one I asked for, for something so I could squeeze to get my hands moving and things like that . . . I was pushing. I mean I woke up and at the time I used to smoke, and they couldn't find me 'cos I woke up and I was trying to find somebody with cigarettes in the hospital. Yeah, so, and I couldn't walk, so how did I do it? I literally shuffled myself across the floor . . . it's definitely stubbornness. It's determination too. I wanted to live as I was living before.* (Dave, P07.343-57)

Similarly, Liam's (P03) narrative resonated with a tone of defiance in response to the starkness of initial clinical opinions about the possibilities for his recovery:

> *the first week I was in there, they'd say I, I would never walk, um, and that was my determination . . . Stubbornness . . . I wasn't prepared to accept that was it. Simple as that.* (Liam, P03.028-9, 053-6)

Likewise, Peter (P08) explained how he lay in hospital immediately following his stroke, his *"whole left side was dead"* (P08.025), fearing the impact on his relationship, his ability to pay his mortgage, and his future in general; and the only way he found to describe his predicament to his brother at that time was *"I'm fucked"* (P08.029), which underlined an overwhelming sense of helplessness and hopelessness. However, when Peter came to the *"horrible, horrible"* (P08.046) realisation that he was unable to walk, rather than sinking further into despair and resignation, this triggered a response of anger and defiance:

> *something in-inside me kicked in. I thought, 'Sod this', you know, 'I'm not having this' . . . and an inner strength, strength seemed to kick in . . . driven by anger. Um, sometimes you can use anger to your advantage, um, and that's what I think I did getting back on my feet.* (Peter, P08.046-51)

Furthermore, the personal quality of being *"bloody-minded"* (P08.336) and being determined *"to live my life"* (P08.332) continued to drive Peter to sustain a defiant attitude towards his predicament, even though he was now five and a half years post-stroke:

> *it's been five and a half years, um, I still get tired but I push on, and that's the way you build your stamina up. So it's been a constant battle with myself . . . to live my life. That's what's driving me on*. (Peter, P08.327-32)

Turning attention away from a specific focus on the continuum of *acceptance-resignation vs. defiance*, whilst still remaining with subcategories that clustered under the main category of *struggling for sense of normality*; there was a small sub-cluster of subcategories that were particularly associated with actions/strategies for managing emotional difficulties. These subcategories included *using medication*, *experiencing professional services*, *using alcohol*, *reclaiming some control*, and *coping and adapting*. And one particular action/strategy that aligned with the latter mentioned subcategories, that is, *reclaiming some control* and *coping and adapting*, involved participants reframing their post-stroke predicament using downward comparison.

That is to say, participants began comparing their post-stroke self with others who were dealing with greater impairment, rather than making comparisons against their own pre-stroke normality. For instance, Peter (P08) highlighted his recovery of speech and especially his progress from being a wheelchair user: *"My speech has come back, not as good as it used to be. I'm walking, I can walk with a stick but I'm not in a wheelchair"* (P08.106-7), before emphasising the importance of making downward comparisons: *"You've got to look at people who's come out worse than you have"* (P08.107-8). And by way of example, Peter had made reference to a fellow stroke survivors from his hospital ward who did not regain function for walking: *"he's still in a wheelchair, um. He give up on the idea of walking"* (P08.099). Similarly, Danny (P09) acknowledged that: *"there are people who are a lot worse off than me"* (P09.801), as did Mark (P10): *"I think we always really should look and see, you know, that there's always someone worse off than yourself"* (Mark, P10.448-9). Indeed, both Danny and Mark provided examples to justify their assertions:

> *there are people who are a lot worse off than me . . there's people there who have had cerebral palsy and it's nice to talk to them and see their side of the story. There's one of the blokes there . . . he's a really nice guy, although he's pe-perpetually wheelchair bound, and he'll talk to you about anything*. (Danny, P09.801-804)

> *I had quite a good life up until a certain point. I've just got a challenge now, whereas some people are not lucky . . . they might have challenges from birth . . . as an example, my ex-girlfriend, she had a stroke at birth . . . she had a weak right side . . . she had to go through that sort of stigma from school . . . whereas for me, I've only had to deal with it for five years of my life*. (Mark, P10.435-43)

Indeed, downward comparison is not an untypical form of meaning-making for stroke survivors, through a reappraisal process for understanding stroke and its implications for one's life in a more benign way. For example, a study of stroke survivors found that reassessing the stroke in more positive ways and comparing their own recovery favourably relative to others (downward comparison) were related to lower levels of depression and anxiety (Gangstad, Norman & Barton, 2009). However, that said, Liam's (P03) narrative offers a stark reminder that ill-judged, insensitively imposed suggestions about making downward comparisons are more likely to cause distress than provide any support. Indeed, rather than providing a means for usefully reframing one's circumstances, it is likely to leave the recipient feeling that their difficulties with emotional distress have been minimalised and dismissed:

> *there were a, a lot of people around me with old-school ideas of 'pull yourself together', you know. 'There's a lot worse, more people worse off than you', and, which, okay, I can accept that, but because, um, mental wellbeing isn't tangible, you see someone with a, a limp, they've got a bad leg, but no one can see, and anybody can't accept emotions as well, and what that causes. Uh, and so the easiest way to do it is: 'we don't believe in depression or anything like that, just pull yourself together'. That doesn't help. In fact, that is the worse thing anybody could say, in my view*. (Liam, P03.125-32)

Another area of participant experience which provided support for the main category of *struggling for sense of normality* was encapsulated under the subcategories of <u>using medication</u> and <u>experiencing professional services</u>. Support for using medication to manage emotional difficulties was not universal across the participant group. Ryan (P01) certainly considered medication to be necessary for his mental wellbeing after struggling with his post-stroke sequelae: *"I, er, very quickly realised it was probably my only lifeline, because I wasn't able to do it myself"* (Ryan, P01.178-9). While Gary (P02) talked as though using medication, for a period of time at least, was expected: *"and then obviously I was on medication as well, so I was on Fluoxetine"* (Gary, P02.217-8); and indeed, early onset mood disturbances are often managed through pharmacological interventions (Fleminger, Oliver, Williams & Evans, 2003). Nevertheless, over time both participants began to develop some ambivalence towards using medication to regulate their emotions, and question whether they should now be coming off it:

> *I question now whether I should come off this Fluoxetine or not . . . I've been taking it for two years now . . . But I don't know if that's part of why I feel the way that I feel or not, so I've been trying to wean myself off it.* (Gary, P02.609-18)

> *I contained it [my anger] and coped with it, but I, you see, you come back to the: "Is, is the doctor absolutely right? If I wasn't on my happy tablets, would I have gone back to [being like an angry monster like] 'The Incredible Hulk'?* (Ryan, P01.667-9)

Whereas other participants were completely against using medication for regulating their emotion, and instead advocate the use of talking therapy:

> *'cos I get angry . . . I actually went to the doctor . . . and said I'm angry, I need something to calm me down. So he just wanted to . . . medicate me. And I didn't want that. I just wanted to able to vent, yeah. I needed somebody to talk to, and all the rest of it. But all he wanted to do was get me on a prescription.* (Dave, P07.235-40)
>
> *I'm okay, I'm, I'm alright, but, um, I just think that, the cycle that patients have to go through to get here could be better, and I think the earliest point that you can get someone in a hospital actually talking to a patient with post-stroke emotional problems and all the depression, um, would be better, instead of leaving them to the clinical side of things where they just give you a happy pill which, to me, just masks something, it doesn't actually get to the root of it.* (Liam, P03.199-205)

And whilst following stroke there is an imperative need to save life (Klonoff, 2014), and subsequently support recovery of physical functioning, relatively less attention can be paid to psychological wellbeing which is possibly relegated to a secondary consideration. And indeed, Liam, in particular, strongly criticised absence of psychological input, an overreliance on medication, and lack of information during his early recovery process:

> *the main point of all of this is for some [psychological] professional help, get involved at the earliest possible stage . . . I honestly believe had that happened with me, I may not have had to go through the dark times [suicidal thinking]. I think I may have been able to have a rational, rational, more rational idea of what was going on, and being able to cope with that . . . From the moment you have your stroke, everybody focuses in on the physical side, and there should be equal focus on the mental side . . . psychological help. . . . [But] it was non-existent, it was a pill . . . Citalopram. There was no discussion, there was no, there was no one, someone to sit down and say, 'Right, recognise this is happening. Liam, this is . . . why it's happening. Don't worry . . . you're going through this process and, but this is why it's happening'. Just to give, to put someone's mind at, at ease.* (Liam, P03.403-23)

The subcategory of using alcohol to cope only featured in one participant account. Pre-stroke, Ryan (P01) only had an *"occasional drink"* (P01.054). However, now *struggling for sense of normality* due to experiencing a lack of manliness, and difficulties with sleep, Ryan is frequently turning to alcohol as a coping strategy:

> *how do you cope with not feeling manliness? It's, it's just another one of the, er, er, tick the failure box, I suppose but .. Erm … I suppose you do rely on, er, rely on is probably not the right word, probably drinking too much, erm, whereas before I'd have a glass of red wine with supper, and the bottle, and the bottle would last three or four days. Now I can quite easily polish off a bottle a night . . . it helps, helps me go to sleep . . . I don't know at what point you become an alcoholic, but certainly, I, I, I do rely on it . . . . there's a limited amount of sleeping tablets I can take. Certainly after a, a few glasses of wine, I can fall asleep, yeah, with a hurricane blowing . . . it puts you in a happier frame of mind … at times of stress helps me, I suppose, deal with, erm, deal with myself*. (Ryan, P01.718-23, 748-53)

Through the process of *struggling for sense of normality* participants' experienced a confrontation with who they now are post-stroke. And, as the data illustrates, the nature of this confrontation can be articulated in terms of positioning on the *acceptance-resignation vs. defiance* continuum for each participant and at different times throughout their individual post-stroke experiences. Furthermore, their accounts revealed that within this process there are opportunities for an increase in *experiencing belongingness* in the psychological domain; this concept represents the central category in the model that relates to outcome, and is supported under the psychological domain by the main category of *confronting who I am*.

During analysis, the main category of *confronting who I am* manifested as interrelated subcategories coalesced, including *identifying with current self*, *having positive emotions*, and *discovering pleasing aspects of self*. In terms of *identifying with current self*, Peter (P08) articulated aspects of a disconcerting confrontation with who he now is when he returned to his familiar work environment and met with *"a mate of mine"* (P08.397) and *"didn't really feel like I belonged"* (P08.399) anymore. Peter goes on to contrast his post-stroke experience of not belonging with his mates with an uncomfortable awareness that he does experience a sense of belonging among other stroke survivors:

> *you don't know what side of the, the fence you belong . . . I went to see a, a mate of mine I used to work for, and sat onsite and had a cup of tea and biscuit with him, amongst the plumbers and carpenters. I didn't really feel like I belonged, um, because my speech is not what it was. I had a walking stick. I didn't feel part of the team, um. And then I come to Headway and I don't feel like I belong here. But really I do belong here, but I don't like it.* (Peter, P08.395-401)

Accordingly, a major source of stress after stroke relates to changes in functioning, which often produce a discrepancy or mismatch between a person's abilities, the environment, and expectations of performance (Ownsworth, 2014). Indeed, earlier in Peter's narrative he explained how he struggled with an acquired identity as a disabled man:

> *For a long time I didn't want to think of myself as disabled. Um, I didn't like the, the word. Even when we went to restaurants or pub, I'd go in the toilet. I wouldn't . . . use the disabled toilet. I thought that's not for me. I'll go, I'll go and stand at the . . . urinal with everyone else*. (Peter, P08.086-92)

In contrast, Liam (P03) talked about his current self more in terms of acceptance: *"I accept my hemiplegia, um, for what it is, but it's going to be on my terms, not its terms"* (P03.371-5), and how he has adopted a more positive view towards his life; and similarly, after five years of experiencing no further recovery gains, Dave (P07) came to accept his post-stroke reality:

> *my life has moved on and, you know, I, I am getting benefits out of life now, whereas before I probably wasn't recognising the benefits of life. All I saw was the negatives*. (Liam, P03.113-5)

> *I'm a far more rational person now than I've ever been, and again, it's self-empowerment to, to really accept things what are happening . . . . I'd look at myself in the mirror and just insult myself . . . the way I looked, why I couldn't do certain things, and things like that. But, um, it's totally changed now. I'm . . . just accepting that the worst isn't always going to happen . . . just take it for what it is . . . my everyday care needs is still affected . . . there are certain things . . . I can't undo buttons . . . so things like that, it still affects me . . .*

> *inasmuch as that I can't do it for myself, I mean. But I've accepted it*. (Liam, P03.106-9, 252-9)

> *I would say, for five years there's been no major difference . . . it doesn't matter how hard I push myself, it, it makes no difference . . . so you do get to a point where you go right, well that's it now*. (Dave, P07.483-9)

Indeed, Peter (P08) similarly went on to explain how he felt aligned with some aspects of his post-stroke self, describing how he sees others rushing around full of their own self-importance, whereas he now takes things more slowly *"and that's not a bad thing"* (P08.566). Additionally, Peter reported *having positive emotions* related to regaining his driving licence and being able to drive his wife to and from her place of work:

> *when you look at the world, everyone's in such a rush. No one's got any time for anyone. Everyone's rushing around full of, self-importance. Well you can't do [that], when you've had a stroke . . . you've got . . . no choice when you've had a stroke but slow down, um. And that's not a bad thing*. (Peter, P08.559-566

> *I must admit, getting my wheels back was a big thing, getting back driving, um. At least I can drive me wife to work and back, which makes me feel good*. (Peter, P08.187-8)

Nevertheless, the notion of defiance and resilience featured strongly alongside acceptance in the subcategory of *identifying with current self*. Many participant narratives contained a strong sense of self-identification with stubbornness, resilience, and a determination to find some inner resource, and battle on:

> *I'd still say I'm really stubborn and . . . for me, it's a good thing 'cos otherwise I'd still be sitting in a chair, not pushing myself to start walking properly . . . I've always set myself [goals]. If I set a goal, I, I, I try and achieve it . . . stubborn bastard is what most [people call me] . . . . self-belief is what got me out the bed and instead of thinking: 'Oh, I can't walk, so I'm not going to move', I thought well if I shuffle on me backside I can get to the other end of the ward, I can disappear down the stairs . . . I believe that's in you, that's inside you, and you've got to feed that*. (Dave, P07.337-8, 360-3, 483-9)

> *At the moment it’s been five and a half years, um, I still get tired but I push on, and that’s the way you build your stamina up. So it’s been a constant battle with myself*. (Peter, P08.327-9)

> *when you drop the walking stick on the floor and . . . bend down to pick it up, if you’re in the wrong place you’ve still got to work it out and put yourself at risk to do that. But, uh, it does teach you to become more resilient and I just, well . . . it’s, well, it’s fuck it . . . fuck the world, you know . . . it’s anger, it’s, it’s self-pity, it’s, um, I can say that, there’s no one there to hear me . . . and then I look at myself and get a grip. Do it. Sort it . . . my father was at Dunkirk; that’s no different than what they had to do . . . you dig deep, you, you find some inner resource to do it.* (Russell, P04.394-414)

Additionally, both Russell (P04) and Terry (P05) related experiences of being provided with feedback about themselves from other stroke survivors, which was facilitated by a group exercise. The information was well-received and the accounts of this provided support for the subcategory of *discovering pleasing aspects of self*:

> *there was a, a task, write five things down that you like about yourself. I could have done 10 easy . . . it sounds conceited, doesn’t it? . . . the paper was passed around the room . . . other people anonymously wrote on the, on the paper good things that, blew my ego away. They said things like: appears determined, knowledgeable, humorous, nice things, things that I like . . . to identify with. So that, that was good . . . they coincided with some of things I put down. I like to think I’m humorous and I like to think I care about people, um, and . . . they sort of identified those things . . . That really helped me.* (Russell, P04.491-512)

> *And when mine came back and I read it, I was surprised what people wrote about me. And, uh, basically they said that I'm the first person that gets up and helps people, um; if they want a drink of tea I'd go and get it, chairs. But I didn't, I didn't know that, you know. Perhaps it's just my way . . . It made you feel better 'cos, uh, you knew that you were helping other people and they appreciate it. But I didn't know I was doing it. I didn't set out to do it, to make other people like me. I just did it*. (Terry, P05.364-71)

Having reviewed the psychological domain with respect to its overarching dimensionality of *acceptance-resignation vs. defiance* and how the psychological domain unfolds across the central categories of the model, the focus now shifts to presentation of the social domain. As in previous subsections, the next subsection continues to denote any subcategory that has not previously been mentioned with *underlined italics*. Refer to *Appendix 20* for evidence of these subcategories being grounded in the data.

7.3.3.3 Social domain

The social domain is concerned with areas of intimate, relational, and collective connectivity. Lived experience, action, and outcome are encapsulated across this domain through the dimensionality of *isolation vs. participation*, with post-stroke life being reflected through the central categories of enduring otherness, seeking connectedness, and experiencing belongingness. Within this domain the category of *seeing relationships fracture* emerged as the main category supporting the central category of *enduring otherness*. Underlying subcategories captured participants' experiences of difficulties both with maintaining pre-stroke relationships and developing new relationships post-stroke, and included *being isolative*; *becoming a recluse*; *distancing family*; *losing friendships*; and *having hidden disabilities*, among others. Accordingly, experiences under this main category tend towards the isolation end of the *isolation vs. participation* continuum, with many reports of how participants became isolative in their own home due to concerns about their post-stroke deficiencies, fear of failing to meet others' expectations, and anxiety about being negatively perceived by others:

> *the first real problems I encountered were people wanted to come and see me . . . I just wanted to become, I think the best word is a recluse, just didn't want to see anyone, erm, because . . . the p-person they were coming to see, wasn't the person I was . . . I didn't want to see anyone, apart from, yeah, [my wife]. Even my parents, I didn't want them to see me as, as I was. And, er, yeah, that's, that's, it was hard*. (Ryan, P01.065-9, 104-6)

> *I didn't want to go to do anything socially. Um, I felt abnormal, um, so the best thing was not put myself into a, a situation where I would feel worse. So I wouldn't go out, I wouldn't answer the telephone, I wouldn't open the post.*

> *I mean, I was . . . a recluse in my own home. And that's the best way I could handle it, at that time*. (Liam, P03.299-304)

> *as soon as I came ho-, home, you initially feel embarrassed 'cos all your neighbours are going to see you getting out the ambulance, um. I went from the ambulance into my living room, and that's where I stayed for three months. Um. My therapist used to come round to the house, and my physio, um, try to get me out the house, so I didn't want to leave the living room. I virtually be-, became housebound because of fear, um. That's how scary it was, um. It took me a long time to get, to go out into the world as a disabled man.* (Peter, P08.149-55)

In addition to participants engaging in isolative behaviours to manage their anxieties about interacting with others, many participants reported experiences of being unexpectedly rejected by friends. For instance, Danny (P09) described how "*I'm losing my friends gradually"* (P09.226) as key friendships became strained by the effects of his post-stroke condition, friends drifted away, and Danny was left feeling abandoned: *"I feel they've deserted me"* (P09.654). Indeed, Danny narrated how one friend, *"who was a really good friend'* (P09.198) told Danny that: "*I don't want to come and see you sat in a chair like a bloody walking corpse, because it will make me feel so horrible"* (P09.198-200); and another previously close friend of over 10 years "*doesn't come to see me very often"* (P09.190); while an ex-work associate who maintained contact and *"came round regularly and he'd take me out somewhere for the afternoon"* (P09.208) inexplicably *"stopped coming as well"* (P09.213). Similarly, Peter (P08) reported that *"most of my mates have gone"* (P08.198), explaining that *"they wanted to know me before, but now I'm disabled they don't"* (P08.226) because *"it's not cool to be seen with me"* (P08.227, 228). Peter went on to conclude that:

> *a lot of people find it so difficult . . . to feel, like friends [with a stroke survivor]. Maybe that's . . . why a lot of my friends have gone off and never seen them since. They can't deal with it.* (Peter, P08.593-5)

Along with difficulties relating to isolative behaviours and loss of friendships, many participants experienced periods of difficulty in relations with their family. Russell (P04) described that relations with his wife and adult children had broken down, while Ryan (P01) explained how at one time difficulties with emotional regulation were adversely impacting on his relationship with his school-age children:

> *I'm still of working age and suffered the stroke . . . approximately 12 months ago. In that time, my wife has indicated she's filing for divorce . . . I've lost the occupation of my home; my wife lives there . . . I'm ostracised from the rest of my family. I have three children, all adult*. (Russell, P04.007-17)

> *the kids sort of kept out of my way . . . 'cos one minute I'd be absolutely fine, er, and the next minute, you know, I'd [. . . be . . .] shouting at them . . . at 50 years of age [acting like an unreasonable teenager] is not a pretty sight, especially when they didn't understand why . . . I would change at the drop of a hat if something went wrong or something that I couldn't do that I could before, that kind of thing and I would go into shouting, screaming, uncontrollable teenage mode . . . After I'd . . . very strong feelings about feeling stupid, er,: "Why did I do that?", "It's not me" . . . I've lost control with my emotions and . . . I didn't understand why . . . [There's] guilt: . . . 'Why did I take it out on the kids? It's not their fault'. And once again you start feeling even worse about yourself, that you can't cope with, with, you can't cope with yourself, that's, I think that sums it up*. (Ryan, P01.106-28)

Another aspect of enduring otherness within the social domain relates to the notion of stroke as a hidden disability. This phenomenon was particularly highlighted by Dave (P07):

> *the way that you are, which is difficult to explain, um, and it's really difficult to explain to somebody who's never been in contact with anybody else or, or, or experienced it themselves, of recovering from head injury. Because a lot of people look at me and they go, 'Well what's wrong with you?', 'cos they can't physically see it . . . especially now it's been 10 years since I, I've learnt to basically mask when I have, you know, the problems I've got.* (Dave, P07.021-5)

Whereas for Terry (P05), he was more concerned about people not knowing how to relate to someone who has suffered a stroke:

> *it is difficult 'cos, um, just going to a room full of strangers, I don’t, I don't know how they're going to, uh, accept me . . . I find that certain people or a lot of people don't know how to treat you when you've got a, a brain injury . . . it's difficult because I'm basically . . . taken myself away from people because I'd rather do that and, um, have them ask about how I feel . . . [But] inside I know I've got to do it, you know, but, uh, it's stressful . . . if you don't talk about it, uh, people won't learn how, how, how you are. And I find that . . . once they know how you are and they accept it, it's good. It's like a lot of the help that's out here [at Headway], can I say they deal with it most of the time, uh, it's [sighs], they treat you as normal . . . it's good*. (Terry, P05.025-42)

Nevertheless, at times, in contrast to the issue of stroke as a hidden disability, other participants expressed more focus towards actively attempting to hide the extent of their disability. This might be seen as a response to experiences of *enduring otherness*, motivated by a desire to shift their position in the social domain along the dimensionality of *isolation vs. participation* towards greater acceptance from others, increased sense of belonging, and to create more opportunity for participation in their local community and wider society in general. Indeed, Krefting (1989) highlighted concealment of disabilities as a strategy individuals may use to reduce the visibility of their deficits in an effort to appear normal to others. And, as Ownsworth (2005) notes, conscious efforts to conceal difficulties may reflect a strategy to protect one’s social persona as well as self-image. As such, this phenomenon adds support to the rationale for development of the central category of *seeking connectedness* within the social domain, which is further underpinned by the grouping of subcategories which include <u>trying to appear normal</u> and <u>joining social activities</u>. In particularly, during their interviews both Mark (P10) and Peter (P08) shared examples of how they have attempted to diminish the perceptibility of their disabilities in order to look more normal and natural to others:

> *probably I should wear some splints more often for my hand when I'm out, but I don't, I'll only wear them in bed now because I don't want people to see me with a, make my disabilities more obvious . . . I still want myself to be, be perceived as more normal, I guess.* (Mark, P10.584-8)

> *I said ‘if I manage to walk, I’m not going to . . . limp along like people do . . . who’s had a stroke without a st-, a stick. I shall walk with, with style, with and*

> *a walking stick'. So I've tried to perfect my walking with a nice old, I've got a nice walking stick, a wooden one and I've tried to perfect that walking . . . so I can look nice and natural, um, rather than sort of walking along . . . like people do, um. I've even got a man-bag, like I can park my hand. I call it park, so it doesn't sort of hang like there, you know. I actually put my, my hand on my man-bag and walk with my stick so I can look natural.* (Peter, P08.488-96)

Furthermore, both Gary (P02) and Mark (P10) foregrounded the importance of continuing their engagement with social participation to help them deal with their post-stroke predicament. Indeed, social resources are known to provide a buffer for the losses associated with brain injury (Ownsworth, 2014):

> *I'm quite a sociable person . . . so, part of the way I deal with it is I keep myself busy seeing people or doing things as opposed to concentrating on me rehab exercises . . . in one aspect, it's positive 'cos mentally I'm probably quite strong as a result. But on the negative side . . . probably, I should be doing more work on my hand to try and get it to work . . . but I think it's trying to find the ba-balance between how you cope with the, disability that you've, you're left with.* (Mark, P10.084-93)

> *every Monday I go to a general knowledge [quiz] in a pub and it's for charity, but, um, we came second last night . . . there's five of us in the team and we've all got a sort of specialisation . . . I surprised myself by how much history I can remember and geography and things like that. So I do make an effective contribution and again, that reinforces the fact that your brain is still working . . . it's a social context as well.* (Gary, P02.544-50)

Moreover, within the social domain, the notion of *seeking connectedness* is firmly supported by the main category of *shifting relations and associations*, and underlying subcategories such as <u>*being in the same boat as others*</u>, <u>*being mentored*</u> and <u>*being understood by others*</u>, whereby participants experienced camaraderie and opportunities for developing new friendships with other stroke survivors. For some participants such opportunities presented during their hospitalisation after being *"selected [for] a specialist programme for recovery"* (P02.119), which not only facilitated new associations and friendships, but allowed for peer support to develop in terms of information sharing and informal mentoring:

> *I was really lucky . . . I never quite understood how, why I was selected. It's a specialist programme for recovery of stroke victims and it's like going back to school . . . you get hydrotherapy on a Friday . . . double gym in the morning . . . psychological evaluation which was right at the end of the day . . . the support mechanism of being on a ward with other people that are in the same boat . . . you become a little band and you, you eat together and you, you have breakfast together and so you look out for one another . . . and that was a bond that was fantastic, and I still stay in contact*. (Gary, P02.119-25,142,154-9)

> *I shared rooms with, um, some amazing people, and that was great again to have a newbie in with an old hand*. (Gary, P02.166-8)

However, most participants did not have the option to engage with a programme of extended rehabilitation while in hospital, and thus did not have the same opportunities for developing new associations and friendships during that stage of their recovery process. Furthermore, in these cases there was often a focus towards getting discharged from hospital as soon as possible:

> *'My goal was just to get out the hospital . . . I just had to get out of it'*. (Ryan, P01.021)

> *my main focus . . . was really just to get out of hospital, to be quite honest with you. That was my main focus.* (Liam, P03.012-3)

Nevertheless, following their hospital discharge participants reported that over time they experienced opportunities for meeting and associating with other stroke survivors, primarily through attending charity-based support organisations, such as Headway. Indeed, as well as the formal rehabilitation support provided by Headway, participants found the environment provided opportunities for peer-to-peer information sharing, facilitated establishment of informal support networks, and allowed opportunities for developing new friendships; all of which assisted the realisation that *"you're not the only one that's struggling"* (P01.528-9) and helped with normalising their situation:

> *there's actually, er, er, a lot of mileage in sitting around a table with other people who have similar problems to yourself. Erm, and, erm, openingly*

> *discussing how they overcome things. Er, what things they're experiencing, and more importantly it helps, or it helped me come to terms with things because you realise you're, you're not alone, you're not the only one that's, that's struggling. And, er, so there's this massive hidden benefit of, of just talking with other, other stroke survivors*. (Ryan, P01.524-30)

> *It's about having a network of people who are-, that's why coming somewhere like this [Headway], I mean I know you just have coffee and everything but you do bond, you know, I've made very good friends here.* (Gary, P02.197-9)

> *'Cos I think, e-even though I've got a good social life outside of somewhere like Headway, when you've got a disability, to be in an environment where you're interacting with people that are going through si-similar issues as yourself, you can help each other to, to get through things . . . So it's like a, a separate community, I guess, almost*. (Mark, P10.213-8)

Through a process of gradually *shifting relations and associations*, participants were able to discover an increasing sense of *experiencing belongingness* in the social domain, which can be understood as a movement along the dimension of *isolation vs. participation* towards the participation end of the continuum. This process was facilitated by encounters and events that allowed for action and experience that is represented by subcategories such as meeting up with other survivors, knowing you're not the only one, being witnessed and celebrated, teaming up with my dog, being valued by family, and being supported by friends. And these subcategories coalesced under the main category of *engaging meaningfully with others*. Indeed, Douglas (2012) identified facilitators that supported people's sense of connection with society, including family, friends, carers, pets, and *social snacks*. The latter term referring to tangible reminders of social bonds such as photos, cards, and certificates that represent relationships and shared experiences. For instance, Gary (P02) provided an example of being witness and celebrated and the role of social snacks in the form of a certificate and video recording for increasing his sense of belonging and social bonding:

> *I had to do my walk, my 10-yard certificate . . . in the gym . . . and everyone would cheer and clap and everything when you achieved it . . . . and I've got the video to this day. My sister video-ed me walking with my two*

> *physiotherapists, and you know, the sense of achievement . . . when you haven't walked for, um, five months*. (Gary, P02.168-71, 184-7)

> *when I go to church, I've got friends that say, we have coffee afterwards who say, 'I remember you came into this church in a wheelchair, look at you now. You walk up to take communion . . . you don't even use a stick anymore, you're walking' . . . and that gives you, that fills you with pride . . . it's not only you that's seen your change, it's other people as well, and I, I value that*. (Gary, P02.291-6)

With respect to pets, the significant role a pet dog can play in providing support and another sense of social connection was foregrounded by both Ryan (P01) and Gary (P02). Ryan describes how he owes a lot to his four-legged friend for inspiring him to go for walks and improve mobility. Ryan also conveys a supportive connection with his dog, who "*seemed to know things had changed*"; never pulled on the lead; and, when off the lead, always came back to sit next to Ryan whenever Ryan had fallen over:

> *Going back to the question of coping, erm, I've got a very good four-legged friend called [dog's name] . . . And, somehow he seemed to know things had changed . . . but he still loves his walks and I used to love taking him for a walk. So . . . the wife went and bought me a pair of, erm, Nordic [walking] ski-sticks . . . Bless him, he didn't used to pull at all on the, on the lead . . . I would pick routes where the, the ground was soft 'cos I was falling over a lot . . . so I'd come back covered in mud, I'd often get quite tearful about . . . really struggling just to walk the dog, but he kept wanting to go for walks, so I kept taking him. And that was, really, it was getting inspiration from my dog that he needed to walk that I actually got off my arse and did it . . . So I owe a lot to my dog really in that respect, yeah. He'd never run off when I f-fell over, because he'd be off the lead. He'd always just come and sit by me and wait for me to pull myself up on my sticks, or, whatever. But eventually I got better about walking further and faster*. (Ryan, P01.077-94)

Similarly, Gary (P02) talked about his plans to get a dog and how getting a pet dog would benefit his fitness and health, and additionally provide increased opportunities for social interaction:

> *when I get a dog I should be able to do a lot more walking . . . you have to, so again, that will improve your endurance. And they say petting a dog lowers your blood pressure so that's another benefit of it . . . and obviously when you're out with a dog, you, you know, you have great social interaction with other people.* (Gary, P02.086-91)

Furthermore, in accordance with Douglas (2012), the benefits of maintaining healthy relationships with significant family members and friends was evident from participant accounts. These relationships allowed survivors to contribute to others' wellbeing as well as themselves feeling supported by the relationship, thus further facilitating a sense of *experiencing belongingness* through feeling both valued and supported within a mutually respectful, enduring relationship:

> *I'm very close to my son and he's, he's a huge confidant in my life . . . and I help him with his university. When he's down . . . he's on the phone to me, so it really is a two-way thing . . . he's been studying for a degree and trying to hold down a full-time job as well, and things like this, and, uh, at some points, been very close to throwing the towel in. Um, and we've just worked through that together, and he's come out and he got his degree last week. So, hey, that's brilliant. And he's done it, you, you know, he's amazing how he's coped, um, because he's had personal problems as well, and he's had to cope with all of that, plus his degree work, plus, get, keeping his full-time job going, and he's amazing, absolutely amazing. A far better man than me, far better . . . [I feel] immensely proud*. (Liam, P03.274-92)

> *I've always, uh, been choosy with friends . . . I was taught . . . at a very young age, um, you'll only ever have a handful of friends but you could have a roomful of acquaintances, yeah. And I've been lucky, uh, all but one of my handful have supported me fully for 10 years . . . when they see things are getting too much for me they might say, okay, we're going to go away for a weekend. And they'll just get me out of the environment that I'm in . . . instead of being sitting at home . . . they'll take me somewhere . . . 'cos they know I can't do it on my own. So they're there to support me . . . they know when I'll need to get away . . . they've just always supported me. That's . . . because I'd do it for them, yeah. You know, for years before, beforehand I've always done that for them*. (Dave, P07.284-301)

And in terms of *experiencing belongingness* in society, Gary (P02) and Mark (P10) accounts seemed to convey something of them feeling more connected and participatory in aspects of society in ways that never occurred to them prior to their stroke:

> *I've been amazed by the kindness of strangers. There's been quite a few occasions . . . I'll give you a for example . . . stepping off the train . . . I fell and went down between the train and the platform . . . then two complete strangers . . . came along and hauled me out and then one went down and got my luggage . . . it's acts of kindness like that . . . demonstrated examples of where you, we look out for one another. And now, you know, anything I can do to, you know, to help . . . if I'm just out walking and I see someone struggling with their wheelchair or whatever, I know exactly where they're coming from so, you know, even if it's just to put the brakes or whatever, then I will more than willing stop and help. It's changed me I think profoundly I think, hopefully for the better*. (Gary, P02.585)

> *it probably opened up a world that I never knew . . . I was working and I thought it was all about earning, as much money as possible to give yourself the best lifestyle. Whereas, when you're in a situation like this, you see a lot of volunteers and people at places like Headway . . . giving up their time for nothing, and it's a different world . . . kind and good people that are giving up their time to help others . . . it opens your eyes . . . life's not just about money . . . I kind of felt a bit privileged that I was able to, to be looked after by people that cared . . . I was quite humbled, really . . . I didn't realise there was lots of organisations out there where people gave up their time for nothing . . . and I fel-felt quite privileged that I was allowed to really be part of these groups.* (Mark, P10.172-8)

Having reviewed the social domain with respect to its overarching dimensionality of *isolation vs. participation* and how the social domain unfolds across the central categories of the model of *enduring otherness*, *seeking connectedness*, and *experiencing belongingness*, attention now focuses on the domain of the philosophical. As for the previous subsections, the final subsection denotes any newly introduced subcategory with <u>*underlined italics*</u>.

7.3.3.4 Philosophical domain

Within the philosophical domain lived experience, action, and outcome are expressed across the dimension of *pointlessness vs. meaningfulness* (as life post-stroke develops across the central categories of enduring otherness, seeking connectedness, and experiencing belongingness). As such, this domain is concerned with areas of meaning, purpose, and transcendence. Under the central category of *enduring otherness* subcategories such as asking 'why me?', facing a meaninglessness existence and feeling suicidal clustered around the main category of *perceiving life as pointless*. Indeed, brain injury survivors will often experience lamentations of *'Why me?'* (Delmonico, Hanley-Peterson & Englander, 1998) typically driven by the stark contrasts between life before and life after stroke, discordant external feedback, and a plateau in recovery signalling imperfect healing. Other factors include depression and the deep sense of loss that accompanies increased awareness of sequelae:

> *you just lay there, I wouldn't say thinking: 'Why me?', but . . . 'Why can't I do these things anymore?' What, almost like you disbelieve that you've had a stroke, and you think: 'Well, I can't have done'. I was 49 at the time and, you know, fit, didn't smoke, occasional drink, worked hard and, you know, [sighs] yeah, [laughs]: 'What's going on?' . . . . the mind would wander very quickly into, you know, back to the same problems, you know: "Why me? Why now? Why?" And it's like this continual cycle of, of that*. (Ryan, P01.050-5, 074-6)

> *no one's able to tell me why I had it, um, but it was a sizeable stroke to, to, to have caused the damage that I had . . . . I'm not terribly keen on having experienced what I have, um, I would have far rather it had happened to somebody else [laughs], selfishly*. (Russell, P04. 178-9, 452-4)

> *I felt as though I was worthless that I couldn't, couldn't do anything for myself. Um, although I'd had quite a lot of phys-physio and psychotherapy afterwards, I still felt um, 'Why has this happened to me?' . . . I felt very sorry for myself that I was unable to do what I wanted to do . . . . So why is it all happening? And the more you think about it, the more depressed you get about it and there's nothing you can do . . . . I feel angry sometimes that what I'm suffering is not my fault either. So why am I, why has it happened to me?*

> *It's that 'Why me?' syndrome that I was warned about*. (Danny, P09.103-7, 229-230, 725-6)

Furthermore, there is risk for suicide due to the sudden, unexpected and extreme changes in life circumstances, which typically leave survivors feeling stripped of their identity, autonomy and aspirations (Fleminger et al, 2003; Klonoff & Lage, 1991, 1995; Klonoff, 2010; Leon-Carrion et al., 2001; Simpson & Tate, 2007). Contributory circumstances often include failing relationships, social alienation, compromised functioning, and faltering employment and financial prospects. For instance, Gary (P02) described how *"I was quite negative about my future and I didn't know about work, employment, where I was going to live or anything"* (P02.054-5). Accordingly, suicidal ideation and intent were a feature of several participants' narratives:

> *I must admit when I was in hospital I remember thinking, "Well, you know, this is it, life is over" . . . I had, you know, help with absolutely everything in the beginning . . . it was horrendous. And I remember the first time I was left in the bathroom on my own . . . I went to the window to look out to see how far it was if you jumped out, how, how far the fall was, because I was seriously thinking about doing it; and then it'd all be over . . . . when I went home, my sister said to me . . . "What would you like to do?" And I said, 'I'd like to go to Beachy Head'. And she said, "Why?" And I said, 'Well, I can just off on my, in my wheelchair . . . and it'll be over'. But then I found out that a lot of people survive the fall.* (Gary, P02.026-9, 035-40)

> *I had the stroke . . . from that point I spent time in the general hospital. I then had rehab in a recovery ward. When I came out there, things were so bad with my wife, I did consider . . . taking steps to end my life . . . I felt unwanted . . . and unable to contribute to my nearest and dearest lives . . . so that seemed to be a practical solution.* (Russell, P04.187-95)

> *all of this leads to a . . . backlog of bashing you up all the time, and your self-esteem is non-existent, no confidence whatsoever, which, it's a vicious circle. You can't understand things, you've got no confidence and it, it just gets out of control. And then in my case, um, dark thoughts come into your mind: 'Do I really want to go through the rest of my life like this?' . . . . I was waiting for a cold winter, a really cold winter and I'd go and sit outside . . . and hopefully hypothermia would do it . . . I was looking for the easy way out . . . it was*

> *suicide thoughts, because I couldn't see any way out of it. I had a life that was just crumbling away, business-wise, family-wise, and I was just losing everything, and part of me thought, 'Well, what's the point in fighting?'* (Liam, P03.088-93, 149-56)

> *definitely had a plan. In fact, w-when I wasn't sleeping, I'd be planning, right down to some quite intricate details. And, erm, I sort of set myself goals, if you like, that, er, to cause m-minimum effect on every, everything from people that might find me through to the, the family, so they knew why and how I did it. So obviously there'd be a, a detailed [clears throat] letter, which I'd rewritten in my mind time and time again, changing things*. (Ryan, P01.211-6)

> *when I sat in, in that living room at home, like I explained earlier, um, for three months I was in that living room, and I felt, I, the only thing that made me want to go on was, was [my partner] and my, my daughters . . . but I felt like I had no, nothing to go on for*. (Peter, P08.506-9)

As the data illustrates, participants' experiences of *enduring otherness* in the philosophical domain tended towards pointlessness on the dimension of *pointlessness vs. meaningfulness*. However, their accounts further revealed that over time aspects of their life came into focus which served to ameliorate the intensity of feelings of hopelessness and helplessness. This process was captured under the main category of *valuing something before self*, and was supported by subcategories such as <u>protecting my family</u>, <u>appreciating friendships</u>, and <u>exploring spirituality</u>, which further aligned under the central category of *seeking connectedness*. Indeed, family as a protective factor is highlighted in the last excerpt presented above where Peter (P08) tells that in the midst of his existential despair *"the only thing that made me want to go on was, was [my partner] and my, my daughters"* (P08.507-8). Furthermore, Mark (P10) described how his priority shifting away from being overwhelmed by the consequences of his stroke towards an acceptance that facilitated a focus on ensuring his 12 year-old son was protected against further upheaval and potential distress:

> *For me, it was just, you know, this has happened to me, I can't change it, and, there's two ways of looking at it. You can either go down the route of 'Woe is me', 'Why has this happened to me?' But, but for me, I was more,*

> *you know, I've got a son who's, at-at-at-at that time he nearly had a breakdown of what was happening to me . . . I think he was about 12 . . . and I needed to show him that you don't give up in life*. (Mark, P10.340-8)

Similarly, Gary (P02) explained how his priority for protecting his family from distress served to ameliorate his tendencies towards suicidal thinking, which was further supported by the comfort he found through engaging with religious faith:

> *I could see the, the effects it would have on my family so I realised that that was not really an option, so I used that to build on, and then through, you know, going to church and faith and everything . . . and intense feeling of calm after, you know, being to church on a Sunday. I used to come home and I would feel cleansed and, um, and forgiven for those, um, those dark thoughts, those dark places*. (Gary, P02.211-8)

And likewise, the notion of *valuing something before self* was evident when Liam (P03) emphasized the importance of protecting his family from the distress of his suicidal thinking. Perhaps unsurprisingly, participant narratives accord with extant findings that suggest stroke survivors will try to shield their family by not disclosing experiences of negative feelings (McPherson, Wilson, Chyurlia & Leclerc, 2010). But in terms of moving passed those *"dark thoughts"* (P03.140), Liam additionally described how the mutually supportive relationship with his son, and an ability to find *"a worthwhile reason for me to continue"* (P03.143) further facilitated this:

> *these waves of, uh, of low times, it was, it was awful, it was awful, and, uh, I'm just glad that I didn't have the guts to follow through my dark thoughts . . . and that's what stopped it, because I haven't got the guts. And my son; and finding something to continue for, a worthwhile reason for me to continue going on . . . . I've never, ever, ever told people close to me on my dark thoughts . . . I feel that not doing that, I'd protect them*. (Liam, P03.138-43, 263-70)

Finding renewed meaning provides powerful protection against suicidality, where survivors become invested in new identities, different ways of contributing, and a new life meaning (Klonoff & Lage, 1995; Klonoff, 2010). Indeed, through the process of *valuing something before self* participants' encountered opportunities for re-evaluating and reframing their worldviews, and discovering new meanings and fresh purpose. And along with this, there was the possibility for experiencing a sense of transcending their predicament as a victim of stroke towards that of surviving and thriving beyond the event of stroke. For instance, Mark (P10) conveyed something of this notion when he asserted that *“as long as I, I get to see me son grow up and my sister's girls grow up, then that's all that matters, really”* (P10.451-2). As such, this represents an increase in *experiencing belongingness* within the philosophical domain, and a shift towards the meaningfulness end of the dimension of *pointlessness vs. meaningfulness*. Furthermore, this corresponds with the central category in the model relating to outcome within the philosophical domain, and is underpinned by the main category of *feeling part of something beyond oneself*. The subcategories that coalesced to produce this main category include *giving something back*, *helping others*, *gaining empathy for others*, and *finding my faith*. The notion of finding meaning and purpose through *giving something back*, especially in terms of volunteering to support other stroke survivors, was evident within several participant accounts:

> *one of my long-term aims is to be able to make a difference to other stroke survivors . . . I think it’s time to give something back . . . to being a volunteer and helping out any way I can in terms of helping people to, um, recognise that there is a life after a stroke*. (Gary, P02.106-12)

> *I think I sort of gained in terms of working out how lucky I was, in terms of nothing seriously, nothing serious happened to me. And at that time, I thought, because somebody helped me, then I ought to also help oth-, other people. So I've been sort of been working here as, as a volunteer for six years now . . . I should think that is the major change to me in as far as I've felt that somebody's obviously helped me and now it's my turn to help others.* (Thomas, P06.145-53)

> *I was so pleased when . . . Headway approached me . . . to come back as a volunteer. Gave me a real good, a real lift. It made me feel wanted, um, and use, use, useful, um, and it’s been a good role. I’ve quite enjoyed it and you, I work with people who’s had stroke. I understand it, and hopefully I’ve been some of, some help to someone*. (Peter, P08.381-5)

> *I think it's important . . . if people help you . . . then really you should return that favour by trying to help someone else . . . At the stroke unit . . . I've gave*

> *. . . my details . . . if anyone want to, to know, um, experiences of, if you go to the rehab place where I went to, or if someone's feeling a bit low after what's happened and they're a similar age, 'cos I'm not particularly an older stroke patient . . . I'm fo-forty-six . . . then I'd be quite happy to speak to them, to try and say there are things out there to help you along the way . . . 'cos I think if someone's been through . . . that similar process, if somebody can maybe talk to them about it, it might help . . . it's got to be worth a try*. (Mark, P10.245-64)

Along with meaning and purpose that accompanied a desire to get involved with *helping others*, some participants explicitly expressed a shift in their views towards disadvantaged people and individuals with disabilities, whereby a lack of concern prior to their stroke was replaced with compassion for others' suffering, sympathy towards others' plight and an experience of *gaining empathy for others*:

> *one thing I have, I have gained that I didn't, I didn't have before my stroke was empathy with other people and I think that's the one thing I've learnt from post-stroke is that how important empathy is* . . . . *I had a view on disability pre-stroke and now I have a completely different view . . . I didn't give it a second thought . . . And now . . . if I'm just out walking and I see someone struggling with their wheelchair or whatever, I know exactly where they're coming from so . . . I will more than willing stop and help. It's changed me I think profoundly I think, hopefully for the better.* (Gary, P02.370-2, 577-82, 597-601)

> *I've gained sympathy for, for people, um, disadvantaged people in the world, um. I mean before I had the stroke, you look at someone in a wheelchair or walking . . . with a stick, or watch the news or watch things on TV, and you had no sympathy. Maybe you did, but you didn't think about it. It didn't concern you, but . . . when you've been through it, it makes you have sympathy for other people, um. It makes you more . . . compassionate.* (Peter, P08.550-5)

And additionally, for some participants new meaning was discovered as they went through a process of *finding my faith*:

> *I was feeling at a very low ebb, I'd, I'd refused breakfast and I was very depressed and, um, t-this lovely lady, um, she just said to me one day, she said just, "Oh, you haven't had your breakfast. W-what's the matter?" And I said, "Oh, I don't know what, I don't know what I'm doing, don't know where I'm going, don't know what's ahead." And she just said to me, "Don't worry, the man from Nazareth is beside you", which I, for some reason I took, I got a great emotional, um, I just felt, I felt calm after that. And I, um, and then I, I, I asked to see the hospital chaplain and I started going to services on a Sunday and stuff and I, I got a lot out of that.* (Gary, P02.058-66)

> *since my stroke, I've found faith . . . I don't actively go to church, but . . . we talk most nights, put it that way . . . things have happened for the good for that . . . I've found faith and, and I enjoy that as part of my life . . . it was never in the hospital, at all. Although I had people come round, um, to talk about it, at that point I wasn't ready for it. My focus was getting out of a wheelchair, and that was all I was focusing on . . . it was out of hospital when I possibly had time to myself, and I could think things through and, really act upon what I'm, I thought was, uh, the right thing to do . . . I felt better within myself, um, and that . . . enabled me, empowered me to do other things, and to help with this process of healing, I suppose*. (Liam, P03.456-82)

Certainly, these poignant accounts rouse the plausibility of male stroke survivors recasting personal meaning and discovering renewed purpose in their lives post-stroke, despite the profound consequences of their acquired impairments. Indeed, the themes covered herein overlap with Frankl's (1946/2004) concept of three principal ways of making life meaningful, which were categorised as *creativity*, *experience*, and *attitude*; and notably, as elucidated in the participants' accounts, encompass finding meaning within experiences that are beyond one's personal needs, and instead derive from the care for and about others. There is further consideration of Frank's ideas and the implications for stroke survivors in the discussion section that follows.

The above subsection reviewed the philosophical domain, described its overarching dimensionality of *pointlessness vs. meaningfulness*, and how this particular domain unfolds across the central categories within the model of *enduring otherness*, *seeking connectedness*, and *experiencing belongingness*. Having reviewed the last of the four domains of lived experience, this concludes the section *7.3.3 Experience, action, and outcome*. Along with this comes the end of the section *7.3 Substantive grounded theory*, which completes the presentation of the *Finding and Analysis* for this research project.

The chapter that now follows discusses the substantive theory, which was generated from this study, in relation to existing literature and current bodies of knowledge, as well as evaluating and critiquing the project, and reflecting on the research process.

8. Discussion

8.1 Discussion overview

This final chapter begins by providing an overview of the study findings. This is immediately followed by a broader discussion of the findings in light of the existing knowledge in the field of stroke rehabilitation and acquired brain injury and pertinent aspects of existential phenomenological literature. Following this, the significance of the study findings are presented reviewing the role of counselling psychology, the relevance of taking an existential perspective, and implications for clinical practice; before attention then turns towards critical reflections on the strengths and limitations of the study, which then leads on to recommendations for future research. Finally, there is a reflective account of the author's experience of the research process, before the chapter ends with concluding remarks on the research project.

8.2 Overview of findings

The previous chapter put forward a theoretical model with the aim of adding to our understanding of how men of working age deal with psychological and emotional difficulties post-stroke. The theory was developed using Straussian grounded theory methodology; that is to say, the analysis of the data took a bottom-up, inductive approach to constructing a conceptual model that is grounded in, and representative of, the data. The data itself was captured from semi-structured interviews which enquired into experiences of ten male stroke survivors of working age. Three central categories: *enduring otherness*, *seeking connectedness,* and *experiencing belongingness* emerged from the analysis to form the hub of a substantive theory about men's lived experience following stroke and their response to psychological and emotional difficulties. Through these central categories the theory aims to convey the lived experience of working-age male stroke survivors in terms of action (*seeking connectedness*) in response to experience (*enduring otherness*) and the consequent outcome (*experience belongingness*). Furthermore, the constructed theory seeks to clarify these lived experiences through a quadruple lens comprising the domains of the *physical*, the *psychological*, the *social*, and the *philosophical*; and thus offers a broad framework for understanding this phenomenon and for informing practitioners' considerations and interventions accordingly. Moreover, having positioned philosophical concern alongside the biological, psychological, and social considerations (which ordinarily underpin the mainstream biopsychosocial model), the constructed theory seeks to assert the corresponding relevance of existential meaning-making in responding to the phenomenon of stroke survival. In this way, the proposed theory argues for practices in the field of stroke rehabilitation, and subsequent support, to explicitly go beyond the biopsychosocial approach by elevating the significance of individual philosophical attitude, acknowledging importance of subjective meaning-making in general, and attending to existential meaning-making in particular. Indeed, the theory calls for movement towards a bio-psycho-social-existential framework for expanding practitioners' understanding for conceptualising emotional difficulties and adjustment issues in individuals' everyday life struggles following stroke.

8.3 Discussion of findings

Three central categories emerged from the analysis of the interview data to form the hub of the substantive theory. These three categories are *enduring otherness*, *seeking connectedness*, and *experiencing belongingness*, and together represent a process that unfolds within the context of four domains of lived experience, namely: the *physical*, the *psychological*, the *social*, and the *philosophical*. The substantive theory itself has been comprehensively described in the previous chapter with reference to the proposed model of *seeking connectedness* post-stroke (see *figure 1.*), hence this current section seeks to avoid unnecessary repetition and instead shifts focus more towards locating the theoretical model with respect to existing literature, and offering further interpretations of the research findings with reference to the current knowledge in this field.

At the heart of the current study are the subjective narratives about post-stroke life for working-age men. Broadly speaking, the findings from this study align with the general literature on stroke and findings from other studies that have focused on experiences of stroke survivors (e.g., Kouwenhovenet et al., 2011; Luker, Lynch, Bernhardsson, Bennett & Bernhardt, 2015; Simeone et al., 2015). And similarly, the current findings reflect existing understandings of masculinity within the field of male psychology, and particularly the notions of gender strain (Pleck, 1995) and gender role conflict (O'Neil, 2015)—which are underpinned by traditional masculine ideology (Connell, 1987; refer back to *2.13 Masculinity as a social construct*, for a review). Indeed, seen through the bifocal perspective of gender strain and gender role conflict, the analysis and findings lay bare the burden of expectations put on men by society and, consequently, by themselves due to the internalisation of these stereotypical beliefs about of masculinity—the principal imperatives are avoid displaying feminine traits; never express emotions that might be seen as weakness; be physically strong; and never ask for help. Yet, post-stroke it becomes problematic for men to meet these obligations to traditional masculinity, further layering on the anguish of their predicament. Indeed, the participant narratives revealed overarching themes of self-evaluated failings as a man, which implicate feelings of being *almost* emasculated; experiencing sex as a problem post-stroke and feeling less of a man; not doing what a man *should* be physically doing—earning money, driving, home maintenance, and so on; being a burden on the family—as though the man inside had gone. And all this accompanied by feelings of eroded self-worth and self-hatred for failing to meet the traditional standards of masculinity.

In terms of the stroke event itself, as anticipated, the study findings—particularly under the category of *surviving stroke*—indicate that stroke is typically experienced as a sudden and unexpected event which, along with hospitalisation and the acute treatment that follows, is often experienced as a confusing and somewhat terrifying ordeal. Indeed, the event of stroke has previously been characterised as a small death or a personal catastrophe (Backe, Larsson & Fridlund, 1996; Wade, Langton-Hewer, Skilbeck & David, 1985).

Following on from the phenomenon of *surviving stroke*, the category of *comprehending consequences* encompasses a more protracted timeframe, conveying how post-stroke life is predominately shaped by several overlapping concerns. Firstly, there is an unfolding awareness of impairments that begins immediately following survival of stroke and continues through to a reengagement with community living; secondly, there is contention with the uncertainty surrounding future recovery prognosis; and then later, comes a confrontation with the reality of an imperfect recovery and its implications for life to come, accompanied by the realisation of permanent losses, and the need for adaptation to leverage residual functioning. As such, these findings are reflective of the understandings of brain injury survival provided by prominent authors in the field (c.f. Klonoff, 2010; Ruff & Chester, 2014; Wilson et al., 2009), and echo findings from many other studies that have focused on subjective experience of stroke (e.g., Alaszewski, Alaszewski & Potter, 2006; Karlovits & McColl, 1999; Kouwenhovenet et al., 2011; Leahy et al., 2016; Luker et al., 2015; Martinsen, Kirkevold, Bronken & Kvigne, 2013; Simeone et al., 2015; Turner et al., 2009; Turner et al., 2011).

Indeed, the category of *ruptured embodiment* (identified under the concept of *problem areas*) particularly reflects the susceptibility for stroke survivors to experience disconnection with their own body such that it is experienced as something other than oneself, and often objectified and distrusted as being unreliable. This phenomenon is further conveyed under the central category of *enduring otherness*, specifically within the physical domain of lived experience under the category of *suffering ruptured embodiment*. This finding aligns with the concept of a *self-body split* (Ellis-Hill, Payne & Ward, 2000) that can contribute to negative experiences of disempowerment, dependency, and lack of control (Luker et al., 2015).

In terms of phenomenological philosophy and the concept of a *self-body split*, there is a long tradition of endeavour to characterise the felt sensations in mental life and bodily action (Husserl, 1931/2012; Heidegger, 1926/1962; Merleau-Ponty, 1945/1962; Sartre, 1943/2003; Sheets-Johnstone, 2011). And indeed, the participants' frustrated experiences of *suffering disrupted embodiment* might be additionally understood through borrowing from Heidegger's concept of modes of being that relate to objects or *entities*, where the world is full of entities that can be *ready-to-hand* or *unready-to-hand* (Heidegger, 1926/1962). Heidegger posited that our primary way of engaging with the world is through ready-to-hand entities; when we competently engaged with an entity then that entity becomes ready-to-hand, such that it fits seamlessly into a meaningful network of actions, purposes and functions. For example, in the hands of an experienced tradesman, a hammer *disappears* from conscious attention, so to speak. Thus, when we are coping skilfully in the world we experience entities as ready-to-hand, *seeing through* them to the task we are engaged in, with little or no explicit awareness of their properties. Furthermore, as a corollary of being part of one's action, the entity becomes part of oneself, one's body, part of a domain of *ownness* or *mineness*.

Conversely, unreadiness-to-hand, as articulated by Blattner (2006), is a deficient mode of readiness-to-hand. It is when we experience some difficulty or frustration where an entity is failing to appropriately serve its function. For instance, in the case of a hammer, the hammer might be too unwieldy for a particularly delicate task, or the head of the hammer might become loose from the handle, or the handle itself become broken. In these moments, we can no longer *see through* the tool to focus on the task; instead, we must explicitly attend to the unready-to-hand entity that the tool has transformed into. The entity ceases to be part of one's actions and one's self, whereas previously the hammer was being experienced no differently to the hand that wielded it.

Applying this Heideggerian concept for further interpreting the findings of this study prompts the notion that a part of one's body can become un-ownness or un-mineness when it does not function in a ready-to-hand manner. That is, similar to how a hammer is only observed as an *object* when it is broken and needs to be fixed, when part of one's body is *broken* it becomes an object to us, such that we objectify that part of our body. And when that broken part of our body is not readily fixed, it can become something other than ourselves, something alien; and thus we can, in a sense, engage with *othering* our own body as an alien object. And indeed, this phenomenon of *othering* one's own body was evident across the participant accounts, and particularly prominent in several.

Returning to the category of *enduring otherness* but now shifting focus of discussion towards the psychological domain of lived experience, a number of possible cognitive processes have been identified that relate to the adjustment process and to self and identity issues following brain injury (Gracey & Ownsworth, 2008). And although much of this body of work concerned traumatic brain injuries, accordance with the findings of the current study is notable whereby issues of self-discrepancy (Cantor et al., 2005), self-criticism (Freeman, Adams & Ashworth, 2015), loss and grief (Carroll & Coetzer, 2011), and threat appraisal (Riley, Brennan & Powell, 2004; Riley, Dennis & Powell, 2010) were all reflected in the participant data and categorised under *enduring otherness* within the psychological domain. Alongside the abovementioned concordance, many themes emerged from the current study that align with findings from existing research in the field (e.g., Douglas, 2012; Freeman et al., 2015; Muenchberger et al., 2008; Riley et al., 2004, 2010), which included such themes as: *being a burden on others*; *feeling useless*; *experiencing loss of skills and knowledge*; *not fitting in*; *feeling at odds with myself*; and *being preoccupied with who I am*. And in the current study it was under the central category of *enduring otherness* that all these themes coalesced and were represented.

Moreover, the studies by Riley and colleagues (2004, 2010) suggest that the aforementioned themes relating to appraisal of threat and increased anxious avoidance are only markedly present for those with low self-esteem. As such, these findings indicate a link between the research on self-identity and the literature on coping (Gracey et al., 2015); and thus provide another layer of support for the current study's proposed core category of *seeking connectedness* (as a means of coping) in response to experiences of *enduring otherness* (and consequent low self-esteem) especially within the psychological and social domains which are concerned with selfhood, and isolation and participation, respectively. Indeed, this is consistent with established mainstream mental health literature, which suggests that low self-esteem reinforces co-morbid depression and anxiety, where low mood, withdrawal and hopelessness result from cognitions involving failure and rejection, and anxiety and safety-seeking occur following cognitions concerning anticipated or feared negative outcomes (Fennell, 1997).

Accordingly, the current study offers a model that foregrounds the importance of motivation for *seeking connectedness* across different domains of lived experiences, and within the psychological domain this manifests under the main category of *struggling for a sense of normality*, which accords with responses aimed at minimising self-discrepancy and threat-to-self (see Gracey, Longworth & Psaila, 2015). However, although immediate reactions or coping responses can be seen as natural and understandable, studies have revealed some particular coping styles are maladaptive, including avoidance, self-blame, worry, and wishful thinking (Anson & Ponsford, 2006; Brands, Kohler, Stapert, Wade & Heugten, 2014; Curran, Ponsford & Crowe, 2000; Malia, Powell & Torode, 1995; Moore, Stambrook & Peters, 1989; Wolters, Stapert, Brands & Heugten, 2010). Additionally, diminished coping skills and poor adaptive problem solving predispose individuals to substance use (Schmit & Heinemann, 1999), with previous studies indicating moderate to heavy drinking among as many as 43% of the brain injury population (Kolakowsky-Hayner et al., 2002). In line with these existing understandings, the current study elicited participant accounts littered with narratives of maladaptive coping, including social withdrawal and avoidance behaviours, self-loathing and self-blaming, and rumination and worrying, along with some instances of moderate to heavy use of alcohol.

But what also emerged from the participant accounts is that maladaptive coping can be perpetuated and driven over the longer term by expectations associated with anxiety about failure or social rejection. And here, what is most concerning is that this situation can set up a cycle which further increases negative sense of self and negative sense of the future, and thus maintains or exacerbates sense of low self-efficacy, low self-worth, and low self-regard, leading to longer-term patterns of maladjustment. Indeed, during the current study several participants shared experiences of responding strongly to interpersonal events or situations in a disinhibited manner, which typically involved some level of verbal anger or aggression, followed later by experiences of shame and confusion related to an increase in self-discrepancy and reduced sense of self-efficacy, which in turn led to lower self-esteem.

Added to this, other accounts highlighted participants' avoidant behaviours due to fear of being unable to meet (imagined and actual) expectations of others, and being judged in social settings. Thus, it would appear likely that the survivors' decisions about what goals they might set themselves, and thus how they spend their time, along with choices about avoiding or getting involved in particular activities and situations, would be overshadowed and unhelpfully influenced by motivation to protect against any possible events or circumstances that could threaten their selfhood (Gracey et al., 2015).

However, despite accounts of engagement with typical unhelpful coping strategies, the participant data nevertheless revealed that for many there was a convoluted process towards some form of acceptance, rather than a fixed position of resignation, or even denial. Accordingly, this process was represented within the psychological domain across the dimension of *acceptance-resignation vs. defiance*. And when turning to existential literature, strong views can be found on how confronting intractable predicaments can shape either new opportunities or represent further barriers to experiencing another way of living. Jaspers (1971) wrote how we are always in situations, some of which we can work to change but others which we cannot. Our human condition means we are subject to chance, we must struggle, we must suffer, and we must die. These fundamental situations of human existence are referred to as boundary or limit situations. However, according to Jaspers, it is how we meet these limit situations that decides whether we remain in *simply being* or enter into *real existence*. To enter *real existence* means to face the limit situation with one's eyes wide open without denial, and only then might we reach the meaning and core of existence and be transformed into someone else than before. Furthermore, Jaspers tells us that to realise and accept these conditions provides the possibility to experience real fulfilments that only spring forth in the shadow of suffering. And indeed, something of this sentiment was evident within a number of participant accounts, with narratives including themes of new appreciations, different understandings, and wider perspectives, which emerged as the experience of post-stroke living unfolded. These aspects are further reviewed when later considering the philosophical domain of lived experience.

Conversely, in addition to the notion of acceptance the study data revealed a phenomenon of being defiant in the face of adversity. This stance is presented under the category of *struggling to gain a sense of normality* in terms of asserting that *I'm not having this*; *being stubborn*; and *bloody-mindedness*; that is to say, for some participants, at least at times, there was a distinct lack of acceptance or resignation towards their current predicament. And although existing literature (e.g., Klonoff, 2010) has highlighted that maladaptive presentations such as denial or unrealistic hopefulness can inhibit rehabilitation, to the author's knowledge there has not been a focus within the literature on survivors' taking a position of defiance, which the proposed model suggests is a somewhat different attitude all together. This notion of being defiant in the face of adversity seems to resound strongly with common gender stereotypes of what personal qualities an archetypal man should be displaying. And certainly for some participants this attitude emerged and presented strongly especially during the early stages of recovery and rehabilitation. Speculatively, this attitude may be more evident among males of working age compared with older adults or females; and if so, possibly due to internalised social expectations of what a man should be, whether perceived or otherwise. But in any case, as seen in the participant data, experiencing an attitude of defiance may serve to combat a sense of self-discrepancy and protect self-esteem, and thus protect against emotional difficulties, as well as provide motivation to engage with the rehabilitation process. That said, the end goal of stroke rehabilitation from a psychological perspective is widely seen within the field as reaching some form of acceptance (c.f. Klonoff, 2010; Ruff & Chester, 2014). However, while considering the relevance of assuming an attitude of defiance against the predicament of stroke, it is possible to once again draw upon existential thinking. Camus (1942/1991) contended that absurdity “arises out of human need to understand a world that cannot be reduced to a rational and reasonable principle” (p. 51). Attempts to explain the world only lead to meaningless abstractions; and whilst we build our life on the hopes of tomorrow, tomorrow brings us closer to death which is the ultimate enemy. Camus argues the only appropriate response to the absurd condition is not resignation, and certainly not suicide, but to adopt an approach of “constant confrontation, constant revolt” (p. 54). Something of this attitude is elucidated in chapter four of Camus’ (1942/1991) book *The Myth of Sisyphus*, where the protagonist is eternally condemned to a meaningless task of laboriously moving a rock up a mountain, only for the rock to roll back down, leaving the forsaken hero, Sisyphus, to start over again. Camus uses this imagery to suggest that when one becomes conscious of one’s wretched condition, “*[acknowledging]* the truth will conqueror it” (p. 94); and goes on to further assert that "there is no fate that cannot be surmounted by scorn" (p. 121). Similarly, the proposed model in this study acknowledges the *scorn* or defiance expressed by several participants at some points in their recovery and rehabilitation, and has considered the benefits of this attitude for their motivation and wellbeing.

