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Investigating therapy in the rehabilitation of physical function after severely disabling stroke- a mixed methods study.

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INVESTIGATING THERAPY IN THE REHABILITATION OF PHYSICAL FUNCTION AFTER SEVERELY DISABLING STROKE- A MIXED METHODS STUDY

Thesis presented for the degree of
Doctor of Philosophy
By
Mark Patrick McGlinchey

King's College London
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Abstract

Background: Stroke is a major cause of global disability which is largely managed by rehabilitation. Survivors of severely disabling stroke experience poorer outcomes compared to less disabled stroke survivors. One possible explanation for poor outcomes is that rehabilitation of physical function, which involves physiotherapy and occupational therapy, does not fully address the sequelae of severely disabling stroke. However, there is a paucity of research to identify what current therapy practice involves, how rehabilitation interventions are decided upon, and their effectiveness in managing the consequences of severely disabling stroke.

Aim: To investigate therapy in the rehabilitation of physical function after severely disabling stroke.

Method: Using the theoretical framework of evidence-based practice and its use in clinical decision making, mixed methods research was undertaken involving three studies: a national survey of physiotherapy and occupational therapy practice, comprising an on-line questionnaire and follow-up interviews; a systematic review examining the effectiveness of rehabilitation interventions on improving physical function and reducing immobility-related complications; and an ethnographic exploration of therapy practice, involving participant observation and interviews, in five stroke services.

Results: 440 therapists completed the survey questionnaire, including 18 therapists who participated in follow-up interviews. The survey found that interventions were delivered to achieve identified aims as part of goal-directed therapy and differed according to professional role and type of stroke service. The systematic review included 28 randomised controlled trials and found a lack of high-quality evidence supporting the use of rehabilitation interventions to improve physical function and reduce immobility-related complications after severely disabling stroke. The ethnographic exploration of therapy practice involved over 400 hours of participant observation conducted over an 18-month period, as well as 52 in-depth semi-structured interviews. Findings demonstrated that clinical expertise and the stroke survivor's clinical presentation were two of the most influential factors guiding therapist decision making. Research evidence and the stroke survivor's treatment preferences were less influential factors guiding decision making. Other factors guiding therapist decision making included professional role, the therapist's beliefs and attitudes about post-stroke recovery, organisational function, and the stroke pathway design. Integrating findings across the studies demonstrated that current therapy practice for survivors of severely disabling stroke is infrequently based upon a limited and low-quality research evidence base. Findings also demonstrated that current therapy practice is guided by a variety of factors, some of which may negatively influence how therapists select interventions in the rehabilitation of severely disabling stroke.

Conclusions: Current therapy practice does not always address the needs of severely disabled stroke survivors, which may contribute to the poor outcomes experienced by this cohort of the stroke population. Alternative aims and models of stroke rehabilitation, as well as ways of therapist working, should be considered to address the needs of severely disabled stroke survivors more fully.

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Abbreviations

Abbreviation	Meaning
ACPIN	Association of Chartered Physiotherapists Interested in Neurology
ADL	activity of daily living
AMED	Allied and Complementary Medicine Database
ASU	acute stroke unit
AVERT	A Very Early Rehabilitation Trial
BI	Barthel Index
CENTRAL	Cochrane Central Register of Controlled Trials
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DORIS	Database of Research in Stroke
EBM	evidence-based medicine
EBP	evidence-based practice
ESD	early supported discharge
FES	functional electrical stimulation
FIM	Functional Independence Measure
GAS	Goal Attainment Scale
GCS	Glasgow Coma Scale
GRADE	Grading of Recommendations, Assessment, Development and Evaluation
HASU	hyperacute stroke unit
HRA	Health Research Authority
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disabilities and Handicap
LOS	length of stay
MDT	multidisciplinary team
MMR	mixed methods research
mRS	Modified Rankin Scale
NHS	National Health Service
NIHR CRN	National Institute for Health Research Clinical Research Network
NIHSS	National Institutes of Health Stroke Scale
OPS	Orpington Prognostic Scale
OT/OTA	occupational therapist/occupational therapy assistant

Abbreviation	**Meaning**
PEDro	Physiotherapy Evidence Database
PICO	Participant, Intervention, Comparator, and Outcome
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PRISMA-P	Preferred Reporting Items for Systematic Review and Meta-analysis Protocols
qual/QUAL	qualitative/Qualitative
quan/QUAN	quantitative/Quantitative
PROSPERO	International Prospective Register of Systematic Reviews
PT/PTA	physiotherapist/physiotherapy assistant
RCT	randomised controlled trial
R&D	Research and Development
REC	Research Ethics Committee
SPSS	Statistical Package for the Social Sciences
SRU	stroke rehabilitation unit
SSNAP	Sentinel Stroke National Audit Programme
SSNP	Specialist Section Neurological Practice
SU	stroke unit
THMT	targeted health management pathway
UK	United Kingdom
USA	United States of America

Chapter 1- Introduction

1.1 Rationale for the PhD- The Challenge of Severely Disabling Stroke

Despite being a clinical specialist physiotherapist (PT) with over 20 years' experience in stroke rehabilitation, treating patients who have experienced a severely disabling stroke continues to be the most challenging aspect of my clinical career. It is challenging to devise individualised physiotherapy management plans- targeting the multiple physical, cognitive, and communicative impairments that these patients experience- that frequently have to be modified due to the development of acute post-stroke complications (Langhorne *et al.*, 2000; Roth *et al.*, 2001; Kim *et al.*, 2017). It is challenging to deliver regular physiotherapy- which is labour intensive, physically demanding, and sometimes emotionally draining- in a pressurised healthcare environment where the drive to reduce hospital length of stay (LOS) is at odds with the time required to facilitate recovery in this cohort of the stroke population (Kwakkel, 2006). It is challenging, and perhaps disheartening, to see so much time and effort invested by the stroke multidisciplinary team into the rehabilitation of these patients, for these patients to sometimes die or end up being discharged from hospital with high levels of dependency and an increased likelihood of care home placement (Jorgensen *et al.*, 1995a; Godoy, Piñero and Di Napoli, 2006; Saxena *et al.*, 2006; Saposnik *et al.*, 2008). Wanting to help patients who have experienced a severely disabling stroke by ameliorating these clinical challenges was the impetus behind this PhD.

Most of my clinical career has involved working in acute and inpatient stroke rehabilitation services, and the challenges I have described focus on the initial part of the stroke pathway. However, I am aware that there are other challenges involved in the rehabilitation of these patients, or survivors of severely disabling stroke, once they are discharged from hospital. Most of these challenges arise due to the lack of consistent, longer-term rehabilitation support as highlighted in a recent audit report of stroke care in the United Kingdom (Sentinel Stroke National Audit Programme, 2019). How can we reduce the high number of post-stroke complications, such as contractures, musculoskeletal pain, and falls (Sackley *et al.*, 2008; Kuptniratsaikul *et al.*, 2013), if there is no physiotherapy to address these complications? How can we reduce the number of long-term carers looking after survivors of severely disabling stroke if there are no occupational therapists (OTs) to teach these stroke survivors how to participate in grooming and dressing tasks? How can we address the high levels of burden experienced by those individuals looking after survivors of severely disabling stroke, as reported by Rigby, Gubitz and Phillips (2009), if there is no access to psychological support? Over 20 years ago, Sackley and Gladman (1998) highlighted these and other issues in their review of rehabilitation after severely disabling stroke. They stressed that more research was required, and more work was to be done to improve rehabilitation for this group of patients. Clearly, there remain many unresolved issues and clinical challenges that affect stroke survivors, their carers, as well as the healthcare professionals involved in their rehabilitation.

1.2 Management of Severely Disabling Stroke

Since Sackley and Gladman's review of the evidence for rehabilitation after severely disabling stroke (Sackley and Gladman, 1998), there have been several developments in the medical management of stroke. New technologies designed to limit the extent of the stroke event itself, such as thrombolysis and mechanical thrombectomy, have become part of routine clinical practice internationally (Intercollegiate Stroke Working Party, 2016; Boulanger *et al.*, 2018; Powers *et al.*, 2019; Stroke Foundation, 2019a). Meta-analyses of randomised controlled trials (RCTs) investigating the effectiveness of these interventions have demonstrated that they can significantly reduce residual disability post-stroke (Emberson *et al.*, 2014; Bush *et al.*, 2016). However, consensus guidelines by Mokin *et al.* (2019) estimated that these medical technologies are only applicable for up to 20% of the stroke population. Rehabilitation, however, is considered to be the mainstay of treatment post-stroke (Langhorne, Bernhardt and Kwakkel, 2011).

According to the World Health Organization, rehabilitation can be defined as a set of interventions designed to optimise functioning and reduce disability in individuals in interaction with their environment (World Health Organization, 2017). Stroke rehabilitation forms part of the usual recovery process for individuals with stroke in most developed countries (Mendis, 2013). There is moderate-quality evidence from several systematic reviews supporting the use of rehabilitation in organised, multi-disciplinary stroke units (SUs) and early supported discharge teams (Stroke Unit Trialist's Collaboration, 2013; Langhorne, Baylan and Trialists, 2017; Langhorne and Ramachandra, 2020). For survivors of severely disabling stroke, several trials comparing SU rehabilitation to general medical ward care have demonstrated that stroke rehabilitation can reduce mortality and the likelihood of institutionalisation for this group of stroke survivors (Kalra, Dale and Crome, 1993; Kalra and Eade, 1995; Jorgensen *et al.*, 2000). As well, observational studies of survivors of severely disabling stroke undergoing rehabilitation have demonstrated that functional recovery is possible, albeit less complete compared to survivors of less disabling stroke (Jorgensen *et al.*, 1995a, 1995b; Ancheta *et al.*, 2000; Horn *et al.*, 2005). Findings from these studies suggest that stroke rehabilitation can positively influence some outcomes after severely disabling stroke. Therefore, there is merit in exploring current stroke rehabilitation practice further to determine if anything could be done differently to address the clinical challenges described previously.

1.3 Unanswered Questions in the Rehabilitation of Severely Disabling Stroke

Before changing current rehabilitation practice, it is necessary to understand what current rehabilitation practice entails and how it addresses the needs of survivors of severely disabling stroke. Unfortunately, it is not clear what current rehabilitation practice for severely disabling stroke involves. Although trials of rehabilitation for survivors of severely disabling stroke have demonstrated reductions in mortality, hospital LOS, and the likelihood of institutionalisation (Kalra, Dale and Crome, 1993; Kalra and Eade, 1995; Jorgensen *et al.*, 2000), the authors of these trials did not provide details of the individual interventions delivered as part of the stroke rehabilitation process. As such, it is not known which interventions contributed to these positive outcomes. Observational studies have reported the types of therapy interventions provided to stroke survivors in several European and North American stroke services (Ballinger *et al.*, 1999; Bode *et al.*, 2004; Latham *et al.*, 2005; De Wit *et al.*, 2006; Tyson *et al.*, 2009; Kimberley *et al.*, 2010; Tyson, Woodward-Nutt and Plant, 2018). However, these studies provided limited detail regarding which interventions were delivered to survivors of severely disabling stroke. Therefore, it is not possible to say if current rehabilitation practice is addressing the needs of survivors of severely disabling stroke because the components of current rehabilitation practice for severely disabling stroke are not known. As such, research is required to understand what interventions are currently provided in the rehabilitation of severely disabling stroke.

Assuming that some of the reported therapy interventions are being provided to survivors of severely disabling stroke, it should be possible to determine if these interventions could address the needs of these stroke survivors by reviewing the evidence for the effectiveness of these interventions when delivered to survivors of severely disabling stroke. However, most trials reported in several systematic reviews investigating the effectiveness of rehabilitation interventions on improving physical function, such as gait, balance, and activities of daily living, have either not recruited survivors of severely disabling stroke or not provided results specifically for survivors of severely disabling stroke (Legg, Drummond and Langhorne, 2009; Pollock *et al.*, 2014; Veerbeek *et al.*, 2014). Therefore, it is not possible to know whether current rehabilitation interventions are effective at addressing the needs of severely disabled stroke survivors. As such, research is required to investigate the effectiveness of rehabilitation interventions on improving function specifically for survivors of severely disabling stroke.

Knowledge of the effectiveness of rehabilitation interventions in addressing the needs of survivors of severely disabling stroke is also important because of the current practice in healthcare to use the “best available, current, valid and relevant evidence” to guide decisions about healthcare (Dawes *et al.*, 2005, pg. 4). This model of practice, termed evidence-based practice (EBP), relies on the integration of research evidence with the healthcare professional’s clinical expertise and the patient’s views and preferences to guide decisions about healthcare (Haynes *et al.*, 1996; Sackett *et al.*, 1996; Haynes, Devereaux and Guyatt, 2002). However, adopting EBP in the rehabilitation of severely disabling stroke may be challenging for two reasons. Firstly, there is uncertainty regarding the effectiveness of rehabilitation interventions used in the rehabilitation of severely disabling stroke as reported above. Secondly, several authors have reported that many survivors of severely disabling stroke may have difficulty or be unable to express their views due to communication or cognitive impairments (Asplund and Britton, 1989; Geurts *et al.*, 2014; Visvanathan *et al.*, 2017). Consequently, it is not clear how therapists decide upon different rehabilitation interventions for survivors of severely disabling stroke within an EBP framework. Understanding this aspect of therapist decision making more deeply will provide greater insight into why certain interventions are used or not used in the rehabilitation of severely disabling stroke, which has direct implications on outcome after severely disabling stroke. As such, research is required to understand what factors guide PTs and OTs to select certain interventions in the rehabilitation of severely disabling stroke.

1.4 Research Aim and Objectives

The preceding section has highlighted several unanswered questions in the rehabilitation of severely disabling stroke and that research is required to understand current rehabilitation practice more fully in order to guide future changes in rehabilitation practice. Due to the multi-faceted nature of these unanswered questions, there is a need to use a research approach incorporating a range of methods to address these unanswered questions. Mixed methods research (MMR) is recognised as a suitable research approach to understand the complexity of healthcare delivery (O'Cathain, Murphy and Nicholl, 2007; Curry *et al.*, 2013). Therefore, a mixed methods approach will be used to understand current therapy practice more fully in the rehabilitation of severely disabling stroke.

As a PT, my clinical expertise and area of interest relates to improving the physical function of stroke survivors. Physical function can be defined as the ability to perform various bodily activities, which range from basic movements to complex activities (Bruce *et al.*, 2009; Painter and Marcus, 2013). Physical function is also addressed by OTs, a professional group that works closely alongside PTs to provide therapy to stroke survivors. Therefore, the aim of the thesis is to investigate therapy in the rehabilitation of physical function after severely disabling stroke. Using MMR, the aim will be attained by achieving the following objectives:

1) to ascertain the different interventions and outcome measures used by PTs and OTs in the rehabilitation of physical function after severely disabling stroke
2) to systematically review the effectiveness of rehabilitation interventions on improving physical function and reducing immobility-related complications for survivors of severely disabling stroke
3) to understand what factors guide PTs and OTs to select particular interventions in the rehabilitation of physical function after severely disabling stroke

1.5 Thesis Structure

Chapter 2 – Literature review. This chapter will review the literature on the practice of stroke rehabilitation globally for survivors of severely disabling stroke. It will commence with an overview of stroke and explore the concepts of stroke severity and severe disability. It will continue with a review of the poor outcomes experienced by survivors of severely disabling stroke and a discussion of the key issues in the rehabilitation of severely disabling stroke. It will conclude with an exploration of therapy in stroke rehabilitation, focusing on the role of physiotherapy and occupational therapy in addressing physical function post-stroke.

Chapter 3– Theoretical Framework. This chapter will present the theoretical framework of the thesis, which is EBP and its use within clinical decision making. It will commence with a review of the literature on clinical decision making, including the underlying cognitive processes involved in making decisions and the influence of clinical expertise in decision making. It will continue with a critical review of EBP as a model for clinical decision making, the use of EBP within physiotherapy and occupational therapy, and the challenges of EBP in the rehabilitation of severely disabling stroke. It will conclude with a discussion of how the framework will address the thesis' aim.

Chapter 4– Methodology and Methods. This chapter will provide an overview on the use of MMR to investigate therapy in the rehabilitation of physical function after severely disabling stroke. It will commence with a critical review of MMR, addressing common criticisms that have been directed towards this research approach. It will outline the rationale for using MMR in health service research and explain the rationale for using MMR for this research. It will introduce the three studies that form this research, which will be expanded upon in subsequent chapters. It will conclude with a description of how the different studies will be integrated to achieve the thesis' aim.

Chapter 5 – Survey. This chapter will present the first study of the research, which is a national survey of therapy practice in the rehabilitation of physical function after severely disabling stroke. It will commence with a critical review of survey use and an overview of the therapist survey, including its aims, development, dissemination, and analysis. It will continue with a discussion of key survey findings, as well as the survey’s strengths and weaknesses. It will conclude with an explanation of how integrating survey findings with the other studies will provide more insight into the investigation of therapy practice in the rehabilitation of severely disabling stroke.

Chapter 6 – Systematic Review. This chapter will present the second study of the research, which is a systematic review of the evidence investigating the effectiveness of rehabilitation interventions to improve physical function and reduce immobility-related complications after severely disabling stroke. It will commence with a critical review of the use of systematic reviews in healthcare research and the use of RCTs in the evaluation of complex healthcare interventions. It will continue with an overview of the systematic review and a discussion of its key findings, including its strengths and weaknesses. It will integrate the systematic review and survey findings to highlight the mismatch between the research evidence base and current clinical practice. It will conclude by highlighting how the third and largest study, an ethnographic exploration of therapy practice, can provide more insight into what factors guide therapist decision making in the rehabilitation of severely disabling stroke.

Chapter 7 – Ethnography. This chapter will present the third and main study of the research, which is an ethnographic exploration of therapy practice in the rehabilitation of severely disabling stroke. It will commence with a review of ethnography and an explanation of the rationale for using ethnography to understand therapist decision making in the rehabilitation of severely disabling stroke. It will continue with a discussion of the selection and recruitment of study sites and participants. It will conclude with a description of the study sites and participants, the methods used for data collection and analysis, and how trustworthiness was established during the research process.

Chapter 8 – Fieldwork Findings. This chapter will present the findings from the ethnographic exploration of therapy practice in the rehabilitation of severely disabling stroke. It will commence with an overview of the five themes developed through thematic analysis: professional expertise, beliefs and attitudes about post-stroke recovery, research evidence, attributes of the severely disabled stroke survivor, and therapy within the wider stroke pathway. It will continue with an exploration of each theme, which describe the factors that guide PTs and OTs to select particular interventions in the rehabilitation of physical function after severely disabling stroke. It will conclude with a discussion of the study's findings, including its strengths and weaknesses.

Chapter 9 – Discussion and Conclusion. This chapter will present a discussion of this MMR thesis. It will revisit the rationale for undertaking the research and present a summary of the findings from the three studies. It will continue with a discussion of the thesis' findings and how they may explain the poor outcomes experienced by survivors of severely disabling stroke. It will position the thesis' findings within the context of stroke rehabilitation policy and suggest recommendations for future research and clinical practice. It will conclude with a discussion of the thesis' strengths and weaknesses.

1.6 The Use of Language

Throughout this thesis, the normative conventions in the use of terminology and writing style will be followed. "Stroke survivor" is the term preferred by individuals who have experienced and survived a stroke and priority will be given to this term throughout this thesis. However, "patient" and "client" are terms commonly used by healthcare professionals to describe an individual who has experienced a stroke and will be used when detailing the personal experiences of therapy staff treating stroke survivors. Certain multi-word terms will be written without a hyphen when used as a noun (e.g. "decision making", "evidence base") and with a hyphen when used as an adjective (e.g. "decision-making process", "evidence-based practice"). Use of the third person will generally be followed throughout the thesis. However, use of the first person will be evident in the Ethnography and Fieldwork Findings chapters to acknowledge my position as the researcher and to demonstrate reflexivity. In order to maintain confidentiality, pseudonyms will be used for names of people and stroke services.

Chapter 2- Literature Review

2.1 Introduction

This chapter reviews the literature on the practice of stroke rehabilitation globally for survivors of severely disabling stroke. It will commence with an overview of stroke and explore the concepts of stroke severity and severe disability. It will continue with a review of the poor outcomes experienced by survivors of severely disabling stroke and a discussion of the key issues in the rehabilitation of severely disabling stroke. It will conclude with an exploration of therapy in stroke rehabilitation, focusing on the role of physiotherapy and occupational therapy in addressing physical function post-stroke.

2.2 Understanding Stroke

Stroke is a clinical syndrome defined as “a neurological deficit attributed to an acute focal injury of the central nervous system by a vascular cause” (Sacco *et al.*, 2013, pg. 2065). Whilst this definition can refer to any part of the central nervous system, it is most commonly used to refer to neurological dysfunction of the brain. As stroke can affect different regions of the brain, resulting in disorders of movement, cognition, communication, and behaviour, stroke has profound repercussions for affected individuals, their family and carers, as well as society. The Global Burden of Disease study reported that stroke was the second most common cause of death and disability globally (GBD 2016 Stroke Collaborators, 2019). In 2016, 5.5 million deaths and 116.4 million disability adjusted life years were attributed to stroke (GBD 2016 Stroke Collaborators, 2019). The study also revealed that there were 80.1 million prevalent cases of stroke and 13.7 million new case of stroke worldwide during 2016 (GBD 2016 Stroke Collaborators, 2019). In the United Kingdom (UK) alone, it is estimated that there are over 110,000 new cases of stroke each year and over 1.2 million stroke survivors (Patel *et al.*, 2017a; Stroke Association, 2018c). The authors of the Global Burden of Disease study stated that stroke incidence and mortality rates have reduced in recent decades due to improvements in the prevention and clinical management of stroke. However, they stated that the social burden of stroke is expected to rise over the coming decades due to population growth and ageing.

In addition to the considerable number of people affected by stroke, stroke has a significant economic burden. An international comparison of stroke cost studies demonstrated that stroke care accounts for approximately 3 – 5% of total healthcare expenditure in Europe and North America (Evers *et al.*, 2004). However, this expenditure does not include the economic cost of lost productivity or informal care provided to individuals who have sustained a stroke, which can result in substantially higher total economic costs (Patel *et al.*, 2017b, 2017a). For example, Patel *et al.* (2017b) estimated that the cost of formal care provided in the UK by the National Health Service and social services was £8.6 billion in 2015. However, the value of care provided by informal and unpaid carers was estimated to be worth £15.8 billion in the same year.

2.3 Classification of Stroke

The heterogeneous nature of stroke, including its aetiology, clinical course, and effect on individuals, has resulted in several ways to classify stroke. The World Health Organization defines classification as “an exhaustive set of mutually exclusive categories to aggregate data at a pre-prescribed level of specialisation for a specific purpose” (Madden, Sykes and Ustun, 2007, pg. 7). The use of a classification system simplifies the process of understanding large or complex subject matters and enables the identification of relationships between different aspects of a particular subject matter that might be overlooked if it were to be examined as a whole (Madden, Sykes and Ustun, 2007). In their article describing the different published stroke classification systems, Amarenco *et al.* (2009) summarised the rationale for classifying stroke into different subtypes. They stated that the classification of stroke has facilitated our understanding of the aetiology and pathophysiology of stroke, which has led to the development of different treatments for different stroke subtypes. They also stated that stroke classification has enabled us to explore the relationship between different stroke subtypes and outcomes, which has guided clinical practice in the management of the sequelae of these subtypes. However, the usefulness of any classification system is dependent upon the construction of categories that are clearly defined, mutually exclusive, and collectively exhaustive (Madden, Sykes and Ustun, 2007). Issues may arise in deciding how cases should be grouped together if there are no clearly identified or agreed boundaries between categories. This lack of clarity may affect how stroke survivors are treated. Therefore, careful consideration is required when basing treatment decisions in situations where classification is unclear or inaccurate.

In stroke, the most commonly used classification system is according to pathophysiology- an occlusion of a blood vessel results in an ischaemic stroke, whereas a rupture of a blood vessel results in a haemorrhagic stroke (Amarenco *et al.*, 2009). Use of a pathophysiological classification system has guided the use of different management strategies to modify the clinical course of stroke. For example, use of reperfusion therapy to restore cerebral blood flow in survivors of ischaemic stroke has been clinically demonstrated to significantly reduce disability (Emberson *et al.*, 2014; Bush *et al.*, 2016). However, reperfusion therapy is contraindicated in haemorrhagic stroke, which may be managed with neurosurgical interventions and medication to lower blood pressure and reverse the effects of anticoagulant medication (Hemphill *et al.*, 2015). Additionally, some classification systems further subtype these two broad types of stroke based upon the underlying aetiology. For example, the TOAST (Trial of Org 10172 in Acute Stroke Treatment) classification and National Institute of Neurological Disorders and Stroke (NINDS) Stroke Data Bank subtype classification divide ischaemic stroke into five – six different categories based upon the underlying cause, such as large artery atherosclerosis and cardiac embolism (Sacco *et al.*, 1989; Adams *et al.*, 1993). This further subtyping of stroke can facilitate the use of different secondary prevention strategies to manage these ischaemic stroke subtypes, such as angioplasty or long-term anticoagulation respectively. The success of these treatment strategies in managing ischaemic and haemorrhagic stroke, as well as their subtypes, may be attributed to categorising these stroke subtypes differently from one another and providing different treatment strategies according to their distinct subtype.

2.4 Stroke Severity as Disease Impact

Another way to classify stroke is according to its severity. Before reviewing the most commonly used methods to classify stroke according to severity, it is important to explore the concept of severity. Disease severity refers to the impact of a disease on an individual, their carers, and society (Gambert, 2013). Stein *et al.* (1987) described a framework of disease severity that has since been applied in a variety of disciplines, including cardiovascular medicine, neurology, orthopaedics, and respiratory medicine (Greenfield *et al.*, 1993; Notermans *et al.*, 1994; Corti, Salive and Guralnik, 1996; Lee, Kirking and Erickson, 2003). According to Stein *et al.* (1987), severity can be conceptualised at physiological, functional, and societal levels. In stroke, physiological severity refers to the impact a stroke has on the brain and the body systems controlled by the brain. The physiological severity of stroke can be assessed with brain imaging to determine stroke size and location, as well as scales that measure residual neurological impairments, such as weakness, communication difficulties, or visual loss (Norrving, 2014). Functional severity refers to the impact a stroke has on an individual's ability to perform their usual activities of daily living (ADLs) and can be assessed using scales that measure ADL performance (Sackley and Gladman, 1998). Burden of illness refers to the impact a stroke has on an individual's family and wider society, and considers a broad range of psychological, social, and economic measures to determine severity.

Whilst the framework developed by Stein and colleagues highlights the multi-faceted nature of disease severity, there is no consensus in the literature as to how to measure stroke severity. The lack of consensus may arise due to the use of many scales measuring different constructs of severity, which Stein *et al.* (1987) suggested are perceived differently by and have different importance to individuals with a particular disease, their carers, and healthcare professionals involved in their care. In the absence of a definitive method to measure stroke severity, Stein and colleagues recommended the use of multiple measures of disease severity to understand the impact of a disease more fully on an individual, their carers, and society. Selection of a particular measure also needs to consider an assessment of its psychometric properties, such as validity, reliability, and responsiveness (Keszei, Novak and Streiner, 2010). In their review of rehabilitation after severe stroke, Teasell, Pereira and Cotoi (2018) reported that stroke severity has been mainly defined using physiological and functional measures rather than the burden of illness to society. These measures of stroke severity will now be critically reviewed.

2.4.1 Physiological Severity

In his critical review of the use and interpretation of stroke scales, Kasner (2006) reported that measures of physiological stroke severity, such as stroke lesion size and neurological impairment, are routinely assessed in acute stroke care and commonly used in research as indicators of stroke severity. Evidence from several observational studies supports a correlation between the size and location of the stroke lesion and a range of stroke survivor outcomes, such as neurological impairment, independence in ADLs, and quality of life (Brott *et al.*, 1989; Lövblad *et al.*, 1997; Saver *et al.*, 1999; Pineiro *et al.*, 2000; Maddox, Macwalter and Mcmahon, 2001; Schiemanck *et al.*, 2005). Stronger correlations (Spearman's ρ 0.54 – 0.79) tended to be found between lesion size and neurological impairment, particularly motor function, during the acute and subacute phases post-stroke (Brott *et al.*, 1989; Lövblad *et al.*, 1997; Saver *et al.*, 1999). Weaker correlations (Spearman's ρ 0.27 – 0.35) tended to be found in the chronic phase post-stroke and between lesion size and ability to perform ADLs (Lövblad *et al.*, 1997; Pineiro *et al.*, 2000; Maddox, Macwalter and Mcmahon, 2001; Schiemanck *et al.*, 2005). These weaker correlations suggest that factors other than lesion size and location impact upon a person's ability to perform ADLs in the longer term. It is worth noting that most studies investigating relationships between lesion size and outcomes excluded stroke survivors with significant neurological impairment, although reasons for this exclusion are not reported. Therefore, the strength of the relationship between lesion size and outcomes in this group of stroke survivors is not clear.

Similar to lesion size, evidence supports a stronger relationship between neurological impairment and performance of ADLs in the acute phase post-stroke, which lessens during the subacute and chronic phases post-stroke (Roth *et al.*, 1998; Adams *et al.*, 1999; Glymour *et al.*, 2007). Roth *et al.* (1998) prospectively investigated the relationship between impairment and activity performance in 402 consecutively admitted patients to a stroke rehabilitation facility in the United States of America (USA). They found a weak relationship (R^2 0.26 – 0.35) between neurological impairment, measured with the National Institutes of Health Stroke Scale (NIHSS), and independence in various functional activities, measured with the Functional Independence Measure (FIM). The authors concluded that stroke survivors were still able to perform functional activities despite having residual neurological impairment. Therefore, physiological severity may be less useful in determining the impact of a stroke on an individual, particularly in the post-acute phase.

Another limitation of using physiological severity to determine the impact of a stroke on an individual is that physiological severity does not consider the impact of an individual's co-morbidities or previous level of function on their ability to perform ADLs after a stroke (Stein *et al.*, 1987). For example, two individuals with a similarly sized stroke lesion on brain imaging may have very different clinical presentations if one individual was younger, previously independent in ADLs, and had no medical co-morbidities, whereas the other individual was older, required assistance for ADLs, and had several medical co-morbidities. This additional limitation of physiological severity suggests that other severity measures are required to understand the impact of a stroke on an individual more fully.

2.4.2 Functional Severity

As functional severity reflects the impact of a disease on the ability of an individual to conduct their daily life, measures of functional stroke severity may seem more relevant to use than measures of physiological stroke severity, particularly to stroke survivors. Similar to physiological stroke severity measures, functional stroke severity measures are used regularly in clinical practice and in research (Kasner, 2006). Evidence suggests that commonly used functional stroke severity measures, such as the FIM, Barthel Index (BI) and Modified Rankin Scale (mRS), can predict short term outcomes, such as hospital length of stay, and longer-term outcomes, such as discharge destination and independence in ADLs (Oczkowski and Barreca, 1993; Ancheta *et al.*, 2000; Kashihara *et al.*, 2011; Quinn, Langhorne and Stott, 2011). Therefore, these measures have the dual benefit of describing the current impact of stroke on the affected individual and predicting future outcomes.

Although functional stroke severity measures are conceptually more likely to ascertain the impact of stroke on an individual than physiological stroke severity measures, the constructs that these scales measure are the degree of independence or amount of additional assistance required to perform various activities. These constructs may be useful for healthcare professionals and researchers to gauge the effect of different treatments in the management of stroke. However, these constructs may be less meaningful and relevant to stroke survivors. In her ethnographic study describing the experience of 13 stroke survivors undergoing stroke rehabilitation in the USA, Doolittle (1991) highlighted that most stroke survivors viewed successful rehabilitation as regaining their lifestyle before stroke rather than the completion of discrete functional tasks. Consequently, rehabilitation that focussed on practising previously valued activities was seen as more meaningful than practising discrete self-care and mobility tasks. A similar finding was seen by Bendz (2000, 2003), who explored how Swedish stroke survivors and their healthcare professionals understood and dealt with stroke rehabilitation. In these two studies, Bendz interviewed 27 stroke survivors and reviewed their medical records to obtain the perspectives of stroke survivors and healthcare professionals respectively. Bendz reported that whilst stroke survivors highlighted the emphasis of physical training and task completion during rehabilitation sessions, the perceived aims of these sessions differed between stroke survivors and their healthcare professionals. The aim of training from a healthcare professional’s perspective was to increase independence in functions. However, the aim of training from a stroke survivor’s perspective was to regain their life before stroke. Consequently, the measurement of functional task performance in stroke rehabilitation, due to the focus of stroke rehabilitation on practising functional tasks, may not describe the impact of stroke on stroke survivors in any meaningful way to stroke survivors.

On a similar theme, the validity of functional stroke severity measures assessing the impact of stroke on an individual may be questioned due to the types of activities that they measure. Whilst Kasner (2006) reported that the BI and mRS have moderate to strong inter-rater reliability (Pearson’s r 0.89 – 0.99 for the BI and Cohen’s κ 0.74 for the mRS), these scales only include physical activities, such as walking, feeding, and toileting, and exclude social activities and psychological functioning (New and Buchbinder, 2005; Quinn, Langhorne and Stott, 2011). This limitation may reflect the wider emphasis on physical training and improving physical function in stroke rehabilitation, as identified by Bendz (2000, 2003). This limitation may also reflect the lack of attention in addressing the social and psychological consequences of stroke during rehabilitation, as reported by 21 Danish stroke survivors in a qualitative study by Lewinter and Mikkelsen (1995). The limited range of activities included in these functional stroke severity measures reduces their content validity and ability to measure the full impact of stroke on an individual.

Another issue with functional stroke severity measures relates to the method of measurement and the nature of the construct actually being measured. These scales are usually completed by healthcare professionals observing a stroke survivor complete a task in a standardised manner. However, this observation measures a stroke survivor’s capacity, or the ability to execute a task in a controlled environment, as opposed to a stroke survivor’s performance, or the ability to execute a task in their usual environment (World Health Organization, 2001). Performance and capacity may be different, particularly if a stroke survivor would struggle to complete a task without specialist equipment or environmental adaptations. For example, a stroke survivor may be able to roll over independently in a hospital bed using cot sides or sit independently on a firm treatment plinth but may be unable to roll over in their own bed and sit upright without assistance due to the softness of their bed mattress. Whilst it is not possible to replicate a stroke survivor’s exact environment in a hospital setting, measuring a stroke survivor’s ability to complete a task in hospital may not accurately assess what a stroke survivor could do in the community. Therefore, this may limit the utility of some functional stroke severity measures that fail to recognise the influence of environment on task performance.

2.4.3 Burden of Illness

In Stein and colleagues' framework, burden of illness refers to the impact a stroke has on a stroke survivor's family and wider society in social, emotional, and financial terms. These measures include caregiver burden, defined by Rigby, Gubitz and Phillips (2009) as the physical and psychological load carried by caregivers due to adopting the caregiver role. These measures also include the financial costs associated with treating and managing stroke. In their systematic review of caregiver burden post-stroke, Rigby, Gubitz and Phillips (2009) identified relationships between physiological, functional, and societal stroke severity measures. They found that more neurological impairment and increased patient dependency were likely to be associated with increased caregiver burden. However, this finding was not observed in every study included in the systematic review due to the variety of measurement tools used to assess caregiver burden and the different constructs each tool measured. Additionally, a large prospective observational study completed by Xu *et al.* (2018) estimated the financial burden of stroke in the UK. Using data from over 80,000 stroke survivors, the authors found that increasing neurological impairment was associated with increased health and social care costs. These findings are consistent with previous research indicating that longer-term care costs, which mostly support survivors of severely disabling stroke, constitute approximately 49% of total healthcare spending towards stroke (Evers *et al.*, 2004). However, measures of illness burden are less frequently used to define stroke severity than physiological and functional measures of stroke severity as they do not measure the direct impact of stroke on the stroke survivor. Therefore, they should be used in addition to other measures of severity to understand the impact of stroke more fully.

2.4.4 The Impact of Stroke on Function and Disability

Whilst the framework developed by Stein and colleagues is useful to conceptualise disease severity and understand the different levels of disease severity, it demonstrates several limitations. The framework does not qualify or quantify the magnitude of disease severity. As a disease can have a varying impact upon different physiological systems or functional tasks, establishing the magnitude of disease severity is important to know. The framework also does not consider several aspects known to influence the impact of a disease on an individual. These aspects include personal factors, such as age and co-morbidities, as well as environmental factors, such as building design and personal relationships. An alternative framework that considers these aspects is the International Classification of Functioning, Disability and Health (ICF). The ICF is an internationally recognised framework that describes an individual’s level of function and disability, which results from the interaction between an individual’s health condition and their environment (World Health Organization, 2001). Functioning and disability are opposing multi-dimensional constructs, each composed of three inter-related components (Figure 1). Body functions and structure, activity, and participation are components of functioning, whereas impairments, activity limitations, and participation restrictions are components of disability (World Health Organization, 2001). Components are further subdivided into different domains and the extent of functioning within each domain can be measured or qualified using standardised scales.

Although the ICF is recognised internationally, Stucki (2005) reported that the comprehensive nature of the ICF, containing 1,454 categories of function, may limit its applicability in routine clinical practice. This limitation led to the development of the ICF Core Sets, which are selections of ICF categories for specific health conditions and settings designed to facilitate the use of the ICF in clinical practice (Cieza *et al.*, 2004; Geyh *et al.*, 2004). Content validation of the ICF Core Set for stroke by stroke survivors and various healthcare professionals, such as doctors, physiotherapists (PTs), and occupational therapists (OTs), has demonstrated that most functional categories experienced by stroke survivors are covered in the ICF Core Set for stroke (Glässel *et al.*, 2010, 2011, 2012; Lemberg *et al.*, 2010; Paanalahti *et al.*, 2014; Kinoshita *et al.*, 2016). Accordingly, the ICF Core Set for stroke may be considered suitable for use clinically.

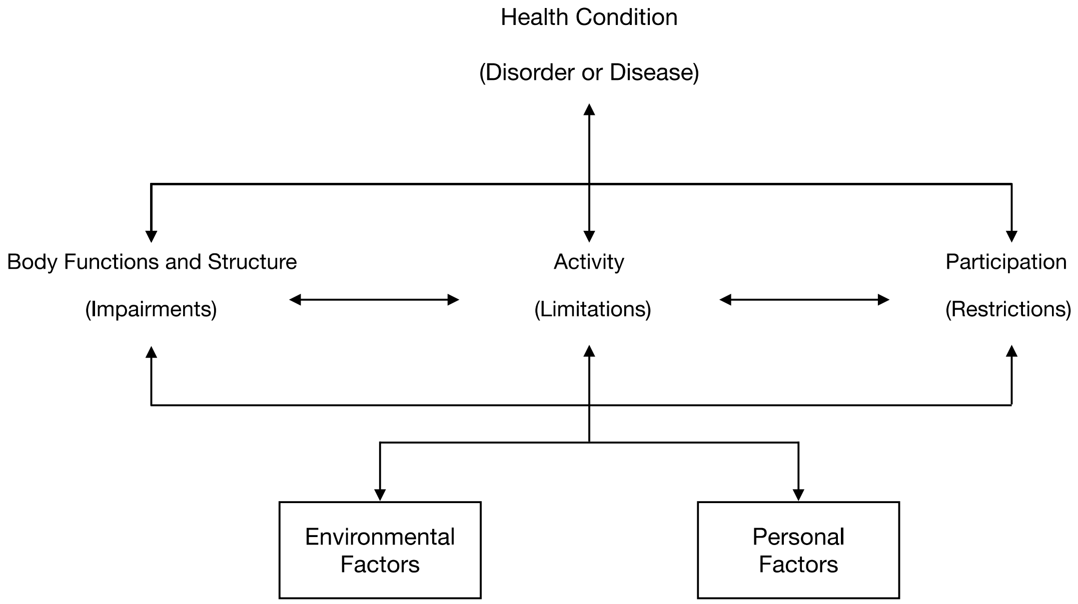


Figure 1- Overview of the International Classification of Functioning, Disability and Health

Using the ICF framework, stroke results in dysfunction, or disability, at one or more of the three levels of functioning. This dysfunction could be impairments of muscle power and touch sensation, limitations in communication and walking, and restrictions in work and employment. Each of these disability domains can be qualified to measure the impact of stroke on an individual's level of functioning, such as moderate impairment of muscle power or severe difficulty in walking. Due to the comprehensive nature of the ICF framework, it will be used in conjunction with Stein and colleagues' disease severity framework to understand the broad impact of stroke on an individual.

2.5 Classification of Stroke Severity

In addition to pathophysiology, stroke can be classified according to severity, or the impact that it has on the stroke survivor. As reported by Amarenco *et al.* (2009), grouping similar stroke survivors together based on severity can be used to guide the development of different treatment strategies for each severity group. Grouping similar stroke survivors together based on severity may also enable us to explore the relationship between different severity groups and outcomes. This exploration can guide clinical practice in the management of these outcomes. Therefore, it is necessary to review the most commonly used methods to classify stroke according to severity.

One of the earliest severity classification systems divided stroke into three bands- upper, middle, and lower- based upon the degree of consciousness at stroke onset, the presence of weakness, and the degree of dependency in ADLs (Garraway *et al.*, 1981). This classification system, which uses both physiological and functional measures of stroke severity, has since evolved to trichotomise stroke severity as mild, moderate, and severe, as well as variations that include very mild and very severe categories. Approaches to classify stroke into different levels of severity are used frequently in observational studies (Jorgensen *et al.*, 1995a, 1995b; Navarrete-Navarro *et al.*, 2003; Luengo-Fernandez *et al.*, 2013; Gittins *et al.*, 2020; McGlinchey and Buttery, 2020) as well as randomised controlled trials (RCTs) of stroke rehabilitation and its constituent components (Kalra, Dale and Crome, 1993; Redzuan *et al.*, 2012; AVERT Trial Collaboration Group, 2015; Sackley *et al.*, 2015; Lindley *et al.*, 2017). Despite the continued use of the trichotomous classification of stroke severity, the classification system proposed by Garraway and colleagues used vague terms to categorise stroke severity, such as “conscious at onset” and “established hemiplegia”. Their classification system also provided no objectification of only two neurological impairments to categorise the three different severity bands. Garraway *et al.* (1981) also reported the prognosis for survival and independence in ADLs for each severity band but provided limited data to substantiate these claims. As of result of these limitations, the validity of the trichotomous classification of stroke severity currently used in healthcare and research may be questioned.

Another classification system based upon the range and type of post-stroke neurological impairments is the Oxfordshire Community Stroke Project Subtype Classification (Bamford *et al.*, 1991). This classification system was developed using data from a prospective, community-based study of first ever stroke and divides stroke into one of four subtypes- total anterior circulation infarcts, partial anterior circulation infarcts, lacunar infarcts, and posterior circulation infarcts. The classification system can be used to predict the site and size of an ischaemic stroke, as well as mortality and functional recovery in the first year post-stroke (Bamford *et al.*, 1991; Wardlaw *et al.*, 1996; Mead *et al.*, 2000). Although the classification system has good intra-observer reliability and has been validated by several authors (Lindley *et al.*, 1993; Anderson *et al.*, 1994; Wardlaw *et al.*, 1996), the classification system was designed for subtyping ischaemic stroke and not haemorrhagic stroke. Therefore, this classification system is limited in classifying stroke severity for all types of stroke. Whilst stroke survivors diagnosed with a total anterior circulation infarct have a greater range of neurological impairments compared to stroke survivors diagnosed with partial anterior circulation or lacunar infarcts, the classification system does not quantify the magnitude of these impairments. In addition, the variety of signs arising from posterior circulation infarcts can range from relatively mild cerebellar signs, such as ataxia and diplopia, to relatively severe brainstem signs, such as quadriparesis and coma (Merwick and Werring, 2014). For these reasons, the different subtypes of stroke identified by this classification system may not fully correlate with differing degrees of stroke severity.

Subsequent classification systems have categorised different levels of stroke severity using cut-off scores on physiological and functional stroke severity measures. One benefit of using cut-off scores to classify stroke is that they provide greater transparency regarding classification. For example, the Orpington Prognostic Scale (OPS), which measures strength, proprioception, balance, and cognition post-stroke, classifies stroke severity as mild (<3.2 points), moderate (between 3.2 and 5.2 points) and severe (>5.2 points) (Kalra, Dale and Crome, 1993). Cut-off scores to classify stroke have also been used to facilitate prognostication of outcome in stroke survivors. For example, Oczkowski and Barreca (1993) explored the ability of the FIM to predict longer-term outcomes post-stroke, such as independence in ADLs and discharge destination. In a small sample of 113 stroke survivors, they found that 100% of stroke survivors with an admission FIM score <37 were discharged to a care home, whereas 100% of stroke survivors with an admission FIM score >96 were discharged home. As the study was conducted over 25 years ago in the USA, the study’s findings may not be generalisable to other healthcare settings due to geographical differences in criteria for care home admission that may have changed over time. However, the study highlighted the potential use of outcome measures in the prognostication after stroke.

Whilst cut-off scores provide greater transparency regarding the classification of stroke and may facilitate prognostication, their use may pose some issues. Firstly, the value of the cut-off score needs to be agreed upon by those who use it to classify stroke severity. Whilst some outcome measures use the same pre-defined cut-off scores to classify stroke severity, such as the mRS and OPS (Kalra, Dale and Crome, 1993; New and Buchbinder, 2005) other outcome measures do not have clearly defined cut-off scores to classify stroke. For example, the literature reports that severe stroke can be classified using the NIHSS with scores ranging from greater than 11 to greater than 16 out of 42 (Adams *et al.*, 1999; Redzuan *et al.*, 2012; Luengo-Fernandez *et al.*, 2013; Corso *et al.*, 2014; AVERT Trial Collaboration Group, 2015). The literature also reports that severe stroke disability can be classified using the BI with scores ranging from less than 40 to less than 55 out of 100 (Jorgensen *et al.*, 1995a, 1995b; Yamaguchi *et al.*, 1998; Navarrete-Navarro *et al.*, 2003; Holloway *et al.*, 2005). This variation in cut-off scores makes accurate classification difficult. Secondly, use of a single cut-off point on an outcome measure that operates on a continuum may be arbitrary if it does not create clearly distinct categories. Whilst stroke survivors who score at the extremes of an outcome measure may be classified in the correct severity category, stroke survivors who score close to or at a cut-off score risk being misclassified. Similarly, Altman and Royston (2006) stated that categorising a continuous variable, such as a continuous outcome measure, may limit the statistical ability to detect relationships between the variable of interest, such as stroke severity, and patient outcome. Finally, a cut-off score on a physiological stroke severity measure may not correlate with a cut-off score on a functional stroke severity measure. As a result, a stroke survivor who presents with moderate neurological impairment yet has only mild difficulties in performing ADLs could be classified as having both a mildly disabling stroke and a moderately disabling stroke. One consequence of misclassifying stroke is that stroke severity has been identified as a factor affecting access to ongoing stroke rehabilitation (Longley *et al.*, 2019) In their systematic review exploring factors affecting decision making about access to stroke rehabilitation, Longley *et al.*, (2019) found that survivors of more severe stroke were less likely to be referred or accepted for rehabilitation due to perceptions about poor recovery and limited gains from participating in rehabilitation. Therefore, misclassifying a stroke survivor as severely disabled when they may actually present as moderately disabled may affect their chance of accessing rehabilitation.

Due to the methodological issues associated with the classification of stroke according to severity, it is important that these issues are carefully considered before treatment decisions are made based on severity. It may be that several measures of stroke severity are required to account for these issues and accurately classify stroke according to severity. Despite these problems, stroke severity remains one of the most commonly used methods to classify stroke. Its classification can guide the selection of different treatment strategies for each severity group. Its classification can also facilitate the exploration of outcomes for each severity group. One severity group where this is particularly important is those most severely affected by stroke.

2.6 Understanding Severely Disabling Stroke

2.6.1 Defining Severely Disabling Stroke

Applying the terminology used within the ICF framework, stroke results in dysfunction, or disability, at one or more of the three levels of functioning. Therefore, severely disabling stroke refers to a stroke that significantly impacts upon an individual’s functioning and causes significant disability, which could be any one or combination of impairments, activity limitations, and participation restrictions. Whilst the terms “severe stroke” and “severely disabling stroke” have been used interchangeably in the literature to describe a stroke that has a severe impact on an individual, “severe stroke” tends to be used to describe the initial stroke event- a stroke that affects a large or significant amount of brain tissue- and the residual neurological impairments (Teasell, Pereira and Cotoi, 2018). “Severely disabling stroke” tends to be used to describe the impact of a stroke on an individual’s ability or degree of additional assistance required to perform their usual activities (Sackley and Gladman, 1998). The studies reported in Sackley and Gladman's review of the rehabilitation evidence in severely disabling stroke focused on activity limitation when defining severely disabling stroke. This focus may have been based upon an older definition of disability provided by the International Classification of Impairment, Disability and Handicap (ICIDH), the framework that preceded the ICF (World Health Organization, 1980). In the ICIDH, disability was defined as limitations of functional performance or activity. However, using the current ICF terminology, disability is a broader term that refers to the negative impact of a disease on an individual’s body systems, activities, and participation. Therefore, “severely disabling stroke”, using the current ICF terminology, more accurately describes the broad impact a stroke has on an individual than “severe stroke”. For this reason, “severely disabling stroke” will be the preferred term that is used in this thesis to describe a stroke that significantly impacts upon an individual’s functioning and causes significant disability.

2.6.2 Prevalence of Severely Disabling Stroke

Determining accurate figures for the current prevalence of severely disabling stroke using the available literature is problematic for several reasons. Many cross-sectional observational studies measuring stroke severity and disability were conducted over 20 years ago, as reported by Sackley and Gladman (1998) and Hankey *et al.* (2002). These studies may not be relevant to understanding the current prevalence of severely disabling stroke due to changes in clinical practice over the past 20 years that may have directly impacted upon the prevalence of residual stroke disability. For example, the introduction of organised stroke units (SUs) has resulted in reductions in mortality, dependency, and institutionalisation post-stroke (Stroke Unit Trialist's Collaboration, 2013; Langhorne and Ramachandra, 2020). As well, advances in the medical management of stroke and use of interventions such as thrombolysis and thrombectomy can directly alter the stroke event itself and reduce its disabling effects (Emberson *et al.*, 2014; Bush *et al.*, 2016). Therefore, data from these older studies may provide an overestimation of the current prevalence of severely disabling stroke.

Cross-sectional observational studies conducted more recently, which have generally focused on the acute phase post-stroke, have used different outcome measures to classify stroke severity (Navarrete-Navarro *et al.*, 2003; Bhaskar *et al.*, 2017; Douiri *et al.*, 2017). These measures, which include the BI, GCS and NIHSS, assess different components of stroke severity in different ways. Therefore, the prevalence of severely disabling stroke reported in these studies may not be directly comparable with one another. As well, some studies using the same outcome measure (e.g. NIHSS) have adopted different cut-off scores to classify a stroke as severely disabling (Luengo-Fernandez *et al.*, 2013; Bhaskar *et al.*, 2017; McGlinchey *et al.*, 2019; Gittins *et al.*, 2020), furthering the challenge of determining the prevalence of severely disabling stroke. Comparing the prevalence of severely disabling stroke across different studies is also complicated as some observational studies have examined the prevalence of stroke in a defined community population, such as the Oxford Community Stroke Project and Oxford Vascular Study (Bamford *et al.*, 1990; Rothwell *et al.*, 2004), whereas other studies have examined the prevalence in patients admitted to hospital with stroke (Kimura, Minemaisu and Yamaguchi, 2005; McGlinchey *et al.*, 2019; Gittins *et al.*, 2020). Consequently, the variety of outcome measures and cut-off scores used, as well as the different populations under investigation, compounds the challenge of accurately determining the current prevalence of severely disabling stroke.

Finally, determining the prevalence of severely disabling stroke from longitudinal studies that have followed up stroke survivors over time is also problematic. Many longitudinal studies have not specifically reported data on severe disability (Hackett *et al.*, 2000; Hankey *et al.*, 2002; Anderson *et al.*, 2004; Hardie *et al.*, 2004; Dhamoon *et al.*, 2009; Wolfe *et al.*, 2011). Therefore, it is not possible to estimate the prevalence of severely disabling stroke from these studies. As well, many longitudinal studies have been conducted over 20 years ago, which presents similar issues as described earlier

(Andrews *et al.*, 1982; Wade and Hewer, 1987; Kojima *et al.*, 1990; Greveson *et al.*, 1991; Dennis *et al.*, 1993; Kappelle *et al.*, 1994; Jorgensen *et al.*, 1995a, 1995b; Lindmark and Hamrin, 1995; Gresham *et al.*, 1998). Consequently, recent estimates of the prevalence of severely disabling stroke in the chronic phase post-stroke are lacking. Due to these reasons, there is a considerable lack of clarity regarding the actual current prevalence of severely disabling stroke.

In the acute phase post-stroke, recent global estimates of the percentage of people who have sustained a stroke initially classified as severe range from 9.6% to 33.8% (Table 1). Most of these studies used the NIHSS to measure stroke severity, which is reported to be the most commonly used measure of physiological severity post-stroke (Quinn, Langhorne and Stott, 2011). Kasner (2006) and Quinn, Langhorne and Stott (2011) stated that physiological severity measures may be more informative in the acute phase post-stroke than functional severity measures due to fluctuations in task performance early post-stroke that reduce the sensitivity of functional severity measures. The largest and one of the most recent studies, conducted by McGlinchey *et al.* (2019), included data from over 250,000 hospitalised stroke patients in England and Wales. Findings from the study demonstrated that 15.3% of individuals admitted to hospital with stroke were classified as having either a severe or very severe stroke, as measured with the NIHSS. Due to the large sample size and the nature of the stroke register used in the study, estimated to capture 90 – 95% of all hospitalised stroke admissions in England and Wales, this percentage may be a more accurate representation of the prevalence of severely disabling stroke in the acute-phase post-stroke than other studies.

In the chronic phase post-stroke, two recent longitudinal studies monitored stroke survivors for up to 15 years post-stroke and found similar results. The more recent study, by Crichton *et al.* (2016), monitored 2,626 stroke survivors recorded on a population-based stroke register for up to 15 years since their first stroke. The proportion of stroke survivors classified as having a severe disability, defined as a BI score <10, at 10 years post-stroke was 14.4%. At 15 years post-stroke, the proportion remained similar at 15%. The size of the surviving stroke population at 10 and 15 years was 723 and 262 respectively, which was larger than the study by Jönsson *et al.* (2014). In their study of 145 patients, Jönsson *et al.* (2014) found that the proportion of stroke survivors at 10 years post-stroke classified as having a severe disability, defined as an mRS >3, was 15%. One limitation of these chronic phase studies is the relatively small sample sizes compared to the acute phase studies, attributable to high rates of attrition over time.

However, these studies demonstrate that the issue of severely disabling stroke is not confined to the acute or subacute phases post-stroke.

Table 1- Prevalence of severely disabling stroke in the acute phase post-stroke

Authors	Time Post-Stroke	Population	Sample Size	Number of Severe (%)	Assessment Scale
Kimura et al. (2005)	Within 7 days	Hospital	15,831^	27.2	NIHSS (≥11)
Luengo-Fernandez *et al.* (2013)	Not reported- acute stroke	Hospital and community	748	17.8	NIHSS (≥11)
Corso *et al.* (2014)	Not reported- acute stroke	Community	1057^	15.3	NIHSS (≥16)
Bhaskar *et al.* (2017)	Not reported- acute stroke	Hospital	608^	33.8	NIHSS (≥17)
Douiri *et al. (*2017)	Not reported- acute stroke	Hospital and community	1,524	9.6	GCS (≤ 8)
McGlinchey *et al. (*2019)	Within 72 hours	Hospital	253,672	15.3	NIHSS (≥16)

NIHSS – National Institutes of Health Stroke Scale. GCS- Glasgow Coma Scale. ^ only ischaemic stroke included

2.6.3 Impact of Severely Disabling Stroke

Understanding the impact of severely disabling stroke is important as this cohort of the stroke population is more likely to experience worse outcomes compared to survivors of less disabling stroke across all stages of life after stroke. In the acute hospitalisation phase, survivors of severely disabling stroke are more likely to develop acute medical complications (Langhorne *et al.*, 2000; Roth *et al.*, 2001), which are negatively associated with independence in functional activities (Kim *et al.*, 2017). Greater stroke severity is also positively associated with higher mortality (Heuschmann *et al.*, 2004; Godoy, Piñero and Di Napoli, 2006; Saposnik *et al.*, 2008; Safatli *et al.*, 2016). As many as 40% of individuals with severely disabling ischaemic stroke have died within the first month post-stroke compared to just under 5% of those with mildly disabling ischaemic stroke. For individuals with severely disabling haemorrhagic stroke, the one-month mortality rate can range between 55 – 100%.

Survivors of severely disabling stroke spend longer in hospital, leading to increased hospital costs (Saxena *et al.*, 2006; Xu *et al.*, 2018; Gittins *et al.*, 2020). Survivors of severely disabling stroke also demonstrate slower and less recovery of ADLs, resulting in greater dependency and need for carer support upon hospital discharge (Wade and Hewer, 1987; Duncan *et al.*, 1992; Jorgensen *et al.*, 1995a, 1995b; Ancheta *et al.*, 2000; Douiri *et al.*, 2017; Clery *et al.*, 2020).

For those individuals discharged from hospital alive, results from two recent systematic reviews investigating factors predictive of discharge disposition suggested that survivors of severely disabling stroke are more likely to be discharged to a care home, particularly if they are older and lack carer support (Van Der Cruyssen *et al.*, 2015; Mees *et al.*, 2016). Longer-term care costs, which mostly support severely disabled stroke survivors, represent 49% of total stroke care spending globally (Evers *et al.*, 2004). In the first year post-stroke, the mortality rate for individuals with ischaemic stroke can be as high as 66% (Navarrete-Navarro *et al.*, 2003). Due to the high initial mortality rate in haemorrhagic stroke, individuals of haemorrhagic stroke experience similar levels of mortality compared to the acute phase post-stroke (Navarrete-Navarro *et al.*, 2003). Survivors of severely disabling stroke also experience high levels of immobility-related complications, such as falls, contractures, pain, and pressure sores (Sackley *et al.*, 2008; Kuptniratsaikul *et al.*, 2013). Immobility-related complications are not only distressing to the stroke survivor but require additional resources to manage (McGlinchey, Walmsley and Cluckie, 2015). As of a result of the persistent dependency in ADLs, the amount of physical assistance provided by caregivers and the psychosocial impact of stroke on caregivers result in high levels of caregiver burden (Rigby, Gubitz and Phillips, 2009). This extra burden placed on caregivers may potentially affect the care that survivors of severely disabling stroke receive.

From this overview, it can be seen that the range of issues experienced by survivors of severely disabling stroke, their carers, and society are significant. These issues are not just confined to the acute phase post-stroke but persist throughout a severely disabled stroke survivor's life. As stroke rehabilitation is the mainstay of treating stroke, it is worth exploring how stroke rehabilitation deals with these issues.

2.7 Rehabilitation in Severely Disabling Stroke

Whilst there is no single definition of stroke rehabilitation, several international clinical guidelines in stroke management adopt a similar conceptual stance that stroke rehabilitation is a process enabling people to optimise their function and level of independence through the provision of individually tailored interventions (Intercollegiate Stroke Working Party, 2016; Winstein *et al.*, 2016; Stroke Foundation, 2019b; Teasell *et al.*, 2020). The guidelines also recommend that stroke rehabilitation commences as soon as an individual experiences a stroke and is provided by a range of healthcare professionals with expertise at addressing the range of issues caused by stroke. Function is described according to the ICF definition and considers physical, cognitive, emotional, communicative, and social elements (Hebert *et al.*, 2016). Whilst these clinical guidelines do not specifically define what constitutes an intervention, they do recommend the use of interventions that have demonstrable effectiveness, with priority given to evaluation by RCTs. The guidelines also recommend that rehabilitation interventions are selected to address specific patient-centred goals jointly set between the healthcare professional team and stroke survivor, and are delivered at a sufficient intensity to optimise post-stroke recovery. Results from several systematic reviews have demonstrated the effectiveness of different stroke rehabilitation models, such as inpatient SU care (Stroke Unit Trialist's Colloboration, 2013; Langhorne *et al.,* 2020) and early supported discharge services (Langhorne *et al.,* 2017), on reducing mortality and hospital length of stay, increasing the likelihood of returning and remaining at home after hospital, and increasing independence in ADLs.