Nevertheless, acquired impairments in physical, cognitive and emotional functioning can impact a stroke survivor’s “experience of self in the world” (Gracey et al., 2008, p. 639). Certainly, these impairments can negatively affect individuals’ self-esteem, and in turn self-esteem has been expressly associated with poor emotional outcome after acquired brain injury (Cooper-Evans et al., 2008). The subjective meaning of these impairments and individuals’ capacity to participate in society and life roles is central to maintaining or reconstructing one’s sense of self, which has often been undermined by increased dependence, reduced sense of agency, and inability to continue valued activities. What is more, reliance on particular unhelpful strategies will likely over time negatively affect social participation, and therefore potentially disrupt opportunities for an individual to engage in meaningful and adaptive social activities, create social connections, and maintain social identity. Yet, from an existential perspective, being with others is an indispensable aspect of being human and becoming ourselves. According to Heidegger (1926/1962), human beings are fundamentally “being-with” (p. 114). That is to say, Heidegger views our ability to understand ourselves as individuals always shapes, and is shaped by, the ways in which we comprehend and conduct our relationships with others (Mulhall, 1996).

Similarly, Buber (1954/2002) emphasized the importance of recognising human life as it is lived in all its relatedness, asserting that “the individual, in fact, is essentially related to something other than himself” (p. 197). While Bion (1961) reminds us that “we all live in groups, and have plenty of experience, however unconscious, of what that means” (p.64). With this in mind, the proposed model reflects the importance of the social domain for stroke survivors. The study data reveals that self-isolative behaviours were a common response to the consequences of stroke among the participant group, especially following discharge from hospital, and that these behaviours were driven by anxiety about judgement from others. In addition, participants experienced loss of friendships and affiliations, either immediately or over a period of time, due to their physical and socio-emotional impairments. The participant accounts underlined motivation to associate with others, but crucially under circumstances that reduced threat to self-esteem. For instance, participants felt a sense of camaraderie engaging with other stroke survivors; tended to feel less judged when interacting with individuals who did not know them pre-stroke; and when in public settings employed strategies to hide the extent of their impairments. Accordingly, these contending processes, of wanting to avoid negative judgements from others but desiring social interactions, are represented in the model within the social domain through the dimension of *isolation vs. participation*.

Having reviewed three of the proposed model’s four domains of lived experience, being the three domains that most closely align with a biopsychosocial perspective, attention now shifts towards reviewing the fourth, namely the philosophical domain. This domain of lived experience is primarily concerned with individuals’ subjective meaning-making and sense of purpose following stroke. Klonoff (2010) writes how stroke survivors often experience profound feelings of dissatisfaction and purposelessness once they recognise their losses, which might comprise physical impairment, cognitive deficiencies, psychological complications, and social difficulties and rejection. Underpinning this sense of purposelessness are deficits to executive function which affect flexible thinking, planning, and goal setting, where survivors can be left feeling bewildered and adrift, and struggling to make sense of the abstract notion of a meaningful existence (ibid.). Indeed, often foreshadowed by lamentations of *‘Why me?’* (Delmonico et al., 1998), stroke survivors will tend to engage in fraught quests for meaning in their post-injury life (Prigatano, 1999). And accordingly, the participant accounts were full of narratives that featured both lament of loss and longing for meaning and purpose. These conditions are particularly represented within the philosophical domain of lived experience outlined by the proposed model, and are emphasized through the dimension of *pointlessness vs. meaningfulness*.

It is at this point in the discussion that turning once again to existential literature can provide some useful perspectives for considering how stroke survivors might want to respond to their profound suffering. That is to say, separately from seeking to diminish it, how might a survivor confront their predicament such that they do not experience intense despair? One particular possibility stems from Nietzsche's assertion that our problem "[i]s not suffering itself, but that there [i]s no answer to the crying question, 'why do I suffer?'" (Nietzsche, 1887/2003, p.118), thus advancing the notion that it is the meaninglessness of suffering that is the problem rather than the actual suffering itself. Accordingly, Frankl later wrote that "in some way, suffering ceases to be suffering at the moment it finds a meaning" (Frankl, 1946/2004, p. 117). Frankl goes on to elucidate this phenomenon by highlighting that, for instance, meaning can surpass suffering under circumstances of personal sacrifice: "that is why man is even ready to suffer, on the condition, to be sure, that his suffering has a meaning" (ibid.).

However, as the accounts of the participants revealed, survivors will typically suffer the consequence of stroke against a backdrop which does not readily offer any meaning towards their suffering. For instance, two participants spoke of being told how a pre-existing heart condition may have been contributory to their stroke event, while others described how they were variously told the event was *a chance in a million*; *it's just one of those things*; and, it *could happen to anybody at any time*. And although in the first instance, research on stroke indicates that understanding the cause of the condition can be of great importance for how to focus on future life (Bendz, 2003; Veenendaal, Grinspun & Adriaanse, 1996), and in the second instance, such platitudes seemed to offer some comfort to participants; the salient point here is that an explanation for the stroke event does not in itself tend to provide meaningfulness to the suffering that follows. That is, some explanation might assist in making sense of one's *thrownness* into circumstances not-of-their-choosing, but does not diminish the existential meaninglessness of the consequent suffering.

That said, we can further learn something useful from existential philosophical thinking. Frankl (1946/2004) states that desire for meaning is one of the fundamental features of being human, and refers to three principal ways in which life can be made meaningful (sometimes referred to as the *meaning triangle*). Firstly, through creativity, in what we do creatively and what we give to life. Secondly, through experiencing, especially through loving the world and everything in it. Lastly, through change of attitude, whereby we can find meaning in the attitude we adopt towards a fate that can no longer be changed. Frankl (1967) contends that this latter way is the meaning of suffering, which is much underrated given that we are fallible and finite beings faced with life’s tragic triad of unavoidable suffering, guilt, and death. Thus, Frankl suggests that rather than asking what meaning life has for us, we should be asking ourselves what meaning we should be giving to life. And whilst clarifying that suffering is not *necessary* to find meaning, Frankl (1946/2004) insists that meaning is possible in spite of suffering. Hence, despite us being bound by bio-psycho-social limitations, it is possible for us to take a stance when we are confronted with boundaries that cannot be exceeded. Thus, although the participants were thrown into their post-stroke circumstances, which were not of their choosing, and were confronted with bio-psycho-social limitations that could not be surpassed; nonetheless, the participants still have the freedom to choose how to relate to their predicament. These well-established notions: that we always have freedom to choose our stance against insurmountable limitations, and that we always have an ultimate responsibility for giving meaning to our own lives, have potential applicability for supporting stroke survivors with psychological and emotional difficulties. And, consequently, they lend further support to the research findings which contend for the incorporation of a philosophical stance, and accordingly an adjustment towards a bio-psycho-social-existential model for supporting post-stroke living. Indeed, given that meaning and life values motivate human existence, in terms of stroke survival one’s meanings and values can provide inspiring signposts along the road towards recovery and a redefined life (Jemmer, 2006; Klonoff, 2010). As such, the proposed model further advocates for the consideration of existential meaning-making and life values when delivering psychotherapy and psychological interventions; particularly for facilitating shifts in survivors’ preoccupations with a loss perspective towards both a resources perspective and a healing orientation, and for promoting motivation and adaptiveness (Ben-Yishay & Daniels-Zide, 2000; Stroebe & Schut, 1999).

Perhaps unsurprisingly, this study is not alone in advocating for expansion of the biopsychosocial model in some way (c.f. Katerndahl, 2008; Sulmasy, 2002; Bowen, Yeates & Palmer, 2010). Indeed, as far back as 1999, proposed amendments to the constitution of the World Health Organisation (WHO) included the addition of spiritual wellbeing into the WHO concept of health (WHO, 1999), where the new text would read: *Health is a dynamic state of complete physical, mental, spiritual and social well-being and not merely the absence of disease or infirmity*. Undoubtedly, such an amendment would have supported the notion for replicating such change in the biopsychosocial model. However, in the event, despite being initially approved during the assembly of the organisation, the revised version was later vetoed. All that said, this study is not calling for changes to the principles held by the WHO. Rather focus is more limited towards promoting an inclusion of the existential perspective specifically for understanding lived experiences of stroke survivors; and potentially, following further research, for understanding the lived experiences of the wider mildly to moderately brain injured population. Accordingly, an existential perspective has been incorporated into the proposed model through inclusion of a philosophical domain. As already highlighted, the philosophical domain of the model comprises an overarching dimensionality of *pointlessness vs. meaningfulness*, and the notions of meaning, purpose and transcendence. This domain of meaning-making is further underpinned by categories of *valuing something before self* and *feeling part of something beyond self*, which certainly embraces spiritual features of the human condition, along with other avenues for experiencing meaning-based connectedness and belongingness. Indeed, it has been noted that experience of life crisis reminds individuals of their spiritual needs (Chen, 1997), and that both spirituality and religious faith can help an individual cope with their limitations through recreating a meaningful life and relationship with the world (McColl et al., 2000a, 2000b; Klonoff, 2010). Moreover, given the term *spiritual* is rather nebulous when the notion of spirituality is considered within our contemporary pluralistic society, with its culture of individuality and with diversity of interpretation ranging from nonreligious and nontheistic views (e.g., the power of positive thinking) through to profoundly religious experience (Haight, 2009); its influence is all the more far-reaching. Thus, on the basis that individuals' beliefs and existential worldview can have a significant impact on construction of the meaning of acquired impairment, coping behaviour, and preferences for support; it appears pertinent to acknowledge this feature of human thinking. Further, given that an existential aspect is clearly evident within the participant data, it seems necessary and appropriate to incorporate it into the notion of the philosophical domain in the proposed model, and to help ensure that it is not seen as a private and subjective area that lies outside of the therapeutic context.

8.4 Significance of the study

As already outlined in the introduction chapter, this research project has been conducted and authored as partial fulfilment of a doctorate in counselling psychology, and adopts an existential perspective towards the topic under investigation. To the knowledge of the author, this project is the first study to specifically focus on an exploration of subjective lived experience of post-stroke predicament and emotional difficulties faced by men of working age with a cross-section of participants spanning 1 to 10 years post-injury. As such, it is hoped that this study might contribute to further development of understanding and provision in this field. With this in mind, the following three subsections consider the significance of the current study with respect to the role for counselling psychology for informing post-stroke mental healthcare, the relevance of taking an existential perspective towards experience of post-stroke circumstances, and the implications for clinical practice that flow from this study.

8.4.1 Role of counselling psychology

The findings from this counselling psychology study offer a model, which might be useful for further understanding and supporting male stroke survivors with adjustment and acceptance in post-injury life. Notably, the model was derived from subjective experience and it is based on a notion of extending the biopsychosocial model to include an existential perspective. As intimated at the outset of this thesis, the ethos of counselling psychology does not readily align with the clinical approaches underpinned by the biomedical model predominant in UK mental healthcare. Against this background, it is acknowledged that the findings from the current study may jar somewhat with the stance of clinical psychology in the UK which is firmly under the influence of the medical model of psychological pathology and wellbeing. Certainly, although both existential and psychodynamic concepts have been quite strongly represented in clinical psychology training in continental Europe, clinical psychology in the UK is not often associated with phenomenological and existential ideas (Frankland, 2017). Indeed, Frankland (2017) recently went as far as to suggest that what passes for clinical psychology training in the UK is actually for a particular kind of psychology practice in the NHS, and thus it might be more accurate to call such practitioners “NHS psychologists” (p. 14). But to be clear, making reference to this rather provocative observation is not intended to be in any way undermining, nor provoke confrontation between differing disciplines. Far from it. Instead the purpose is to elucidate something of the political backdrop against which this study seeks to helpfully contribute towards psychological practice and research for stroke survivors in the UK. That is to say, a backdrop of healthcare services that have been predominately shaped by the biomedical model, and which this counselling psychology study is seeking to gently question and perhaps tentatively challenge in the hope of contributing an additional understanding of lived experience post-stroke which might help facilitate some further development of post-stroke psychological support.

Indeed, overarching this counselling psychology study is the notion that therapeutic encounter essentially grounded in a medical model of diagnosis and prescriptive treatment, although predominately practised by clinical psychologists in the UK, does not align well with the ethos of counselling psychology; and is certainly eschewed from the existential therapeutic standpoint. That is, the philosophy of counselling psychology emphasizes “being-in-relation rather than doing” (Strawbridge & Woolfe, 2010, p. 11), and thus it places an importance on “how we are with clients not what we do to clients” (ibid.). Indeed, Yalom (2001) advises that the diagnostic approach typically reduces opportunity for therapists to relate to their client as a person. Furthermore, Spinelli (2005) warns that diagnoses and treatment of symptoms can merely provide some respite, arguing that such symptoms are manifestations of endeavours to counter existential anxieties, which are beyond the reach of medical interventions and behavioural treatments. Kleinplatz (2004) concurs, saying that concentrating merely on symptoms reduction disregards the importance of intrapersonal and interpersonal meanings, and the systemic and sociocultural contexts that encompass clients’ lived experiences. And correspondingly, Deurzen-Smith (1990) asserts that the tasks of facilitating a way for clients to live more meaningful lives ultimately operates within the field of philosophy, rather than within narrow scientific principles; which additionally provides support for the theoretical model generated by the current study.

Furthermore, as Murphy (2017) highlights, healthcare, at least in the field of mental healthcare, informed as it is by the medical model is not concerned with human growth and development. Instead focus is principally on repair, restoration, fixing, and addressing deficits in functioning. And where this might seem perfectly reasonable to many, for counselling psychology this is essentially unsatisfactory given that counselling psychology is based in the growth paradigm rather than the deficit paradigm. And, indeed, this important principle of counselling psychology has been reflected to some extent in the model offered by this study, and stands in response to current prevailing attitude towards post-stroke mental healthcare.

8.4.2 Relevance of an existential perspective

As reviewed in the discussion of the findings, an existential perspective offers an additional understanding about the lived experiences of male stroke survivors of working age and their responses to psychological and emotional difficulties post-stroke. This research illustrates how an existential stance towards the phenomenon of stroke survival, developed using the framework of the four domains of existence, can expand on the more traditional biopsychosocial model of wellbeing. As such, this research offers a theoretical model for understanding the experience of stroke survival that incorporates a philosophical domain and, by inference, advances the proposition that existential phenomenological therapy has a role to play in helping clients confront and relate to the sequelae of stroke, and shape their post-stroke living. Indeed, “first and foremost existential therapy is philosophical” (Deurzen, 2013, p. 155). An existential perspective on stroke survival provides an opportunity to consider what it means to be human; and thus can afford support to an individual while in existential crisis, who is trying to make sense of the world and the transitory nature of life. An existential understanding of the world and their place in it can enhance a client’s understandings, not only of their experience of stroke, but of their place in the world as a whole, of the extent of their freedom to choose, and of the limitations upon them. And rather than seeking to fit the client into pre-established categories and interpretations, there is a commitment to openly and receptively explore and clarify a person’s worldview and what it means to them to be alive.

In light of this, incorporating an existential perspective on treating and supporting clients with emotional difficulties post-stroke might seem incompatible with predominate CBT models. But the point here is that, arguably, an existential perspective can offer something beyond the current standardised provision by providing more individually focused treatment and tailored support. For instance, practitioners using CBT following brain injury can only meet competency for delivering treatment under the Improved Access to Psychological Treatment (IAPT) framework (Roth & Pilling, 2008) by demonstrating knowledge of the model of the specific mental health problem being treated (for example, major depressive disorder or social anxiety), alongside knowledge of models of the neuropsychological consequences of brain injury. Thus, it would not be possible to demonstrate competence according to this framework when working with those whose emotional needs do not meet specific diagnostic criteria, present as co-morbidities. This might include presenting problems such as depressed mood, non-specific anxieties, low self-esteem, aggression, socially inappropriate behaviour, disrupted relationships with others, and sub-optimal coping. And, given the heterogeneity of presentations (including range of emotional responses, as well as type and extent of acquired difficulties; along with socio-economic, pre-injury, family, and other contextual factors), perhaps unsurprisely, the need has already been highlighted for developing alternatives to the diagnostic understandings of emotional issues following acquired brain injuries (see Gracey et al., 2015; Shields & Ownsworth, 2013; Shields, Ownsworth, O’Donovan & Fleming, 2016). Considering all this, the approach of using a psychiatric model of classifying symptoms (which leads to diagnostic understandings followed by prescribed treatment models for achieving symptom reduction) seems overly narrow and somewhat rigid for the task of supporting male stroke survivors with their psychological and emotional difficulties in all their subjective diversity. Indeed, when content of treatment is vastly privileged above (and to the near exclusion of) any focus on subjective experience, it risks medicalising and pathologising emotional difficulties. And then - borrowing from Frankland (2017) - the burning question for counselling psychology becomes: How do we ensure “that the ordinary humanity in relationships between help seekers and providers does not get lost in standardised and manualised brief work”? (p. 17).

8.4.3 Implications for clinical practice

Two decades ago, Prigatano (1999) was highlighting that rehabilitation is likely to fail if emotional issues are not addressed sufficiently. In response to this long established concern, the grounded theory model generated from this research project provides an additional framework for understanding the lived experiences and emotional difficulties of male stroke survivors of working age with mild to moderate injuries. The model asserts that emotional diffculties might be better elucidated when survivors' subjective narratives are clarified across four domains of lived experience, these being: the physical, psychological, social and the philosophical. In doing so, the model asks the mental health professionals to not only bring attention to areas of subjective post-stroke experience typically explored by a biopsychosocial approach, but to go beyond this, and additionally consider a subjective existential perspective.

Thus, this model offers a framework for information gathering and assisting an individualised formulation-based understanding of factors, and their interactions, that underpin subjective experience of emotional difficulties. Indeed, lack of a cognitive-behavioural model for working with people with brain injury, or of evidence-based guidance about how to adapt existing mental health disorder specific models, was highlighted not so long ago; along with recognition that developing formulation-based rather than diagnosis-based understandings would serve development of effective practice in this area (Gracey et al., 2015).

Additionally, whilst stroke rehabilitation has tended to prioritise treatment of impairments, independence, and skills acquisition over any focus on interdependence and growth of self through life goal attainment (Kuenemund et al., 2013), the proposed model encourages the mental health practitioner to incorporate consideration of the roles of meaning-making, purposeful living and self-growth, rather than merely focusing on addressing deficits. The rationale for this recommendation is grounded in the research data and informed by existential thinkers, such as Frankl (1946/2004) who wrote extensively on the importance of meaning-making, and how motivation emerges from having a *why* for living. The assertion is that an understanding of a survivor's particular worldview can provide a greater insight into what is existentially meaningful for an individual, and thus provide opportunities to increase motivation and engagement with activities and interventions.

However, overarching all the theoretical material, and in keeping with a counselling psychology based study, it is argued that *how* information gathering is performed against the framework of the proposed model is fundamental for leveraging opportunities for therpeutic gain. Indeed, the early roots of counselling psychology grow from the field of humanistic psychology, with its centrality of the therapeutic relationship. From this standpoint, success in therapy is reliant on the relationships built with clients. Within these relationships counselling psychologists are able to draw on their skills and high level of competency and creativity to find the best ways to support their clients towards personal change and growth. Indeed, Yalom (1989) asserted that “it’s the [therapeutic] relationship that heals” (p.91).

With this in mind, application of the proposed model might be most appropriately provided by practitioners with training in, or having a working appreciation of, the ethos of counselling psychology and/or existential phenomenological therapy. It is argued that there is value in staying with individual subjective experience of stroke and distress to develop a shared understanding of psychologial and emotional difficulties. And to some extent this reflects the self-same process that elicited the data for the construction of the model in this study. It is about being-with the client and encouraging a phenomenological exploration, rather than attempting to classify problems and applying standardised treatment models.

8.5 Strengths and limitations of the study

This study uses Straussian grounded theory method to explore the experiences of male stroke survivors of working age, with an emphasis on elucidating experiences of emotional difficulties. Furthermore, whilst drawing on the triple lens of the biopsychosocial perspective, this study aimed to additionally understand the predicament of stroke survival from an existential perspective. To the researcher’s knowledge, this is the first study to conduct research with this specific client group in this particular manner, and therefore the first research project to develop a substantive theoretical model to represent and elucidate this phenomenon in this way. Indeed, commonly other studies have explored early stages of post-stroke experience, with few capturing participant narratives at 10 years post-stroke or sourcing cross-sectional experiences within an extended time range, such as from 1 to 10 years; and none, to the author’s knowledge, have focused on the experiences of men of working age across such as extended timeframe. Hence, the current research has been able to consider how the experiences of post-stroke life might shift over a more extended period of time, in a manner in which other studies have not placed as strong an emphasis. This emphasis provides an opportunity to more fully appreciate *problem areas* that arise across time and across different environmental situations, and in turn assist with clarifying how *comprehension of consequences* develop to create the backdrop against which survivors' act in response to their difficulties. In particular, the strength of this study lies in the theory offered which, on the basis of the data analysis, provides a novel perspective and conveys significant information about experiences, actions and outcomes for male stroke survivors of working age as post-stroke life unfolds over time and within different domains of lived experience. Indeed, the theory not only summaries themes previously identified as being prevalent in subjective experience of stroke survival but also draws on an existential perspective to provide a broader framework for considering how survivors confront their predicament. In this way, the theory is a relevant addition to the existing models for understanding stroke and brain injury survival, such as the Patient Experiential Model (PEM) of recovery after brain injury (Klonoff, 2010), which depicts the phases of recovery and rehabilitation process for patients after moderate to severe brain injuries who participate in holistic milieu-oriented therapies and/or insight-oriented treatment (Klonoff, 2010, p. 14); the Y-shaped model of rehabilitation (Wilson et al., 2009), which focuses on identity and on stages of change; and the Longitudinal, transdiagnostic cognitive-behavioural model of post-ABI adjustment (Gracey et al., 2015), which highlights components of emotional distress and emphasizes the role of threat reaction in maintaining experience of threat to self and its impact on psychosocial adjustment.