2.7.1 Rehabilitation Issues- Stroke Survivors' Perspectives

Although this overview of stroke rehabilitation is generally accepted by healthcare professionals, it poses several issues for stroke survivors, particularly survivors of severely disabling stroke. Authors of several qualitative studies exploring stroke survivors' understanding of stroke and stroke recovery have highlighted that stroke survivors often perceive stroke rehabilitation differently to healthcare professionals (Doolittle, 1991; Lewinter and Mikkelsen, 1995; Bendz, 2000, 2003; Dowswell *et al.*, 2000; Morris *et al*., 2007). Consequently, these authors have questioned the normative focus on improving function and independence after stroke. Dowswell *et al.* (2000) interviewed 30 stroke survivors who were enrolled in an RCT exploring the benefits of home visits conducted by stroke specialist nurses. In their study, stroke survivors viewed progress in terms of the degree of congruence between their lives before and after the stroke. This individualised marker of successful recovery was similar to how stroke survivors viewed successful rehabilitation in Doolittle's ethnographic study (Doolittle, 1991). In her study, successful rehabilitation was seen as the resumption of previously valued and meaningful activities as opposed to the completion of discrete functional tasks. Stroke survivors may also perceive that stroke rehabilitation focusses more on physical care to regain physical function and independence, as opposed to dealing with psychological, emotional, and social issues (Lewinter and Mikkelsen, 1995; Morris *et al*., 2007). In their qualitative study exploring the experiences of stroke survivors, their carers, and hospital staff, Morris *et al*. (2007) found that many stroke survivors valued the high level of commitment of hospital staff but felt that their broader human needs were not met due to the overwhelming focus on physical care during rehabilitation. These perceptions of stroke recovery and rehabilitation provided by stroke survivors differ to healthcare professionals working in stroke rehabilitation. Bendz explored the process of stroke rehabilitation using interviews of stroke survivors and analysis of medical documentation (Bendz, 2000, 2003). She suggested that healthcare professionals usually perceived stroke recovery as regaining lost function through the amelioration of physical and cognitive impairments. Similarly, Doolittle's study suggested that healthcare professionals emphasised recovery and progress in terms of strength, movement, and the completion of functional tasks, sometimes to the detriment of what mattered most to the stroke survivor- a return to a meaningful life (Doolittle, 1991). If rehabilitation "belongs to the person, it is their process" (Ellis-Hill, Payne and Ward, 2008, pg. 155), understanding what matters to stroke survivors is essential to guide the delivery of stroke rehabilitation and perhaps reconcile some of the conceptual differences between stroke survivors and healthcare professionals about what stroke rehabilitation should be.

However, recommendations from international clinical guidelines to incorporate stroke survivors' perspectives in the rehabilitation process may be difficult to enact for those individuals most severely affected by stroke. This cohort of the stroke population may have cognitive and communication impairments that limit their ability to engage in the rehabilitation process and express their wishes about meaningful goals to work towards (Asplund and Britton, 1989; Geurts *et al.*, 2014; Kelly, Sahin and Holloway, 2014; Visvanathan *et al.*, 2017). There could be a risk that, without incorporating their views, rehabilitation decisions are made for them rather than with them. This lack of stroke survivor involvement may potentially lead to the formation of goals that are less meaningful or contextualised to their individual circumstances, thereby contradicting the ethos of stroke rehabilitation. One way to minimise this risk would be to involve those people who know the stroke survivor, such as family members, in the goal setting process to guide rehabilitation. Although the extent to which this occurs in clinical practice is not known, Sackley and Gladman (1998) highlighted that the burden of severely disabling stroke affects not just the stroke survivor but their family as well. Therefore, consideration of the family’s perspectives in the rehabilitation of those severely affected by stroke seems reasonable, particularly when the stroke survivor is unable to express their wishes. However, studies reviewing end of life decision making in severe stroke and brain injury have reported that surrogate decision makers, such as family members, may bias the decision-making process due to having unrealistic expectations of recovery or inaccurately predicting a stroke survivor’s future quality of life (Creutzfeldt and Holloway, 2012; Geurts *et al.*, 2014; Kelly, Sahin and Holloway, 2014). Whilst these studies were conducted in the very early stages of severe stroke and brain injury, when prognostication may be less accurate, it is important to note that involving family members in decisions about rehabilitation may present challenges that require careful consideration by healthcare professionals.

2.7.2 Rehabilitation Issues- Focus of Rehabilitation

Another issue about the normative focus of stroke rehabilitation relates to its applicability to survivors of severely disabling stroke. Stroke rehabilitation is considered a process to optimise function and independence, yet the extent to which rehabilitation actually optimises function and independence for survivors of severely disabling stroke is not clear. Pereira *et al.* (2012) conducted a literature review of studies investigating the effect of inpatient rehabilitation in severe stroke. Findings suggested that survivors of severely disabling stroke who received inpatient stroke rehabilitation made limited improvements in function and independence compared to those who received general medical ward care. However, survivors of severely disabling stroke had reduced mortality, decreased hospital lengths of stay, and an increased likelihood of discharge home when compared to those who received rehabilitation in other settings. The authors concluded that rehabilitation in severely disabling stroke should focus more on discharge planning than improving functional recovery. However, this conclusion was based on two small trials included in the review comparing SU care to general medical ward care for survivors of severely disabling stroke (Kalra, Dale and Crome, 1993; Kalra and Eade, 1995). Results from the larger trial revealed a median difference in BI scores of two points between trial groups, which was not considered statistically significant (Kalra and Eade, 1995). However, Hsieh *et al.* (2007) suggested that a change of at least 1.85 on the BI may be considered a clinically important difference. Therefore, there may have been a clinically important functional difference between trial groups in Kalra and Eade's study. It should also be noted from Pereira and colleagues' review that improvements in FIM scores were reported for survivors of severely disabling stroke undergoing stroke rehabilitation in the observational cohort studies included in their review (Sandstrom, Mokler and Hoppe, 1998; Schmidt, Drew-Cates and Dombovy, 1999; Ancheta *et al.*, 2000; Horn *et al.*, 2005; Teasell *et al.*, 2005). However, improvements were more limited compared to survivors of mildly disabling stroke. Consequently, the extent to which stroke rehabilitation facilitates functional recovery after severely disabling stroke is unclear from Pereira and colleagues' review.

In their commentary article supporting the case for rehabilitation in severely disabling stroke, Gladman and Sackley (1998) stated that even small reductions in the level of dependency brought about by rehabilitation for survivors of severely disabling stroke may have clinical and economic benefits, such as reducing the amount of staff needed to care for someone. Therefore, focussing on reducing dependency on carers in certain care tasks, rather than attaining complete or nearly complete independence in ADLs, may be a justified rehabilitation goal in the rehabilitation of severely disabling stroke. Another justified rehabilitation goal may be the prevention or reduction of post-stroke complications (Gladman and Sackley, 1998; Sackley and Gladman, 1998). As previously reported, survivors of severely disabling stroke are more likely to develop complications than survivors of less disabling stroke across all stages of the stroke pathway. The presence of these complications is problematic as they are positively associated with reduced independence in ADLs, reduced quality of life, and increased caregiver burden. However, the management of post-stroke complications is not usually referred to in any conceptual definition of stroke rehabilitation.

2.7.3 Rehabilitation Issues- Pathway Design

A further issue about the stroke rehabilitation process pertains to the timing of stroke rehabilitation in relation to the nature of post-stroke recovery in severely disabling stroke. Several observational studies of differing patient sample sizes have mapped the recovery trajectory of stroke survivors, in terms of independence in ADLs (Wade and Hewer, 1987; Duncan *et al.*, 1992; Jorgensen *et al.*, 1995a; Jorgensen *et al.*, 1995b; Ancheta *et al.*, 2000; Sackley and Dewey, 2001; Douiri *et al.*, 2017).

Results have demonstrated that stroke survivors with greater initial neurological impairment or dependency in ADLs not only achieve a lower level of independence in ADLs and a smaller reduction in neurological impairment but recover at a much slower rate compared to stroke survivors less affected by stroke. This may suggest that stroke rehabilitation should be provided for a longer period of time to survivors of severely disabling stroke in order to optimise recovery. However, data from the Sentinel Stroke National Audit Programme (SSNAP), a national register of stroke patients in the UK that measures stroke care processes and outcomes, suggest that formalised stroke rehabilitation care tends to be delivered in the first few months post-stroke and mostly within inpatient SU settings (Sentinel Stroke National Audit Programme, 2019). Data from SSNAP also suggest that the availability of longer-term rehabilitation services, particularly community-based rehabilitation, is relatively limited compared to inpatient rehabilitation services. As well, survivors of severely disabling stroke may experience access issues to ongoing rehabilitation services due to lack of goal attainment in inpatient SU settings and perceptions of limited rehabilitation potential, as identified by Longley *et al.* (2019). Therefore, the current pathway design may not be providing rehabilitation care at the right time nor facilitating access to longer-term rehabilitation services for survivors of severely disabling stroke. This pathway design issue may be exacerbating the burden experienced by their caregivers once discharged from hospital.

These conceptual and pathway design issues may indicate that the needs of survivors of severely disabling stroke are not being fully met. Stroke rehabilitation has been demonstrated to reduce some of the poor outcomes experienced by survivors of severely disabling stroke, such as increased mortality, long hospital length of stay, and increased likelihood of institutionalisation (Pereira *et al.*, 2012). However, the role of stroke rehabilitation in the management of other disabling outcomes, such as increased dependency in ADLs, development of post-stroke complications, and caregiver burden, is less clear. Therefore, the next section will explore the role of therapy, a key component in stroke rehabilitation, in the management of these outcomes.

2.8 Therapy in the Rehabilitation of Severely Disabling Stroke

One of the identified reasons for the effectiveness of stroke rehabilitation is the delivery of care by a multi-disciplinary team (MDT) with expertise in the management of stroke (Clarke and Forster, 2015). Whilst the staffing composition of a stroke MDT may vary, core members of the team reported in international clinical guidelines include therapy staff, such as PTs, OTs, and speech therapists, as well as doctors and nurses (Veerbeek *et al.*, 2014; Intercollegiate Stroke Working Party, 2016; Winstein *et al.*, 2016; Stroke Foundation, 2019b; Teasell *et al.*, 2020). The rationale for this composite staff mix in stroke rehabilitation stems from the range of functional problems experienced by stroke survivors. Although these problems can be physical, cognitive, communicative, emotional, and social in nature (Clarke and Forster, 2015), the archetypal clinical presentation of a stroke survivor involves a combination of these problems, necessitating the input of disparate professions with specialist expertise in addressing these different problems.

Some of the most common problems experienced by stroke survivors are physical in nature. A recent prospective observational study involving over 94,000 hospitalised stroke patients in England, Wales, and Northern Ireland reported that motor impairment was the most common neurological impairment experienced by stroke survivors (Gittins *et al.*, 2020). Limitations of self-care ADLs, such as washing, dressing, and walking, are frequently experienced by stroke survivors across all phases post-stroke and arise due to a variety of impairments (Lawrence *et al.*, 2001; Legg, Drummond and Langhorne, 2009; Pollock *et al.*, 2014) . As a result, a key focus of stroke rehabilitation has been on addressing problems of physical function (Langhorne, Bernhardt and Kwakkel, 2011; Veerbeek *et al.*, 2014). Whilst a variety of definitions of physical function are reported in the literature, they all refer to the ability to perform various bodily activities, that range from basic movements to complex activities (Painter, Stewart and Carey, 1999; Bruce *et al.*, 2009; Garber *et al.*, 2010; Cooper *et al.*, 2011; Seidel, Brayne and Jagger, 2011; Dobson *et al.*, 2012; Painter and Marcus, 2013). Some authors have also included the functions of the underlying physiological systems responsible for these bodily activities, that include but are not limited to the neuromuscular, musculoskeletal, and cardiorespiratory systems (Garber *et al.*, 2010; Painter and Marcus, 2013). The term “function” used by authors in this context focuses more on activity performance, which differs to the broader definition of functioning used within the ICF framework. This difference may reflect alternative definitions of function found in older disability models, such as Nagi’s Disablement Model (Nagi, 1964). This older disability model referred to functional limitations as restrictions in the performance of tasks at an individual level. This difference may also reflect the individual preference of authors in defining physical function, as most authors that have used the term “physical function” did not refer to any existing conceptual framework of health or disability when defining physical function. Nevertheless, this definition of physical function- the ability to perform various bodily activities, ranging from basic movements to complex activities- is frequently used in the literature across a range of diseases and health conditions, including stroke. This definition also describes a key focus of work performed by therapists, such as PTs and OTs, when treating stroke survivors.

Although physiotherapy and occupational therapy are two distinct core healthcare professions within the stroke MDT, they share some similarities that explain their focus on improving physical function post-stroke. Both professions can trace their origins back to Ancient Greek times, where practitioners used massage, exercise, and hydrotherapy to treat physical and mental illness (Rawson, 1982; Yapijakis, 2009). However, the roots of modern versions of occupational therapy and physiotherapy lie in the 18th – 19th centuries. Occupational therapy stemmed from the use of rigorous work and meaningful activities, or occupations, to address the mental well-being of patients with psychiatric illness, whereas early physiotherapy practice utilised massage, joint manipulation, and exercise to strengthen muscles (Peloquin, 1989; Bakewell, 1997). Although both professions use physical activities to address health and well-being, the philosophical assumptions and theoretical frameworks underpinning each discipline are different. The formalisation of physiotherapy as a distinct profession in the early 20th century and its affiliation with medicine led to the adoption of the prevailing healthcare model, the medical or biomedical model (Roberts, 1994). The biomedical model posits that illness arises due to an identifiable pathology, focuses on the separation of the mind and body in health and illness, and adopts a reductionist approach to understanding the workings of the human body (Roberts, 1994). However, the promotion of occupations by psychiatry to improve mental well-being and the belief in a holistic approach to treat disease led to the adoption of the biopsychosocial model by occupational therapy, which emphasises the complex interplay between social, biological, and psychological factors in illness (Meyer, 1922; Borrell-Carrio, Suchman and Epstein, 2004). This different emphasis on improving physical function using disparate healthcare models is evident in currently used definitions to describe each therapy, which may explain the contrasting roles in improving physical function post-stroke:

> “Occupational therapy is an important part of your recovery and rehabilitation. It involves re-learning everyday activities to enable you to lead a full and independent life. It helps you regain the skills you need to do what you want.”
>
> (Stroke Association, 2018a, pg.1)

> “The main focus of physiotherapy will be to help you learn to use your arms and legs again and regain as much strength and movement as possible… Exercises to build up your stamina and stretching exercises to prevent muscle and joint stiffness are also beneficial”
>
> (Stroke Association, 2018b, pg. 2)

In addition to providing a straightforward, task-orientated understanding of each profession to the public, these definitions address a common misconception that therapy is synonymous with rehabilitation. In their narrative review of factors shaping the delivery of acute stroke therapy, Taylor, McKevitt and Jones (2015) discussed the lack of clear definitions of terms used in the literature to describe the nature of stroke rehabilitation, such as therapy, therapeutic activity, and rehabilitation. They recommended that rehabilitation should be defined as a process or ethos by all members of the stroke MDT, which is similar to the previously reported definition. They suggested that therapy should be considered to be something that is done by therapists and therapy assistants. However, it was not clear from their review whether all aspects of a therapist’s role, such as patient education or attending team meetings, should be included as therapy and whether therapy can be done by other people, such as nurses or the stroke survivor’s family. In their systematic review investigating the effectiveness of therapy interventions for upper limb motor dysfunction after stroke, Winter *et al.* (2011) similarly highlighted the uncertainty of therapy’s constituent components in stroke rehabilitation. They advocated for a greater identification of the individual interventions delivered by therapists to facilitate investigation of their effectiveness in improving function post-stroke.

2.9 Unanswered Questions in the Rehabilitation of Severely Disabling Stroke

In order to ascertain whether current therapy practice addresses the needs of survivors of severely disabling stroke, it is necessary to explore current therapy practice in more detail. Several observational studies conducted in Europe and North America have explored the content of physiotherapy and occupational therapy sessions for stroke survivors undergoing inpatient stroke rehabilitation (Ballinger *et al.*, 1999; Bode *et al.*, 2004; Latham *et al.*, 2005; Richards *et al.*, 2005; De Wit *et al.*, 2006; Tyson *et al.*, 2009; Kimberley *et al.*, 2010; Tyson, Woodward-Nutt and Plant, 2018). Study findings have supported a focus on improving physical function and have demonstrated differences in the delivery of interventions between PTs and OTs. Physiotherapy sessions were more likely to focus on walking practice, transfers, standing balance, and exercises in standing and lying. Occupational therapy sessions were more likely to focus on ADLs, social and leisure activities, sensory and perceptual training, and cognition. However, these studies provided no information about which interventions were delivered to survivors of severely disabling stroke. One observational study describing physiotherapy activities during inpatient stroke rehabilitation presented the type of and time spent in different rehabilitation activities according to walking ability (Latham *et al.*, 2005). However, the authors dichotomised walking ability into those stroke survivors that needed total or maximal assistance to walk and those that could walk with moderate assistance to complete independence. As such, the broad categorisation of walking ability as a surrogate indicator for stroke severity may be questioned. As it was not clear from these studies what interventions were being delivered to survivors of severely disabling stroke, it is not possible determine if current therapy practice is addressing problems of physical function for this cohort of the stroke population. This knowledge gap would suggest that further research is required to understand what interventions are currently performed by PTs and OTs in the rehabilitation of physical function after severely disabling stroke.

Although it is not clear what therapy interventions are being provided to survivors of severely disabling stroke, it could be assumed that some of the reported therapy interventions are being provided to this group of stroke survivors. Therefore, it should be possible to determine if these interventions could address the needs of these stroke survivors by reviewing the evidence for their effectiveness. Several systematic reviews have demonstrated the effectiveness of rehabilitation interventions to improve aspects of physical function post-stroke, such as motor function, balance, walking ability, and activities of daily living (Legg, Drummond and Langhorne, 2009; Pollock *et al.*, 2014; Veerbeek *et al.*, 2014). However, most trials reported in these reviews either did not recruit survivors of severely disabling stroke nor provide results specifically for survivors of severe stroke. As well, there are no published systematic reviews that investigate the effectiveness of rehabilitation interventions in the management of post-stroke complications arising due to problems of physical function in survivors of severely disabling stroke. Consequently, it is not possible to know whether current rehabilitation interventions are effective at addressing the needs of severely disabled stroke survivors. This knowledge gap would suggest that further research is required to investigate the effectiveness of rehabilitation interventions on improving physical function and reducing physical disability, such as post-stroke complications, for survivors of severely disabling stroke.

Knowledge of the type and effectiveness of rehabilitation interventions performed by PTs and OTs is important in order to understand whether current practice is effective at addressing the needs of severely disabled stroke survivors. However, another aspect that may be more important to understand is why therapists select the interventions they do in the rehabilitation of severely disabling stroke. Several qualitative studies have explored the decision-making processes of PTs and OTs working in stroke on a range of factors (Unsworth, Thomas and Greenwood, 1995; Jette, Grover and Keck, 2003; McGlinchey and Davenport, 2015; Kleynen *et al.*, 2017; Longley *et al.*, 2019). These factors included the duration and frequency of therapy sessions, the treatment approach to facilitate motor learning and gait training, access to stroke rehabilitation, and the selection of different discharge destinations. However, no study has investigated what factors guide therapists to select certain interventions in the rehabilitation of physical function after severely disabling stroke. As the selection or non-selection of rehabilitation interventions has direct implications on outcome after severely disabling stroke, understanding this aspect of therapist decision making will provide greater insight into why some of the poor outcomes for survivors of severely disabling stroke occur.

2.10 Chapter Summary

Stroke is a clinical syndrome that has profound repercussions for the affected individual, their family and carers, and society. Due to its heterogeneous nature, there are several ways to classify stroke. One way to classify stroke is according to severity, or the impact it causes on the affected individual, their carers, and society. Severely disabling stroke, experienced by approximately 15% of the stroke population, significantly impacts upon an individual's functioning and causes significant disability. The poor outcomes and range of issues experienced by survivors of severely disabling stroke, as well as their carers, suggest a need to explore the process of stroke rehabilitation, the mainstay of treating stroke, and its role in addressing their needs. Rehabilitation for survivors of severely disabling stroke can reduce some poor outcomes, such as increased mortality, long hospital length of stay, and increased likelihood of institutionalisation. However, its role at addressing other poor outcomes, such as increased dependency in ADLs, development of post-stroke complications, and caregiver burden, is less clear. Uncertainty also surrounds the role of physiotherapy and occupational therapy, key components in stroke rehabilitation, on improving physical function after severely disabling stroke. The paucity of research in this area suggests an urgent need to ascertain what rehabilitation interventions are provided to survivors of severely disabling stroke by PTs and OTs. Research is also required to determine the effectiveness of rehabilitation interventions on improving physical function and reducing post-stroke complications for survivors of severely disabling stroke. Finally, research is needed to understand what factors guide PTs and OTs to select certain interventions in the rehabilitation of physical function after severely disabling stroke. Due to the importance of this aspect of therapy practice, the next chapter will focus on evidence-based practice and its use within clinical decision making, which will form the theoretical framework of the thesis.

Chapter 3- Theoretical Framework

3.1 Introduction

This chapter presents the theoretical framework of the thesis, which is evidence-based practice (EBP) and its use within clinical decision making. It will commence with a review of the literature on clinical decision making, including the underlying cognitive processes involved in making decisions and the influence of clinical expertise in decision making. It will continue with a critical review of EBP as a model for clinical decision making, the use of EBP within physiotherapy and occupational therapy, and the challenges of EBP in the rehabilitation of severely disabling stroke. It will conclude with a discussion of how the framework will address the thesis' aim.

3.2 Clinical Decision Making

Clinical decision making can be defined as the process of making a choice between options by healthcare professionals (Thomas, Wearing and Bennett, 1991; Banning, 2008; Smith, Higgs and Ellis, 2008; Smith and Higgs, 2019). In their review of the factors influencing decision making in healthcare, Smith and Higgs (2019) stated that these options include categories, such as diagnoses; courses of action, such as clinical tests and treatments; and judgements, such as evaluating treatment outcomes. Whilst this definition may seem simplistic, clinical decision making represents a complex phenomenon that involves multiple factors and individuals; occurs in dynamic, time-pressured contexts; and is often characterised by high levels of uncertainty (West and West, 2002; Banning, 2008; Smith, Higgs and Ellis, 2008; Han, Klein and Arora, 2011; Smith and Higgs, 2019). Given its fundamental importance in clinical practice, Edwards *et al.* (2004) argued that effective clinical decision making is a mandatory requirement for autonomous professional practice. Therefore, understanding the factors that positively influence or negatively impact upon clinical decision making is vital in understanding how healthcare professionals make sound clinical decisions to optimise patient outcomes.

It is noticeable when reviewing the clinical decision-making literature that authors have used terms such as “clinical reasoning”, “clinical decision making”, “practice decision making”, and “clinical judgement” interchangeably when referring to the same or similar concepts. Recognising this synonymous use of terms, Higgs and Jensen (2019) made the distinction that clinical reasoning is the overall process of thinking during clinical practice, whereas clinical decision making concerns the outputs of clinical reasoning and the decisions made by healthcare professionals. Smith and Higgs similarly stated that clinical decision making “is both an outcome and component of clinical reasoning” (Smith and Higgs, 2019, pg. 445). As such, the term “clinical decision making” will be used in this thesis as the process of making a choice between different assessment and management options in healthcare, whereas the term “clinical reasoning” will be defined as the overarching cognitive processes involved in clinical practice.

In the 4th edition of their book “Clinical Reasoning in the Health Professions”, Higgs *et al.* (2019) presented a range of theoretical models reported in the literature to understand the underlying cognitive processes involved in making decisions. One model common to several healthcare professions, such as medicine (Schwartz and Kostopoulou, 2019), nursing (Banning, 2008; Ritter and Witte, 2019), physiotherapy (Jones, Edwards and Jensen, 2019) and occupational therapy (Chapparo and Ranka, 2019), is the dual-process theory of decision making. The dual-process theory, and its influence on making decisions, has most notably been described by Daniel Kahneman in his seminal book, “Thinking, Fast and Slow” (Kahneman, 2011). Kahneman stated that there are two distinct cognitive systems or types of processing involved in making decisions- System 1 and System 2. System 1, which is the cognitive system involved in intuitive decision making, is a faster and more automatic process that uses context-dependent tacit knowledge in making decisions (Kahneman, 2011). Pattern recognition is an example of a clinical reasoning strategy used within intuitive decision making that relies on the identification of cues or patterns derived from experience with similar patients to guide decision making (Edwards *et al.*, 2004; Edwards and Jones, 2007; Higgs and Jones, 2019). System 2, which is the cognitive system involved in analytic decision making, is a slower and more deliberate process that uses explicit knowledge sequentially and logically in making decisions (Kahneman, 2011). Hypothetico-deductive reasoning is an example of a clinical reasoning strategy used within analytic decision making that involves the formulation and evaluation of competing hypotheses as clinical data are continually collected and interpreted (Edwards *et al.*, 2004; Edwards and Jones, 2007; Higgs and Jones, 2019).

The popularity of the dual-process theory is evident in the clinical reasoning and decision-making literature across medicine, nursing, physiotherapy and occupational therapy (Banning, 2008; Chapparo and Ranka, 2019; Jones, Edwards and Jensen, 2019; Ritter and Witte, 2019; Schwartz and

Kostopoulou, 2019). However, this theory has faced criticism, particularly that the full range of cognitive processes involved in decision making cannot be neatly divided into two disparate cognitive systems (Osman, 2004). In response to this criticism, alternative theories have been proposed, such as the cognitive continuum theory (Standing, 2010; Parker-Tomlin *et al.*, 2017). The cognitive continuum theory proposes that these two cognitive systems lie on a continuum, with intuitive processing at one end and analytic processing at the other end of the continuum (Standing, 2010; Parker-Tomlin *et al.*, 2017). In her review of the use of cognitive continuum theory in healthcare, Standing (2010) stated that different decision-making approaches are used that match the nature of the decision task, such as the degree of task complexity; the attributes of the decision maker, such as their level of experience; as well as the environment in which the decision is being made. Whilst cognitive continuum theory has been applied mostly to medical and nursing decision making, Parker-Tomlin *et al.* (2017) recommended in their critical analysis of cognitive continuum theory that it has applicability for a variety of healthcare professions.

Although several different theoretical models have been proposed to understand the underlying cognitive processes involved in clinical decision making, there is a shared recognition of the differences in decision making between novice and expert healthcare professionals within these theoretical models (Benner, 1982; Benner and Tanner, 1987; Higgs and Jones, 2019; Jensen, Resnik and Haddad, 2019). Using the Dreyfus Model of Skill Acquisition, Benner (1982) notably described the performance and decision making characteristics of 67 nurses of varying clinical experience using participant observation and interviews. Benner identified five different levels of proficiency: novice, advanced beginner, competent, proficient, and expert. These levels of proficiency develop through continual critical reflection upon clinical experience, culminating in expert practice. In their review of expertise and clinical reasoning in healthcare, Jensen, Resnik and Haddad (2019) stated that expert clinical practice has been described as the goal to which all healthcare professionals should aim towards. Several qualitative studies have described the characteristics of expert practice in physiotherapy (Jensen *et al.*, 2000; Doody and McAteer, 2002; Edwards *et al.*, 2004; Wainwright *et al.*, 2011) and occupational therapy (Strong *et al.*, 1995; Gibson *et al.*, 2000; Unsworth, 2001). In terms of decision making, experts adopt different clinical reasoning strategies compared to novices. Pattern recognition, which relies on the identification of cues from prior experience, is more commonly seen amongst expert healthcare professionals (Higgs and Jones, 2019). However, hypothetico-deductive reasoning is more commonly performed by more novice healthcare professionals or in novel, atypical or complex clinical situations that require more deliberation (Higgs and Jones, 2019). Experts are reported to be faster than novices in performing skills, have superior short-term and longer-term memory, and possess a wider and context-specific knowledge base that is informed by research evidence and updated by reflexive practice (Jensen, Resnik and Haddad, 2019). The importance of research evidence in clinical decision making is fundamental to one of the key clinical decision-making models in recent decades, evidence-based practice (EBP), which will be explored in the next section of this chapter.

3.3 Evidence-Based Practice

EBP has been described as both a movement to apply sound research evidence to patient care and a model of clinical decision making that incorporates sound research evidence, clinical expertise, and patient preferences (Evidence-Based Medicine Working Group, 1992; Haynes *et al.*, 1996; Sackett *et al.*, 1996; Haynes, Devereaux and Guyatt, 2002). Popularised in the early 1990s, evidence-based medicine (EBM), the predecessor of EBP, was described by its proponents as a paradigm shift in the teaching of medical undergraduate students and subsequent practice of clinical medicine (Evidence-Based Medicine Working Group, 1992). EBM de-emphasised “intuition, unsystematic clinical experience, and pathophysiologic rationale as sufficient grounds for clinical decision making” (Evidence-Based Medicine Working Group, 1992, pg. 2420) and highlighted the integration of best research evidence with clinical expertise and patient values in making decisions. Since then, many allied healthcare professions have embraced the principles of EBM, resulting in the broadening of the original term to EBP (Dawes *et al.*, 2005). Reported benefits of EBP include high quality and more individualised patient care, more efficient use of healthcare resources, greater accountability of professional practice, and improved patient outcomes (Scurlock-Evans, Upton and Upton, 2014; Upton *et al.*, 2014). In this thesis, the term “evidence-based practice” will be used to refer to a model of clinical decision making that incorporates research evidence and patient preferences alongside clinical expertise.

The original model for evidence-based clinical decisions proposed by Haynes *et al.* (1996) identified three integrated components guiding clinical decision making: research evidence, clinical expertise, and patient preferences (Figure 2). Research evidence encompassed evidence obtained from clinical research, notably randomised controlled trials (RCTs) evaluating the safety and efficacy of treatment interventions, but also research investigating the precision and accuracy of diagnostic tests and prognostic markers (Sackett *et al.*, 1996). Clinical expertise was originally defined as the “proficiency and judgment that individual clinicians acquire through clinical experience and clinical practice” (Sackett *et al.*, 1996, pg. 71). Clinical expertise was viewed as vital in the decision-making process to prevent a step-by-step approach to medicine and the “mindless application of rules and guidelines” (Haynes *et al.*, 1996, pg. 197). Patient preferences highlighted the increasing recognition of patient involvement in clinical decisions, driven by patients’ greater access to medical information and their resultant level of knowledge about their health conditions (Haynes *et al.*, 1996). Whilst the authors recognised that other decision-making models existed and proposed that their model had greater practical applicability in clinical situations, this claim was not substantiated by any empirical evidence.