In terms of the current study's strengths and limitations as a consequence of its sample, issues of homogeneity, and generalisability are now discussed. As previously highlighted in the methodology chapter under section *4.7.5 Sample size considerations*: "the current study recruited a participant sample that was homogeneous in terms of the participants being adult male stroke survivors of working age who are at least one year post-injury" (pp. 50-51). And furthermore, criteria for recruitment required a high level of cognitive functioning post-injury. However, in addition to these common features, the sample group also shared characteristics relating to nationality, ethnicity, sexual orientation, and, to some extent, religious belief. That is, all participants were white, British-born, and heterosexual, with two participants articulating their Christian faith, two expressing less formal spiritual views, and the majority conveying an atheistic position. Further sample homogeneity derived from the participants being of working age, with all participants having experienced a minimum of two decades of pre-stroke working life, with the youngest participant aged 38 years at time of stroke and the oldest aged 60 years. Finally, all participants had attended the same branch of Headway and would have broadly received a similar service.

Indeed, the homogeneity of the sample provided strength to the study in terms of contributing towards the saturation process during the analysis of the data. However, an inherent drawback that accompanies the aforementioned benefit is the limitations to which the findings of the study can be confidently generalised across wider diversity within the stroke survivor population, given that the sample obtained effectively resulted in a study skewed towards middle-aged white males. What is more, given the sample size, it might be prudent to exercise some caution in generalising findings across the stroke population closely represented by the sample itself.

8.6 Recommendations for future research

As previously discussed, the current study is grounded in data provided by a relatively small participant group of 10 males with comparatively similar demographics and somewhat overlapping experiences of post-stroke survival. Hence, it follows that the study sample potentially limits the applicability of the proposed model across a wider, more diverse population of stroke survivors. With this in mind, future research might seek to recruit participants with more diverse characteristics, especially in terms of ethnicity, age, and time since stroke event.

Such research will potentially provide justification for generalisability of the model across a wider population, either as it is presented in this study or following refinements of the model necessary to encompass additional findings. Leading on from any revisions to the model, further studies working with a more established model could be aiming to determine the model’s applicability to other categories of acquired brain injuries. Additionally, research could go on to explore the model’s explanatory power for understanding working-age females’ experiences of stroke and/or other acquired brain injuries. Indeed, an overarching aim for further research could be towards developing the substantive theoretical model into a more formal theory for understanding an even wider acquired brain injury population.

8.7 Author’s response to the research

This section aims to further increase transparency for the reader on how the author interacted with and responded to the research process. In particularly, I have focused on the two areas of the study that seem most relevant in terms of the impact I would have had on research outcomes. These areas cover my experience of interviewing participants, along with the task of recruiting for the study, and my engagement with the analysis process, including the relationship I developed with the data. My reflections are provided in the subsections that follow.

8.7.1 The interviews

The task of recruiting participants and conducting the interview itself presented several difficulties for progressing the research, as well as generally challenging me in my role as a researcher. In terms of progressing the research the first interview was particularly important, as the data would be analysed and presented in a pilot study for my supervisory team to evaluate. In the event, approval of the pilot study was given, and the data permitted to contribute to the main study itself. However, my anxieties did not abate. Further enquiries from potential participants were few and far between, and the recruitment process was to become a protracted ordeal, where each participant recruited providing a brief moment of relief for me, before I once again began to wonder when I might next be contacted by another potential participant. Indeed, even though I am no stranger to the difficulties of sourcing participants for research, my previous experiences did not fully prepare me for the time it would take to recruit participants for this study; and at times I found the uncertainty and slow pace of recruitment rather anxiety provoking. In any case, over time participants came forward and I was able to conduct 10 interviews, all of which provided a wealth of data. But, with some hindsight, I can now reflect on how I particularly appreciated the interview data, and even cherished it; while especially experiencing gratitude towards each individual participant. Coupled with this, at times, I experienced a strong sense of duty to honour the information provided by the men participating in my research, and to produce work that warranted the time they had taken to share their personal accounts. This sense of duty was heightened by the reason the men gave for deciding to participate: *they all wanted to contribute to something that might possibly help other stroke survivors in some way*. Undoubtedly, to some extent, my relationship with the data was influenced by my experiences of a difficult participant recruitment process, and the respect I felt for the participants, which I will elaborate on when I reflect on the analysis process in the next section.

In terms of the interview process, I was mildly surprised and extremely grateful for the unguarded and generous sharing of experience that the participants were willing to provide during their interview. Indeed, it has been suggested that some interviewees are not always prepared to fully narrate their experiences, and might sometimes even misrepresent them in an attempt to meet imagined expectations of the interviewer (Polkinghorne, 1988); but given the rich, and sometimes raw, accounts of lived experience, it seemed that such concern was not so warranted in this instance. Nonetheless, conducting the interviews themselves felt oddly challenging at times; it felt strangely familiar. Similar to countless therapeutic encounters, I was intent on gathering information and, to some extent, containing the participant when emotional material was being disclosed; yet I was barred from the task of formulating difficulties and delivering any interventions. Employing a subset of my skills in this way necessitated a mindful shift from a much practised position of psychotherapist and counselling psychologist in training, to that of inexpert researcher.

That said, I believe my experience of providing psychotherapy and psychological interventions to the stroke survivor client group was beneficial for my role as a researcher in this area. Indeed, my familiarity with the common difficulties that present as a consequence of stroke often provided me with useful contexts for understanding the participants’ narratives during the interview. Additionally, I envisage that my experience of building rapport within a therapeutic relationship, along with my practise of adopting a non-judgemental, phenomenological stance towards client material assisted the quality of the interview data by shaping an interaction with the participants that was characterised by respect and validation, and a sense of safety and containment. Indeed, although semi-structured in content, the interview was conducted more in the spirit of an unstructured interview, while still drawing on the interview schedule, allowing the interviewee to have as much freedom to express their experiences as they would like.

But returning to my position as a researcher with experience of working with the client group under investigation; what was needed to leverage this as an advantage was a strong awareness that this self-same prior knowledge could equally act to unhelpfully shape the interview process. And correspondingly, this necessitated a mindful commitment towards bracketing my assumptions about the narratives being shared. To assist me in this task, I maintained a personal journal throughout the research process—again, advocated by Corbin and Strauss (2015, p. 102)—and used personal therapy sessions to explore some of my emotional responses to the research material, as well as my previous therapeutic encounters with this client group, and my own personal life experiences of stroke survivors. Furthermore, I believe the quality of my research benefited from the experience I previously gained conducting semi-structured interviews (while undertaking a qualitative research project at Masters level), where supervisory input on a pilot interview transcript helped raise my awareness of how to refine my approach towards interviewing research participants by bracketing my perspectives as a therapeutic practitioner.

8.7.2 The analysis

To be unguardedly honest, I found the task of analysing the interview data to be an extremely challenging, and at times overwhelming endeavour. And it is with some ease that I can reflect on my experiences and highlight three aspects that contributed to the difficulties I encountered. Broadly, these aspects relate to the interrelated areas of processing interview information and managing the vast resultant volume of data; my relationship with the data shaped by a sense of responsibility towards honouring the participants' narratives; and my struggle with the process of developing a satisfactory theoretical model.

Indeed, during the early phases of analysis, I often felt swamped by the time-consuming processes of interview transcription and open coding. Added to this, on a practical level the sheer volume of open codes generated from data often felt barely manageable. I frequently felt besieged and exasperated by the pressing necessity to make sense of the data for the purpose of addressing the research question. Overarching this was that uncomfortable *leap of faith* I had taken in order to commit so much of my time and resources to an inductive process, where the possibility of achieving a meaningful outcome is often unclear until the latter stages of analysis. But with the questions looming: '*Would I produce anything of worth?'*, '*Was I wasting my time?'*, '*Had I wasted the time of my participants?'*; my predominant response was purposefully simple: continue following the Straussian grounded theory method guidelines, and trust that the process would work.

Although it took rather a long time, my persistence began to be rewarded. For extended periods, I felt immersed in, but inundated by the data. However, as I persevered with the process, eventually I experienced a sense of becoming buoyed by the data, rather than feeling drowned in it. This fresh connection with the data seemed to emerge following the process of transcription and open coding, and manifest in several ways. While reading excerpts from interview transcripts I began to find myself hearing the sound of the voice of the corresponding participant in my head. If I experienced a moment of insight or a tentative link came to mind, I was able to recall specific aspects of particular participant narratives that might support or challenge that insight or link. This is the extent to which I had become familiar with the data, and this is what I refer to as feeling buoyed (or supported) by the data.

Then, as mentioned in the previous section, *8.7.1 The interviews*, there was my relationship with the data in terms of feeling a great sense of responsibility towards honouring the accounts provided by the participants. Too often, I found myself becoming unhelpfully preoccupied with my need to preserve the participant narratives in all their richness, apparently attempting to *contain* the data, rather than *explain* the data. Not for the want of trying, I seemed to find it extremely difficult to raise the data to an abstract level of theory, which necessarily losses richness of individual experiences. I regularly reminded myself that grounded theory approaches are based on the proposition that a theoretical model will emerge from the cyclic process of data capture and data analysis. However, to achieve theoretical integration of the main categories an “Aha moment!” (Corbin & Strauss, 2015, p. 166, 196, 297) is often required. And unfortunately in my case, rather than experiencing a timely *Aha moment!*, I was left floundering following several failed attempts at generating a theoretical model that raised the main categories to a conceptual level with sufficient explanatory power for making sense of the originating data that I held in such high regard. Turning to the literature for inspiration and points of reference initially continued to yield inadequate models for appropriately representing the data. Nonetheless, with further persistence that *Aha moment!* did come. And, dare I say, I am somewhat surprised by and satisfied with the end product.

Despite the difficulties I encountered with the analysis process, and with theoretical integration in particular, I would still argue that pursing a grounded theory approach was clearly demanded by the nature of the research question. Though little did I anticipate how hugely challenging I would find this endeavour. Indeed, conducting this study was impactful on both my time and resources; and there were long periods when this research truly appeared to be overwhelmingly endless. That said, having beforehand reviewed advisory books on completing qualitative research, I was not entirely unprepared for what lay ahead; and I am sure that my experiences of conducting qualitative research at this level are not particularly uncommon (c.f. Bloomberg & Volpe, 2012). Furthermore, there were moments, such as after completing a particular task, or receiving feedback from my research supervisors, or writing up of a chapter, which brought a sense of achievement and added to my motivation, renewing my resolve for seeing the project through to the end.

8.8 Conclusion

This study explored how men of working age deal with psychological and emotional difficulties post-stroke, and integrated an existential perspective on this phenomenon. The research design was informed by Straussian grounded theory method, and the analysis generated a theoretical model which explained data captured from individual semi-structured interviews with 10 male stroke survivors of working age. The findings highlight that for understanding the lived experience of stroke survival, from an existential perspective, there is still a dimension missing from the triple lens provided by the biopsychosocial perspective. That is to say, the spiritual, or existential level of meaning-making, values and purpose is also important; and indeed, the current study offers a theoretical model that acknowledges this within the domain of the *philosophical*. In addition to meaningful activity, the emergent model urges for increased consideration of meaningful *being*, and a shift towards a bio-psycho-social-existential model for understanding lived experience of stroke survival, for informing treatment, and for guiding post-stroke support. Finally, in acknowledgement of the wealth of existential philosophical material that encouraged me to explore additional perspectives on life following stroke survival, I would like to close this thesis by offering a final notion. In doing so, I am borrowing from both Kierkegaard's ideas about the centrality of anxiety and Nietzsche's emphasis on suffering. Kierkegaard famously told us that: "Whoever has learned to be anxious in the right way has learned the ultimate" (Kierkegaard, 1844/1980, p. 155), whilst Nietzsche (1887/2003) emphasized the importance of *how* we relate to our suffering. At the risk of overstretching poetic licence, I offer this concluding notion inspired by the aforementioned existential philosophers, with a nod towards the theoretical model generated by this research project and its philosophical domain which places an emphasis on existential meaning-making:

whoever learns to relate with suffering in the right way has learned the ultimate

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Appendices

Appendix 1: Middlesex University library databases

Summon is a licensed product, which was implemented at Middlesex University, that provides a unified library search tool, enabling a simultaneous search of scholarly material listed on the library catalogue and other resources including books, scholarly journals, newspaper articles, reports, e-books, theses and dissertations, conference proceedings, and 161 academic databases. The 20 most relevant databases for the current study have been listed below:

- AMED
- British Nursing Database
- Cambridge Journals Online
- CareKnowledge
- CINAHL
- Cochrane
- Conference Proceedings Citation Index: Social Science and Humanities
- Index to Theses
- Medline
- NICE Evidence
- OECD Statistics (iLibrary)
- OVID Full Text Journals
- Oxford journals
- ProQuest Dissertations & Theses: UK & Ireland
- PsycARTICLES
- PsycINFO
- PubMed
- RCN Journals
- Sage Journals Online
- Web of Science

Appendix 2: Interview Schedule

Interview Schedule

How men of working age deal with emotional difficulties post-stroke

---

Question: **Could you describe your experiences of dealing with emotional difficulties after your stroke?**

Clarification: The meaning of emotional difficulties refers to your own perspective of any circumstances that cause you distress.

Prompts:

- When was the last time you experienced emotional difficulties?
    - What happened?
    - How did you feel?
    - How did you deal with them?
    - How did you cope?
- Have you encountered any other difficulties?
- Other domains

Question: **Could you describe your experiences of how these emotional difficulties affect yourself or others?**

Prompts:

- Socially
- Physically
- Psychologically
- Spiritually

Question: **Could you describe how might your emotional difficulties affect your recovery journey?**

Prompts:

- Adjustment process
- Limit situations
- Using compensatory strategies
- Learning new skills
- Sense of self (pre-/post-stroke)
- Identity
- Roles

Question: Could you tell me what it is like to do this interview?

Appendix 3: Ethics Approval Letter

NSPC
NEW SCHOOL OF PSYCHOTHERAPY
AND COUNSELLING

258 Belsize Road
London NW6 4BT
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Prof. Emmy van Deurzen – Principal
Prof. Digby Tantam – Deputy Principal

Barry Hannon
XXXXXXXXX
XXXXXX
XXX XXX

5th July 2014

Dear Barry

Re: Ethics Approval

We held an Ethics Board on 18th June 2014 and the following decisions were made.

Ethics Approval
Your application was approved by Chair's action and ratified by the board.

Please note that it is a condition of this ethics approval that recruitment, interviewing, or other contact with research participants only takes place when you are enrolled in a research supervision module.

Yours sincerely

Prof Digby Tantam
Chair Ethics Committee
NSPC

Appendix 4: Participant Information Sheet

NSPC Ltd
258 Belsize Road
London NW6 4BT

Information about a research project:

How men of working age deal with emotional difficulties post-stroke

being carried out by
Barry Hannon
as a requirement for a

DCPsych in Counselling Psychology
from
NSPC and Middlesex University

Middlesex
University
London NW4 4BT

Dated: _____ / _____ / 2016

You are being invited to take part in a research study. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve.

Please take your 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. Take your time to decide whether or not you wish to take part.

---

1. What is the purpose of the research?

This study is being carried out as part of my studies at NSPC Ltd and Middlesex University. It aims to gain a better understanding of men's experiences of dealing with emotional difficulties following a stroke in order to better inform practice for those working in this area.

You are being asked to participate because you have replied to my recruitment advertisement for interviewing people who are dealing with the consequences of stroke.

---

2. If I decide to take part, what will happen to me?

Firstly, I would like to have an informal meeting with you to explain in person what will happen if you decide to take part in this study. We can use this meeting to informally discuss and decide whether taking part in this study is appropriate for you on this occasion.

If we decide that it would be appropriate for you to take part then I would like to arrange an interview with you at your convenience.

The management at Headway have given me permission to see you in an empty room at their premises for both the initial meeting and the research interview.

The interview will take about an hour and there will be opportunities for breaks.

The interview will focus on your experiences of dealing with emotional difficulties following stroke. I will have a small number of prepared questions, but will not necessarily ask all of them.

The emphasis of the interview will be on giving you an opportunity to talk freely and openly about your experiences of dealing with your difficulties, and will be conducted in a non-judgemental and sensitive manner.

The information from the interview will be combined with the information from other participants for analysis using Ground Theory Method. That is, I will use a qualitative research method to extract the main ideas of what you and other people tell me about their experiences of dealing with emotional difficulties, and I will draw conclusions about these ideas.

---

3. What will you do with the information that I provide?

Your interview will be audio recorded, and I will transcribe the audio recording for the purpose of analysis. I will be recording the interview on a digital recorder, and will transfer the files to an encrypted USB stick for storage, deleting the files from the recorder.

All of the information that you provide me will be identified only with a project code and stored either on the encrypted USB stick, or in a locked filing cabinet. I will keep the key that links your details with the project code in a locked filing cabinet.

I will offer to send you a copy of the interview transcript for your information. If you decide that you would like a copy of the transcript I will send it to you after I have completed the transcription, which should be within one to two weeks following your interview.

The information will be kept at least until 6 months after I graduate, and will be treated as confidential.

If my research is published, excerpts from your data may be used verbatim as anonymous examples, and therefore I will make sure that neither your name nor other identifying details are used.

Data will be stored according to the Data Protection Act and the Freedom of Information Act.

---

4. What are the possible disadvantages of taking part?

In the interview, I shall be asking you about your experience of dealing with difficulties following your stroke. It is possible that talking about personal experiences may be distressing. If so, please let me know, and if you wish, I will stop the interview.

Although this is very unlikely, should you tell me something that I am required by law to pass on to a third person, I will have to do so. Otherwise whatever you tell me will be confidential.

---

5. What are the possible benefits of taking part?

The study aims to provide findings that will be helpful for some brain injury clients in the future, especially with respect to psychotherapy.

However, it is assumed that the interview process, in itself, will not provide any explicit benefits for participants. Although some people may find this an opportunity to reflect on their experiences and may find this helpful.

6. About signing the Informed Consent form

You will be given a copy of this information sheet for your personal records, and if you agree to take part, you will be asked to sign the attached Informed Consent form before the study begins.

Participation in this research is entirely voluntary. You do not have to take part if you do not want to. If you decide to take part you may withdraw at any time without giving a reason.

Whether or not you participate, will not affect any treatment that you are currently receiving in any way.

7. Who is organising and funding the research?

This research is fully self-funded by the researcher. This research is not being organised or sponsored by Headway, as such. However, Headway is collaborating in terms of allowing recruitment posters to be displayed on their notice boards, and providing a room on their premises for interviews.

8. What expenses will I receive for taking part?

This research is being self-funded, so unfortunately I will not be reimbursing any expenses you incur due to taking part in this study.

9. Who has reviewed the study?

All proposals for research using human participants are reviewed by an Ethics Committee before they can proceed. The NSPC research ethics sub-committee have approved this study.

10. What are my rights as a participant?

You can decline to answer any question that you do not want to answer. For example, if you feel answering the question will be difficult or upsetting. You do not have to give a reason for declining to answer a question.

You have the right to withdraw from this study at any time, without any obligation to explain your reasons for doing so.

The researcher reserves the right to end the interview if you appear to be experiencing undue distress or discomfort.

11. What about my right to confidentiality?

I will edit the information you provide to remove any identifying details, such as names of people or places, so that your privacy is protected in any written or presentation-based communication of the study findings to the University or a wider audience.

After I have edited the interview audio recording (and the transcript of it) to erase any potentially identifying information, only myself, you, the research supervisor and academic assessors would have access to listen to the edited interview audio recording and view the transcript data. Additionally, to ensure validity of the analysis, a co-researcher may be used to review the findings from the transcripts.

The interview audio recording will be kept in a secure location until the research has been assessed by the NSPC and Middlesex University, after which it will be destroyed.

The transcript of the interview will be securely kept for five years (to allow for the possibility of the publication of the research findings), after which it will be destroyed.

In the event that you provide any information that suggests a risk of harm to yourself or others, or any information about criminal activities, the researcher is required to break the confidentiality and disclose this to the appropriate parties.

12. What about taking care of my well-being?

Please be aware that recalling past and present experiences has the potential to evoke emotions from those times, which could be disturbing and distressing. If, for any reason, you feel emotionally distressed during the interview you may want to terminate it and withdraw from the study, and I am aware of this possibility.

After the interview, I will offer you a debrief, listen to any thoughts you might have about your interview experience, and provide details of local counselling services and support groups (as you might consider seeking support to explore thoughts or feelings that may have arisen), and I will be able to discuss these options with you.

Thank you for reading this information sheet.

If you have any further questions, you can contact me at:

Barry Hannon, NSPC Ltd. 254-6 Belsize Road, London NW6 4BT
Email: bh-13@mdx.ac.uk

If you any concerns about the conduct of the study, you may contact my supervisor:

Dr. Jaqcui Farrants, NSPC Ltd. 254-6 Belsize Road, London NW6 4BT
Email: Admin@nspc.org.uk

or

The Principal, NSPC Ltd. 254-6 Belsize Road, London NW6 4BT
Email: Admin@nspc.org.uk Tel: 020 7624 0471

Appendix 5: Written Informed Consent

Informed Consent for research project:

How men of working age deal with emotional difficulties post-stroke

being carried out by
Barry Hannon
as a requirement for a

NSPC Ltd
258 Belsize Road
London NW6 4BT

DCPsych in Counselling Psychology
from
NSPC and Middlesex University

Middlesex
University
London NW4 4BT

Written Informed Consent

Title: **How men of working age deal with emotional difficulties post-stroke**

Academic year:	2015 / 2016
Researcher:	Barry Hannon
Supervisor:	Dr. Jacqui Farrants

I have understood the details of the research as explained to me by the researcher, and confirm that I have consented to act as a participant.

I have been given contact details for the researcher in the information sheet.

I understand that my participation is entirely voluntary, the data collected during the research will not be identifiable, and I have the right to withdraw from the project at any time, without any obligation to explain my reasons for doing so.

I further understand that the data I provide may be used for analysis and subsequent publication, and provide my consent that this might occur.

Print name: ______________________________

Sign name: ______________________________ Date: ____ / ____ / 2016

To the participant:

Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Social Sciences Ethics committee of Middlesex University, if required by institutional audits about the correctness of procedures. Although auditors will have access to your details, this would happen in strict confidentiality.