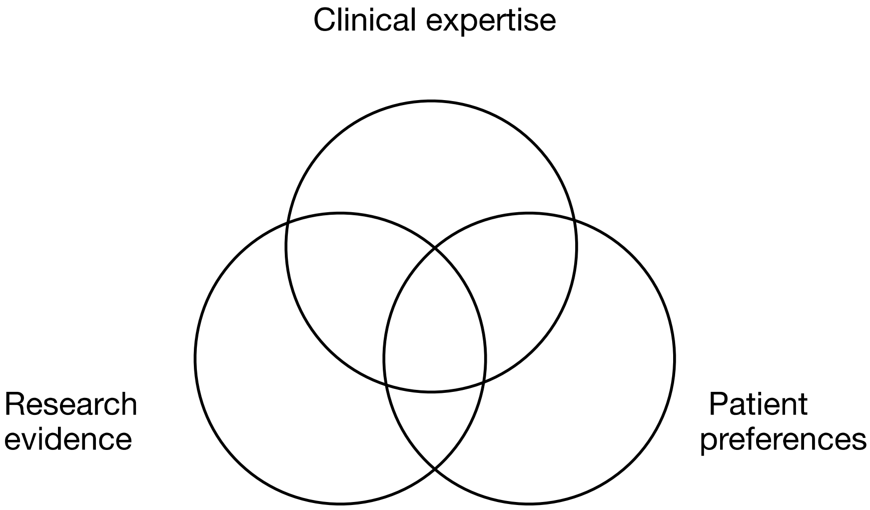


Figure 2- Original model for evidence-based clinical decisions
(Adapted from Haynes, Devereaux and Guyatt, 2002)

Although the original conceptual model became swiftly embedded into clinical practice, EBP has met considerable criticism from the clinical and academic communities since its conception. In her critical review of EBM, Lambert (2006) identified six limitations of EBM reported in the literature: the incommensurability of population-based evidence and individual patient care, a bias towards simple interventions, the exclusion of clinical skills, the production of formulaic clinical guidelines, failure to consider patient views, and difficulties in translating evidence into clinical practice. Lambert noted in her review that some of these limitations had been addressed by members of the Evidence-Based Medicine Working Group who were responsible for developing the original model. For example, in response to criticisms regarding perceived loss of clinician autonomy, Sackett *et al.* (1996) reiterated the importance of integrating clinical expertise with research evidence, rather than replacing clinical expertise with research evidence, in clinical decision making. The members of the Evidence-Based Medicine Working Group also identified alternative forms of acceptable research evidence within an evidence-based approach that included cross-sectional and cohort studies. However, it is notable that qualitative research approaches were excluded in this revised list of acceptable research designs. This may reflect a prevailing belief that qualitative research is less robust and lacks rigour compared to quantitative research, as highlighted by Greenhalgh *et al.* (2015) in their review of biases in EBM. In response to the perceived lack of patient and clinician involvement in the decision-making process, Haynes, Devereaux and Guyatt (2002) presented an updated conceptual model of evidence-based clinical decisions by expanding patients' preferences to include patients' actions and positioning clinical expertise more centrally within the model (Figure 3). Clinical expertise was re-defined as "the general basic skills of clinical practice as well as the experience of the individual practitioner" (Haynes, Devereaux and Guyatt, 2002, pg. 37) and included critical appraisal skills of research evidence and advanced communication skills to ascertain the patient's wishes. Clinical circumstances referred to the setting in which healthcare decisions are made, particularly the available treatment resources required to manage a patient's condition. Despite the criticisms directed towards EBP, it has become widely accepted as a decision-making model in health and social care, leading Lambert to state that current literature seems to be more focussed on how to successfully implement EBP than whether EBP is beneficial (Lambert, 2006).

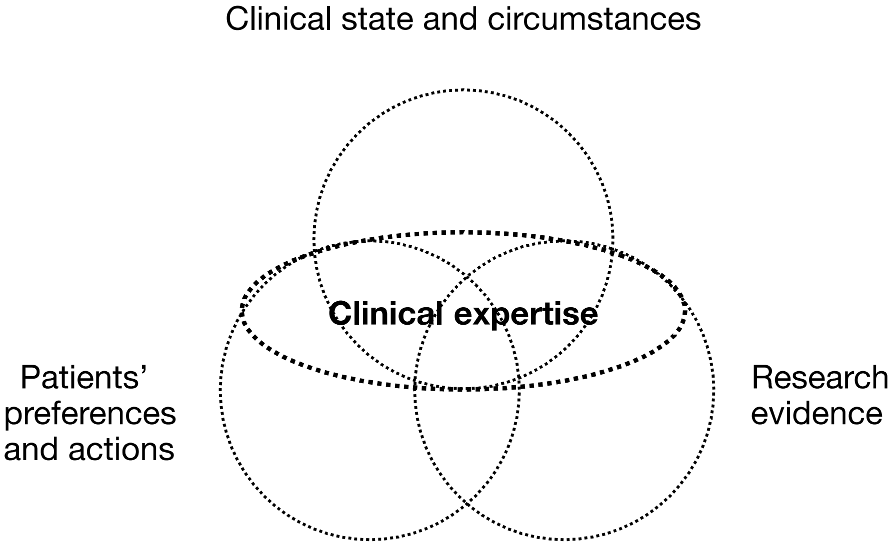


Figure 3- Updated model for evidence-based clinical decisions
(Adapted from Haynes, Devereaux and Guyatt, 2002)

In addition to the criticisms raised by Lambert (2006) and Greenhalgh *et al.* (2015), there is also debate concerning what constitutes acceptable forms of evidence within the wider EBP movement and whether the EBP model needs revision to include these alternative forms of evidence. Evidence can be defined as “the available body of facts or information indicating whether a belief or proposition is true or valid” (Oxford English Dictionary, 2020, point 6). Higgs and Turpin (2019) argued that scientific knowledge derived from research evidence alone is insufficient for addressing the complexities of professional practice and that other sources of evidence are required to guide decision making. These types of evidence include clinical data derived from assessment procedures and observations; experience-based pattern illness-scripts, or mental summaries of a clinician’s knowledge of a disease; arguments constructed from basic scientific principles in the absence compelling clinical research; and theorisation derived from practice-based knowledge. Similarly, in their article debating what counts as evidence in EBP, Rycroft-Malone *et al.* (2004) highlighted the need to blend different types of evidence to inform individual clinical decision making, including the personal knowledge and experience of patients, as well as knowledge from the local care context. Rycroft-Malone *et al.* (2004) acknowledged that some forms of evidence, such as clinical experiences, were subject to more bias and may be perceived as being less robust than other forms of evidence, such as research evidence. However, they identified ways to enhance the rigour of more personalised forms of evidence to inform clinical decision making, such as the systematic gathering and documentation of clinical and patient experiences, and use of multiple verification sources to confirm the trustworthiness of the evidence.

It could be argued that some of the sources of evidence proposed by these authors are already included in the updated model of EBP. For example, clinical data derived from assessment procedures and observations is analogous to the patient's clinical state. Experience-based pattern illness-scripts and experiential knowledge are components of clinical expertise. Local contextual knowledge is synonymous with the clinical circumstances in which care is delivered. Therefore, there may be little need to change the model from its current format. However, EBP is accordingly named because the term "evidence" specifically refers to research evidence derived from quantitative research approaches, particularly RCTs. Therefore, the term "evidence-based practice"- basing clinical practice on research evidence- reinforces the centrality of this type of evidence over other forms of evidence.

3.4 Evidence-Based Practice in Physiotherapy and Occupational Therapy

Physiotherapy and occupational therapy, like other healthcare professions, have embraced the principles of EBP within clinical practice (Bennett and Bennett, 2000; Turner, 2001). The past two decades have seen an exponential rise in therapy related research activity, actively promoted by the World Federation of Occupational Therapists and World Physiotherapy (World Federation of Occupational Therapists *et al.*, 2017; World Physiotherapy, 2019). An international consensus statement supporting the development of competences to undertake EBP has seen EBP become increasingly integrated as a core component in the curriculum of undergraduate and postgraduate training programmes (Albarqouni *et al.*, 2018). In addition, numerous on-line and printed resources are available to facilitate the development of skills and knowledge in implementing EBP for therapy staff, such as World Physiotherapy's web-page on continuous professional development (https://world.physio/guideline/CPD).

The similarities and differences between physiotherapy and occupational therapy in terms of uptake of EBP can be demonstrated by two separate systematic reviews exploring the attitudes, barriers to, and enablers of EBP within physiotherapy and occupational therapy (Scurlock-Evans, Upton and Upton, 2014; Upton *et al.*, 2014). In both reviews, findings suggested that therapists generally demonstrated a positive attitude towards EBP, particularly those therapists who had graduated more recently, held higher academic qualifications, or possessed recent research experience. This finding signifies the importance of educational strategies in shaping therapists' attitudes towards EBP. Whilst the importance of EBP in improving patient outcomes was accepted by therapists in principle, a lack of consistent performance of high-quality EBP amongst therapists was identified in the reviews. Difficulties in accessing and reading journal articles were reported by therapists, mostly due to insufficient time and increased workload pressures. This phenomenon was reported to be more evident amongst occupational therapists (OTs) than physiotherapists (PTs). Other identified barriers to EBP included lack of organisational support, lack of skills in critical appraisal, and lack of skills in the interpretation of statistics. Some therapists reported that existing research had limited relevance and applicability to clinical practice, questioning the appropriateness of "applying sterile scientific evidence to authentic practice" (Upton *et al.*, 2014, pg. 32). Additionally, colleagues, patients, and in-service training were identified as alternative sources of evidence, which may suggest that therapists interpret evidence differently to the recognised hierarchy of research evidence that gives priority to quantitative research designs (Akobeng, 2005a). From these systematic reviews, despite understanding the importance of EBP, PTs and OTs did not consistently implement the principles of EBP in their clinical practice. Upton *et al.* (2014) suggested that this inconsistent approach to applying EBP may compromise patient care and professional development.

3.5 Evidence-Based Practice in the Rehabilitation of Severely Disabling Stroke

The influence of EBP on stroke rehabilitation is evident by reviewing the range of published international clinical guidelines for stroke management (Intercollegiate Stroke Working Party, 2016; Winstein *et al.*, 2016; Stroke Foundation, 2019b; Teasell *et al.*, 2020). Treatment interventions are recommended according to the strength of research evidence supporting their effectiveness, with priority given to systematic reviews and RCTs. Patient involvement in key aspects of their clinical management, such as goal setting, is considered normative practice and pivotal in providing patient-centred care. As the World Health Organization defines high-quality healthcare as care that is safe, effective, and person-centred (World Health Organization, 2006), evidence-based stroke rehabilitation may be considered synonymous with the provision of high-quality healthcare. Therefore, it would seem logical that decision making in stroke rehabilitation is guided by the principles of EBP in order to provide high-quality stroke rehabilitation care.

Whilst the rationale for adopting EBP in stroke rehabilitation is apparent, there are several issues with the different components of the model for evidence-based clinical decisions that may limit their contribution to clinical decision making in the rehabilitation of severely disabling stroke. These issues relate to the research evidence and patient preference components of the decision-making model. In terms of research evidence, the previous chapter identified that most trials included in several systematic reviews investigating the effectiveness of interventions used in the rehabilitation of physical function either did not recruit survivors of severely disabling stroke nor provide results specifically for survivors of severe stroke (Legg, Drummond and Langhorne, 2009; Pollock *et al.*, 2014; Veerbeek *et al.*, 2014). As stroke survivors with differing levels of severity may respond differently to rehabilitation interventions, findings from trials recruiting less disabled stroke survivors may not be applicable to severely disabled stroke survivors. Therefore, basing treatment selection decisions on these trials may result in the use of an intervention that has no or limited effect when delivered to survivors of severely disabling stroke, negating the principle of providing effective patient-centred care.

Another issue with research evidence relates to the clinical utility of other types of research designs for survivors of severely disabling stroke. Observational studies mapping the recovery trajectory of stroke survivors have been used to indicate the amount and timeframe of recovery for survivors of severely disabling stroke (Wade and Hewer, 1987; Duncan *et al.*, 1992; Jorgensen *et al.*, 1995a, 1995b; Ancheta *et al.*, 2000; Sackley and Dewey, 2001; Douiri *et al.*, 2017). In addition, several studies have presented statistical models to predict outcomes post-stroke, which have been summarised in a recent systematic review by Meyer *et al.* (2015). Whilst observational and statistical modelling studies provide useful information about the average pattern of recovery to inform clinical decision making, Nolfe *et al.* (2003) highlighted that they may have limited use in determining individual prognosis, particularly for survivors of severely disabling stroke who may demonstrate greater variations in recovery than survivors of less disabling stroke. This view is shared by Greenhalgh *et al.* (2015) in their critical review of EBM. Whilst recognising the limitations of using anecdotal evidence from one patient to inform decision making about other patients, they highlighted that applying population level evidence to an individual case may lead to suboptimal care if a patient's clinical presentation differed slightly to the wider population sample. The authors suggested that more research was required to understand how to integrate statistically significant evidence derived from a population sample with personally significant evidence derived from an individual patient's experience to facilitate clinical decision making.

In terms of patient preferences, it is recognised that severely disabling stroke often results in communication impairments, such as aphasia, as well as cognitive impairments, such as reduced levels of consciousness (Asplund and Britton, 1989; Geurts *et al.*, 2014; Kelly, Sahin and Holloway, 2014; Visvanathan *et al.*, 2017). These impairments may limit a stroke survivor's ability to express their wishes and engage in key aspects of the rehabilitation process, such as goal setting. Due to these impairments, it may be difficult or not possible to understand a stroke survivor's preference for a particular course of action. This may result in decisions being made for them rather than with them, which contradicts the principle of patient-centred care. Alternative strategies to ascertain stroke survivors' preferences have been proposed, such as advanced directives and surrogate decision makers (Creutzfeldt and Holloway, 2012; Geurts *et al.*, 2014; Kelly, Sahin and Holloway, 2014). However, these strategies may create additional issues that require deliberation. In their review of end of life decision making in patients with severe acute brain injury, Geurts *et al.* (2014) reported that advanced directives are useful to establish a patient's preference regarding life-sustaining treatment in particular situations, such as coma. However, advanced directives are less likely to document a patient's wishes in different scenarios, such as the provision of rehabilitation if a stroke survivor has aphasia or hemiplegia. As well, Kelly, Sahin and Holloway (2014) highlighted that surrogate decision making is most useful if the surrogate decision maker, such as a family member, is well informed about the stroke survivor's values and wishes about the provision of ongoing healthcare. However, these authors identified several biases affecting the reliability of surrogate decision making. These biases included surrogates having unrealistic expectations of recovery, misinterpreting prognostic information, or inaccurately predicting a stroke survivor's future quality of life. Surrogates may also only be aware of a stroke survivor's general preference for ongoing rehabilitation, which means that the selection of individual interventions will need to be decided by the healthcare professional involved in their care. Therefore, healthcare professionals need to carefully consider the usefulness of these alternative strategies when attempting to ascertain a stroke survivor's preference for different treatment interventions after severely disabling stroke.

As a result of these issues with these components of the model for evidence-based clinical decisions, it may suggest that the decision to perform a particular intervention in the rehabilitation of severely disabling stroke relies more on the therapist's clinical expertise than research evidence and patient preferences. It is also possible that other factors identified in the literature investigating therapist decision making in stroke influence the selection of rehabilitation interventions. These factors include compliance with organisational practice, resource availability, and family or social support (Unsworth, Thomas and Greenwood, 1995; Daniëls, Winding and Borell, 2002; McGlinchey and Davenport, 2015; Longley *et al.*, 2018, 2019). However, these factors were identified in studies that focused on clinical decision making regarding broader aspects of therapy practice, such as general treatment approaches, suitability for ongoing stroke rehabilitation, and discharge planning. These studies did not focus on decision making regarding more specific aspects of therapy practice, such as the selection of different interventions. As such, the paucity of research exploring clinical decision making in the use of particular rehabilitation interventions within EBP requires further investigation.

3.6 Using the Theoretical Framework to Address the Thesis' Aim

The aim of the thesis is to investigate therapy in the rehabilitation of physical function after severely disabling stroke. Following a critical review of the current literature on the practice of stroke rehabilitation for survivors of severely disabling stroke, three unanswered research questions in the rehabilitation of physical function after severely disabling stroke have been generated. These questions are:

- what interventions do therapists use in the rehabilitation of physical function after severely disabling stroke?
- which interventions are effective to optimise physical function and reduce immobility-related complications after severely disabling stroke?
- what factors guide therapists to select particular interventions in the rehabilitation of severely disabling stroke?

One key aspect linking these questions is whether currently used interventions are effective at improving physical function after severely disabling stroke, considering that the normative expectation in healthcare is to base treatment decisions on the best available research evidence. As the selection or non-selection of rehabilitation interventions has direct implications on outcome after severely disabling stroke, understanding the extent to which evidence-based interventions are used in the rehabilitation of severely disabling stroke, as well as how therapists decide upon particular rehabilitation interventions, will provide greater insight into why some of the poor outcomes for survivors of severely disabling stroke occur. Therefore, exploring EBP and its use within clinical decision-making in the rehabilitation of severely disabling stroke is an appropriate theoretical framework to underpin the research, address these unanswered research questions, and achieve the thesis' aim.

3.7 Chapter Summary

Clinical decision making is the process by which healthcare professionals, such as PTs and OTs, makes choices between different assessment and management options. EBP is an internationally recognised model of clinical decision making adopted by a range of healthcare professionals, including PTs and OTs. Despite its perceived importance, uptake of EBP amongst PTs and OTs is inconsistent due to a variety of perceived issues. These issues include practical reasons, such as reduced time and caseload pressures, as well as limited applicability of existing research evidence to clinical practice. EBP by PTs and OTs in the rehabilitation of severely disabling stroke may also be inconsistently applied due to limitations in the research evidence base and difficulties in understanding the preferences of severely disabled stroke survivors. As the selection of rehabilitation interventions for survivors of severely disabling stroke has direct implications on their outcomes, understanding the extent to which evidence-based interventions are used in the rehabilitation of severely disabling stroke, as well as the factors that guide therapists to select certain interventions for this cohort of the stroke population, is important to investigate. The next chapter will present the methodology used to investigate therapy in the rehabilitation of physical function after severely disabling stroke.

Chapter 4- Methodology

4.1 Introduction

The paucity of research in the rehabilitation of physical function after severely disabling stroke has generated a number of unanswered questions that this thesis seeks to answer: what interventions do therapists use in the rehabilitation of severely disabling stroke, which interventions are effective to optimise function and minimise immobility-related post-stroke complications, and what factors guide therapists to select particular interventions in the rehabilitation of severely disabling stroke? Mixed methods research (MMR) offers a pragmatic approach to answer these clinical questions. This chapter provides an overview on the use of MMR to investigate therapy in the rehabilitation of physical function after severely disabling stroke. It will commence with a critical review of MMR, addressing common criticisms that have been directed towards this research approach. It will outline the rationale for using MMR in health service research and explain the rationale for using MMR for this research. It will introduce the three studies that form this research, which will be expanded upon in subsequent chapters. It will conclude with a description of how the different studies will be integrated to achieve the thesis' aim.

4.2 Mixed Methods Research

Mixed methods research (MMR), referred to by Johnson and Onwuegbuzie (2004) as the third methodological movement, has been described as an approach to research that:

> "combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration" (Johnson, Onwuegbuzie and Turner, 2007, pg. 123)

This integrative manner to undertaking research differs from a purely quantitative or qualitative research approach, which are used to investigate different kinds of research questions and employ different types of research methods. In their textbook on research design, Creswell and Creswell (2018) defined quantitative research as an approach to test hypotheses or theories by examining relationships among variables. These variables can be quantified numerically and analysed objectively using statistical procedures free from researcher bias. The authors defined qualitative research as an approach for understanding the meaning that people attribute to social phenomena. It involves the collection of data typically in the person’s setting and analysed through subjective interpretation by the researcher to generate themes from particular instances. Therefore, MMR can be viewed as a research approach that spans the spectrum of these disparate research approaches.

There are several reasons why a mixed methods approach may be used in research. In their review article discussing the challenges of mixing methods from different underlying philosophical assumptions, Greene and Caracelli (1997) stated that quantitative and qualitative research approaches provide different, legitimate ways of knowing and understanding phenomena. Therefore, combining these research approaches may generate broader and deeper insights in order to understand phenomena more fully than if they were to be used in isolation. Several authors have reported that all research methods have inherent strengths as well as weaknesses (Greene and Caracelli, 1997; Johnson and Onwuegbuzie, 2004; Johnson, Onwuegbuzie and Turner, 2007). For example, survey research may be useful to obtain a wide range of respondents’ opinions but survey research is less able to understand the influence of the respondents’ social context in formulating their opinions (Aday and Cornelius, 2006). Participant observation may be useful to understand the complex social relationships and interactions within a small group of individuals but findings from participant observation may not be transferable to wider populations (Holloway and Galvin, 2016). Therefore, use of multiple methods can help counteract their inherent limitations whilst capitalising on their unique strengths. Another reason to combine different methods investigating the same phenomenon is to enhance the validity of study findings if the results of each method corroborate with one another (Greene, Caracelli and Graham, 1989). This concept, known as triangulation, was first described by Campbell and Fiske in 1959 and extended by Greene, Caracelli and Graham (1989) in their conceptual framework of mixed methods evaluation design. Following a review of the mixed methods evaluation literature, the authors identified five purposes for using mixed methods: triangulation, complementarity, development, expansion, and initiation. Expansion aims to extend the breadth of the investigation, development aims to use the results from one method to help develop the other method, and complementarity aims to enhance or clarify the results from one method with the results of the other method. Initiation was seen as a unique purpose compared to the other four purposes, as it seeks out contradictory, rather than complementary, research findings. Thus, initiation may lead to alternative interpretations of a study findings or even reconsideration of a study's research question. Whilst several different reasons have been identified to use MMR, their commonality is to generate a different way of knowing and understanding phenomena compared to a purely qualitative or quantitative research approach.

4.3 Criticisms of Mixed Methods Research

As a relatively newer research approach, several criticisms have been directed towards MMR, which have been summarised by Creswell (2011) in his review of the controversies surrounding MMR. Attention will focus on three of these criticisms due to their direct implications on this thesis. The first and most frequently cited criticism that has dominated the discourse surrounding MMR in the social research literature is that it is inappropriate to mix quantitative and qualitative methods in the same research due to fundamentally different philosophical assumptions guiding their use. These philosophical assumptions include ontological assumptions, about the nature of reality, as well as epistemological assumptions, about how reality can be known. This view, termed the incompatibility thesis by Howe (1988), first gained prominence in the 1980s by notable researchers, such as Smith (1983) and Guba and Lincoln (1989). However, it was raised more recently by Sale, Lohfeld and Brazil (2002) in their review article discussing the rationale for using MMR in healthcare research. These authors stated that quantitative and qualitative methods are based upon different philosophical assumptions and therefore investigate different phenomena. As these methods do not study the same phenomena, the authors suggested that combining methods for cross-validation purposes violates philosophical assumptions and misrepresents the data that these methods capture. However, belief in the incompatibility thesis is not shared by the mixed methods community. Several authors have countered the incompatibility thesis by questioning the belief that ontological and epistemological assumptions guide the selection of specific research methods (Bryman, 1984; Johnson and Onwuegbuzie, 2004). Bryman suggested that there is no clearly proven relationship between epistemology and research method, and that the research problem under investigation, rather than the researcher's epistemological orientation, guides the methods of investigation. Johnson and Onwuegbuzie agreed with Bryman's view and argued that researchers who support the incompatibility thesis may be treating epistemology, the philosophy of knowledge, and methods, the specific data collection and analytical tools used by researchers, as being synonymous. Johnson and

Onwuegbuzie posited that this premise may be theoretically incorrect, thereby negating the incompatibility thesis. Another argument against the incompatibility thesis has been proposed by Morgan (2007) in his review article discussing the different interpretations of the term “paradigm” in social science research. Morgan highlighted the impracticability of the metaphysical paradigm- which he defined as the research framework that links ontological and epistemological matters with research methodology and methods- in the conduct of actual research. He identified four different ways to define paradigms and suggested that his preferred definition:

> “shared beliefs within a community of researchers who share a consensus about which questions are most meaningful and which procedures are most appropriate for answering those questions” (Morgan, 2007, pg. 53)

had the greatest applicability to research within the social sciences. Research conducted according to this definition commences by firstly identifying a research question of interest and then selecting the most appropriate research methods to answer the question (Morgan, 2007). Similarly, Crotty (1998) stated in the introduction to his book on the foundations of social research that whilst an awareness of one’s epistemological stance enables a researcher to understand the wider context of their research, the primary justification and starting point of research is to answer a research question. This concept, known as the centrality of the research question (Tashakkori and Teddlie, 2010), is considered one of the defining characteristics of MMR and has been used as key rebuttal against the incompatibility thesis argument.

The second major criticism levelled at MMR described by Creswell (2011) is the lack of a clear overarching paradigm or framework to guide its use. Morgan (2007) stated that the use of an overarching paradigm to guide research became more common in social science research in the 1980s due to a rise in the use of qualitative research approaches in the social sciences. However, the belief that research needs to be guided by either a singular paradigm or any paradigm is not shared by all mixed methods researchers. Some researchers have adopted an a-paradigmatic stance, where paradigms are conceptually unimportant for studies and methods can be used without direct consideration of ontological and epistemological matters (Tashakkori and Teddlie, 2010; Patton, 2014). Other researchers have adopted a singular or alternative paradigm stance, with pragmatism being considered one of the most commonly identified paradigms associated with MMR (Johnson and

Onwuegbuzie, 2004; Morgan, 2007, 2014; Feilzer, 2010). Some researchers have suggested that a multiple paradigm stance may serve as the foundation for MMR (Greene and Caracelli, 1997; Creswell and Plano Clark, 2017). In a dialectic stance, as described by Greene and Caracelli (1997), multiple paradigms can be used in mixed methods studies to generate an enhanced understanding of the phenomenon under investigation, but that each paradigm has distinct philosophical differences that need to be respected. Creswell and Plano Clark (2017) suggested that multiple paradigms might be related to different phases of a research design. For example, an initial phase characterised by survey research may be guided by a positivist paradigm, which seeks to discover generalisable knowledge obtained through valid and reliable observation and measurement of an objective reality (Creswell and Creswell, 2018). However, a subsequent phase characterised by ethnographic fieldwork may be guided by an interpretivist paradigm, which seeks to understand contextually specific phenomena and create knowledge as the researcher investigates the phenomenon under investigation (Creswell and Creswell, 2018). It is apparent from these authors' perspectives that mixed methods researchers have adopted a more flexible approach in the use of overarching paradigms to guide research. As such, Tashakkori and Teddlie's narrative of paradigm pluralism, where a variety of paradigms may serve as the underlying philosophy in MMR (Tashakkori and Teddlie, 2010), seems an apt description of MMR.

The third major criticism of MMR, which is more practically than philosophically orientated, is the myriad of available mixed methods designs to guide the design of MMR (Creswell, 2011). In their book on designing and conducting MMR, Creswell and Plano Clark (2017) identified over 80 mixed methods designs classified into 15 typologies representing diverse disciplines including healthcare, education, social research, and behavioural research. Leech and Onwuegbuzie, who developed a typology that was reported in Creswell and Plano Clark's book, proposed that the vast array of designs may create difficulty for researchers choosing to base their research on an existing mixed methods design (Leech and Onwuegbuzie, 2009). They also stated that different designs may attribute different meanings to similar terminology and vice versa, which may create uncertainty when attempting to understand MMR. Whilst there is considerable diversity amongst the typologies and constituent research designs listed by Creswell and Plano Clark, they stated that all MMR designs include at least one quantitative and one qualitative study component and that designs are guided by four fundamental features: the purpose for mixing methods; the timing of the components (either concurrent of sequential); the relative priority or weighting of the components (either equal status or one being more dominant); and the level of interaction of the different components, including the point where mixing or integrating occurs (at the design, data collection, data analysis, or interpretation phases). Therefore, considering just these four fundamental features may simplify the process of designing an MMR study. As well, several schematic models have been developed that may reduce the conceptual complexity of mixed methods designs and advance a common language in MMR (Morse, 1991; Morgan, 1998; Leech and Onwuegbuzie, 2009; Creswell and Plano Clark, 2017). A notation system, first described by Morse (1991), uses the "+" and "→" signs to indicate respectively the concurrent or sequential timing of the components. Additionally, Morse's notation system uses upper and lower case writing of the abbreviated words "quantitative" and "qualitative" to indicate the relative priority of the research components (e.g. "Qual" and "quan" indicate that the qualitative component has a higher priority or greater dominance than the quantitative component). Additionally, procedural diagrams can be used to pictorially represent the features of the notation system (Creswell and Plano Clark, 2017), which will be demonstrated later in the chapter.

4.4 Mixed Methods Research in Health Services Research

Over the last 30 years, there has been a proliferation in use of MMR within the field of health services research. O'Cathain, Murphy and Nicholl (2007) conducted a mixed methods study exploring the use of MMR in health services research in the UK. They reported that the proportion of studies classified as MMR rose from 17% in the mid-1990s to 30% in the early 2000s. Whilst this study only investigated MMR commissioned by the Department of Health in the UK and therefore may not be representative of research practice in other countries, it demonstrates the expansion of MMR from the social sciences to other disciplines, such as health services and biomedical research. The increased use of mixed methods approaches in health service research may have arisen due to several researchers highlighting the ability of qualitative research to address questions that quantitative research could not answer (Pope and Mays, 1995; O'Cathain, 2009). Some of the questions were, "Why do certain healthcare interventions work whereas other interventions do not work?" and "Why are the results of randomised controlled trials difficult to apply in day to day clinical practice?". O'Cathain, Murphy and Nicholl (2007) stated that the use of qualitative research alongside RCTs is reported to be the most common example of MMR in health services research. This observation might lend support to another criticism of MMR in that MMR prioritises the use of positivist research approaches over the use of interpretivist research approaches (Giddings, 2006). This is because the healthcare RCT, which usually tests the effectiveness of a particular treatment in a systematically controlled manner, has been traditionally associated with a positivist philosophy. However, in their review article summarising MMR in biomedical and health services research, Curry *et al.* (2013) provided several published examples of more qualitatively driven mixed methods approaches in health services research in the past decade, which may reflect current research practice more accurately than previously reported by Giddings. These examples include a sequential exploratory research design, where a primary qualitative study component is followed by a quantitative study component, and a convergent parallel study, where qualitative and quantitative data collection occurs concurrently and the components are given equal weight.

The justification for using MMR within health services research is similar to the reasons previously identified at the start of the chapter. In particular, O'Cathain, Murphy and Nicholl stated that MMR within health service research offers a pragmatic approach to understand the complex nature of healthcare delivery and to evaluate complex healthcare interventions (O'Cathain, Murphy and Nicholl, 2007). The Medical Research Council defined a complex health intervention as one that contains several interacting components which can result in several possible outcomes (Craig *et al.*, 2013). Stroke rehabilitation can be viewed as the archetypal complex intervention due to the complex problems faced by patients; the large number of specific treatments available; and the multiple, interconnecting care processes delivered by multiple teams at different timeframes post-stroke (Wade, 2005, 2015; Langhorne, Bernhardt and Kwakkel, 2011). Due to the complexity of problems in healthcare, Curry *et al.* (2013) suggested that data from quantitative and qualitative methods are required to provide a more comprehensive understanding of these complex phenomena. In stroke rehabilitation, evaluation of treatment effectiveness, such as independence in activities of daily living, and service delivery outcomes, such as hospital length of stay, can be measured using quantitative research methods. However, understanding the lived experience of stroke survivors and the quality of interprofessional relationships amongst the stroke multi-disciplinary team are best ascertained by using qualitative research methods. Therefore, in order to fully understand and evaluate stroke rehabilitation, a research approach that captures different types of data from a range of different approaches should be considered.

Whilst the use of MMR in stroke rehabilitation is limited, there are several published studies that demonstrate its growing use in recent years. This may reflect the relatively recent recommendation by the Medical Research Council to perform qualitative and qualitative research together in the evaluation of complex interventions (Craig *et al.*, 2013). Studies that have undertaken qualitative process evaluations alongside quantitative RCTs include the AVERT trial, which investigated the effect of very early mobilisation post-stroke (AVERT Trial Collaboration Group, 2015; Luker *et al.*, 2016); the ATTEND trial, which explored the effect of family-led post-stroke rehabilitation in India (Lindley *et al.*, 2017; Liu *et al.*, 2019); and the OTCH trial, which evaluated the effect of a three-month occupational therapy intervention for stroke survivors living in care homes (Masterson-Algar *et al.*, 2014; Sackley *et al.*, 2015). The growing use of MMR may also reflect the types of research questions being generated by researchers and the ability of MMR to answer these questions. A recent example is the ReAcT study (Clarke *et al.*, 2018), a multi-centre, mixed-methods case study evaluation exploring therapy provision in English stroke units (SUs). This study design differed from the other reported examples of MMR as the authors undertook participant observation, semi-structured interviews, and documentary analysis to understand why the recommended guidelines for stroke therapy may not be achieved in English SUs. As these studies used MMR to achieve very different study aims, they demonstrate the versatility of MMR in stroke rehabilitation research to address a variety of research questions.

4.5 Rationale for Mixed Methods Research- Overview of Studies

The scarcity of research in the rehabilitation of physical function after severely disabling stroke has generated a number of unanswered questions that this thesis seeks to answer: what interventions do therapists use in the rehabilitation of severely disabling stroke, which interventions are effective to optimise function and minimise immobility-related post-stroke complications, and what factors guide therapists to select particular interventions within an evidence based practice framework? In line with Trow's view that "the problem under investigation properly dictates the methods of investigation" (Trow, 1957, pg. 33), these different research questions require different research methods and approaches to address them. In relation to the first criticism directed towards MMR that was discussed at the start of the chapter, the thesis posits that there is no incompatibility in using different research methods and approaches to investigate the rehabilitation of physical function after severely disabling stroke. These research approaches will be summarised in this chapter and expanded upon in subsequent chapters. In relation to the second criticism directed towards MMR, the thesis takes an a-paradigmatic stance as described by Patton (2002) and Greene (2007). This stance proposes that research methods can be used independently from ontological and epistemological assumptions as these assumptions are viewed more as abstract conceptual ideas that inform, rather than prescribe, the researcher’s practice. However, the traditions of each research approach have been respected in terms of their implementation and analysis of findings.

The first objective of the research is to ascertain the different interventions and outcome measures used by physiotherapists and occupational therapists in the rehabilitation of physical function after severely disabling stroke. To achieve this objective, the first study comprised a national, mixed method survey of therapy practice. The survey involved a questionnaire for all therapist participants and a follow-up structured interview for self-selecting therapist participants to explain questionnaire responses. The second objective of the research is to systematically review the effectiveness of rehabilitation interventions on improving physical function and reducing immobility-related complications for survivors of severely disabling stroke. To achieve this objective, the second study comprised a systematic review of the literature to establish the effectiveness of interventions on improving physical function and reducing immobility-related complications after severely disabling stroke. The systematic review was also performed to identify questions for future rehabilitation research based on the findings from the evaluation of intervention effectiveness. The third objective of the study is to understand what factors guide therapists to select particular interventions in the rehabilitation of physical function after severely disabling stroke. To achieve this objective, the third study comprised an ethnographic exploration of therapy practice in different stroke services across London. Ethnography is a research approach that uses a variety of methods, including participant observation and interviewing, to study or describe people and their behaviour in social settings (Madden, 2010; O’Reilly, 2012; Holloway and Galvin, 2016; Hammersley and Atkinson, 2019). It was used as an approach to understand therapist decision making, particularly why therapists selected particular interventions, in the rehabilitation of physical function after severely disabling stroke.

One of the main reasons for undertaking MMR is to provide a deeper and broader understanding of phenomena, which may arise due to the integration of results from the qualitative and quantitative methods used in a study (Greene and Caracelli, 1997; O’Cathain, Murphy and Nicholl, 2010).

O’Cathain, Murphy and Nicholl (2010) suggested that the integration of study findings, an important aspect of MMR, can generate more knowledge than a separate analysis of a research study’s components. As such, the findings of the three studies comprising this research have been integrated to generate more knowledge and a deeper understanding of therapy practice than would have occurred if the studies were analysed and presented separately. For example, comparing the results from the therapist survey and systematic review established whether commonly used rehabilitation interventions have demonstrable effectiveness. A lack of effectiveness may not only direct future trials investigating these interventions but may suggest that factors other than research evidence guide therapists to select certain rehabilitation interventions for survivors of severely disabling stroke. In addition, the results of the therapist survey were used to guide the selection of different stroke services and the design of the observational framework in the ethnographic exploration of therapy practice. The integration of survey research with fieldwork was first described by Sieber (1973) and is considered by Creswell (2011) to be one of the founding pieces of literature in the mixed methods movement. Sieber (1973) stated that survey findings can be used to guide the theoretical and practical design of fieldwork, as well as verify and facilitate the interpretation of fieldwork observations. Therefore, it is hoped that by integrating the findings from the three studies, new insights into therapist decision making in the use of particular rehabilitation interventions for survivors of severely disabling stroke have been generated.

In relation to the third criticism directed towards MMR discussed at the start of the chapter, use of notation systems and procedural diagrams are two strategies to describe and facilitate understanding of MMR (Morse, 1991; Creswell and Plano Clark, 2017). Therefore, the research in this thesis can be demonstrated by the diagram in Figure 4.

The research employed a sequential mixed methods design. Two smaller studies- one employing a sequential quan→qual design (quantitative followed by qualitative) and one employing a quan design- were conducted and analysed separately. Findings from these studies were integrated to guide a larger ethnographic exploration of therapy practice. Findings from this exploration of therapy practice were analysed with consideration of the two preceding studies.

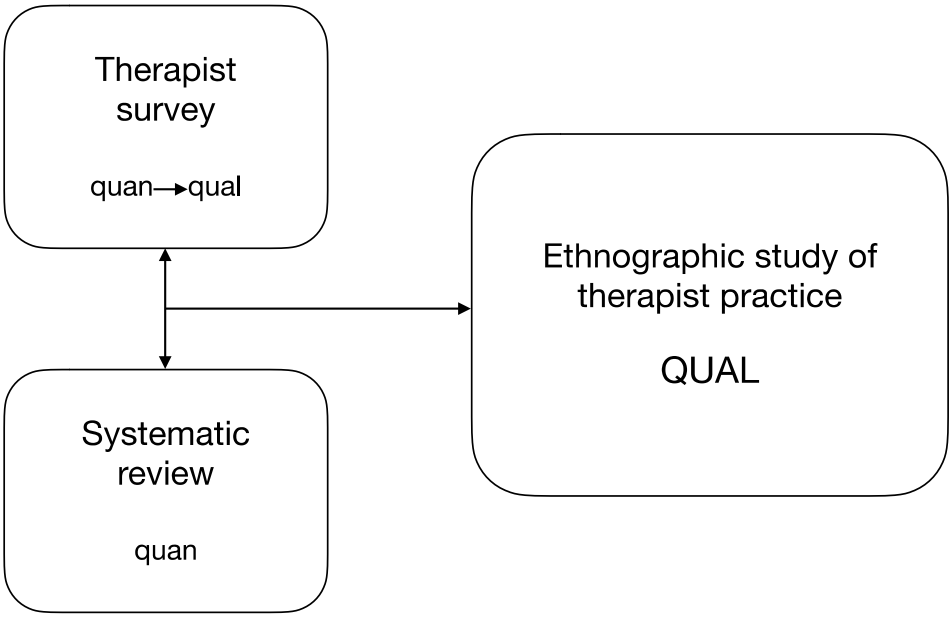


Figure 4- Schematic diagram of the mixed methods research

quan- quantitative, qual- qualitative

4.6 Chapter Summary

This chapter presented the rationale for using MMR to investigate therapy in the rehabilitation of physical function in severely disabling stroke. Despite several criticisms levelled at MMR, it is an increasingly used research approach to understand complex healthcare phenomena, such as stroke rehabilitation, due to its use of quantitative and qualitative research methods. As there is a lack of research investigating therapy in the rehabilitation of physical function after severely disabling stroke, a mixed methods exploratory research approach was used to address the thesis' objectives and achieve the thesis' aim. This approach involved a large ethnographic exploration of therapy practice guided by two smaller, mostly quantitative studies. Subsequent chapters of the thesis will detail and present the findings from these different research studies.

Chapter 5- What Do Therapists Do? Survey of Therapy Practice

5.1 Introduction

This chapter presents the first study of the research, which is a national survey of therapy practice in the rehabilitation of physical function after severely disabling stroke. It will commence with a critical review of survey research and an overview of the therapist survey, including its aims, development, dissemination, and analysis. It will continue with a discussion of key survey findings, as well as the survey's strengths and weaknesses. It will conclude with an explanation of how integrating survey findings with the other studies will provide more insight into the investigation of therapy practice in the rehabilitation of severely disabling stroke.

5.2 Survey Research

Survey research has been defined as the systematic collection of information on a topic of interest from a group of individuals (Bowling, 2005; Aday and Cornelius, 2006; Ponto, 2015; Shankar *et al.*, 2018). In their textbook on designing and conducting health surveys, Aday and Cornelius (2006) reported that survey research incorporates a range of methods to identify and recruit individuals, collect data using quantitative and/or qualitative methods, and analyse data using appropriate techniques. Therefore, survey research may be more accurately described as a methodology, or the research framework that identifies the specific methods to be used to collect information and how the research is to be undertaken. Bowling (2005) stated in her review on survey use in health and social science research that the key aim of survey research is to generate group level summary statistics in order to describe or generalise to the larger population to which the group of individuals belong. Therefore, surveying a sample of therapists with experience of treating survivors of severely disabling stroke is one method to describe wider therapy practice in the rehabilitation of physical function after severely disabling stroke.

As an approach to understanding social phenomena, survey research has several reported advantages. Surveys can obtain information from a large sample of the target population with relatively less resource investment compared to other data collection tools, such as participant observation (Sieber, 1973; Bowling, 2005; Aday and Cornelius, 2006; Shankar *et al.*, 2018). Survey research utilises two main data collection methods: questionnaires and interviews. Both methods have their own strengths, which have been summarised by Bowling (2005) and Aday and Cornelius (2006). For example, self-completed questionnaires are inexpensive, easy to administer, and can be completed by respondents in their own time. Questionnaires enable the provision of standardised and objective responses to survey questions, which can facilitate statistical analysis of survey responses. Interviews are useful as they do not depend on the respondent possessing literacy or computer skills. Interviews also allow the interviewer to explain more complex or detailed questions in language familiar to the respondent, probe the respondent for more detail, and check the respondent's level of understanding.

Surveys also have several reported disadvantages. Surveys have been criticised for providing a superficial level of knowledge or understanding about a topic compared to participant observation (Becker and Geer, 1957). In their commentary comparing participant observation and interviewing, Becker and Geer (1957) highlighted that the structured nature of survey interviews fails to capture the social context in which a respondent lives, which may influence how a respondent chooses to answer a survey question. In addition, the self-reported nature of respondents' answers to questions means that surveys can only provide estimates of respondents' characteristics rather than their actual characteristics, which might be obtained through other data collection methods, such as participant observation (Sieber, 1973). Whilst questionnaires and interviews have known strengths, they also demonstrate several weaknesses. Questionnaires are prone to response bias, where respondents may provide incomplete or inaccurate answers (Ponto, 2015; Shankar *et al.*, 2018). In addition, it is usually not possible to clarify arising queries from questionnaire respondents, which may affect the quality of responses provided. Interviews are more time consuming than self-completed questionnaires and are unable to target a similarly large sample size (Bowling, 2005; Aday and Cornelius, 2006). Interviews are also prone to several biases, which are summarised in Salazar's article on how bias can affect survey research (Salazar, 1990). These biases include interviewer bias, which is the tendency for the interviewer to unduly influence the respondent's answer, and social desirability bias, which is the tendency for respondents to provide socially acceptable answers, particularly when sensitive subject matters are discussed. However, a survey that utilises both methods may capitalise on their respective strengths whilst reducing their respective weaknesses, as highlighted in the previous chapter discussing the rationale for mixed methods research (MMR).

5.3 Survey Research in Stroke Therapy

Surveys exploring physiotherapy and occupational therapy practice in stroke rehabilitation have been used for almost 30 years. These surveys have mostly focused on understanding which treatment approaches are used by physiotherapists (PTs), occupational therapists (OTs), or both professions (Nilsson and Nordholm, 1992; Carr *et al.*, 1994; DeGangi and Royeen, 1994; Sackley and Lincoln, 1996; Davidson and Waters, 2000; Walker *et al.*, 2000; Lennon, Baxter and Ashburn, 2001; Lennon, 2003; Fletcher-Smith *et al.*, 2014; Scott and Bondoc, 2018). Surveys have also explored the use of outcome measures within stroke rehabilitation (Stokes and O'Neill, 2008; Van Peppen *et al.*, 2008; Stapleton and McBrearty, 2009), as well as the extent to which specific treatment interventions are used, such as positioning, dressing practice, functional electrical stimulation, and upper limb therapy (Chatterton, Pomeroy and Gratton, 2001; Walker, Walker and Sunderland, 2003; Connell *et al.*, 2014; Howlett, McKinstry and Lannin, 2018; Stockley *et al.*, 2019). Despite the large number of surveys investigating physiotherapy and occupational therapy in stroke rehabilitation over the past few decades, the use of therapy interventions and outcome measures by PTs and OTs in the rehabilitation of severely disabling stroke has not been previously investigated using survey research.

There are two notable changes in the design of stroke therapy surveys over the past 30 years that have guided the design of the current survey investigating therapy practice in the rehabilitation of physical function after severely disabling stroke. The first change is the type of data collection tool used to collect information about therapy practice. Surveys conducted in the 1990s and 2000s generally utilised postal questionnaires, whereas surveys conducted in the 2010s generally utilised internet questionnaires to explore therapy practice. Ilieva, Baron and Healey (2002) and Wright (2006) proposed that the shift to using internet or web-based questionnaires in survey research has occurred due to technological developments, the rise of the internet in sharing and disseminating information, and the relatively low cost of internet questionnaires. Accordingly, the current survey adopted an internet questionnaire as the primary data collection tool to investigate therapy practice in the rehabilitation of physical function after severely disabling stroke. However, the shift to using web-based questionnaires may have negative consequences on the generalisability of survey findings to the wider population. Whilst postal questionnaires are more resource intensive than internet questionnaires, they usually yield higher response rates than internet questionnaires (Manfreda et al., 2008; Shih and Fan, 2009). The survey response rate is the percentage of individuals in a sample that participate in a survey out of those who receive the survey (Aday and Cornelius, 2006). Consideration of a survey's response rate is important because higher response rates effectively increase the sample size, resulting in a sample that is more representative of the larger population to which it belongs (Bowling, 2005). Therefore, a higher response rate reduces sampling bias, increases the validity of survey findings, and strengthens the inferences that can be made from survey findings to describe or generalise to the larger population to which the sample belongs. This response rate phenomenon is evident in the previously reported stroke therapy surveys. Response rates for postal questionnaires ranged from 47 – 78%, whereas the response rates for internet questionnaires ranged from 8 – 21%. Strategies to address this response rate issue in the current survey are presented later in the chapter.

The second change in the design of stroke therapist surveys is the shift from investigating general therapy approaches to specific therapy interventions. Surveys conducted in the 1990s and early 2000s tended to investigate the use of different treatment approaches in stroke rehabilitation, such as the Bobath concept, the Motor Relearning Programme, and the Brunnstrom approach (Nilsson and Nordholm, 1992; Carr *et al.*, 1994; DeGangi and Royeen, 1994; Sackley and Lincoln, 1996; Davidson and Waters, 2000; Lennon, 2003). However, several issues have been raised in the investigation of therapy practice when it is described as a named approach. A systematic review by Kollen *et al.* (2009) investigating the effectiveness of the Bobath concept highlighted that many reviewed studies failed to clearly identify the constituent interventions delivered as part of Bobath therapy. Therefore, comparison of what was actually provided to participants across these studies was not possible. Several researchers have since recommended that therapy in stroke rehabilitation should be described as clearly defined interventions rather than named approaches in order to investigate the effects of these specific interventions (Langhorne, Bernhardt and Kwakkel, 2011; Winter *et al.*, 2011; Pollock *et al.*, 2014). In line with these recommendations, there has been a shift in stroke therapy surveys to investigate the use of specific interventions in stroke rehabilitation, such as dressing practice, upper limb exercises, and functional electrical stimulation (Walker, Walker and Sunderland, 2003; Connell *et al.*, 2014; Howlett, McKinstry and Lannin, 2018; Stockley *et al.*, 2019). Accordingly, the current survey explored the use of specific interventions and outcome measures to investigate therapy practice in the rehabilitation of severely disabling stroke.

5.4 Therapist Survey

5.4.1 Survey Design

A cross-sectional survey of therapy practice was undertaken to ascertain what interventions and outcome measures PTs and OTs use in the rehabilitation of physical function after severely disabling stroke. The survey incorporated an on-line questionnaire and structured interviews as data collection tools. The mixed method nature of the survey adopted an explanatory sequential design, which uses a qualitative approach (i.e. interview) to explain quantitative data (i.e. questionnaire results) in more detail (Creswell and Plano Clark, 2017).

5.4.2 Survey Aims and Objectives

The aims of the questionnaire were to ascertain the most frequently used interventions and outcome measures by PTs and OTs in the rehabilitation of physical function after severely disabling stroke and to establish if there were differences in intervention and outcome measure use between PTs and OTs working in different stroke services. Three specific objectives of the questionnaire were to identify the most frequently used interventions and outcome measures by all therapists, by PTs and OTs, and by PTs and OTs working in each major type of stroke service. The aim of the interview was to explain the questionnaire findings in more detail. The objectives of the interview were to explain the rationale for performing the most frequently used interventions and understand issues with outcome measure use in the rehabilitation of physical function after severely disabling stroke.

5.4.3 Survey Methods- Questionnaire Development

The questionnaire was designed using the principles of the Tailored Design Method, a commonly used approach to survey development (Dillman, Smyth and Christian, 2014). A convenience sample of eight senior PTs and OTs were enlisted to identify and categorise currently used interventions and outcome measures in the rehabilitation of severely disabling stroke. These therapists were identified through attendance at Pan-London stroke rehabilitation meetings and were working in stroke services across London. Therapists had between 4 – 14 years of experience working in stroke rehabilitation across inpatient, community, and outpatient settings. The rationale for using a group of senior therapists working across different stroke services was to ensure a broad range of interventions and outcome measures were identified that reflected current clinical practice. This method of identifying components of therapy practice through therapist participation in the research process has been described as practice-based evidence (DeJong *et al.*, 2004; Zanca and Dijkers, 2014). Practice-based evidence has been used in other studies classifying the therapy process across a variety of inpatient stroke rehabilitation services (Ballinger *et al.*, 1999; Bode *et al.*, 2004; Latham *et al.*, 2005; Richards *et al.*, 2005).

Therapists were initially asked to list any possible intervention and outcome measure used in the rehabilitation of severely disabling stroke. Duplicate responses were removed and due to the large number of identified interventions, interventions were placed into six categories based on the Rehabilitation Treatment Taxonomy (Dijkers, 2014): passive interventions; active interventions; aids, equipment, and seating; training and education; care plans; onward referrals. Categories were presented to the therapist group to confirm the accuracy of intervention classification and to identify any additional interventions. Published articles describing existing therapy intervention taxonomies, as well as documents detailing stroke rehabilitation outcome measures, were also reviewed to contribute to the list of therapist-generated interventions and outcome measures (Ballinger *et al.*, 1999; Bode *et al.*, 2004; Jette *et al.*, 2005; Latham *et al.*, 2005; Richards *et al.*, 2005; De Wit *et al.*, 2006; Lang *et al.*, 2009; Sullivan *et al.*, 2011a, 2011b; Salter *et al.*, 2013). In total, 87 interventions and 20 outcome measures were identified.

As the main aim of the questionnaire was to ascertain the most frequently used interventions and outcome measures, five-point Likert scale questions were developed asking therapists to report the frequency of intervention and outcome measure use. Use was described as “always”, “often”, “sometimes”, “rarely”, and “never”. Whilst the middle three terms are more subjective terms than “always” and “never” and could be interpreted differently by different therapists, most of the convenience sample of senior therapists preferred this phrasing to more objective measures, such as percentages. Each Likert scale question had a concluding section where free-text comments could be added in case a therapist wanted to document an intervention or outcome measure not listed or provide additional comments to explain or expand upon their answers.

Once the questionnaire was developed, paper and internet versions were piloted by a convenience sample of 12 PTs and OTs of all qualified clinical grades (i.e. Band 5 to Band 8). These therapists were based in one central London hospital trust and different to the therapist group who were enlisted to identify clinically used interventions and outcome measures. Therapists self-timed themselves completing the questionnaire and feedback was sought regarding the clarity and length of individual questions, the content and layout of the questionnaire, and the level of motivation or interest whilst completing the questionnaire. The questionnaire was modified based upon therapist feedback and each revised version was piloted by two to three therapists. The questionnaire was considered finalised once no additional comments were provided (Appendix A).

Ethical approval for the survey was granted by the Biomedical and Health Science, Dentistry and Medicine Research Ethics Panel at King's College London- reference number LRS-16/17-3911 (Appendix B).

5.4.4 Survey Methods- Questionnaire Dissemination

An internet questionnaire using a commercial survey design website (SurveyMonkey®) was used as the primary data collection tool. This tool was chosen as it was assumed that the target population sample were computer literate and had access to computers and the Internet. As well, unanimous feedback from the therapists who piloted the questionnaire suggested that an internet questionnaire would be preferable to a paper questionnaire. However, a paper version of the questionnaire was available for therapists if requested.

Consistent with more recent surveys of therapy practice (Connell *et al.*, 2014; Fletcher-Smith *et al.*, 2014; Stockley *et al.*, 2019), the professional networks of PTs and OTs specialising in neurological rehabilitation were approached to facilitate the dissemination of the questionnaire. These networks are the Association of Chartered Physiotherapists Interested in Neurology (ACPIN) and the Royal College of Occupational Therapists Specialist Section Neurological Practice (SSNP). Members of these professional organisations who self-identified as being interested or specialising in stroke rehabilitation were emailed about the study and provided with an electronic version of the study information sheet. Consent was implied by completing the questionnaire, which remained open for 12 weeks (13th February – 8th May 2017). As internet questionnaires may yield lower response rates than other questionnaire tools (Manfreda *et al.*, 2008; Shih and Fan, 2009), strategies to increase the response rate identified by several authors (Boynton, 2004; Kaplowitz *et al.*, 2012; Van Mol, 2017) included sending personalised emails to each therapist and email reminders encouraging therapists to participate.

5.4.5 Survey Methods- Therapist Interviews

At the end of the questionnaire, therapists were asked if they would be willing to participate in a short interview to explain key findings from the questionnaire. As there were specific questions to ask therapists directly related to the analysis of the questionnaire data, a structured interview format was chosen to guide the therapist interviews. Interviews commenced with therapists discussing their role, including where they worked, and their experience with treating survivors of severely disabling stroke. Therapists were then asked questions about four key categories- the aim(s) of stroke rehabilitation, the rationale for performing the most frequently used interventions, the timing and frequency of performing outcome measures, and perceived issues with using outcome measures. Due to my location in London and the wide geographical distribution of therapist interviewees, face-to-face and telephone interviews were conducted with therapists living inside and outside of London respectively. Consequently, contemporaneous technological difficulties in recording telephone interviews meant that therapist responses were written on paper rather than tape recorded. Whilst recording interviews may capture information more accurately than writing responses, thereby facilitating facilitate more in-depth analysis (Holloway and Galvin, 2016), it was felt that the aims of the interview could be achieved by writing therapist responses on paper. Writing interview responses also ensured consistency in data collection between the different interview formats. In order to confirm the accuracy of therapist responses, responses were read back to therapists throughout and at the end of the interview. Therapists were able to amend or add to any response in order to accurately reflect their views. Verbatim quotes were also recorded regarding key questionnaire findings, including the aims of rehabilitation in different stroke settings and issues with outcome measure use in severely disabling stroke. The interviews were performed between June – July 2017 and the interview guide is included as Appendix C.

5.4.6 Data Analysis

Questionnaire data were collected on SurveyMonkey®, transferred to a Microsoft Excel spreadsheet, and imported into the Statistical Package for the Social Sciences (SPSS) Version 25 for analysis. Descriptive statistics were used initially to describe and summarise the questionnaire data. This included therapists' demographic details, as well as the most frequently used interventions and outcome measures overall, according to professional role, and according to type of stroke service. The most frequently used interventions and outcome measures were automatically calculated by

SurveyMonkey®, which are determined by the relative weighting of the frequency choice (i.e. “always used” is weighted higher than “never used”) as well as the response count for each frequency choice. Free text responses from the questionnaires were read and grouped into similar categories. The frequency of each response within each category was also noted.

Chi-squared tests were used to determine if there were differences between intervention and outcome measure use according to professional role across the stroke pathway. Firstly, descriptive statistics were visually inspected to identify where the main differences in intervention and outcome measure use occurred. The number of actual responses in each frequency category (always, often, sometimes, rarely, never) for these interventions and outcome measures were entered into a 5 x 2 contingency table (five frequency categories x two professions). Chi-squared tests were then performed to determine if there were significant differences between observed and expected frequencies in intervention and outcome measure use according to professional role differences. As there were at least 5 responses in more than 80% of the cells in the contingency table, there were sufficient responses to enable the detection of a significant difference if a true difference was present. Results were considered significant if the p value was < 0.05.

Summative content analysis using a framework matrix was used to analyse interview data (Hsieh and Shannon, 2005; Gale *et al.*, 2013). This approach to content analysis involves identifying and quantifying words or phrases with the aim of understanding the contextual use of these words and phrases. Firstly, textual interview responses were entered into a Microsoft Excel spreadsheet. A framework matrix was created by placing responses from an individual therapist in each row and all therapists’ responses to each question in each column. Grouping therapists’ responses for each question enabled an exploration of the similarities and differences between therapists in answering the four key interview categories. Counting the frequency of therapist responses for each question determined the most popular responses in each interview category. Comparing the aims of stroke rehabilitation in each stroke setting and the aims of interventions used in each stroke setting enabled an understanding about the contextual use of rehabilitation interventions. Findings were summarised descriptively.

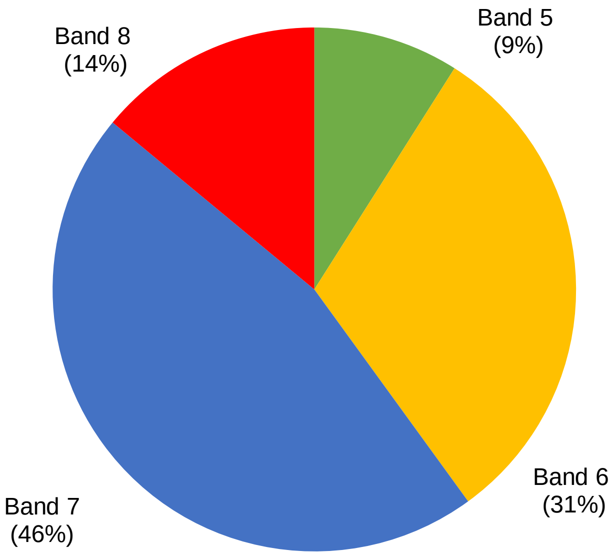
5.5 Therapist Survey Findings

5.5.1 Therapist Demographics

The questionnaire was sent to qualified members of ACPIN and SSNP (n=1810) and 452 questionnaires were returned, resulting in a response rate of 25%. 440 questionnaires were fully completed and analysed, resulting in a completion rate of 97%. 59% of questionnaire respondents were PTs and 41% were OTs. The median number of years qualified as a therapist was nine years (interquartile range 5 – 15). Although the exact staff grade configuration of therapists working in stroke in the UK is not known, there was representation across all qualified staff grades (Figure 5a). As expected, there was greater representation of more senior staff grades (Bands 7 and 8- 60%) than more junior staff grades (Bands 5 and 6- 40%). The most common stroke services in which therapists worked were stroke rehabilitation units (SRUs), acute stroke units (ASUs), and early supported discharge/community stroke teams (Figure 5b). Therapists worked in stroke services across all part of the UK, with most respondents working in England (81.6%), followed by Scotland (10.5%), Wales (4.7%), and Northern Ireland (3.2%).

All therapists (n=18) who self-selected to participate in the interview were interviewed. Demographic data of therapist participants are listed in Table 2. Similar to the questionnaire respondents, there was representation from a range of staff grades, type of stroke services, and regions across the UK amongst the interview participants.