☐ Please tick here if you do **not** wish your data to be included in audits.

Appendix 6: Debrief Sheet

Debrief Sheet for research project:

How men of working age deal with
emotional difficulties post-stroke

being carried out by
Barry Hannon
as a requirement for a
DCPsych in Counselling Psychology
from
NSPC and Middlesex University

NSPC Ltd
258 Belsize Road
London NW6 4BT

Middlesex
University
London NW4 4BT

Debrief Sheet

Thank you for your participation in this study and the contribution you have made towards understanding the consequences of stroke.

If you have any concerns or queries regarding this research study, or if you wish to obtain a summary of the study findings, please do not hesitate to contact Barry Hannon at Middlesex University via email: bh-13@mdx.ac.uk

If you have any concern or complaint about the study and the way you have been treated as a participant, you can contact the researcher supervisor Dr. Jacqui Farrants by writing to: NSPC Ltd. 254-6 Belsize Road, London NW6 4BT, or via email: Admin@nspc.org.uk, or via NSPC office number: 020 7624 0471.

If participation has raised any concerns or issues that you wish to discuss further, you may want to consider some of the following options:

- Contacting your key worker.
- Accessing the in-house counselling service at Headway.
- Using any of the agencies listed below to obtain advice and support:

The Samaritans (24 hours support service)
☎ 08457 90 90 90
email: jo@samaritans.org
website: www.samaritans.org

Stroke Association
☎ Helpline 0303 3033 100 (open Monday to Friday, 9am to 5pm)
email: info@stroke.org.uk
website: www.stroke.org.uk

Brain Injury Rehabilitation Trust (BIRT)
☎ 01924 896100
email: director@birt.co.uk
website: www.thedtgroup.org/brain-injury

Appendix 7: Distress Protocol

Distress Protocol

How men of working age deal with emotional difficulties post-stroke

As an ethical consideration for this research, a Distress Protocol has been established to ensure the researcher is well placed to deal with any distress that participants may experience during their involvement in the interview process.

The participants will be men who have experienced a stroke. The focus of the interview will be towards their experiences of dealing with difficulties following their stroke. Therefore, there is some risk that a participant could experience thoughts or feelings that have the potential to cause them some level of distress during or immediately after the interview.

This Distress Protocol provides the researcher with a framework comprising three levels (namely, mild distress, severe distress, and extreme distress) to monitor participants' emotions for signs of distress using specified criteria, and to respond with an appropriate corresponding level of intervention.

Any proposed actions will be taken in collaboration with the Headway professional staff at the premises where the interview is being conducted.

The three-level framework Distress Protocol is as follows:

Distress Protocol

Level 1: Mild distress

Visible signs:

1. Tearfulness.
2. Appears emotionally upset, with some difficulty speaking.
3. Appears disengaged, distracted and/or agitated.

Proposed action:

1. Ask the participant if they are willing and able to continue.
2. Provide an opportunity for the participant to take a break before continuing.
3. Remind the participant that they can stop at any time if they feel too distressed.

Level 2: Severe distress

Visible signs:

1. Crying uncontrollably, unable to talk clearly.
2. Panic, anxiety attack (observing shaking, sweating, tension observed in body language).
3. Apparent difficulties concentrating / remaining focused, displays of agitation.

Proposed action:

1. The researcher should terminate the interview.
2. The debriefing process should take place, with attention drawn to listed support services.
3. Suggest relaxation techniques (e.g., brief controlled breathing exercises) to ease distress.
4. Normalise the participant's distress and offer reassurance that their distress will gradually pass.

Level 3: Extreme distress

Visible signs:

1. Observed extreme emotional distress, which might include wailing and crying uncontrollably.
2. Extreme agitation with possibility of verbal/physical threat.
3. Expressions of suicidal ideation/intent, and/or expressions of psychotic breakdown.

Proposed action:

1. Seek to ensure safety of both participant and researcher.
2. If the researcher has concerns for the participant's or others' safety then the appropriate mental health services should be contacted.
3. If the researcher believes that the participant is an immediate danger to themselves or others then the participant should be advised to seek immediate psychiatric assistance via a hospital Accident and Emergency Department.
4. In very extreme cases, where a participant refuses to seek immediate help and begins to become violent, then Police should be alerted. It should be suggested the participant is detained under the Mental Health Act pending psychiatric assessment.

Appendix 8: Risk Assessment Form (FRA1)

INDEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT FRA1

This proforma is applicable to, and must be completed in advance for, the following field/location work situations:

1. *All field/location work undertaken independently by individual students, either in the UK or overseas, including in connection with proposition module or dissertations. Supervisor to complete with student(s).*
2. *All field/location work undertaken by postgraduate students. Supervisors to complete with student(s).*
3. *Field/location work undertaken by research students. Student to complete with supervisor.*
4. *Field/location work/visits by research staff. Researcher to complete with Research Centre Head.*
5. *Essential information for students travelling abroad can be found on www.fco.gov.uk*

FIELD/LOCATION WORK DETAILS

Name	Barry HANNON	**Student No** **Research Centre (staff only)** …………………………	M00XXXXXX
Supervisor	Dr. Jacqui FARRANTS	**Degree course**	DCPsych in Counselling Psychology

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Telephone numbers and name of next of kin who may be contacted in the event of an accident	**NEXT OF KIN** **Name** XXXXXXXXXXXX **Phone** XXXXX XXXXX
Physical or psychological limitations to carrying out the proposed field/location work	NONE.
Any health problems (full details) Which may be relevant to proposed field/location work activity in case of emergencies.	NONE.
Locality (Country and Region)	ENGLAND, London and Home Counties.
Travel Arrangements	PRIVATE CAR.
NB: Comprehensive travel and health insurance must always be obtained for independent overseas field/location work.	NOT APPLICABLE.
Dates of Travel and Field/location work	Dates: Dates to be scheduled with participants. Location: Headway premises. Duration: Day trips only.

PLEASE READ THE FOLLOWING INFORMATION VERY CAREFULLY

Hazard Identification and Risk Assessment

List the localities to be visited or specify routes to be followed **(Col. 1).** For each locality, enter the potential hazards that may be identified beyond those accepted in everyday life. Add details giving cause for concern **(Col. 2).**

Examples of Potential Hazards :
Adverse weather: exposure (heat, sunburn, lightening, wind, hypothermia)
Terrain: rugged, unstable, fall, slip, trip, debris, and remoteness. Traffic: pollution.
Demolition/building sites, assault, getting lost, animals, disease.
Working on/near water: drowning, swept away, disease (Weils disease, hepatitis, malaria, etc.), parasites', flooding, tides and range.
Lone working: difficult to summon help, alone or in isolation, lone interviews.
Dealing with the public: personal attack, causing offence/intrusion, misinterpreted, political, ethnic, cultural, socio-economic differences/problems. Known or suspected criminal offenders.
Safety Standards (other work organisations, transport, hotels, etc.), working at night, areas of high crime.
Ill health: personal considerations or vulnerabilities, pre-determined medical conditions (asthma, allergies, fitting) general fitness, disabilities, persons suited to task.
Articles and equipment: inappropriate type and/or use, failure of equipment, insufficient training for use and repair, injury.
Substances (chemicals, plants, bio-hazards, waste): ill health - poisoning, infection, irritation, burns, cuts, eye-damage.
Manual handling: lifting, carrying, moving large or heavy items, physical unsuitability for task

If no hazard can be identified beyond those of everyday life, enter 'NONE'.

1. LOCALITY/ROUTE	2. POTENTIAL HAZARDS
Headway premises.	Participant becomes distressed. Participant becomes aggressive. Participant experiences a physical health issue.

The University Field/location work code of Practice booklet provides practical advice that should be followed in planning and conducting field/location work.

Risk Minimisation/Control Measures PLEASE READ VERY CAREFULLY

For each hazard identified **(Col 2),** list the precautions/control measures in place or that will be taken **(Col 3)** to **"reduce the risk to acceptable levels",** and the safety equipment **(Col 5)** that will be employed.

Assuming the safety precautions/control methods that will be adopted **(Col. 3),** categorise the field/location work risk for each location/route as negligible, low, moderate or high **(Col. 4).**
Risk increases with both the increasing likelihood of an accident and the increasing severity of the consequences of an accident.

An acceptable level of risk is: a risk which can be safely controlled by person taking part in the activity using the precautions and control measures noted including the necessary instructions, information and training relevant to that risk. The resultant risk should not be significantly higher than that encountered in everyday life.

Examples of control measures/precautions:

Providing adequate training, information & instructions on field/location work tasks and the safe and correct use of any equipment, substances and personal protective equipment. Inspection and safety check of any equipment prior to use. Assessing individuals' fitness and suitability to environment and tasks involved. Appropriate clothing, environmental information consulted and advice followed (weather conditions, tide times etc.). Seek advice on harmful plants, animals & substances that may be encountered, including information and instruction on safe procedures for handling hazardous substances. First aid provisions, inoculations, individual medical requirements, logging of location, route and expected return times of lone workers. Establish emergency procedures (means of raising an alarm, back up arrangements). Working with colleagues (pairs). **Lone working is not permitted where the risk of physical or verbal violence is a realistic possibility.** Training in interview techniques and avoiding /defusing conflict, following advice from local organisations, wearing of clothing unlikely to cause offence or unwanted attention. Interviews in neutral locations. Checks on Health and Safety standards & welfare facilities of travel, accommodation and outside organisations. Seek information on social/cultural/political status of field/location work area.

Examples of Safety Equipment: Hardhats, goggles, gloves, harness, waders, whistles, boots, mobile phone, ear protectors, bright fluorescent clothing (for roadside work), dust mask, etc.

If a proposed locality has not been visited previously, give your authority for the risk assessment stated or indicate that your visit will be preceded by a thorough risk assessment.

3. PRECAUTIONS/CONTROL MEASURES	**4. RISK ASSESSMENT** (low, moderate, high)	**5. SAFETY/EQUIPMENT**
All face-to-face contact with participants (and potential participants) will take place during office hours at the premises of a branch of Headway. The service manager will be aware that an interview is being held. In the event of the participant experiencing any emotional distress, becoming aggressive, or suffering physical difficulties, where deemed appropriate and necessary, the in-house staff will be called upon to assist the participant. A Distress Protocol has been devised should any of these circumstances arise.		• Mobile phone (fully charged with good reception) • Next of kin advised of interview arrangements, i.e., venue, date, start and end times. • Distress Protocol (see appendix 7) • Interviews will take place during normal office hours at Headway premises. • Service Manager will be available to call upon in-house staff to assist a participant with any emotional or physical difficulties.
Participant becomes distressed Before a participant has consented to taking part in an interview, the participant will have had time (at least one week) to consider whether they would like to take part. They will have attended an initial/selection interview with the researcher to discuss what is involved in taking part and collaboratively agree whether or not participation is appropriate at this time in their recovery journey. The Distress Protocol covers dealing with the event where a participant becomes distressed.	Low to medium	
Participant becomes aggressive As previously mentioned, before the interview is conducted there will be opportunities for the researcher and participant to discuss the interview process and build some rapport. The Distress Protocol covers dealing with the event where a participant becomes aggressive.	Low	
Participant experiences a physical health issue As previously mentioned, in-house staff will be called upon to assist the participant in the event of physical health issues arising.	Low	

PLEASE READ THE FOLLOWING INFORMATION AND SIGN AS APPROPRIATE

DECLARATION: The undersigned have assessed the activity and the associated risks and declare that there is no significant risk or that the risk will be controlled by the method(s) listed above/over. Those participating in the work have read the assessment and will put in place precautions/control measures identified.

Signature of Field/location worker (Student/Staff) ……………………..………….………….. **Date** …………………….

Signature of Student Supervisor ……………………..………….………….. **Date** ……….…………..…

APPROVAL: (ONE ONLY)
Signature of Director of Programmes (undergraduate students only) ……………………..………….………….. **Date** ……………………..

Signature of Research Degree Co-ordinator or Director of Programmes (Postgraduate) ……………………..………….………….. **Date** ……………………..

Signature of Research Centre Head (for staff field/location workers**)** ……………………..………….………….. **Date** ……………………..

NB: Risk should be constantly reassessed during the field/location work period and additional precautions taken or field/location work discontinued if the risk is seen to be unacceptable.

FIELD/LOCATION WORK CHECK LIST

1. Ensure that **all members** of the field party possess the following attributes (where relevant) at a level appropriate to the proposed activity and likely field conditions:
   - ☐ Safety knowledge and training?
   - ☐ Awareness of cultural, social and political differences?
   - ☐ Physical and psychological fitness and disease immunity, protection and awareness?
   - ☐ Personal clothing and safety equipment?
   - ☐ Suitability of field/location workers to proposed tasks?
2. Have all the necessary arrangements been made and information/instruction gained, and have the relevant authorities been consulted or informed with regard to:
   - ☐ Visa, permits?
   - ☐ Legal access to sites and/or persons?
   - ☐ Political or military sensitivity of the proposed topic, its method or location?
   - ☐ Weather conditions, tide times and ranges?
   - ☐ Vaccinations and other health precautions?
   - ☐ Civil unrest and terrorism?
   - ☐ Arrival times after journeys?
   - ☐ Safety equipment and protective clothing?
   - ☐ Financial and insurance implications?
   - ☐ Crime risk?
   - ☐ Health insurance arrangements?
   - ☐ Emergency procedures?
   - ☐ Transport use?
   - ☐ Travel and accommodation arrangements?

Important information for retaining evidence of completed risk assessments:

Once the risk assessment is completed and approval gained the **supervisor** should retain this form and issue a copy of it to the field/location worker participating on the field course/work. In addition the **approver** must keep a copy of this risk assessment in an appropriate Health and Safety file.

Appendix 9: Participant Recruitment Poster

Are you a **man** who has **survived stroke?**

Are you **under 65** years old?

Were you **over 18** at the time of your stroke?

If so, are you willing to talk about your experiences of dealing with stroke?

My name is **Barry Hannon.**
My doctoral **study** aims to gain a better understanding of **how men** of working age **deal with stroke.**

Findings from this **study** could **help** professionals **develop** and **improve** the **services** currently provided.

I am **interviewing adult males** who:

- had a stroke **at least** one year ago (**no** upper limit)
- are proficient in the use of **English language**
- have had a **neurological assessment** indicating a **high level** of **cognitive functioning**

If you are interested in speaking with me about your experiences of dealing with stroke, then I would be very interested in hearing from you.

Please contact me on **07--- ----13** (mobile)
or email me at: **bh-13@mdx.ac.uk**

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NEW SCHOOL OF PSYCHOTHERAPY AND COUNSELLING

New School of Psychotherapy and Counselling
in partnership with
Middlesex University

Middlesex University

Appendix 10: MoCA and ACE-R assessments

- Montreal Cognitive Assessment ([MoCA] (Nasreddine, n.d.).
- The Addenbrooke's Cognitive Examination Revised (ACE-R; Mioshi, Dawson, Mitchell, Arnold & Hodges, 2006).

The MoCA assesses the cognitive domains of attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation. A score of 26 or more (out of a maximum of 30) is considered to be in the normal range. For a full review of the use of MoCA in patients with stroke, see Chiti and Pantoni (2014) and Burton and Tyson (2015).

The ACE-R assesses cognitive functioning by incorporating the five sub-domains of orientation/attention, memory, verbal fluency, language and visuospatial, with respective lower limits of normal (cut-off scores) as follows: 17, 18, 9, 24, 15. For a review of the validity of the ACE-R in acute stroke, see Morris, Hacker and Lincoln (2012).

Appendix 11: Sample of Open Coding

		Transcript (I: *Interviewer* / R: *Respondent*)	**Open Coding**
001	I	Erm, the first question I'd like to ask you is, erm, could you describe your	
002		experiences of dealing with emotional difficulties after your stroke.	
003	R	Okay. Erm. It's, erm, ….. it's quite hard to actually go back to straight after the	Struggling to connect with event (immediately post-stroke)
004		stroke 'cos I really wasn't on the same planet. Erm, I was unconscious for four	Feeling disconnected (from the world)
005		hours and, erm, w-when I came round, my wife was by the bedside and a couple of	"I really wasn't on the same planet"
006		nurses, and I really hadn't got a clue what had happened to me. That's the first	Feeling clueless (/not understanding what had happened)
007		thing, except, er, erm, yeah, I felt there was something wrong, something different	Feeling something is wrong / something is different.
008		and, and, er, you know, as, … within a few minutes, I think, you realised that left	Realising issue with left arm (not work properly)
009		arm was not working as it wanted to. In fact, it almost looked like someone else's	Feeling disconnected (from left arm)
010		arm, 'cos the brain just didn't seem to connect with the arm and, erm, speech	Experiencing bodily disconnection (with brain/left arm)
011		wasn't particularly good. Er. The best way I can describe it is waking up from an	Noticing issue with speech (not particularly good)
012		almighty drinking session and a hangover where, you know, it's, the world is	Waking up to fuzzy, blurred world
013		fuzzy, blurred and it's, er, yeah, you really weren't quite sure what happened.	Being unsure about what happened
014		[Laughs] And, erm, er, as time goes on, you realise then you're in hospital and,	Realising you're in hospital
015		erm, you're, you're connected up to machines and all that. [Wife's name]	Being connected up to machines
016		explained I'd had a stroke and, er, erm, er, yeah, I, I was on a, well, I was kind of	Being told I'd had a stroke
017		lucky enough to have a, erm, thrombolised, throm-, trom-, thrombolised, I think is	Being lucky enough (to receive specialist treatment)
018		the word, erm, which thins the blood down. And then, erm, next week was doing	Doing tests
019		tests to find out what had caused the stroke and what effects there were to it. So,	Finding out cause of stroke. Finding out effects of stroke
020		gradually I sort of becoming more and more aware of my limitations, erm, er, and	Becoming more aware of limitations
021		my goal was just to get out the hospital. It was terrible. People, erm, wandering	Setting goals (to get out of hospital)
022		around. The guy in the bed next to me, I can remember this so clearly, he had, er, a	Experiencing hospital (as a terrible environment)
023		tube in the middle of his throat, looked like a concertinaed vacuum tube and he was	
024		on a ventilation machine. He didn't want to be on the same planet as us. He didn't	
025		want to be here at all. And he kept pulling it out and then his machine, he'd stop	Witnessing neighbouring patient's distress ('suicide
026		breathing and his machines would start flashing and, er, in the end the nurses ended	attempt')
027		up holding his arms down by his sides, so he couldn't pull it out, to keep him alive	Observing nurses restraining patient
028		and with all this going on, you kind of spiral into some sort of immediate	Spiralling into depression (an immediate onset)
029		depression. What's, [Laughs] is this my life now and I just had to get out of it.	Needing to get away (from hospital environment)
030		And, er, my carrot on the end of the stick was if I could walk along the corridor and	Setting short-term goal
031		back, they'd let me go. Erm, yeah, it was, that was my only goal in life then, was	Wanting to be discharged
032		to walk down the corridor and I got out of bed and, er, I had to support myself, so I	Resolving to prove capability
033		realised with my left leg then wasn't taking my weight properly, but with a bit of a	Realising issue with left leg (not function properly)
034		shuffle and whatever, I, I proved that I could … move under my own steam. Erm.	Struggling with mobility. Trying to prove ability to others
035		Got home. Umm. I remember sitting down on the, erm, er, got like a pouffe in the	Getting home
036		middle of the front room, er, a footstool thing, and I sat down on there and I	Sitting down (reflecting)
037		actually burst into tears, 'cos I thought, you know, a-a week ago I was r-running a	Bursting into tears
038		s-site down at erm, [place name], the [company name] engine [coughs] r-repair	Comparing abilities (one week ago with inabilities now)
039		factory. And, er, here I am, can barely walk across the front room and it's like this,	Being barely able to walk (across the room)
040		how much something can change in your life in, in an instant. And, er, that's	Realising on how much life can change in an instant
041		where I started, I suppose, my, let's say a downward spiral, it was almost like a	Starting downward spiral (pretty steep curve)
042		pretty steep curve, er, with everything from lack of sleep and, er, hmm … er, hmm,	Suffering lack of sleep
043		couldn't really remember what I'd done the day before, er, which, you know, you	Struggling with memory (not remembering recent events)
044		think to yourself …. f-from a mind at being able to remember almost everything to	Losing ability to remember (almost everything)
045		… couldn't remember what I did the day before. It's, and still doesn't help, falling	Having difficult remembering (what I did yesterday)
046		over, and bumping into things. And, er, w-when I did lay in bed, the nights just	Falling over. Bumping into things
047		seemed so long. Erm. The brain doesn't seem to shut down, I don't know if that,	Having a brain that doesn't shut down
048		there's this like period that when you go to sleep, you're half-awake, half-asleep,	Being half-awake, not half-sleeping
049		but you never get to the half-asleep bit. You're always the half-awake bit. [coughs]	Lacking sleep. Being always half-awake, never half-asleep
050		And, er, you just lay there, I wouldn't say thinking: "Why me?", but, wh-wh, erm	Lying in bed thinking: "Why me?"
051		… you know, "Why can't I do these things anymore?" What, almost like you	Asking why (did things turn out this way)?
052		disbelieve that you've had a stroke. Erm, [mumbles]. You've had a stroke, and	Almost disbelieving (you've had a stroke)
053		you think: "Well, I can't have done". I was 49 at the time and, you know, fit, didn't	Asking: How did I have a stroke? (49, fit non-smoker, etc.)
054		smoke, occasional drink, worked hard and, you know, [sighs] yeah, [laughs]	Living low risk lifestyle
055		"What's going on?" Erm. And then on top of this, of course, things that you	Asking: "What's going on?"
056		would think of automatic like, like, I'd sit in my chair and I, I had little table in the	
057		front room where I used to put my cup of tea on, and I couldn't reach it anymore,	Experiencing difficulties (performing physical functions)
058		even though it was .. a foot away from me. My left arm just wouldn't respond to	Having left arm not responding (not able to do tasks)
059		go and pick the tea up and, er, so you start to change and twist round to lift the tea	Learning adaptive techniques (for everyday physical tasks)
060		up and then you realise: "Well, why not move the table to the other side of you?"	Noticing opportunities (for small everyday adaptations)
061		And, you know, you try and work all these little things out, but it's, it's trying to	Trying to cope (with the fact you've had a stroke)
062		cope with the fact that you've had a stroke, I think. And then, trying to deal with it.	Trying to deal with the consequences (of stroke)
063		But it's, yeah, to the mind it's just depressing.	Depressing to the mind (the actuality of stroke)
064	I	Hmm …. And, and, how, how did you cope with it, or how did you deal with it?	
065	R	Right, well the first real problems I encountered were people wanted to come and	Not wanting people to visit
066		see me. Erm. They'd phone [wife's name] up and say, "Is it alright if I pop	
067		round?" And she'd say, "Yes". But in my own mind I just, I just wanted to	
068		become, I think the best word is a recluse, just didn't want to see anyone, erm,	Not wanting to see anyone
069		because that's not the p-person they were coming to see, wasn't the person I was.	Not being 'the person' that people are coming to see
070		If that's any logic in what I just said, I'm not sure, but, erm. And I wanted them to	
071		see the person I was, not the person I am now [Laughs]. So I really didn't want to	Not wanting people to see the person I am now
072		see anyone at all. I had no interest in, er, [wife's name] would sit me in front of the	
073		telly, I couldn't concentrate on anything on the television, even things that I really	Not being able to concentrate (on favourite TV programs)
074		loved. Erm. Just the mind would wander very quickly into, you know, back to the	Having a mind that easily wanders
075		same problems, you know: "Why me? Why now? Why?" And it's like this	Ruminating about "Why me?", "Why now?"
076		continual cycle of, of that, so yeah, I didn't want to see anyone. Erm. Er, the, erm,	Feeling: "I didn't want to see anyone"