(a) Respondents by Grade



(b) Respondents by Workplace

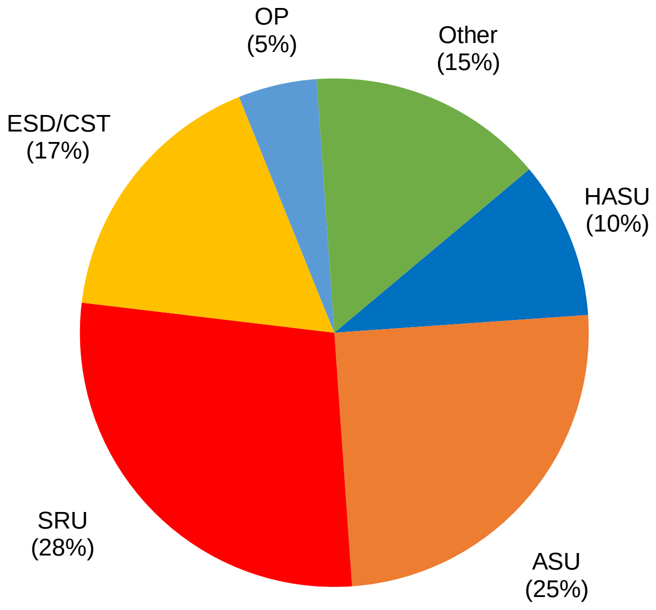


Figure 5- Survey respondents according to (a) professional grade and (b) workplace

HASU- hyper-acute stroke unit, ASU- acute stroke unit, SRU- stroke rehabilitation unit, ESD- early supported discharge, CST- community stroke team, OP- outpatients

Table 2- Demographic information about interview participants

Participant Name	Grade	Profession	Current Workplace	Time Working in Stroke
Catherine	Band 7	PT	ASU/SRU/CST	9 years
Fiona	Band 6	PT	ASU	2 years
Renee	Band 6	OT	SRU	3.5 years
Heather	Band 5	PT	SRU	4 months
Janine	Band 8	OT	HASU/SU	15 years
Janelle	Band 7	OT	All	16 years
Joseph	Band 7	PT	ASU/SRU	4 years
Maria	Band 5	OT	HASU/ASU	6 months
Kelly	Band 8	PT	CST	30 years
Katie	Band 7	PT	CST	10 years
Octavia	Band 5	PT	ASU	4 months
Julia	Band 7	OT	SRU	6 years
Robert	Band 6	PT	SRU	3 years
Rachel	Band 7	PT	HASU/ASU/SRU	25 years
Sarah	Band 6	PT	SRU	14 months
Sallie	Band 7	PT	CST/OP/Care home	25 years
Tom	Band 6	PT	CST/OP/private	4 years
Tabatha	Band 7	OT	ASU	6 years

PT- physiotherapist, OT- occupational therapist, HASU- hyper-acute stroke unit, ASU- acute stroke unit, SRU- stroke rehabilitation unit, ESD- early supported discharge, CST- community stroke team, OP- outpatients

5.5.2 Intervention Use

The most frequently used rehabilitation interventions by all therapist respondents working with survivors of severely disabling stroke were whole body positioning (“positioning”), upper limb and positioning training, and sitting balance practice (Figure 6). As more PTs and inpatient therapists responded to the questionnaire, the most frequently used interventions according to professional role (Figure 7) and main places of work (Table 3) were determined. Whilst positioning, training, and developing seating care plans were frequently performed by both professions, PTs performed sitting balance practice (X^2 (4, N=432) = 109.6, $p < 0.001$), bed mobility practice (X^2 (4, N=432) = 103.1, $p < 0.001$), and active/assisted exercises (X^2 (4, N=432) = 93.9, $p < 0.001$) more frequently than OTs. OTs performed washing and dressing practice (X^2 (4, N=432) = 230.8, $p < 0.001$), grooming practice (X^2 (4, N=432) = 201.2, $p < 0.001$), and referred to social services (X^2 (4, N=432) = 170.8, $p < 0.001$) more frequently than PTs. Across the stroke pathway, there were similarities in intervention use between the main inpatient stroke service settings (hyperacute stroke units (HASUs), ASUs and inpatient SRUs). However, there were differences in intervention use between inpatient and community settings. Active and passive interventions were more frequently performed in inpatient settings, whereas developing care plans and training and education were more frequently performed in community settings. The most similar practice, in terms of the similarity of interventions delivered, occurred between community PTs and OTs. The most diverse practice, in terms of the variety of interventions delivered, occurred between stroke unit (SU) PTs and OTs.

Due to the large number of identified interventions, the frequency of use of each intervention is presented in Table 4. Interventions are presented according to the original six categories: passive interventions; active interventions; aids, equipment, and seating; training and education; care plans; onward referrals. Frequency of use has been automatically calculated by SurveyMonkey® as a weighted average score, ranging from one to five. A score of one indicates an intervention is never used whereas a score of five indicates an intervention is always used.

The most commonly reported reason for stopping therapy was the stroke survivor demonstrating limited or no achievement of their rehabilitation goals with no more appropriate interventions to provide. This reason was identified by 97% of questionnaire respondents. Approximately 80% of respondents highlighted two other reasons for stopping therapy- the achievement of all goals with no more appropriate interventions to provide and the achievement of some goals with other interventions to be provided by others in the stroke pathway.

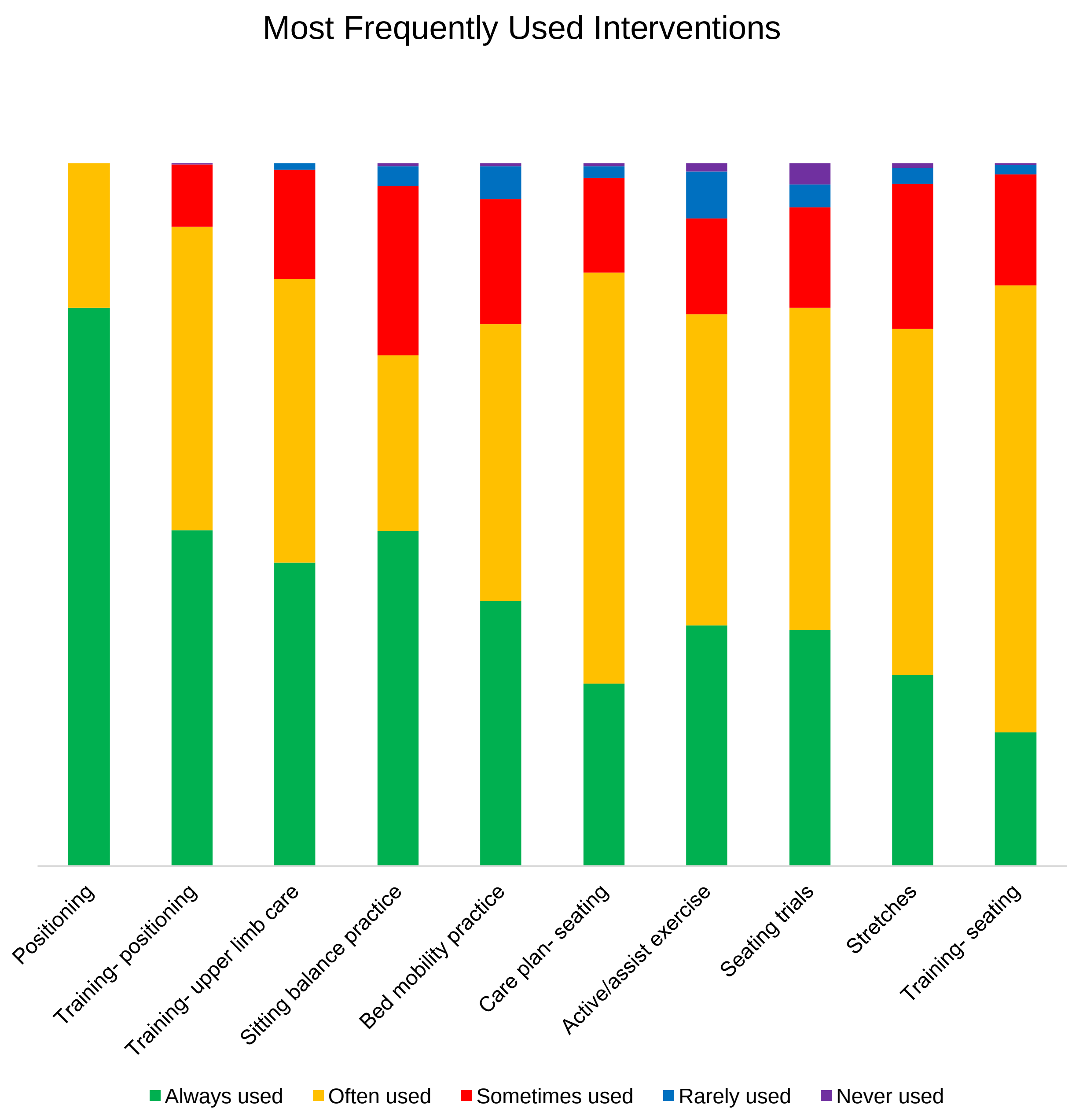
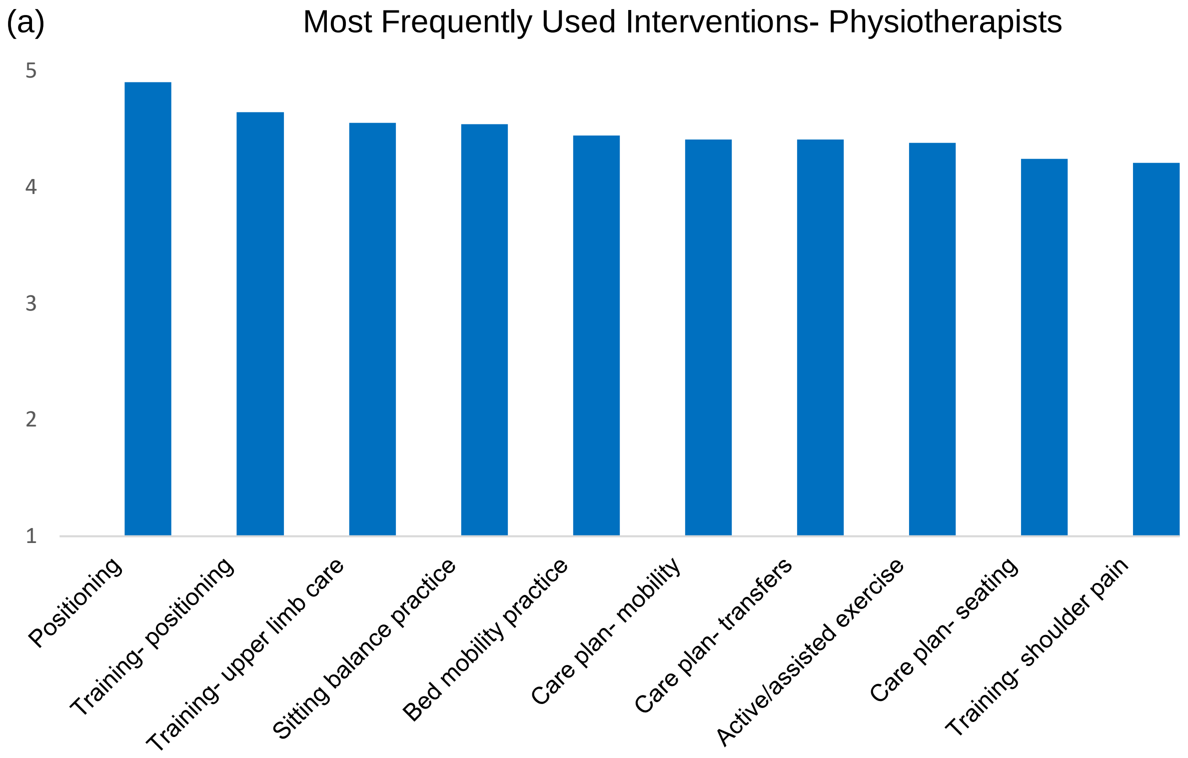


Figure 6- Most frequently used rehabilitation interventions across all respondents



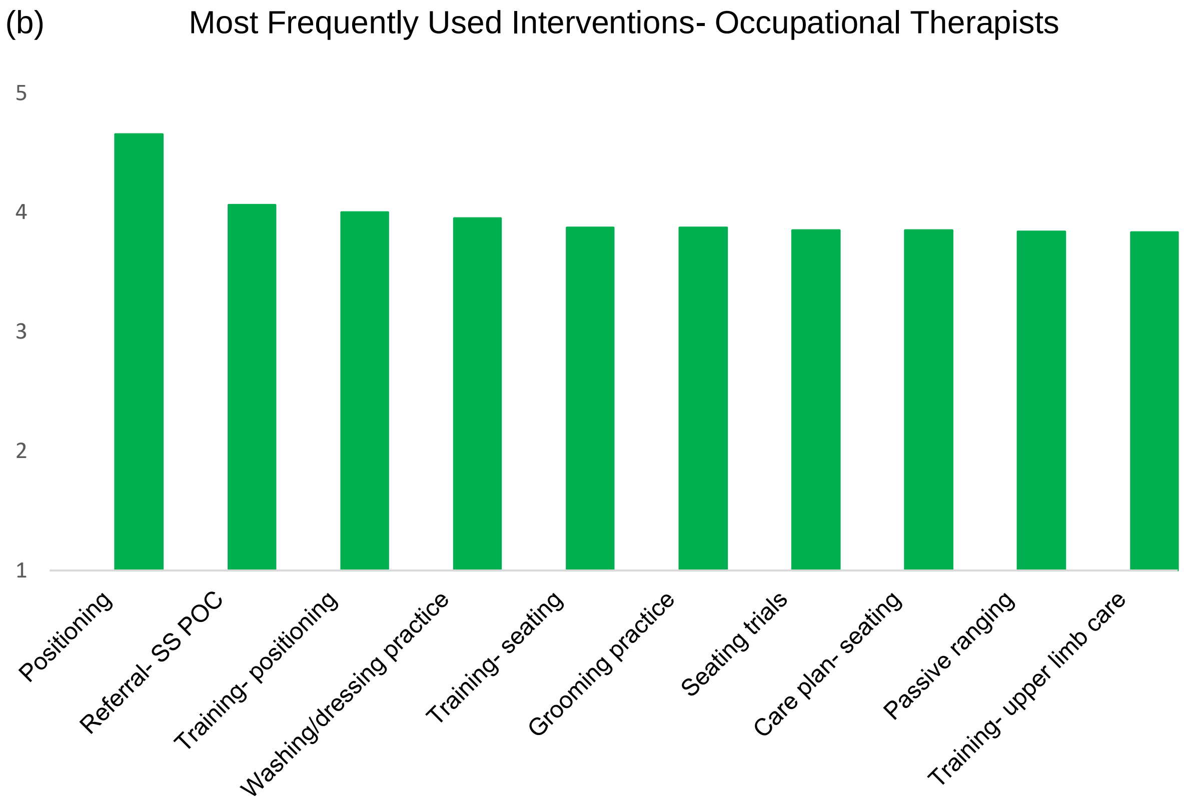


Figure 7- Most frequently used rehabilitation interventions amongst (a) physiotherapists and (b) occupational therapists

5 = Always used, 4 = Often used, 3 = Sometimes used, 2 = Rarely used, 1 = Never used
SS POC- social services package of care

Table 3- Most frequently used rehabilitation interventions by therapists in different settings in descending order

Physiotherapists		
HASU/ASU	**SRU**	**ESD/CST**
Positioning	Positioning	Training- positioning
Sitting balance practice	Sitting balance practice	Positioning
Training- positioning	Training- positioning	Training- upper limb care
Training- upper limb care	Bed mobility practice	Training- transfers
Bed mobility practice	Seating trials	Training- shoulder pain
Seating trials	Care plan- transfers	Care plan- transfers
Active/assisted exercise	Training- upper limb care	Training- seating
Care plan- transfers	Active/assisted exercise	Care plan- seating
Care plan- mobility	Care plan- positioning	Care plan- positioning
Stretches	Care plan- seating	Care plan- mobility

Occupational Therapists		
HASU/ASU	**SRU**	**ESD/CST**
Positioning	Positioning	Positioning
Seating trials	Referral- SS POC	Training- positioning
Referral- SS POC	Washing and dressing practice	Training- seating
Training- positioning	Manual wheelchair	Training- washing and dressing
Washing and dressing practice	Training- positioning	Washing and dressing practice
Care plan- seating	Seating trials	Referral- SS home adaptations
Passive ranging	Sensory stimulation	Care plan- washing/dressing
Sensory stimulation	Passive ranging	Transfers
Referral- community rehab	Referral- community rehab	Stretches
Grooming practice	Care plan- washing/dressing	Grooming practice

HASU/ASU- hyperacute/acute stroke units, SRU- stroke rehabilitation units, ESD/CST- early supported discharge/community stroke teams, SS POC- social services package of care

Table 4- Frequency of intervention use according to intervention category

Active Interventions		Aids and Equipment		Training and Education	
Sitting balance practice	4.2	Manual wheelchair	3.6	Positioning	4.4
Bed mobility practice	4.1	Armchair	3.6	Upper limb care/handling	4.3
Active/assisted exercises	4.0	Specialist wheelchair	3.3	Seating	4.0
Seating trials	4.0	Shoulder sling	3.2	Transfers	3.9
Transfer practice	4.0	Orthosis	3.2	Stretches	3.7
Repetitive task training	3.8	Specialist static chair	3.1	Post-stroke shoulder pain	3.6
Sit to stand practice	3.6	Palm protector	3.0	Splinting/orthosis use	3.6
Standing transfer aid use	3.6	Commode	3.0	Bed mobility	3.5
Sensory stimulation	3.5	Pre-fabricated splint	2.9	Upper/lower limb exercises	3.5
Gait practice	3.2	Adapted cutlery	2.6	Hoist use	3.0
Strengthening exercises	3.0	T-roll	2.4	Fatigue management	2.9
Wheelchair skill practice	2.9	Bed lever	2.4	Oedema massage	2.9
Grooming practice	2.9	Oedema gloves	2.3	Washing and dressing	2.6
Washing and dressing practice	2.9	Powered wheelchair	2.0	Grooming	2.5
Toileting practice	2.7	Eye patch	1.8	Toileting	2.5
Feeding practice	2.6	Helmet	1.7	Feeding	2.3
Standing frame use	2.5	Prism glasses	1.4		
Electrical stimulation	2.1				
Meal preparation	2.1				
Upper/lower limb cycling machine use	1.8				
Tilt tabling	1.8				
Body weight support +/- treadmill training	1.7				
Hydrotherapy	1.3				
Robotics	1.2				

Care Plans		Passive Interventions		Referrals	
Seating	4.1	Positioning	4.8	Community rehabilitation	3.5
Transfers	3.9	Stretching	4.0	Social service (care package)	3.2
Positioning	3.8	Passive ranging	3.9	Wheelchair services	3.1
Splinting/orthosis use	3.5	Oedema massage	3.0	Splinting/orthotic clinic	2.9
Mobility	3.4	Soft and scotch splinting	2.4	Spasticity clinic	2.8
Fatigue management	2.6	Thermoplastic splinting	2.4	Social service (home adaptations)	2.6
Washing and dressing	2.4	Pillow wrapping	2.3	General practitioner	2.6
Toileting	2.3	Injecting BT	1.8	Inpatient rehabilitation	2.4
Grooming	2.3	Taping	1.6	Voluntary sector	2.1
Feeding	2.1	Air splinting	1.4	Private sector	1.6

Scores range from 1 – 5. 1 = Never used , 2 = Rarely used, 3 = Sometimes used, 4 = Often used, 5 = Always used

As questionnaire results revealed the most frequently used interventions overall, according to professional role, and according to main place of work, therapists were asked in the interview to explain the rationale for performing the most frequently used interventions in order to understand why particular interventions are used in the rehabilitation of severely disabling stroke. In the interviews, therapists confirmed that the most frequently used interventions were representative of clinical practice within each stroke service. Therapists reported that the rationale for performing a particular intervention was to achieve an identified aim or aims. Aims of some of the most frequently used interventions reported by therapists are listed in Table 5. Therapists highlighted that interventions were also performed to achieve patient goals as part of the wider rehabilitation process. Interventions were continued by therapists until the aim was achieved or could be performed by others in the longer-term management of the stroke survivor. Longer-term management interventions were usually passive interventions, such as positioning, stretches, and seating. Interventions requiring patient engagement and participation, such as walking or grooming practice, were discontinued if the stroke survivor demonstrated limited or no achievement of goals:

> "If someone had a very severe stroke and they were set up, in terms of 24-hour postural management, they had seating, they had consistent transfer methods, then we would have solved that as their exercise program at the moment. Once you can hand them over to the nurses or their family and you're confident they're being followed out, then you can pull back."
>
> (Joseph, Band 7 PT)

> "I think with some patients- especially if they've been given a huge amount of input on the ward and if they've been seen every day- if they're not reaching their goals you're setting, you reduce the goals further. And they're not reaching those, I think there is a place to stop therapy."
>
> (Janine, Band 8 OT)

Table 5- Aims of common rehabilitation interventions used for survivors of severely disabling stroke

Intervention	Aims
Positioning	• prevent secondary complications e.g. contractures, pressure sores • prevent tonal abnormalities • optimise respiratory and swallowing function • optimise postural control and physical recovery • improve sensory feedback
Carer training and education	• effects of stroke and likelihood of future recovery • correct positioning and handling to prevent limb damage • monitoring of skin condition • performing basic exercises to maintain and improve function
Passive ranges and stretches	• maintain muscle length and joint range of movement • provide sensory input • maintain current function in the event of future functional recovery • prevent contractures • maintain comfort
Bed mobility practice	• enable patient to assist in washing, dressing, and toileting when in bed • improve independence- less dependent on carers • relieve pressure • improve core and limb muscle activity
Sitting balance practice	• establish appropriate seating • increase seating endurance • improve posture for functional recovery • guide appropriate transfer method • improve arousal

As questionnaire results revealed key differences in the use of interventions between inpatient and community settings, therapists were asked in the interview about the aims of stroke rehabilitation and therapy practice in these types of stroke services. Therapists working in acute and inpatient SUs reported that their primary aims were to optimise function and independence, as well as prevent secondary complications. The prevention of secondary complications, which included contractures, pressure sores, and aspiration pneumonia, was considered important as their presence could impact upon functional recovery:

> “Stroke rehabilitation is about maximising patient’s functioning after a stroke event. What we’re doing is allowing patients to be, within an inpatient environment, to improve their function and to engage them with activities that they were doing before.”
>
> (Renee, Band 6 OT)

> “I guess what you’re trying to do with the severe strokes is for them to be medically stabilised and complications prevented. Initially it’s focussed on preventing aspiration pneumonia and making sure they have their swallow assessment. It’s spasticity management if that is an issue. Pressure care management with regular position changes.”
>
> (Robert, Band 6 PT)

Therapists working in community stroke services reported that their primary aim was to ensure that carers looking after stroke survivors were able to implement longer-term management interventions, such as positioning, safe handling, and splint application:

> “What I am doing is more disability management and trying to reduce the carer’s burden. It's being goal-focused and feeling confident that the family can carry on with the exercises that you have prescribed or the positioning chart that you’ve provided. Making sure the family can use that effectively and confidently.”
>
> (Katie, Band 7 PT)

5.5.3 Outcome Measure Use

The Barthel Index (BI), Modified Rankin Scale (mRS) and National Institutes for Health Scale (NIHSS) were the most frequently used outcome measures by all therapist respondents working with survivors of severely disabling stroke (Figure 8). Unlike the most frequently used rehabilitation interventions, all outcome measures listed in Figure 8 were never used by a proportion of therapists. This proportion ranged from 8% for the BI to 47% for the Motor Assessment Scale. For the remaining ten outcome measures included in the questionnaire, their frequency of use was rated between “never used” and “rarely used”. Similar to the rehabilitation interventions, there were differences in outcome measure use between PTs and OTs (Figure 9) and professional roles within the main places of work (Table 6). For spasticity assessment, PTs were more likely to complete the Tardieu scale (X^2 (4, N=431) = 188, $p < 0.001$), whereas OTs were more likely to complete the Ashworth scale (X^2 (4, N=431) = 70.5, $p < 0.001$). The Glasgow Coma Scale was performed more frequently in inpatient services (X^2 (4, N=305) = 132.9, $p < 0.001$), whereas the Goal Attainment Scale was performed more frequently in community services (X^2 (4, N=305) = 23.3, $p < 0.001$). There was very little difference in the range of outcome measures used within each professional discipline working across the different stroke settings.

Despite the relatively small number of outcome measures included in the questionnaire, 8% of therapists had not heard of at least one of the outcome measures. Therapists also identified other outcome measures not included in the original list. The most commonly identified measures not included in the questionnaire were the Berg Balance Scale (identified by eight therapists), the Therapy Outcome Measure (identified by five therapists), and the Wessex Head Injury Matrix (identified by four therapists).

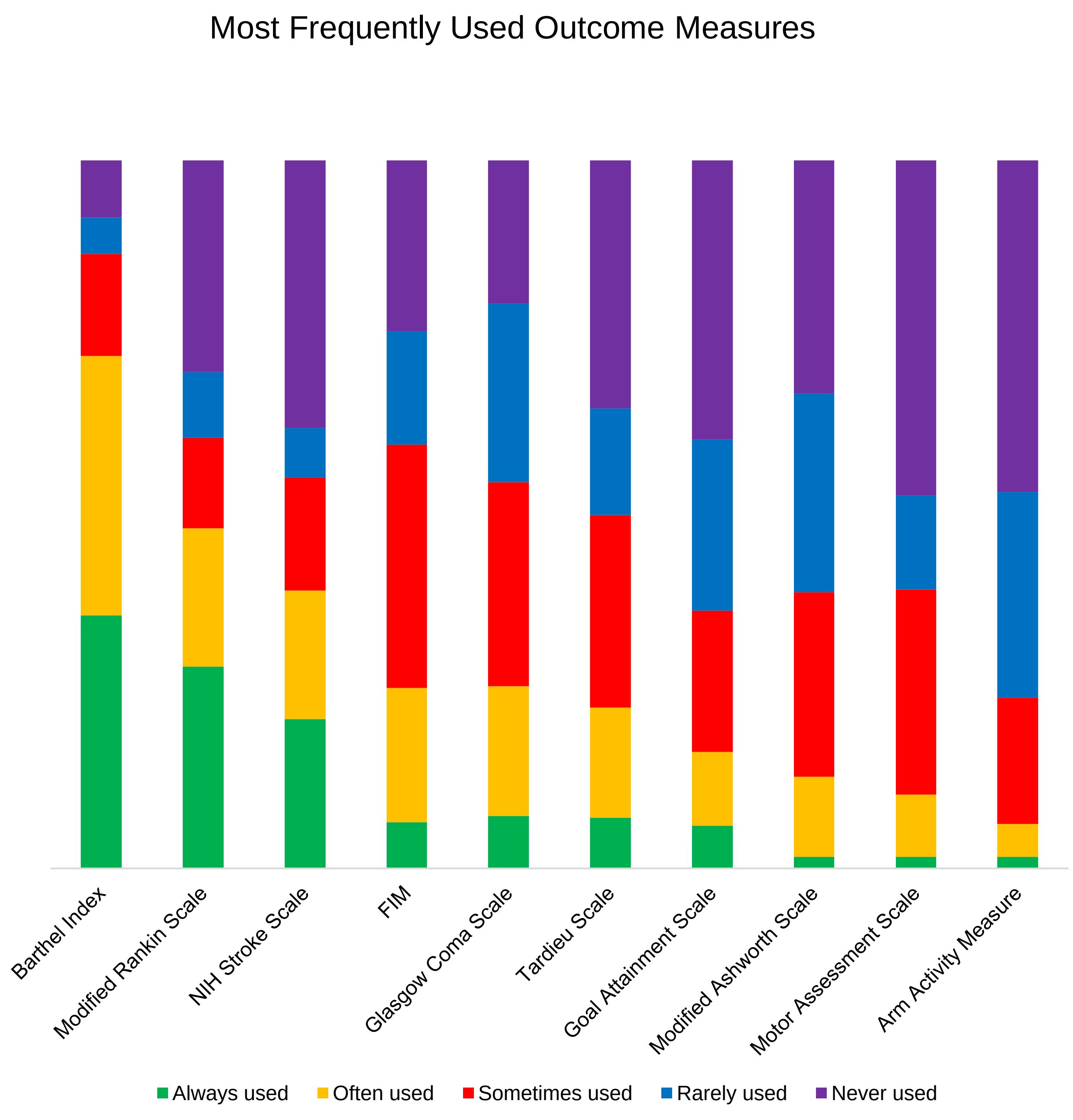
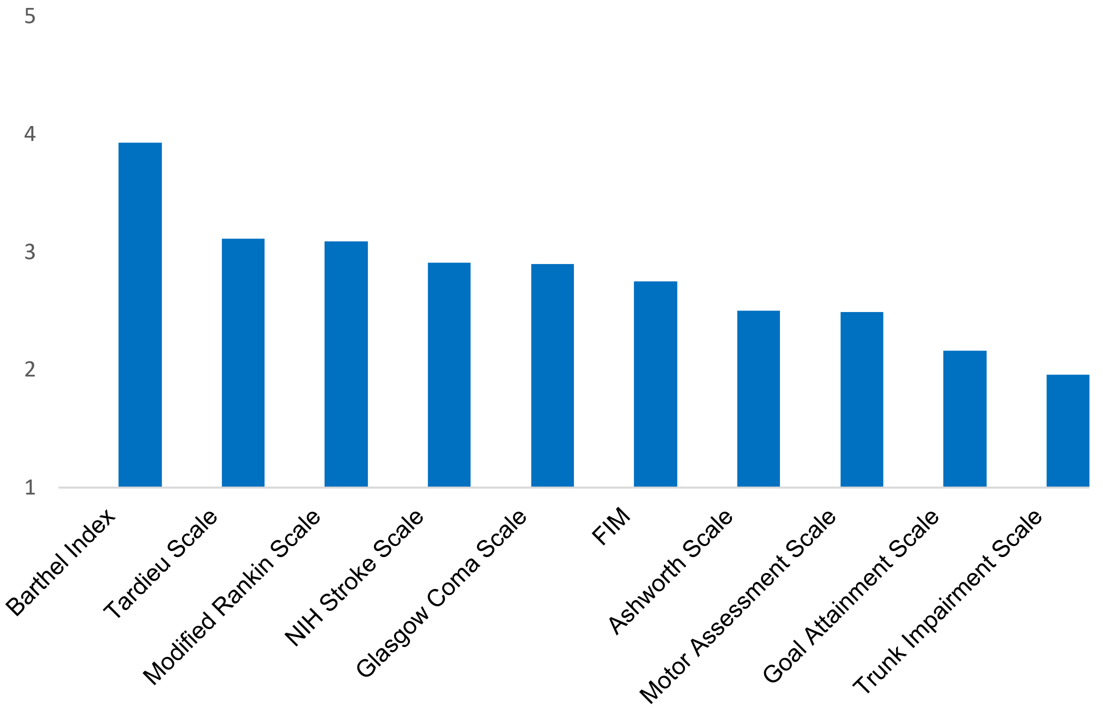


Figure 8- Most frequently used outcome measures across all respondents

NIH- National Institutes of Health, FIM- Functional Independence Measure

(a) Most Frequently Used Outcome Measures- Physiotherapists



(b) Most Frequently Used Outcome Measures- Occupational Therapists

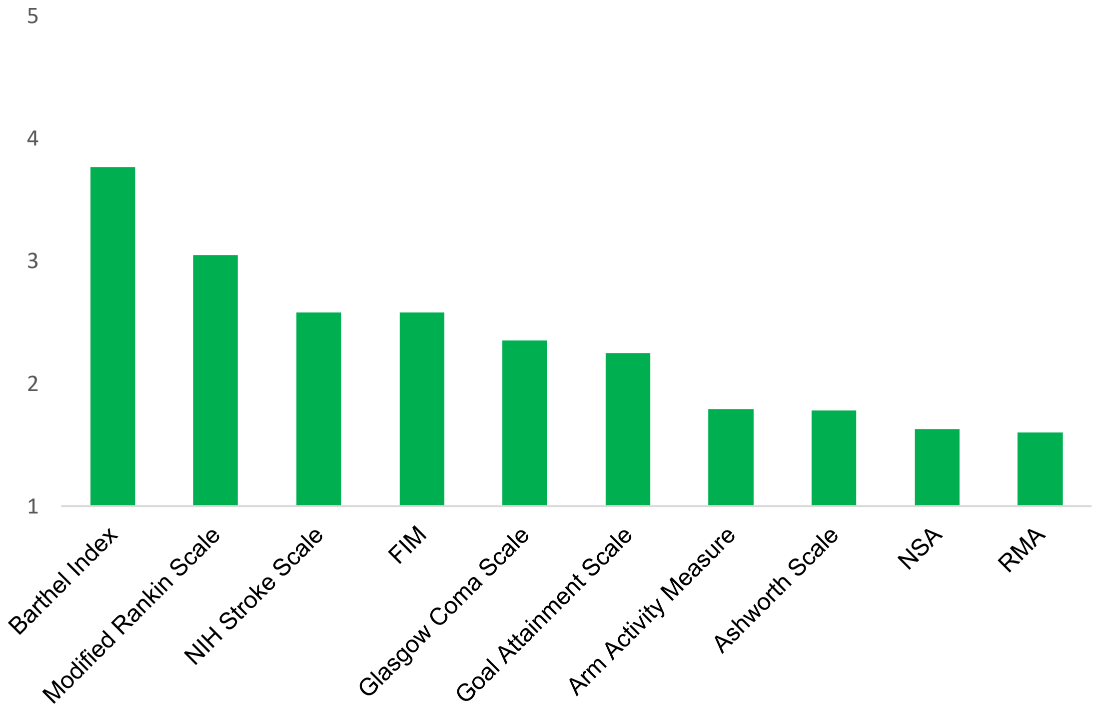


Figure 9- Most frequently used outcome measures amongst (a) physiotherapists and (b) occupational therapists

5 = Always used, 4 = Often used, 3 = Sometimes used, 2 = Rarely used, 1 = Never used
NIH- National Institutes of Health, FIM- Functional Independence Measure, NSA- Nottingham Sensation Assessment, RMA- Rivermead Motor Assessment

Table 6- Most frequently used outcome measures by therapists in different settings in descending order

HASU/ASU	**SRU**	**ESD/CST**
Barthel Index	Barthel Index	Barthel Index
Glasgow Coma Scale	Tardieu Scale	Modified Rankin Scale
NIH Stroke Scale	Functional Independence Measure	Tardieu Scale
Modified Rankin Scale	Glasgow Coma Scale	Functional Independence Measure
Tardieu Scale	NIH Stroke Scale	Goal Attainment Scale
Functional Independence Measure	Modified Rankin Scale	Ashworth Scale
Motor Assessment Scale	Motor Assessment Scale	Motor Assessment Scale
Ashworth Scale	Ashworth Scale	NIH Stroke Scale
Trunk Impairment Scale	Goal Attainment Scale	Trunk Impairment Scale
Orpington Prognostic Scale	Trunk Impairment Scale	Rivermead Motor Assessment

HASU/ASU	**SRU**	**ESD/CST**
Barthel Index	Barthel Index	Barthel Index
Modified Rankin Scale	Functional Independence Measure	Modified Rankin Scale
NIH Stroke Scale	Modified Rankin Scale	Goal Attainment Scale
Glasgow Coma Scale	NIH Stroke Scale	Functional Independence Measure
Functional Independence Measure	Goal Attainment Scale	Arm Activity Measure
Goal Attainment Scale	Glasgow Coma Scale	Ashworth Scale
Arm Activity Measure	Nottingham Sensory Assessment	NIH Stroke Scale
Ashworth Scale	Rivermead Motor Assessment	Rivermead Motor Assessment
Rivermead Motor Assessment	Ashworth Scale	Motor Assessment Scale
Nottingham Sensory Assessment	Arm Activity Measure	Nottingham Sensory Assessment

HASU/ASU- hyperacute/acute stroke units, SRU- stroke rehabilitation units, ESD/CST- early supported discharge/community stroke teams, NIH- National Institutes of Health

As questionnaire results revealed that outcome measure use was generally low across all therapists, therapists were asked in the interview about perceived issues with using outcome measures that might explain why outcome measure use was low. Therapists were also asked about the timing and frequency of completing outcome measures in order to understand use of outcome measures more fully in the rehabilitation of severely disabling stroke. In the interviews, therapists confirmed that the most frequently used outcome measures were generally representative of clinical practice within each stroke service. Similar to the questionnaire respondents, therapists reported a lack of familiarity with some of the listed outcome measures, which resulted in some outcome measures never being used. Therapists agreed that outcome measure use was generally low in clinical practice and identified several reasons for this observation. Whilst outcome measures were more likely to be completed during the initial assessment phase, ongoing outcome measure use was limited due to perceived lack of time. Some therapists reported that reassessment of outcome measures may be performed prior to discharge from a stroke service. However, prioritisation of discharge-dependent tasks, such as referring for equipment or community therapy, prevented routine outcome measure reassessment prior to discharge. Therapists also felt that most outcome measures were not sensitive to the small clinical changes seen in survivors of severely disabling stroke, which further reduced their clinical utility in this cohort of the stroke population. Therapists reported other means to evaluate the effect of their interventions that were more sensitive to the subtle clinical changes seen in survivors of severely disabling stroke:

> “We use the Barthel index currently. And patients with milder impairments might be a bit easier to show change. But you might not see much of change in the Barthel from your therapy intervention with patients who are perhaps more severe. It’s much harder to show change on your outcomes. I think when you go in and see the very severe patients, you’re not going to see a big jump on a scale.”
>
> (Maria, Band 5 OT)

> "Assessing the small changes, such as a patient keeping their eyes open for longer or keeping their sitting balance with minimal assistance as opposed to maximal assistance, is important because outcome measures don't show this level of detail. But it's these small changes that make you keep going with the patient and keep giving them rehab."
>
> (Sallie, Band 7 PT)

Therapists also expressed frustration about the need to complete outcome measures that were not relevant for survivors of severely disabling stroke. Many therapists felt that outcome measures were being completed "to tick a box" rather than to guide rehabilitation or evaluate therapy outcome. In particular, therapists highlighted that two of the most commonly used outcome measures, the mRS and NIHSS, were more likely to be completed to comply with national audit rather than to improve patient care.

5.6 Discussion of Therapist Survey

The survey of therapy practice has provided insight into the frequency of intervention and outcome measure use by therapists in the first 12 months after severely disabling stroke. Interventions were delivered to achieve particular aims as part of goal-directed therapy, which varied between PTs and OTs across the stroke pathway. PTs performed sitting balance, bed mobility, and active/assisted exercises more frequently, whereas OTs performed washing, dressing, and grooming practice more frequently. Previous research comparing the content of physiotherapy and occupational therapy sessions in stroke rehabilitation similarly identified differences in physiotherapy and occupational therapy practice (Ballinger *et al.*, 1999; Bode *et al.*, 2004; De Wit *et al.*, 2006). In these studies, PTs were more likely to practice walking, transfers, standing balance, and active movements, whereas OTs were more likely to practice activities of daily living, leisure activities, sensory tasks, and perceptual training. However, due to the focus of severely disabling stroke in the current survey, the types of interventions identified in the survey differed from these observational studies. Although differences in professional role practice were identified in the survey, the survey also revealed that there were similarities in intervention and outcome measure use between PTs and OTs. For example, both professions frequently performed positioning, training and education, and developed seating care plans.

Both professions frequently completed the BI, mRS, NIHSS, and FIM. This role overlap likely reflects the professions’ common focus and collaboration to promote recovery of function and independence (Booth and Hewison, 2002).

Differences in intervention and outcome measure use were also noted between the main types of stroke services. Active and passive interventions, such as positioning, sitting balance, and seating trials, were performed more frequently in inpatient stroke services. The Glasgow Coma Scale (GCS), which measures a stroke survivor’s level of consciousness, was more frequently performed in ASUs. Developing care plans, as well as carer training and education, were performed more frequently in community stroke services. The Goal Attainment Scale (GAS), which measures the attainment of individualised patient goals, was more frequently performed in community stroke services. These findings are consistent with the aims of therapy practice in the different stroke services reported by therapists in the interviews. The focus of therapy in acute and inpatient SUs is to optimise function and independence, as well as prevent secondary complications which could impact upon functional recovery. This focus would support the use of active and passive interventions delivered by therapists in these settings to improve function and prevent complications. Reduced or fluctuating levels of consciousness are more common in the acute phase post-stroke (Norrving, 2014), supporting the more frequent use of the GCS in ASUs. The focus of therapy in community settings is to ensure that carers looking after stroke survivors are able to implement longer-term management interventions, such as positioning, safe handling and splint application. This focus would support the use of care plans, as well as carer training and education in these settings. Individualised goals adapted to a stroke survivor’s environment are more likely to be set once a stroke survivor is residing in the community, supporting the more frequent use of GAS in community stroke settings. Whilst intervention and outcome measure use by therapists aligned with the broader organisational aims and different post-stroke phases, previous research has identified other organisational factors influencing stroke therapy practice (Kuipers, McKenna and Carlson, 2006; McGlinchey and Davenport, 2015; Clarke *et al.*, 2018; Taylor, Jones and McKevitt, 2018). These factors include resource availability, local protocols and policy, and workplace culture. Due to the design of the current survey, the influence of these factors on therapy practice was not explored.

Whole body positioning (“positioning”) was the most frequently used intervention by therapists for survivors of severely disabling stroke. Positioning involves the use of different body positions in bed and in a chair to counteract the effects of immobilisation that can arise following a stroke (McGlinchey, Walmsley and Cluckie, 2015). As survivors of severely disabling stroke are more likely to experience a range of physical and cognitive impairments preventing regular position changes, it is not surprising that positioning was so widely used. However, the efficacy of positioning post-stroke is unclear. Perceived benefits of positioning post-stroke, such as modulating muscle tone, promoting sensorimotor recovery, and reducing post-stroke complications, have been identified through consensus opinion amongst therapists and nurses rather than through empirical evidence (Chatterton, Pomeroy and Gratton, 2001; Rowat, 2001; Mee and Bee, 2007). Furthermore, a meta-analysis of studies investigating the effect of positioning on shoulder range of motion post-stroke did not demonstrate any benefit of positioning to prevent or reduce shoulder contracture (Borisova and Bohannon, 2009). Further research to determine the effectiveness of positioning after severely disabling stroke is clearly needed.

Several issues with outcome measure use in the rehabilitation of severely disabling stroke were identified by the survey. Outcome measure use was generally low, which is consistent with other surveys of outcome measure by therapists in stroke rehabilitation (Stokes and O'Neill, 2008; Van Peppen *et al.*, 2008; Stapleton and McBrearty, 2009). In the current survey, respondents reported several factors for low use, including perceived lack of time to repeat outcome measures, reduced awareness of key outcome measures, and a lack of sensitivity in detecting meaningful clinical change. Some of the most frequently used outcome measures, such as the BI, mRS and FIM, assess the degree of attainment or independence in activities of daily living (ADLs). However, it was discussed in the Literature Review chapter that the extent to which rehabilitation optimises independence in ADLs for survivors of severely disabling stroke is not clear. It was also discussed in the Literature Review chapter that there are other outcomes that directly impact upon survivors of severely disabling stroke, such as post-stroke complications and caregiver burden. However, the most frequently used outcome measures in severely disabling stroke do not routinely capture these outcomes. This may suggest that there is a clinical need to identify or develop an outcome measure more suitable for survivors of severely disabling stroke. Whilst the development of an appropriate outcome measure is not within the scope of this thesis, an outcome measure that is relevant for survivors of severely disabling stroke would need to focus on key outcomes, such as the degree of assistance required for ADLs, the occurrence of post-stroke complications, and caregiver burden. The outcome measure would also need to be quick to implement to ensure compliance with completion.

There are several strengths of the current survey that need to be highlighted. A key strength was the use of a mixed methods design incorporating two data collection tools. The explanatory sequential mixed-methods design enabled a greater understanding of therapy practice to emerge by using the therapist interviews to explain the questionnaire findings in more detail. Interview data corroborated the results of the questionnaire, thereby enhancing the validity of the study's findings. For example, differences in intervention use between inpatient and community settings identified by the questionnaire, such as active interventions and carer training, aligned with the aims of stroke rehabilitation in inpatient and community settings reported by therapists in the interviews. Another strength of the survey was the exploration of therapy practice in the rehabilitation of severely disabled stroke survivors across the stroke pathway. Several authors have reported that relatively less research has been conducted in investigating the effectiveness of rehabilitation strategies in severely disabling stroke (Gladman and Sackley, 1998; Rodgers, 2000; Wyller, 2000; Sterr and Conforto, 2012). The findings from this survey provided useful information about the type and range of interventions and outcome measures used by PTs and OTs in the rehabilitation of severely disabling stroke. This information can be used to guide future research investigating the effectiveness of the most frequently used interventions.

There are several weaknesses of the current survey that need to be reported. The first weakness was the low response rate. It is recognised that internet surveys result in lower response rates than other dissemination methods, such as telephone and postal surveys (Manfreda *et al.*, 2008; Shih and Fan, 2009). Low response rates are problematic as they may reduce the generalisability of survey findings to the wider population (Bowling, 2005; Aday and Cornelius, 2006). However, an internet questionnaire was chosen due to its ability to target a large audience with relatively little expense and its current popularity in surveying therapy practice. As well, several strategies were employed to increase the response rate, such as personalised emails and email reminders. This may have contributed to the relatively high response rate compared to recent published internet questionnaires exploring therapy practice in stroke rehabilitation (Connell *et al.*, 2014; Howlett, McKinstry and Lannin, 2018; Scott and Bondoc, 2018; Stockley *et al.*, 2019). The second weakness was the risk of sampling bias by using a non-random sample of therapists. Sampling bias may reduce the ability to make inferences from the survey's findings to the wider therapist population. Whilst the exact configuration of therapists working in stroke in the UK is not known, survey respondents came from all qualified staff grades and areas of the UK. This may suggest that different subgroups within the wider therapist population were captured by the survey. The third weakness was the method of capturing therapist responses during the interviews. Due to technological limitations, therapists' responses were manually recorded rather than audio recorded. This may have led to pertinent responses being omitted during data capture, thereby reducing the credibility of interview data and introducing bias during data analysis. However, due to the structured nature of interview questions, it was felt that writing interview responses could capture the focussed interview responses expected from therapists and achieve the aim of undertaking therapists interviews. As well, additional strategies were employed to enhance the credibility of the interview data, such as obtaining verbatim quotes from therapists and allowing therapists to amend or add to any response in order to accurately reflect their views. A final weakness was the limited ability of the survey to explore actual therapy practice in the rehabilitation of severely disabling stroke. The self-reported nature of the survey can only provide an estimate of what therapists say they do in the rehabilitation of severely disabling stroke. It is possible that actual therapy practice, which can be determined by observing therapists working in different stroke services, differs to the findings of the survey. However, triangulating questionnaire responses obtained from a large sample of therapists with findings from the therapist interviews provided logical explanations for therapy practice that are likely to reflect the reality of rehabilitation in severely disabling stroke.

5.7 Integration with other Studies

The therapist survey has provided insight into the type and frequency of intervention use. However, it is not yet clear what factors guide therapists in the selection of these interventions in an era of evidence-based practice. Therefore, there is a need to ascertain the evidence base of rehabilitation interventions and the decision-making processes behind the selection of interventions in the rehabilitation of severely disabling stroke. The next chapter will systematically review the evidence for the effectiveness of interventions in improving physical function and reducing immobility-related complications after severely disabling stroke. It will also integrate survey findings to understand whether the most frequently used interventions have robust evidence to support their use and if there are interventions with robust evidence that are not being used clinically. Subsequent chapters will then investigate the wider context of therapy practice in order to understand the rationale for selecting or not selecting interventions in the rehabilitation of severely disabling stroke. This investigation will require a more exploratory research approach, such as ethnography (Huby *et al.*, 2007).

5.8 Chapter Summary

Survey research is a recognised methodology to systematically collect information from a group of individuals in order to describe or generalise to the wider population to which the individuals belong. Survey research has been used previously in stroke rehabilitation research to understand the clinical practice of PTs and OTs. In this thesis, it has been used to ascertain the most frequently used interventions and outcome measures in the rehabilitation of severely disabling stroke. The use of an internet questionnaire identified variations in clinical practice between PTs and OTs working across the stroke pathway. Follow-up interviews of a small sample of therapists explained the rationale for performing the most frequently used interventions and highlighted several issues with outcome measure use after severely disabling stroke. In order to understand therapy practice more fully in the rehabilitation of severely disabling stroke, survey findings will be integrated with other studies in subsequent chapters.

Chapter 6- The Effect of Rehabilitation Interventions on Physical Function and Immobility-Related Complications in Severely Disabling Stroke: A Systematic Review

6.1 Introduction

This chapter presents the second study of the research, which is a systematic review of the evidence for the effectiveness of rehabilitation interventions to improve physical function and reduce immobility-related complications after severely disabling stroke. It will commence with a critical review of the use of systematic reviews in healthcare research and the use of randomised controlled trials in the evaluation of complex healthcare interventions. It will continue with an overview of the systematic review and a discussion of its key findings, including its strengths and weaknesses. It will integrate the systematic review and survey findings to highlight the mismatch between the research evidence base and current clinical practice. It will conclude by highlighting how the third and largest study, an ethnographic exploration of therapy practice, can provide more insight into what factors guide therapist decision making in the rehabilitation of severely disabling stroke.

6.2 Systematic Reviews in Healthcare Research

A systematic review can be defined as:

> "a review of a clearly formulated question that uses systematic and explicit methods to identify, select, and critically appraise relevant research, and to collect and analyse data from the studies that are included in the review" (Higgins and Green, 2011, para. 26)

In her review article explaining the rationale for systematic reviews, Mulrow (1994) stated that the principle aim of a systematic review is to provide a comprehensive, balanced, and unbiased summary of the available evidence of a specific topic into a single document. Bias is reduced or eliminated by using a transparent framework to guide the review process. Statistical procedures, such as meta-analysis, can be employed to summarise data from individual studies, such as randomised controlled trials (RCTs) (Mulrow, 1994; Akobeng, 2005b; Liberati *et al.*, 2009). Liberati *et al.* (2009) stated that meta-analysis can increase the ability to detect risks and benefits of the healthcare intervention under investigation. Findings from the systematic review can then be used by healthcare professionals to guide the selection of the most effective healthcare intervention or by policymakers to develop clinical practice guidelines. As the systematic review of RCTs has been described by Sackett *et al.* (1996) as the “gold standard” for determining the effectiveness of a healthcare intervention, it forms a key research method within the evidence-based practice (EBP) framework. Systematic reviews are also used to identify healthcare topics with uncertain or limited research evidence (Mulrow, 1994; Akobeng, 2005b; Liberati *et al.*, 2009). This information can be used by researchers to prioritise future research, as well as research funders to finance new research. Therefore, well-designed systematic reviews can benefit a range of stakeholders, including patients, healthcare professionals, researchers, research funders, and policymakers.

Despite the proposed benefits of the systematic review, several authors have identified a range of issues with the quality of published reviews that may limit their utility (Shojania *et al.*, 2007; Ioannidis, 2016; Chevret, Ferguson and Bellomo, 2018; Møller, Ioannidis and Darmon, 2018). The drive for transparency in the systematic review process has led to efforts to register systematic reviews and publish review protocols prior to their commencement (Ioannidis, 2016). However, Ioannidis (2016) suggested in his critical review of systematic reviews and meta-analyses that pre-registration of systematic reviews in recognised registers of systematic reviews, such the International Prospective Register of Systematic Reviews (PROSPERO), may be as low as 10-20%. Furthermore, Ioannidis (2016) suggested that the publication of a review protocol does not necessarily indicate that the conduct, analyses, and reporting of the actual systematic review will be of high quality. Systematic reviews may also become outdated quickly due to an increasing number of published studies each year. A review by Shojania *et al.* (2007) of 100 medical systematic reviews published over a 10-year period highlighted that 7% of reviews required updating just before publication, which increased to 15% at one year and 23% at two years. These findings were seen in rapidly changing areas of medicine and may not be applicable to other healthcare areas, such as stroke rehabilitation. However, these findings indicate the need for regular monitoring and updating of systematic reviews in order to ensure that the latest published research is made available. Finally, systematic reviews that include studies with low methodological quality due to high risk of bias can increase the likelihood of overestimating the benefits and underestimating the risks of the healthcare intervention under investigation (Chevret, Ferguson and Bellomo, 2018; Møller, Ioannidis and Darmon, 2018). Whilst meta-analysis can increase the ability to detect treatment benefits and risks, it does not necessarily eliminate the inherent biases of the individual studies (Møller, Ioannidis and Darmon, 2018). Meta-analysis is also not appropriate when included studies demonstrate marked heterogeneity, or variability in key clinical, methodological, and statistical characteristics (Møller, Ioannidis and Darmon, 2018). Due to the complex nature of stroke rehabilitation, heterogeneity of study participants (e.g. type of stroke, time post-stroke), interventions (e.g. dosage, length of treatment), and outcome measures is a common finding in many systematic reviews of stroke rehabilitation interventions (Bowen *et al.*, 2013; Demetrios *et al.*, 2013; Pollock *et al.*, 2014; Laver *et al.*, 2015; das Nair *et al.*, 2016; Xu, Li and Zhang, 2018).

6.3 Reviewing the RCT in the Evaluation of Complex Interventions

In the published hierarchy of research evidence within EBP, the RCT is placed towards the top of the hierarchy pyramid (Figure 10) (Akobeng, 2005a). In his review of the use of RCTs in healthcare, Akobeng (2005a) stated that the position of the RCT reflects its importance in medical research investigating the effectiveness of healthcare interventions.

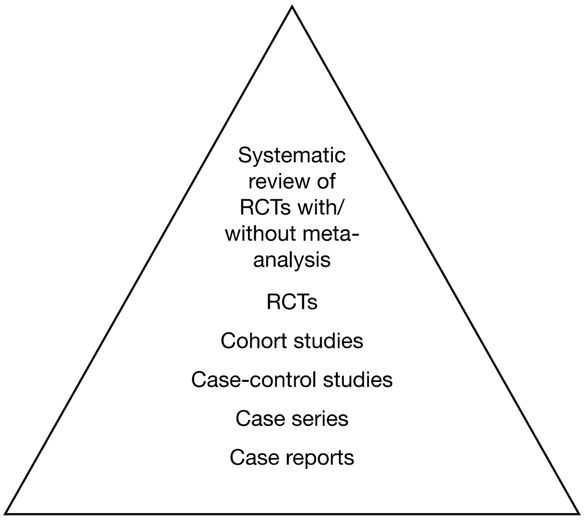


Figure 10- Hierarchy of evidence investigating the effectiveness of healthcare interventions

In medicine, RCTs were traditionally used to investigate the efficacy of pharmacological interventions (Mustafa, 2017). Pharmacological interventions can be viewed as simple interventions, as they usually involve one or a few intervention components (e.g. one tablet taken daily) and have simple linear pathways that link intervention use and outcomes (e.g. taking an anti-hypertensive tablet reduces blood pressure). More recently, RCTs have been used to investigate the effectiveness of more complex healthcare interventions (Craig *et al.*, 2013; Moore *et al.*, 2015; Mustafa, 2017). Complex healthcare interventions are those interventions that demonstrate several interacting components, variation when delivered in different contexts, target multiple and complex outcomes, and have non-linear pathways that link intervention use and outcomes (Petticrew, 2011; Craig *et al.*, 2013; Moore *et al.*, 2015). Stroke rehabilitation may be considered a complex healthcare intervention due to the range of available rehabilitation interventions, which may be complex in themselves, that are delivered by many individuals across a range of healthcare settings.

The RCT is the most commonly used research method to evaluate the effectiveness of healthcare interventions, as evidenced by the design of systematic reviews published by Cochrane (Higgins and Green, 2011). However, its ability to evaluate complex healthcare interventions has been questioned by several authors (Redfern, McKevitt and Wolfe, 2006; Blackwood, O'Halloran and Porter, 2010; Mustafa, 2017). In their systematic review investigating the development of stroke care interventions, Redfern, McKevitt and Wolfe (2006) highlighted the challenge of using RCTs to evaluate stroke care interventions due to the difficulty of standardising interventions and their sensitivity to features of the local context. Redfern, McKevitt and Wolfe (2006) also argued that even when RCTs of a complex intervention are executed well, it can be difficult to understand how and why the intervention works. In their critical review of mixing RCTs with qualitative research to evaluate complex healthcare interventions, Blackwood, O'Halloran and Porter (2010) suggested that the effects of a complex intervention may be dependent on a range of factors, such as the setting for the intervention, the participants' characteristics and preferences, and the investigator-participant relationship. In light of the challenges posed by the complexity of healthcare interventions, the Medical Research Council has recommended that evaluation of complex interventions include both an outcome evaluation, by using an RCT or other experimental design, as well as a process evaluation (Craig *et al.*, 2013; Moore *et al.*, 2015). A process evaluation aims to understand how an intervention functions by investigating its implementation, mechanisms of impact, and contextual factors. As a process evaluation can provide insight into why an intervention succeeds or fails, as well as how a successful intervention can be optimised, it is considered a suitable approach in the evaluation of complex healthcare interventions. The Medical Research Council has also identified a range of experimental designs to evaluate complex healthcare interventions, such as stepped wedge designs and randomised consent trials (Craig *et al.*, 2013; Moore *et al.*, 2015). However, as discussed in the Methodology chapter, the rationale for selecting a particular research design is based upon the underlying research question (Crotty, 1998; Morgan, 2007). As many groups and organisations, such as the Evidence-Based Medicine Working Group and Cochrane, regard the RCT as the optimal method to obtain unbiased estimates of intervention effectiveness (Haynes *et al.*, 1996; Sackett *et al.*, 1996; Haynes, Devereaux and Guyatt, 2002; Higgins and Green, 2011), it should be considered in the first line of research designs to evaluate the effectiveness of healthcare interventions. As such, a systematic review of RCTs was undertaken to evaluate the effectiveness of interventions used in the rehabilitation of severely disabling stroke in the current study.

6.4 Systematic Review of the Effectiveness of Rehabilitation Interventions

6.4.1 Scoping Review

A scoping review of the literature was conducted prior to the systematic review to determine if there were any published systematic reviews on the effectiveness of rehabilitation in severely disabling stroke and identify search parameters of a proposed systematic review. Arksey and O'Malley (2005) and Armstrong *et al.* (2011) stated that scoping reviews provide a preliminary assessment of the existing literature. As such, they can be used to determine the value of undertaking a full systematic review. The scoping review identified one literature review investigating the effect of inpatient rehabilitation in severely disabling stroke (Pereira *et al.*, 2012). However, there were no previously published systematic reviews on the effectiveness of individual interventions used in the rehabilitation of severely disabling stroke. The scoping review also identified possible search parameters for a proposed systematic review that could include interventions designed to improve physical function and reduce post-stroke complications. These parameters were chosen as they had not been investigated in detail in the literature review by Pereira *et al.* (2012).

6.4.2 Systematic Review Aims

Based on the findings from the scoping review, a systematic review of RCTs was undertaken to evaluate the effectiveness of rehabilitation interventions on improving physical function and reducing immobility-related complications after severely disabling stroke. Although there are recognised limitations of RCTs in the investigation of complex healthcare interventions, the RCT was chosen as the primary study design in order to evaluate intervention effectiveness with minimal bias that may affect the interpretation of study findings. As a systematic review can identify healthcare topics with uncertain or limited research evidence, a secondary aim of the systematic review was to identify questions for future rehabilitation research based on the findings from the evaluation of intervention effectiveness.

6.4.3 Systematic Review Methods

In order to improve transparency of the systematic review process, thereby addressing one of the identified criticisms of systematic reviews, the systematic review was registered in PROSPERO, the International Prospective Register of Systematic Reviews (registration number CRD477737). The protocol for the systematic review was also published in the journal “Systematic Reviews” to further improve transparency of the review process (McGlinchey *et al.*, 2018; Appendix D). The systematic review protocol and systematic review were conducted according to PRISMA, the Preferred Reporting Items for Systematic Reviews and Meta-analyses (Liberati *et al.*, 2009; Shamseer *et al.*, 2015). The PRISMA statement is an established, evidence-based set of items deemed necessary to report a systematic review fully and transparently (Moher *et al.*, 2009). PRISMA-P is an extension of the PRISMA statement designed to facilitate the reporting of systematic review protocols (Moher *et al.*, 2015). As PRISMA and PRISMA-P are recommended by Cochrane, they were considered suitable frameworks to guide the systematic review and review protocol. PRISMA provides guidance regarding the main components of conducting a systematic review, including study identification and selection, data extraction, risk of bias and quality assessment, and data analysis. The next paragraphs provide an overview of these systematic review components.

RCTs for potential inclusion in the systematic review were identified using the PICO (Participants, Intervention, Comparator and Outcome) framework. PICO is a recognised framework used within healthcare research to facilitate literature searching (Liberati *et al.*, 2009; Moher *et al.*, 2009; Higgins and Green, 2011). An example search strategy is included as Appendix E. Eligible studies were RCTs of:

- adult survivors of severely disabling stroke (P) that compared
- one type of rehabilitation intervention (I) to

- another intervention, usual care, or no intervention (C) on
- physical function and immobility-related complications (O)

Key terms and concepts used in the systematic review were defined or operationalised in order to improve clarity and understanding. A severe stroke was defined as a stroke that results in "a significant amount of brain tissue damage and multiple neurological impairments, which leads to a significant loss of function and residual disability" (McGlinchey *et al.*, 2020, pg. 2). Stroke severity was measured using a score on any validated outcome measure used routinely in clinical practice, such as the National Institutes of Health Stroke Scale (NIHSS) or the Barthel Index (BI). A rehabilitation intervention was defined as "any non-surgical or non-pharmacological intervention used in current clinical practice as part of the usual rehabilitative care of stroke survivors" (McGlinchey *et al.*, 2020, pg. 2). Physical function was defined as the ability to perform various physical activities and assessed using measures of body function, activity, and participation (Bruce *et al.*, 2009; Painter and Marcus, 2013). An immobility-related complication was defined as "any medical problem arising after a stroke because of immobility or reduced physical activity" (McGlinchey *et al.*, 2020, pg. 3).