Appendix 12: Sample of Axial Coding

* Feeling like a failure *

==========================
Property: Pre-stroke relationships
Characteristics: avoiding contact with any pre-stroke associations/relationships
Data:
(P01.69) Not being ‘the person’ that people are coming to see
(P01.71) Not wanting people to see the person I am now
(P01.106) Not wanting anyone to see me as I am
(P01.133) Not wanting others to see me (like I am)

Property: Role as a father
Characteristics: relating differently, being distanced, reduced tolerance
Data:
(P01.107) Being avoided (by my children)
(P01.108) Being labelled (as The Incredible Hulk by my kids)
(P01.109) (suddenly, inexplicably) Shouting at my children

Property: Self-critical voice
Characteristics: feeling stupid and disappointed with self
Data:
(P01.385) Feeling really numb
(P01.385) Calling myself stupid
(P01.396) (still) Feeling disappointed with myself
(P01.409) * Feeling like a failure *
(P01.416) Criticising self (for missing a better way of doing things)
(P01.762) Seeing difficulties in interview as “another little bit of failure”

Property: Employment
Characteristics: failure, de-skilled, reduced worth
Data:
(P01.468) Admitting that your mind has failed (to employees) .
(P01.469) Failing as a leader of the company
(P01.470) Taking a backseat (in the company because of failure)
(P01.174) Understanding barriers (to performing pre-stroke job role)

Property: Struggling with acceptance of failure
Characteristics: failure, acceptance only as a concept
Data:
(P01.410) Struggling to accept (that part of your life is a failure)
(P01.474) The feeling of failure. The difference between what you could do before and what you can do now
(P01.400) Having to accept limitations (in solving work based problems)
(P01.402) Still struggling to accept (loss of cognitive abilities)
(P01.518) Having a strong sense of failure
(P01.519) Struggling/failing with acceptance
(P01.467) Coming back to the word: Failure
(P01.412) Feeling strong enough to deal with failure
(P01.764) Seeing small failures as part of the (bigger) problem
(P01.399) (Getting to the point where) Improvements are levelling out

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Property: What is or is not a failure
Characteristics: organic aspect, mitigating factors
Data:
(P01.797) Losing “space awareness” is not a failure
(P01.810) Identifying parts of the mind that went completely

Appendix 13: Memo Writing – Post-Interview

P01.M01 - Post-interview

Ryan (pseudonym) seemed extremely motivated to share his experiences of emotional difficulties. He stated that he had made a conscious decision to be as open and honest as he possibly could. This commitment seemed increasingly evident as the interview proceeded, especially when he disclosed his previous experiences of suicidal ideation, and the detailed suicide plan he had devised and refined again and again over time. It struck me as being ironic that his 'project' to end his life seemed to eventually become a catalyst for, or at least a contributory factor towards, him being able to move beyond his despair and sense of hopelessness. It seemed to provide a sense of comfort to him, as though he was not helpless —it was evidence that he still had some control over his life post-stroke even if that was the ability to end his life— and having some control was so important to him at that time. Indeed, his plan had to be prefect in every detail —and it not only became more elaborate but also a vehicle for considering what was meaningful to him, and an opportunity for the exploration of the cycle of life itself.

Appendix 14: Memo Writing – First Listen

P01.M02 – First Listen

Listening to the audio recording of Ryan's (pseudonym) interview immediately took me back to the face-to-face encounter in all the richness I had experienced. Ryan seemed determined to provide as much helpful information as he possibly could. I recall one aspect that initially jarred with me was, despite my focus on emotional difficulties post-stroke, Ryan was undeterred in providing a complete story of his experiences post-stroke, and that this story inevitably began with the stroke event itself. I reflected on how this was perhaps unsurprising. The event of stroke is sudden and without warning, and Ryan reported that he was not obviously in the 'at risk' group —which had further prompted the question for him: Why me? I considered how this interview might prepare me for other participants' accounts that begin with their stroke event. I also recalled how 'invisible' the impact of stroke for Ryan seemed to be at times, as he came across as confident, educated, accomplished and articulate, and for the majority of the interview his cognitive impairments, such as difficulty concentrating, were not self-evident.

Appendix 15: Memo Writing – Open Coding

P01.M03 – Open Coding

Making sense of the world immediately post-stroke

it's quite hard to actually go back to straight after the 'cos I really wasn't on the same planet. Erm, I was unconscious for four hours and, erm, w-when I came round, my wife was by the bedside and a couple of nurses, and I really hadn't got a clue what had happened to me. That's the first thing, except, er, erm, yeah, I felt there was something wrong, something different and, and, er, you know, as, … within a few minutes, I think, you realised that left arm was not working as it wanted to. In fact, it almost looked like someone else's arm, 'cos the brain just didn't seem to connect with the arm and, erm, speech wasn't particularly good. Er. The best way I can describe it is waking up from an almighty drinking session and a hangover where, you know, it's, the world is fuzzy, blurred and it's, er, yeah, you really weren't quite sure what happened.

Ryan (pseudonym) describes how the world initially seemed puzzling when he first recovered consciousness following his stroke. He did not know what had happened to him. But he quickly felt "there was something wrong, something different". He was completely unaware about his stroke and felt confused about his situation.

Appendix 16: Memo Writing – Axial Coding

P01.M23 – Axial Coding

I am struck by the pervasive sense of failure experienced by Ryan (pseudonym). This negative self-judgement extends across all domains of his life and even extends to his concern about his performance in this interview. Post-interview disclosure revealed that he is aware of setting himself high standards and that this was a pre-stroke characteristic which remains very much a part of how he relates to himself now. But rather than being only a hindrance to rehabilitation, Ryan seems to have also benefited from this 'perfectionism' trait in terms of motivation and determination to become the best he can with the resources he now has post-stroke.

Appendix 17: Axial coding – categories/concepts grounded in data

- **Causal Conditions**
- **Problem Areas**
- **Experience**: Enduring Otherness
- **Action**: Seeking connectedness

Outcome: Experiencing belongingness

- Physical
- Psychological
- Social

Philosophical

Feeling part of something beyond oneself

  - : Religiosity
  - : Devotion to family/children
  - : Helping others
  - : Gaining New Perspectives

: Finding Purpose

Data:

Line No.	*Open Code*
	Have goal of getting out of hospital
(P01.021)	Setting goals (to get out of hospital)
(P03.012)	Focusing on getting out of hospital
(P03.430)	Focusing on first getting out of hospital - focus on returning to run business
(P07.855)	Even though I've had a stroke, the first thing I wanted was to be back in my own place
(P01.022)	Experiencing hospital (as a terrible environment)
(P01.025)	Witnessing neighbouring patient's distress ('suicide attempt')
(P01.027)	Observing nurses restraining patient
(P01.029)	Needing to get away (from hospital environment)
(P01.030)	Setting short-term goal
(P01.031)	Wanting to be discharged
(P01.032)	Resolving to prove capability
(P01.034)	Trying to prove ability to others
(P01.035)	Getting home
	Contradiction - negative case
(P08.082)	Feeling safe in hospital. (suddenly) Not trusting my body
(P08.083)	Not trusting myself
(P08.085)	**(suddenly) Being let down by your body**
(P08.141)	(initially) Coming out of hospital was really scary
(P08.142)	Perceiving world as moving very fast, being very noisy
(P08.143)	Being very scared coming out of hospital
	Keeping myself busy
(P08.289)	Working within your limitations
(P08.290b)	(still) Doing little jobs around the garden
(P08.303)	Moving forward from stroke, you move within your limitations
(P10.096)	Having quite a set weekly routine

Appendix 18: Theoretical integration – Model of interaction

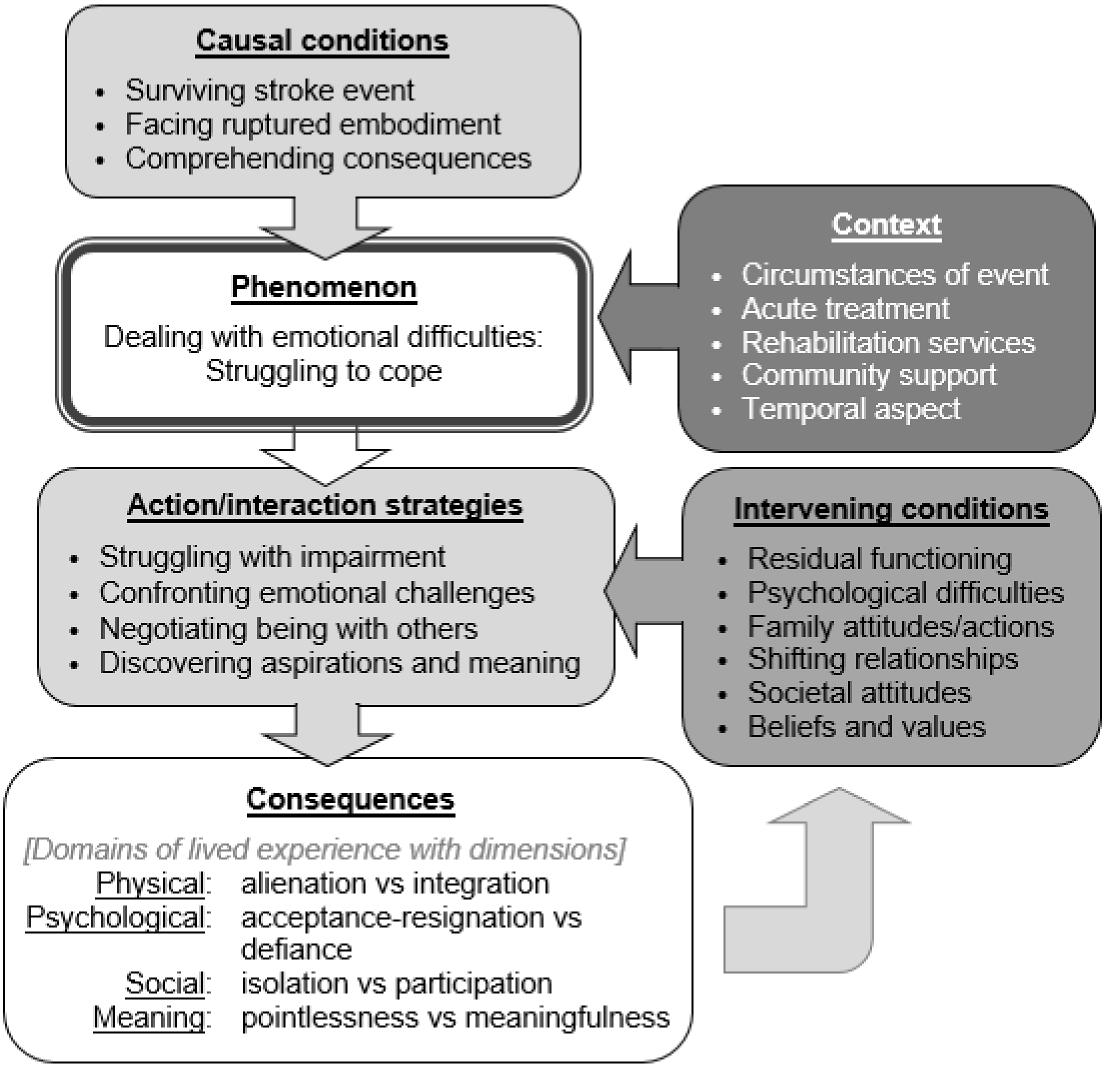

Figure A6. Model of interaction - adapted from Straussian coding paradigm (Strauss & Corbin, 1998, p.127)

Appendix 19: Evolution of proposed theoretical model

A19.1 Introducing the evolution of the model

Undoubtedly, attempting herein to provide an exhaustive account of the iterative process that unfolded during the analysis of the participant data would constitute a huge and impractical endeavour. That said, the purpose of this extended appendix is to further open a window on how the analysis for this project progressed towards theoretical integration and theory construction. The overarching aim is to provide a fuller sense of the developmental journey and milestone moments in the evolution of the theoretical model; and in doing so, facilitate increased transparency and greater trustworthiness in the analysis and the resultant model.

In accordance with advice offered by Corbin and Strauss (2015), diagramming was use to underpin the process of integrating concepts around a selected core category, and provide a basis for identifying any issues with internal consistency, logic, and dimensional range. To demonstrate something of this endeavour, two earlier iterations of the diagrammatic model are presented along with narrative on how these integrative diagrams evolved (in the light of ongoing analysis and theoretical integration, and in the face of instances of incompatible or outlying data). Indeed, Corbin and Strauss remind us that the “core category and the major categories should apply to and can be found in all participants in some form, though that form might vary” (ibid, p. 370). To achieve this end, a range of Straussian GTM techniques and processes were employed throughout the data analysis process. Instances of such techniques and processes are woven into the narrative that follows shorty, and covers dealing with outlying cases; checking for variations; negative case analysis; the flip-flop technique; and waving the red flag (see Corbin & Strauss, 2015 for details of these methods).

To be clear, the illustrative section that now follows picks up the analysis at the point where the notion of seeking connectedness was identified as having promising potential for selection as the core category. Needless to say, this moment felt pivotal at the time, and proceeded to be exactly that. And it felt hard won (following several unsatisfactory, and rather disheartening, attempts at selecting a central category - none of which turned out to be adequately abstract nor broadly representative enough of all the pertinent data).

A19.2 Initial model of seeking connectedness

The first noteworthy iteration of the model for seeking connectedness is displayed below in *figure A7*. Its structure adheres to the notion of Straussian GTM theory comprising features of temporality, experience within a particular context, action in response to the experience, and a resultant outcome.

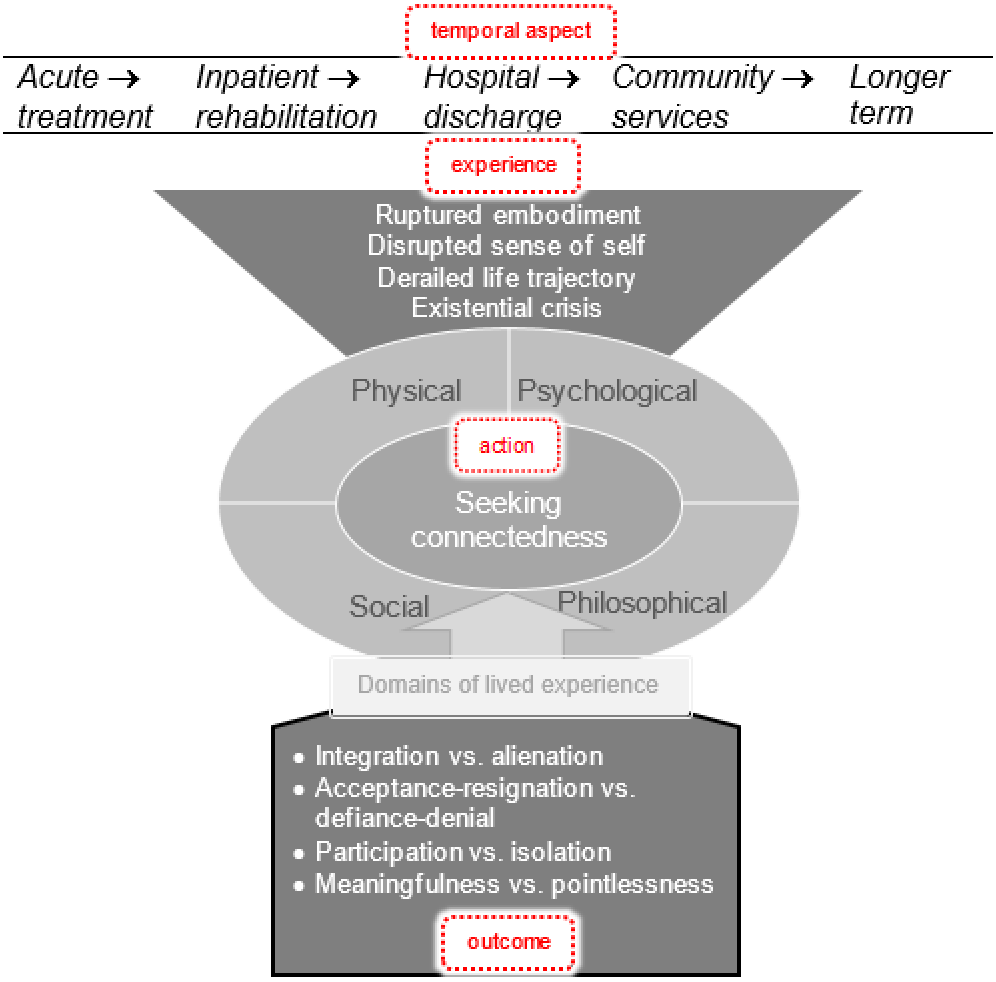

Figure A7. Initial model of seeking connectedness

Furthermore, this embryonic model comprised many elements of the finalised version, described in section *7.3 Substantive grounded theory*. But even so, it quickly became evident that further analysis and theoretical development were needed to advance the model sufficiently to be adequately grounded in all the available germane data. Indeed, various nascent features of the model were worked and reworked in light of continued data analysis. Following some sustained mental effort, two central components of the theory were substantially remodelled; and these are both now detailed below, ahead of revealing the resultant revised model in *figure A11*. The two aforementioned components concern the temporal aspect of the theory (along with the introduction of causal conditions), and a repositioning of outcome (as a feature within the four domains of lived experience - namely, the physical, psychological, social, and philosophical).

A19.3 Temporal aspect and Causal conditions

The temporal aspect of the model convincingly and expectedly emerged as being bound up with the recovery and rehabilitation journeys of the participants. Analysis of the data initially led to a conceptualisation which was essentially determined by the participants' experiences of different locations and the transitions between these locations (i.e., acute treatment, inpatient rehabilitation, hospital discharge, community services, and the longer term) - see *figure A8.* below:

Figure A8. Temporal aspect for initial model

However, additional analysis began to reveal negative and outlying cases, which highlighted variations that were as yet unaccounted for in the model. These included, not least, experience of the stroke event itself; that is, some participants were conscious throughout the whole stroke event including their hospitalisation, while others regained consciousness in a hospital bed confused and unaware of what had befallen them. Similarly, striking variations in experience of rehabilitation become more apparent. Furthermore, it became progressively clear that pathways towards securing support post-discharge was equally disparate. And although the initial conceptualisation illustrated in *figure A8.* captured something of the process, it conveyed little of lived experience or sense of immersion in the phenomenon: it increasingly felt disconnected and dissatisfactory. Consequently, representation of temporality was fundamentally reworked. Accordingly, in the light of subsequent analysis three categories where chronologically presented from left to right, namely Stroke event, Surviving stroke, and Comprehending consequences. An arrow was diagrammatically used to further convey the notion of temporality (rather than the label: temporal aspect). Dropping the temporal aspect label then paved the way for the three new categories: Stroke event, Surviving stroke, and Comprehending consequences, to be grouped and characterised under the notion of causal conditions. This better reflected the Straussian model of interaction, which in itself can help with modelling phenomenon (for an example, see Appendix 18: Theoretical integration - Model of interaction). In addition, the structure of the two categories: Surviving Stroke and Comprehending consequences adhered to the tactic of a two-word coding format comprising a verb (in present participle form) and a noun, for conveying action and interaction, which is so fundamental to grounded theory. The result is displayed in *figure A9*. below (with a graphic explosion shape - available in Microsoft Word - to symbolise the sudden and shocking nature of stroke event):

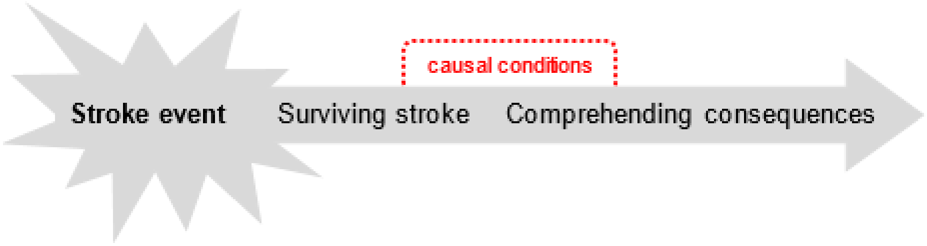

Figure A9. Temporal aspect for revised model

Corbin and Strauss (2015, p. 84) warned that “theories tend to balloon”, and advised us “to be meaningful without trying to do too much”; and accordingly, this reworking and development of the model felt meaningful and rigorously reductive.

A19.4 Experience aspect

The revised model conveyed how causal conditions (i.e., stroke event, surviving stroke, and comprehending consequences) lead to experience (of ruptured embodiment, disrupted sense of self, derailed life trajectory, and existential crisis). Thus, attention next turned to the aspect of experience itself - see *figure A10*. below:

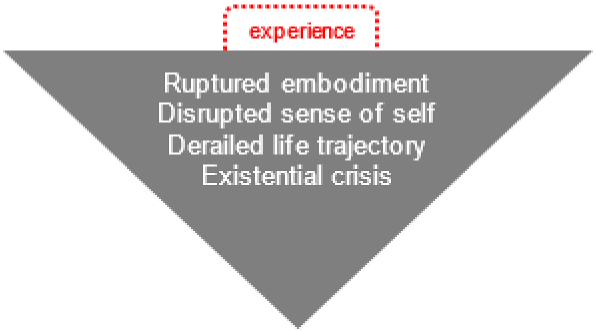

Figure A10. Experience aspect of initial model

After repeatedly revisiting the components of experience with respect to the data it was determined that including the category of existential crisis was rather needless, as it added little to conceptualisation provided by the associated categories of ruptured embodiment, disrupted sense of self, and derailed life trajectory. Subsequently, coded concepts that had been grouped under existential crisis were appropriately reassigned to other categories. Accordingly, when this was actioned the model seemed tighter and all the more aligned with the data. Indeed, not only had the category of existential crisis appeared increasingly redundant, it had begun to look almost naively forced on the data by presumptions about the nature of the phenomenon under investigation. Yet now it clearly felt too far removed from the layered narratives of lived experience; and re-examining each of the participant accounts bore out this suspicion. Corbin and Strauss (2015) refer to this process as waving the red flag on biases and assumptions. Thereafter, it seemed apparent that the concept of existential crisis was better placed, if anywhere, under the aspect of outcome rather than experience. That is, experience led to existential crisis which was represented as outcome. But moreover, the notion of existential crisis was already being accounted for under outcome along the dimension of meaningfulness vs pointlessness. And thus, the category of existential crisis was dropped from the model at this point. At one time this decision would have felt counterintuitive, given that the research was adopting an existential perspective; but nevertheless, every time the data was inspected this decision continued to hold its ground.

A19.5 Outcome

Following the abovementioned revisions, concerns began to surface about the outcome aspect (as detailed in *figure A7*). This aspect now felt underdeveloped and comparatively unintegrated. Reviewing the model and revisiting the data confirmed that the elements of dimensionality within outcome (i.e., integration vs alienation, acceptance-resignation vs. defiance-denial, participation vs isolation, and meaningfulness vs pointlessness) could each be assigned to corresponding domains of lived experience (i.e., the physical, psychological, social, and philosophical, respectively); and this led to another significant structural revision.

Moreover, this revision allowed more density to be added to each of the four domains of lived experience - which have been detailed further below on the revised model in *figure A11.* below; for instance, the physical domain has dimensionality of alienation vs. integration relating to the newly specified areas of corporality, resources, and security. Incidentally, the aforementioned area of resources was subsequently revised to employment. This amendment was facilitated by the flip-flop technique, which can encourage comparisons of extremes along one dimension and help analytical rather than descriptive thinking. Although conceptually resources is more abstract, and can encompass employment, it was the concept of employment that was most salient in participant accounts. Another, perhaps more impactful application of the flip-flop technique concerned the psychological domain itself regarding dimensionality. Originally conceptualised as acceptance-resignation vs. defiance-denial, the aspect of denial was dropped from the dimensionality. Indeed, the flip-flop technique consists of turning a concept inside out or upside down to obtain a different perspective (Corbin & Strauss, 2015). Even though the concept of denial features highly in extant stroke literature, asking questions of the participant data, such as: *What would denial, defiance, acceptance, and resignation look like?* revealed that the concept of denial did not substantially feature in any participant narratives; rather, it was the novel concept of defiance that properly captured an antithesis to positions of acceptance and/or resignation.

Plainly, the advancements outlined thus far were facilitated by diagramming (as advocated by Corbin & Strauss, 2015). In terms of evolving the model, these significant structural changes felt elegant and innovative, as they more fully allowed for variation and thus better explained the data in its entirety. The Initial model of seeking connectedness (in *figure A7.*) was remodelled with respect to all the revisions described above; the resultant model is now displayed below in *figure A11*:

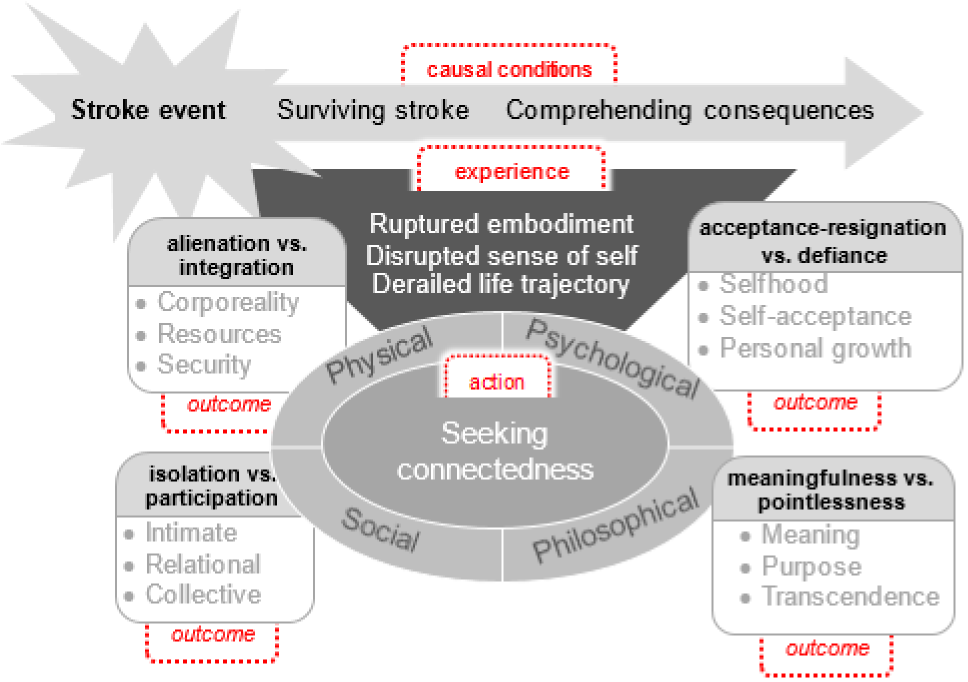

Figure A11. Revised model of seeking connectedness

The Revised model of seeking connectedness (see above in *figure A11*.), ostensibly stood up to scrutiny in light of all the data, and represented a concise model that appropriately captured the most salient aspects of a vast amount of data, and the complexities of the related processes. Nevertheless, further review of the analysis highlighted one concept that had somewhat unsatisfactorily been subsumed, and effectively trimmed from the model as it now stood. This concept that demanded further attention was the notion of *otherness*—refer to section *7.3.3 Experience, action, and outcome* for further details. The more this feature was inspected and considered, the more it emerged as being underpinned by other categories that were clustering together in support (for examples, see *figure 5. Matrix of central categories and domains of lived experience*). Thus, further reworking ensued, which led to the formulation of a theoretical hub within the model.

A19.6 Three-category hub of the model

The category of suffering otherness was developed and elevated alongside the core category of seeking connectedness. Bound up with this undertaking was the corresponding development and elevation of the strongly associated category of experiencing belongingness. Identifying these three interrelated higher-level categories facilitated further advancements in the arrangement of the model, and sharpen its fit with the data. In particular, the temporal aspect that these three higher-level categories conveyed was striking; as was the significance of a renewed emphasis on distinguishing experience, action, and outcome in relation to a phenomenon (which so strongly aligns with Straussian GTM practise). That is, the category of suffering otherness encapsulates the experience that precedes and motivates action related to the category of seeking connectedness, with outcome associated with the category of experiencing belongingness. For reference, the newly conceptualised hub is illustrated below in *figure A12*.

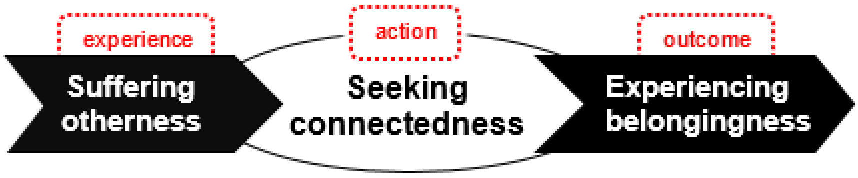

Figure A12. Three-category hub of the model

A19.7 Finalising model of seeking connectedness

The development of a three-category hub for the model (see above in *figure A12.*) further sharpened the notion of temporality by foregrounding relations between experience, action, and outcome. The model itself was accordingly refined to incorporate this enhancement (with particular reference to the Straussian model of interaction - see the associated model in Appendix 18). These refinements involved completely dropping the outcome label from the four domains of lived experience; and, on the component of the model that followed on from causal conditions (see *figure A10.*) the existing label of: experience was changed to read: problem areas. Henceforward, in terms of the experience-action-outcome interaction across the model, the aspect of experience was conceptualised as being entirely bound up with the notion of otherness. Finally, revisiting the data alerted a need for waving the red flag (see Corbin & Strauss, 2015, p. 98) on biases and assumptions relating to the category name of suffering otherness. Indeed, further inspection and consideration revealed more than just suffering was taking place - and this was addressed by introducing the notion of enduring rather than suffering, to reflect the range of experience within the data. The finalised model for seeking connectedness is illustrated below in *figure A13.*, which concludes this appendix.

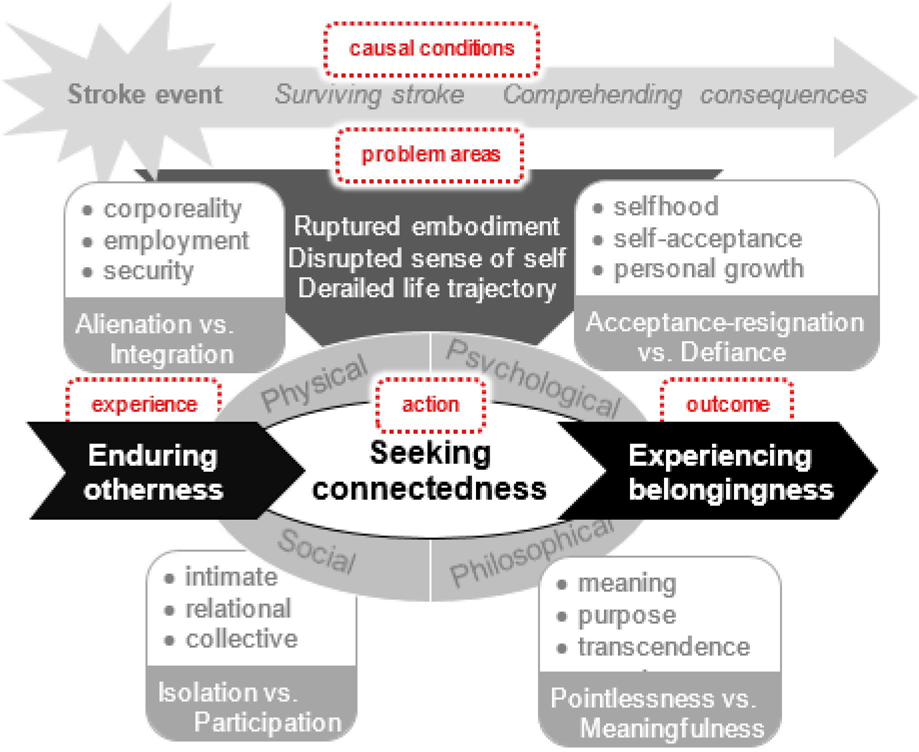

Figure A13. Finalised model of seeking connectedness

Appendix 20: Theoretical integration – Categories: central, main, and sub

Physical:	*Alienation vs. Integration*
Psychological:	*Acceptance-Resignation vs. Defiance*
Social:	*Isolation vs. Participation*
Philosophical:	*Pointlessness vs. Meaningfulness*

Causal conditions

surviving stroke

- sudden and unexpected stroke event (P04.008, 094; P09.004; P06.004-5; P08.235-6, 022-7)
- regaining consciousness in hospital (P01.004-6; P05.291-3; P02.048-050)
- being conscious and aware during stroke event and hospitalisation (P06.021-2; P08.511-2)
- feeling scared (P03.057, 068, 071, 085; P09.036, 056, 143)

comprehending consequences

- becoming increasingly aware of difficulties with mobility (P06.086-7; P01.032-3).
- experiencing uncertainty surrounding recovery prospects (P03.028; P02.006-9; P08.522-3; P09.154)
- facing a battle to regain normality (P03.131; P07.009-10; P09.146)
- Realising life has changed completely (P07.008-018)
- Knowing what it meant for the rest of my life (P08.513-9)
- Struggling for financial stability (P03.430-8, 083-4; P09.359, 360)

Problem areas

Ruptured embodiment

- disconnection with body (P04.127-8, 132, 169-70; P08.061-2; P01.007-011)
- asserting intention to regain bodily ownership (P08.062-065)
- being disconnected from parts of one's own body (P02.271; P04.169-70; P08.025)
- feeling let down by body (P08.062)

Disrupted sense of self

- *"it's the inside bit that's changed"* (P01.453-7)
- feeling less of a man / feeling somewhat emasculated (P01.474-5)
- not being able to do what a man should be doing (P09.565-84; P01.474-5)

- comparing with pre-stroke self (P01.474-5)
- self-loathing due to altered sense of self (P03.244-54)
- unfamiliar disproportionate emotional responds (P01.624-630, 633-4)
- feeling stupid after experiencing disproportionate emotional response (P01.663; P07.077, 083)
- emotional reactions misaligning with sense of self (P01.667-72; P07.057-8, 043, 083-4; P05.113-20, 127-8; P07.029-38)
- feeling different, abnormal, and intimidated by other people at social events (P03.326-46; P05.013-26)
- avoiding pre-stroke relationships (P01.453-7)

Derailed life trajectory

- roles within family (P03.068-70; P04.007-017; P08.009-17)
- employment and financial security (P01.434-41, 468-70; P04.007-017; P08.013-4; P08.009-17)
- long-imagined holidays (P08.009-17; P09.131-44, 127-8; P10.399-405)
- lifelong hobbies and interests (P08.037, 073-4, 197-8, .238-43; P09.127-8, 131-44; P05.084-5; P10.131-153)

Experience, Action, Outcome

Central category
Domain of lived experience
Main category

==

Physical domain - corporeality, employment, security
(dimension: *alienation vs. integration*)

enduring otherness
suffering ruptured embodiment
not being employable (P01.173-5; P02.476-8; P05.149-50; P08.009-12, 190-1; P10.523-4)
struggling to securing resources (P07.114-9, 162-71, 201-3, 491-2, 715-9; P08.012-7)
feeling nothing has actually changed, apart from these minor ailments” (P06.116-8)
being barely able to walk (Further excerpts in *7.3.2.3 Ruptured embodiment*)
having an unfamiliar body and *experiencing an unresponsive body* (P01.008-10, 058, P02.042-3, 140-1, 262-5; P04.009, 130-1; P05.085-6; P06.26-7; P08.62-3, 113-4; P09.693-4; P10.526-7)
pursing physical recovery and rehabilitation (P01.093-4; P07.009-10)
fearing ongoing dependency (P04.068)
having lack of agency (P08.054-7)

Seeking connectedness
meeting limits and adapting

coming up against limitations / *regularly falling over* (P01.084-6; P03.382-3, 389, 391; P06.106-7)
seeking ways to adapt (P01.096-100; P03.362; P03.362-75)

experiencing belongingness
salvaging bodily ownership
feeling helpless to go out and earn a living (P08.518-9; P08.520-7; P10.523-4)
facing prospects of financial hardship (P04.058-61)
not being understood or acknowledged by social services (P07.122-38)

==

Psychological domain - selfhood, self-acceptance, personal growth
(dimension: *acceptance-resignation* vs. *defiance*)

enduring otherness
encountering being less
reflecting on pre-injury abilities (P01.372-81, 474-5, 698-9; P04.058-9, 064-5, 160-2; P05.127-30; P07.205-9; P08.395-402; P09.131-41, 595-6)
being a prisoner to my illness (P03.382-93)
feeling of failure (P01.474; P01.518-9; P04.064-8)
struggling with memory (P01.043; P02.246, 303-4; P05.255-6)
loss of manliness (P04.064-8; P08.166-169; P08.194)
living on its terms, not its on my terms (P03.382-93)
feeling emasculated (P08.257-9; P09.553-4; P09.565)
loss of manliness (P01.719; P05.405-6; P05.419; P08.257-9; P09.584)
having sexual problems (P01.502-7; P08.257-9)
feeling less of a man (P05.403; P05.408; P05.405-6; P08.257-9; P09.584).
increased dependency on their partner (P01.503-4; P01.696; P05.427-8).
feeling belittled (P04.301-3)

seeking connectedness
struggling for sense of normality
being stubborn (P03.052; P07.337,356,363)
deciding this isn't going to be it (P03.046)
finding my determination (P07.363)
fighting to get back to normal (P01.518-9, 564-8; P07.006-10)
"learn to live with it, what you've got left" (P01.378-81, 396-400; P08.104-6)
defiance and determination to regain sense of normality (P07.343-57; P03.028-9, 053-6; P08.046-51; P08.327-32)
using medication (P01.161, 178, 187, 196; 668; P02.217, 609; P03.207, 213-5, 219, 450-1; P04.175-6; P07.243-4, 327; P08.327-32; P09.248)
experiencing professional services (P01.094-9, 181-7, 258-60, 293-6; P02.012-4, 180-2, 273-6, 297-9; P03.043-7, 060-1, 403-5; P05.074-7)
using alcohol (P04.720-3, 727-8, 732-3, 740-2, 748-53; P07.734, 741)
reclaiming some control (P01.243-6, 632-4, 690-4; P04.090-2, 364-5; P07.747; P08.301-4)
coping and adapting (P03.370; P03.371-5)
using downward comparison (P03.126-32; P08.106-7; P08.107-8; P08.099; P09.801-4; P10.435-43; P10.448-9)
making downward comparisons (P10.415-24; 426-43; 448-9)

emotional distress have been minimalised and dismissed (P03.125-32)
using medication (P01.178-9; P02.217-8)
experiencing professional services
no early psychological input (P03.403-23)
questioning whether to come off medication (P02.609-18; P01.667-9)
being against medication for psychological difficulties (P07.235-40; P03.199-205; P03.403-23)
using alcohol to cope (P01.718-23; P01.748-53)

experiencing belongingness
confronting who I am
not feeling I belong anymore (P08.399; P08.395-401)
sense of belonging among other stroke survivors (P08.395-401)
not wanting to think of myself as disabled (P08.086-92)
accepting post-stroke reality (P03.113-5; P03.106-9, 252-9; P07.483-9)
having positive emotions (P08.559-566; P08.187-8)
identifying with current self (P07.337-8, 360-3, 483-9; P08.327-9; P04.394-414; P08.566)
being stubborn (P03.052; P07.337,356,363)
finding some inner resource, and battling on (P04.394-414)
discovering pleasing aspects of self (P04.491-512, P05.364-71)

==

Social domain - intimate, relational, collective
(dimension: *Isolation vs. Participation*)

enduring otherness
seeing relationships fracture
being isolative / *becoming a recluse* (P01.065-9, 104-6, P03.299-304; P05.017; P08.149-55; P08.172-173)
distancing family (P04.007-17; P01.106-28)
losing friendships (P09.190; P04.204-6; P09.213; P09.231; P09.654; P08.198; P08.226; P08.227, 228; P08.593-5)
having hidden disabilities (P07.021-5; P05.025-42)

seeking connectedness
shifting relations and associations
trying to appear normal / attempting to hide the extent of deficits (P08.488-96; P10.584-8)
joining social activities (P02.544-50; P07.847-890; P10.084-93)
being in the same boat as others (P01.524-30; P02.119-25,142,154-9)
experiencing informal peer mentoring (P01.524-30; P02.166-8)
being understood by others (P01.524-30; P02.119-25,142,154-9)
pursuing hospital discharge (P01.021; P03.012-3)
meeting and associating with other stroke survivors (P01.524-30)
sharing information peer-to-peer (P01.524-30; P10.213-8)
establishing informal support networks (P01.524-30; P02.197-9; P10.213-8)
developing new friendships (P02.197-9)
realising *“you’re not the only one that’s struggling”* (P01.528-9)

experiencing belongingness
engaging meaningfully with others
meeting up with other survivors (P01.524-30; P02.197-9; P07.857-859; P07.873-874; P10.213-8)
knowing you're not the only one (P01.528-9)
being witnessed and celebrated (P02.168-71, 184-7; P02.291-6)
teaming up with my dog (P01.077-94; P02.086-91)
being valued by family (P03.274-92)
being supported by friends (P07.284-301)
Feeling connected in new ways (P02.585; P10.172-8)
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Philosophical domain - meaning, purpose, transcendence
(dimension: *pointlessness* vs. *meaningfulness*)

enduring otherness
perceiving life as pointless
asking 'why me?' (P01.050-5, 074-6; P04. 178-9, 452-4; P09.103-5, 234-5, 730-1))
facing a meaninglessness existence (P02.054-5)
feeling suicidal (P01.211-6; P02.026-9, 035-40; P03.088-93, 149-56; P04.187-95; P08.506-9)

seeking connectedness
valuing something before self
protecting my family (P08.507-8; P10.340-8).
appreciating friendships (P01.078; P02.011, 097, 162-4, 177, 199, 230, 233, 291, 417; P09.462, 469-70, 501, 515; P10.012)
exploring spirituality (P01.562; P02.063-6, 092-3; P03.456; P07.555; P08.427; P09.363; P10.329)
protecting family from distress of my suicidal thinking(P02.211-8; P03.138-43, 263-70)
finding *"a worthwhile reason for me to continue"* (P03.143)
wanting to see children grow up (P10.451-2)

experiencing belongingness
feeling part of something beyond oneself
giving something back and *helping others* (P02.106-12; P06.145-53; P08.381-5; P10.245-64)
gaining empathy for others (P02.370-2, 577-82, 597-601; P08.550-5)
finding my faith (P02.058-66; P02.211-8; P03.456-82)