Electronic databases (MEDLINE, EMBASE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Allied and Complementary Medicine Database (AMED), Physiotherapy Evidence Database (PEDro), Database of Research in Stroke (DORIS) and the Cochrane Central Register of Controlled Trials (CENTRAL)) were searched over the previous 30 years (between January 1987 and November 2018). The search timeframe was guided by the scoping review, which highlighted very few published RCTs before 2000. In addition to searching electronic databases, ongoing studies were identified by searching the Stroke Trials Registry and reference lists from included studies. Studies in any language or country were included to avoid language or cultural bias.

The results from the literature search were uploaded to a reference management programme (RefWorks) and duplicate references were removed. Titles and abstracts of the search results were screened independently by two review authors (myself and a senior physiotherapist (PT) with research experience). Full text articles were obtained for relevant studies and reviewed by the same two review authors independently to determine if studies met the inclusion criteria using a pre-piloted inclusion/exclusion checklist. The two review authors independently performed data extraction for all eligible articles using a pre-piloted data extraction proforma. Differences in opinion between the two authors at any stage of the study selection and data extraction process were resolved by a third review author.

Bias is defined by Cochrane as “a systematic error, or deviation from the truth, in results or inferences” (Higgins and Green, 2011, para. 4). As bias can lead to an underestimation or overestimation of an intervention’s effect, assessing for the risk of bias is an important component of the systematic review process. Risk of bias was assessed by the two review authors independently using the Cochrane Collaboration tool for assessing the risk of bias across six main domains: sequence generation, allocation concealment, blinding, incomplete outcome data, selective outcome reporting, and other bias (Higgins and Green, 2011). A risk of bias judgement of “high”, “low” or “unclear” was determined for each of these main domains. The strength of evidence was assessed using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach (Higgins and Green, 2011). The five criteria considered by the GRADE approach include risk of bias, inconsistencies between studies, indirectness, imprecision, and publication bias. Studies were given a baseline rating of “high” and downgraded if any of the five criteria were present. The quality of the evidence was ranked “high”, “medium”, “low” or “very low” by the two review authors independently. Differences in opinion between the two review authors at any stage of the quality assessment process were resolved by a third review author.

6.4.4 Systematic Review Analysis

The limited number of studies investigating each individual intervention, which will be discussed in the next section, and the marked heterogeneity of the selected studies meant that it was not appropriate to undertake a meta-analysis of selected studies. Heterogeneity was seen in the rehabilitation interventions (type, dosage, method of delivery, and timeframe completed post-stroke) as well as outcomes (type, cut-off score, and timeframe completed post-stroke). Therefore, a descriptive review of results was performed. As the amount and rate of stroke recovery may change according to the time post-stroke, studies were grouped into three timeframes post-stroke based on when participants were recruited to the study and when the study’s intervention finished. These timeframes were the acute to early subacute stage (up to three months post-stroke), acute to late subacute stage (up to six months post-stroke), and chronic stage (greater than six months post-stroke). Timeframes were chosen based on recommendations for the standardised measurement of sensorimotor recovery in stroke trials (Kwakkel *et al.*, 2017). Review findings were presented according to these timeframes.

6.5 Systematic Review Findings

The systematic review was published in “BMJ Open” (McGlinchey *et al.*, 2020; Appendix D). Key findings from the published review are included in this section.

28 studies were included in the systematic review (Figure 11). 2,677 participants were recruited to these studies- participants had a mean age of 72.7 years, 49.3% were male, and 87% of stroke survivors sustained a cerebral infarction. The characteristics of the included studies, including an assessment of their quality of evidence, are provided in Tables 7 – 9. An assessment of the studies’ risk of bias is presented in Figure 12.

As demonstrated in Tables 7 – 9, 16 study interventions were completed within the acute to early subacute phase, eight study interventions were completed within the acute to late subacute phase, and four study interventions were completed within the chronic phase post-stroke. 20 different interventions were evaluated across the 28 studies.

Across the studies, 60 measures of physical function and immobility-related post-stroke complications were identified. Measures were classified as measures of body function (n=18), activity (n=26), participation (n=8), and post-stroke complications (n=8). Measures were grouped together as 16 different outcomes (Table 10).

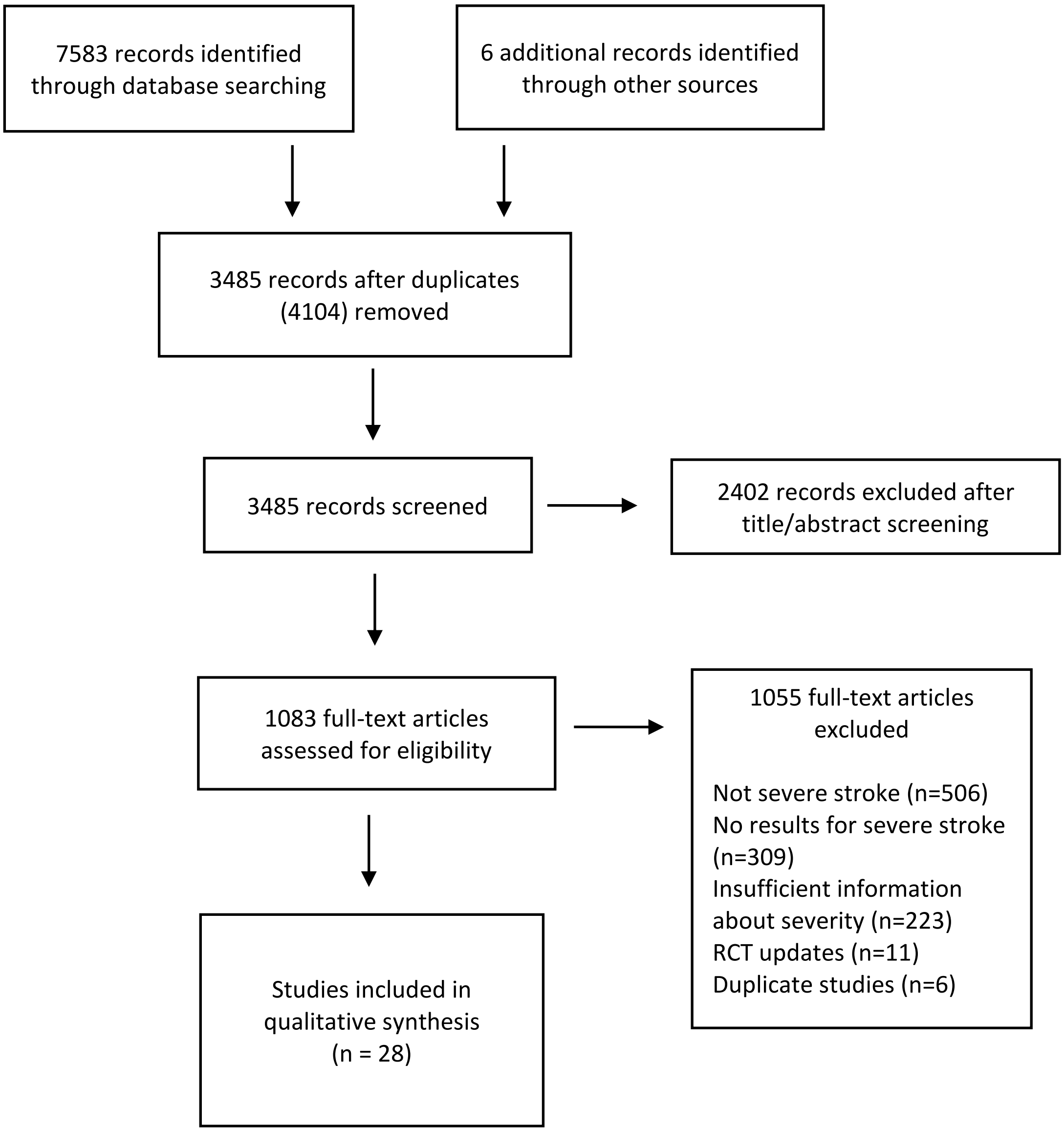
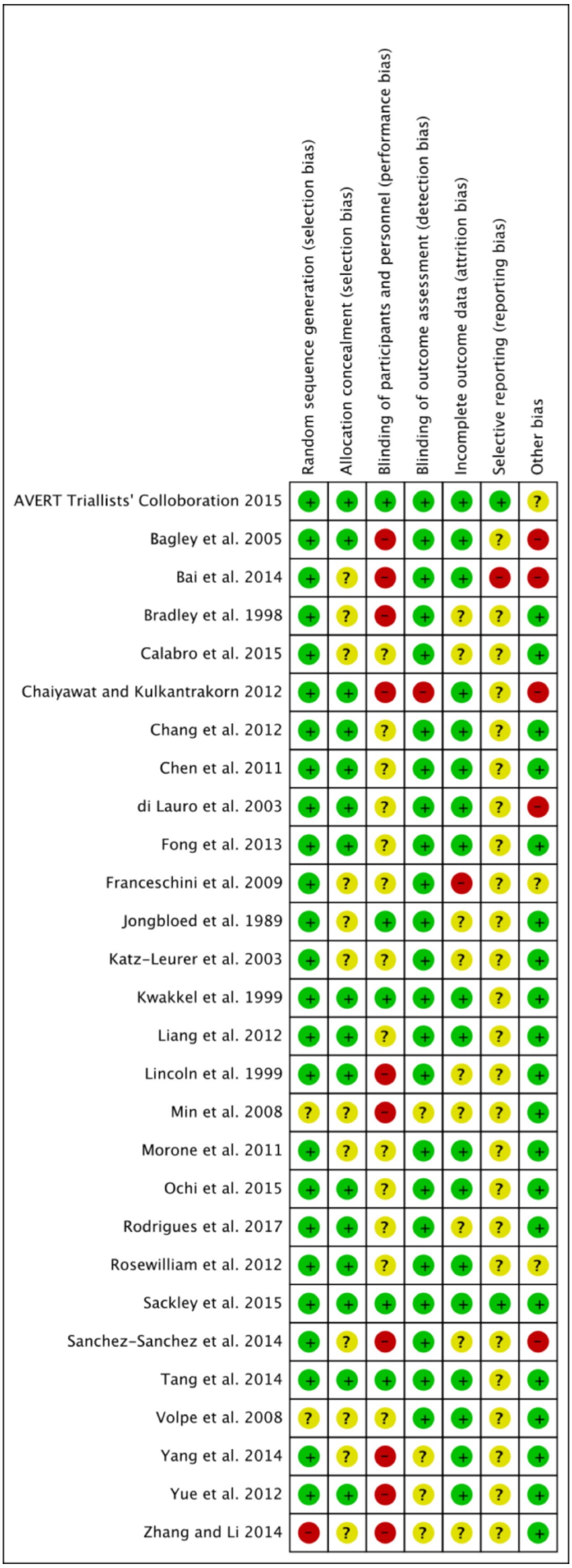


Figure 11- PRISMA flowchart of studies



	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
AVERT Triallists' Colloboration 2015	+	+	+	+	+	+	?
Bagley et al. 2005	+	+	−	+	+	?	−
Bai et al. 2014	+	?	−	+	+	−	−
Bradley et al. 1998	+	?	−	+	?	?	+
Calabro et al. 2015	+	?	?	+	?	?	+
Chaiyawat and Kulkantrakorn 2012	+	+	−	−	+	?	−
Chang et al. 2012	+	+	?	+	+	?	+
Chen et al. 2011	+	+	?	+	+	?	+
di Lauro et al. 2003	+	+	?	+	+	?	−
Fong et al. 2013	+	+	?	+	+	?	+
Franceschini et al. 2009	+	?	?	+	−	?	?
Jongbloed et al. 1989	+	?	+	+	?	?	+
Katz–Leurer et al. 2003	+	?	?	+	?	?	+
Kwakkel et al. 1999	+	+	+	+	+	?	+
Liang et al. 2012	+	+	?	+	+	?	+
Lincoln et al. 1999	+	+	−	+	?	?	+
Min et al. 2008	?	?	−	?	?	?	+
Morone et al. 2011	+	?	?	+	+	?	+
Ochi et al. 2015	+	+	?	+	+	?	+
Rodrigues et al. 2017	+	+	?	+	?	?	+
Rosewilliam et al. 2012	+	+	?	+	+	?	?
Sackley et al. 2015	+	+	+	+	+	+	+
Sanchez–Sanchez et al. 2014	+	?	−	+	?	?	−
Tang et al. 2014	+	+	+	+	+	?	+
Volpe et al. 2008	?	?	?	+	+	?	+
Yang et al. 2014	+	?	−	?	+	?	+
Yue et al. 2012	+	+	−	?	+	?	+
Zhang and Li 2014	−	?	−	?	?	?	+

Figure 12- Risk of bias assessment for each study

Green circle = low risk, red circle = high risk, yellow circle = unclear risk

Table 7- Studies conducted in the acute – early subacute (<3 months) phase post-stroke

Study	Intervention Description	Intervention Duration	Intervention Delivered By	Stroke Severity Measure	Sample Size and Characteristics	Main Outcome Measures	Main Results	Quality of Evidence
AVERT Trial Collaboration Group (2015)	Very early mobilisation vs Usual care	Up to 14 days	PT and nursing staff	NIHSS	Very early mobilisation group NIHSS >16 (n=147) Usual care group NIHSS >16 (n=144)	Favourable outcome (mRS 0-2) and mortality at 3 months	No difference in favourable outcome or mortality between groups	High
Bagley *et al.* *(*2005)	Oswestry standing frame + standard physiotherapy vs Standard physiotherapy	14 daily sessions	PTs	BI^	Oswestry group (n=71) Median BI 1 (IQR 0-3) Control group (n=69) Median BI 2 (IQR 1-3)	RMI, BI, HADS, NEADL, RMA, MAS (balance, sit to stand sections), TCT, CSI, GHQ-28	No differences between groups for all outcome measures. No differences in number of treatment sessions between groups or number of staff members required to treat each patient.	Low
Bradley *et al.* (1998)	EMG biofeedback + conventional physiotherapy vs Placebo EMG + conventional physiotherapy	6 weeks	PTs	RMI	EMG group RMI ≤3 (n=7) Conventional PT group RMI ≤3 (n=6)	MBS, mAS, 10MWT, RMI, sensation, proprioception NEADL	No differences between groups for MBS, RMI, NEADL and 10MWT. No improvements in mAS, sensation, and proprioception for both groups.	Very low
Chang *et al.* (2012)	Robot-assisted BWS treadmill gait training + conventional physiotherapy vs Conventional physiotherapy	2 weeks	PTs	FAC LL FMA	Robot-assisted group (n=20) Mean FAC 0.5 (SD 0.5) Mean LL FMA 17.2 (SD 5.5) Conventional group (n=17) Mean FAC 0.4 (SD 0.5) Mean LL FMA 16.8 (SD 5.7)	FAC, LL MI, LL FMA, Peak VO_2	Improvements in LL FMA and peak VO_2 in robot-assisted gait training group. No improvements in LL MI and FAC for both groups.	Low

Chen *et al.* (2011)	Thermal stimulation + standard rehabilitation vs Standard rehabilitation	6 weeks	Thermal stimulation- PTs Standard rehabilitation- PTs and OTs	FAC LL FMA	Thermal stimulation group (n=17) Median FAC 0 (IQR 0-1) Median LL FMA 7 (4-11.5) Standard rehab group (n=16) Median FAC 0 (IQR 0-1) Median LL FMA 6 (4.3-12.0)	LL FMA, LL MRC, mAS, mMAS, PASS (trunk control items), BBS, FAC	Thermal stimulation group demonstrated greater recovery gains compared to standard rehabilitation group in all outcomes except PASS. No difference between groups in MAS.	Low
Di Lauro *et al.* (2003)	Intensive rehabilitative treatment vs Ordinary rehabilitative treatment	14 days	Therapists and nursing staff	BI^	Intensive rehab group (n=29) Mean BI 1.4 (SD 1.4) Ordinary rehab group (n=31) Mean BI 1.5 (SD 1.5)	BI, mNIHSS	No differences between groups in BI or mNIHSS	Very low
Fong *et al.* (2013)	Cueing wristwatch + conventional rehabilitation vs Sham wristwatch + conventional rehabilitation	3 weeks	Wristwatch- OTs Conventional rehab- OT, PT, ST	Motor FIM	Cueing wristwatch group (n=19) Mean motor FIM 25.6 (SD 8.3) Sham wristwatch group (n=16) Mean motor FIM 28.2 (SD 10.0)	UL FMA, FTHUE, motor FIM, total number of UL movements	No differences between groups for UL FMA, FTHUE and motor FIM. More total UL movements in cueing wristwatch group but not significantly different between groups.	Low
Franceschini *et al.* (2009)	BWS treadmill gait training + conventional treatment vs Conventional treatment	4 weeks	PTs	BI^	Treadmill training group (n=52) Median BI 6 (IQR 3-9) Median FAC 0 (IQR 0-0) Conventional group (n=45) Median BI 5 (IQR 3-7) Median FAC 0 (IQR 0-0)	MI, TCT, mRS, BI, FAC, AS, LL proprioception, 6MWT, 10MWT, BS, WHS	No differences between groups. All patients were able to walk at discharge.	Low

Katz-Laurer, Carmeli and Shochina, (2003)	Leg cycle ergometer + regular therapy vs Regular therapy	8 weeks	Leg cycle ergometer- PTs Regular therapy- PT, OT, ST	SSS	Leg cycle ergometer and regular rehabilitation groups- actual number of patients with severe stroke (SSS <30) not reported	FAI	No differences in decline in FAI between groups	Low
Liang *et al.* (2012)	Thermal stimulation + standard rehabilitation vs Standard rehabilitation	6 weeks	Thermal stimulation- PTs Standard rehabilitation- PTs and OTs	BI*	Thermal stimulation group (n=15) Mean BI 30.3 (SD 11.1) Standard rehab group (n=15) Mean BI 27.7 (SD 14.3)	LL FMA, LL MRC, FAC, BBS, mMAS, BI	Improvements in LL FMA, LL MRC, FAC and mMAS in thermal stimulation group post-intervention and at 3-month follow-up. Improvements in BBS and BI in thermal stimulation group only at 3-month follow-up. Except for LL-FMA, all improvements disappeared at 6-month and 12-month follow-up.	Low
Lincoln, Parry and Vass (1999)	Standard physiotherapy + additional qualified PT therapy vs Standard physiotherapy + additional PTA therapy vs Standard physiotherapy	5 weeks	PTs/ PTAs	BI^	Qualified PT group (n=94) Median BI 6 (IQR 3-9) PTA group (n=93) Median BI 6 (IQR 4-8) Standard PT group (n=95) Median BI 7 (IQR 3-9	RMA- arm scale, ARAT, THPT, grip strength, mAS, BI, MCA	No differences between the groups across all outcomes	Low
Min *et al.* (2008)	Acupuncture + systemic functional exercise vs Systemic functional exercise	? 3 months	Not reported	BI*	Acupuncture group (n=30) Mean BI 27.3 (SD 5.4) Systemic exercise group (n=30) Mean BI 28 (SD 4.5)	FMA, BI	Acupuncture group demonstrated greater improvements in FMA and BI compared to the systemic exercise group	Very low

Ochi *et al.* (2015)	Robot-assisted treadmill gait training + standard physiotherapy vs Conventional overground gait training + standard physiotherapy	4 weeks	Robot-assisted gait training- not reported Conventional gait training- PTs	FIM mobility FAC	Robot-assisted group (n=13) Median FAC 0 (IQR 0-1) Median FIM mobility 7 (IQR 6-10) Conventional group (n=13) Median FAC 1 (IQR 0-1) Median FIM mobility 7 (IQR 7-9)	FAC, FMA, LL muscle torque, 10MWT, FIM (mobility scores)	Robot-assisted gait training group demonstrated greater improvements in FAC and peak LL muscle torque compared to the conventional group	Low
Rosewilliam *et al.* (2012)	Wrist and finger NMES + usual care vs Usual care	6 weeks	NMES- staff group not reported, patients and carers Usual care- PTs	BI^	NMES group (n=31) Mean BI 4.4 (SD 3.9) Mean ARAT 0.0 (SD 0.0) Usual care group (n=36) Mean BI 2.5 (SD 2.9) Mean ARAT 0.6 (SD 3.5)	ARAT, BI, wrist AROM, wrist strength, grip strength	No differences in ARAT, BI or wrist AROM between groups. Improvements in wrist extensor and grip strength in the NMES group post-intervention but not maintained at follow-up.	Moderate
Sánchez-Sánchez *et al.* (2014)	Functionally targeted physiotherapy techniques + conventional physiotherapy vs Conventional physiotherapy	Not reported	PTs	BI*	Functional techniques group (n=5) Mean BI 13 (SD 10.95) Conventional therapy group (n=8) Mean BI 11.43 (SD 13.13)	BI	Functionally targeted physiotherapy group demonstrated greater improvement compared to the conventional physiotherapy group when using functional principal component analysis	Very low
Tang *et al.* (2014)	Contemporary Bobath approach with early sitting, standing, and walking vs Contemporary Bobath approach	8 weeks	PTs	STREAM, BBS	Early contemporary group (n=24) Mean STREAM 1.4 (SD 1.0) Mean BBS 0 (SD 0) Contemporary group (n=24) Mean STREAM 1.3 (SD 0.9) Mean BBS 0 (SD 0)	STREAM, BBS	Improvements in STREAM and BBS in the contemporary Bobath approach with early mobilisation group	Low

Table 8- Studies conducted in the acute – late subacute (<6 months) phase post-stroke

Study	Intervention Description	Intervention Duration	Intervention Delivered By	Stroke Severity Measure	Sample Size and Characteristics	Main Outcome Measures	Main Results	Quality of Evidence
Bai *et al.* (2014)	Staged physical rehabilitation interventions + routine care vs Routine care	6 months	PTs and OTs	BI*	Staged rehab group (n=83) Mean BI 28 (range 24-31) Routine care group (n=82) Mean BI 23 (range 19-27)	BI, mAS	Staged rehab group demonstrated higher BI scores than the routine care group at 1, 3- and 6-months post-stroke. 42.9% of patients in the routine care group demonstrated spasticity in at least one body part compared to 36.4% of patients in the staged rehab group.	Low
Calabrò *et al.* (2015)	Robotic verticalisation + standard physiotherapy vs Physiotherapy-assisted verticalisation + standard physiotherapy	6 weeks	PTs	PASS LL FMA	Robotic group (n=10) Mean PASS 3 (SD 1) Mean LL FMA 13 (SD 3) Physiotherapy group (n=10) Mean PASS 3 (SD 3) Mean LL FMA 12 (SD 6)	PASS, LL FMA, MRC, vertical posture tolerance	Both interventions were well tolerated. Robotic group demonstrated greater improvements in MRC, LL FMA and PASS compared to the physiotherapy group	Very low
Chaiyawat and Kulkantrakorn (2012a, 2012b)	Home based physiotherapy programme vs Usual care	6 months	PTs	BI*	Home PT group (n=30) Mean BI 31.7 (SD 5.9) Mean NIHSS 16.4 (SD 4.1) Usual care group (n=30) Mean BI 33.2 (SD 4.8) Mean NIHSS 17.8 (SD 3.9)	BI, HADS, mRS, EQ-5D	Home therapy group demonstrated greater improvements in BI, HADS, mRS and EQ-5D compared to the usual care group which were maintained at 2-year follow-up.	Very low
Jongbloed, Stacey and Brighton (1989)	Functional treatment approach vs Sensorimotor integrative treatment approach	8 weeks	OTs	BI*	Functional treatment group (n=13) Mean BI 31.5 Sensorimotor integrative treatment group (n=9) Mean BI 30	BI, meal preparation, eight subtests of Sensorimotor Integration Test Battery	No differences between groups on all outcome measures	Very low

Kwakkel *et al.* (1999); Kwakkel and Wagenaar (2002); Kwakkel, Kollen and Wagenaar (2002)	Additional UL training + usual care vs Additional LL training + usual care vs UL/LL pressure splint immobilisation + usual care	20 weeks	PTs and OTs	BI^	UL training group (n=33) Median BI 5 (IQR 3-7) LL training (n=31) Median BI 6 (IQR 3-8) Splint control group (n=37) Median BI 5.5 (IQR 3-7)	BI, FAC, ARAT, 10MWT, SIP, NHP, FAI	LL training group had significantly higher BI, FAC, walking speed and ARAT than splint control group post-intervention. UL training group had significantly higher ARAT than splint control group post-intervention. No significant differences in all outcomes were seen between groups from 6 months onwards up until 12-month follow-up.	Moderate
					CRP substudy UL training group (n=18) Mean BI 5.0 (SD 2.0) LL training (n=17) Mean BI 6.3 (SD 2.7) Splint control group (n=18) Mean BI 5.3 (SD 2.7)	10MWT, mean CRP of arm/leg movements	LL training group had significantly higher comfortable walking speed than UL and splint control groups post-intervention. No differences were seen for the mean CRP of arm/leg movements between groups.	
Morone *et al.* (2011, 2012)	Robot-assisted BWS treadmill gait training + standard physiotherapy vs Conventional gait training + standard physiotherapy	3 months	PTs	BI*	Robotic groups Low motricity (n=12) Mean BI 14.2 (SD 11.8) High motricity (n=12) Mean BI 20.0 (SD 17.2) Conventional groups Low motricity (n=12) Mean BI 7.9 (SD 8.9) High motricity (n=12) Mean BI 24.6 (SD 15.3)	FAC, LL AS, RMI, MI, TCT, CNS, BI, RS, 6MWT, 10MWT	Higher FAC in low motricity robotic training group compared to low motricity conventional training group post-intervention. At discharge, higher RMI, BI, TCT, RS and 6MWT in low motricity robotic training group compared to low motricity conventional training group. No differences were seen between the higher motricity groups post-intervention or on discharge. At 12-month follow-up, low motricity robotic training group had higher FAC, BI and RMI compared to low motricity conventional training group. No differences were seen between the higher motricity groups.	Very low

Yang, Liu and Ouyang (2014)	Acupuncture + rehabilitation training vs Rehabilitation training	8 weeks	Acupuncture- not reported Rehabilitation - PTs	NIHSS BI*	Acupuncture group (n=33) Mean NIHSS 25.5 (SD 2.4) Mean BI 39.4 (SD 3.9) Rehabilitation group (n=31) Mean NIHSS 24.1 (SD 3.1) Mean BI 38.1 (SD 4.3)	NIHSS, FMA, BI	Acupuncture group demonstrated higher scores on all outcome measures compared to the rehabilitation group	Very low
Yue, Jiang and Wong (2012)	Acupressure treatment + routine care vs Routine care	3 months	Nurses	BI*	Acupressure group (n=35) Mean BI 26.8 (SD 15.2) Routine care group (n=34) Mean BI 24.4 (SD 16.8)	FMA, BI	Acupressure group demonstrated greater improvements in BI and FMA only at 3-month time frame	Very low

ARAT- Action Research Arm Test, AROM- active range of movement, AS- Ashworth Scale, BBS- Berg Balance Scale, BDS- Becks Depression Scale, BI*- Barthel Index (original version scored out of 100), BI^ - Barthel Index (revised version score out of 20), BS- Borg Scale, BWS- bodyweight supported, CNS- Canadian Neurological Scale, CRP- continuous relative phase, CSI- Caregiver Strain Index, EMG- electromyography, EQ-5D-3L- EuroQoL questionnaire, FAC- Functional Ambulation Category, FAI- Frenchay Activities Index, FIM- Functional Independence Measure, FMA- Fugl-Meyer Assessment, FTHUE- Functional Test for the Hemiplegic Upper Extremity, GDS- Geriatric Depression Scale, GHQ-28- General Health Questionnaire-28, HADS- Hospital Anxiety and Depression Scale, LL- lower limb, MAS- Motor Assessment Scale, mAS- Modified Ashworth Scale, MCA- Motor Club Assessment, MI- Motricity Index, mMAS- Modified Motor Assessment Scale, MMSE- Mini-Mental State Examination, mNIHSS- Modified National Institutes of Health Stroke Scale, mRS- Modified Rankin Scale, MRC- Medical Research Council Scale for Muscle Strength, NEADL- Nottingham Extended Activities of Daily Living, NHP- Nottingham Health Profile, NIHSS- National Institutes of Health Stroke Scale, OT- occupational therapist, PASS- Postural Assessment Scale for Stroke Patients, PROM- passive range of movement, PT- physiotherapist, PTA- physiotherapy assistant, RMA- Rivermead Motor Assessment, RMI- Rivermead Mobility Index, RS- Rankin Scale, SIP- Stroke Impact Profile, SSS- Scandinavian Stroke Scale, ST- speech therapist, STREAM- Stroke Rehabilitation Assessment of Movement, TCT- Trunk Control Test, THPT- Ten-Hole Peg Test, TUG- Timed Up and Go, UL- upper limb, WHS- Walking Handicap Scale, 6MWT- 6 minute walk test, 10MWT- 10 metre walk test

Table 9- Studies conducted in the chronic (>6 months) phase post-stroke

Study	Intervention Description	Intervention Duration	Intervention Delivered By	Stroke Severity Measure	Sample Size and Characteristics	Main Outcome Measures	Main Results	Quality of Evidence
Rodrigues *et al.* (2017)	Robot-assisted BWS treadmill gait training with progressively increased speeds vs Robot-assisted bodyweight supported treadmill gait training with progressively decreased speeds	6 weeks	Not reported	LL FMA FAC	Faster speed group (n=10) Median FAC 1.5 (1–2) Mean LL FMA 19.5 (SD 4.6) Slower speed group (n=10) Median FAC 1 (1–2) Mean LL FMA 17.5 (SD 2.8)	FAC, TUG, 6MWT, 10MWT, BBS, LL FMA	Improvements in FAC, FMA, TUG and 6MWT in the slower speed group compared to the faster speed group.	Very low
Sackley *et al.* (2015)	OT intervention vs Usual care	3 months	OTs	BI^	OT intervention group- BI 0-4 n=268 BI 5-9 n=129 Usual care group- BI 0-4 n=234 BI 5-9 n=104	BI, RMI, GDS, EQ-5D-3L	No differences between the groups on any outcome measure at 3-, 6- and 12-months post-randomisation. Higher fall rate per resident in OT intervention group at 3 months.	High
Volpe *et al.* (2008)	Intensive standard UL therapy vs Intensive robot-assisted UL therapy	6 weeks	Therapists	NIHSS	Therapist group (n=10) Mean NIHSS 17 (SD 1) Robot group (n=11) Mean NIHSS 17 (SD 1)	FMA- UL, MRC-shoulder/ elbow, mAS, UL PROM, SIS, ARAT, BDS, shoulder dislocation, pain	No difference between groups in shoulder and elbow strength and motor function. No improvements in other outcome measures for both groups.	Very low
Zhang and Li (2014)	Trunk acupuncture + rehabilitation training vs Rehabilitation training alone	16 weeks	Not reported	BI*	Acupuncture group (n=30) Mean BI 22.50 (SD 6.79) Rehabilitation group (n=29) Mean BI 24.48 (SD 7.23)	BI, BBS	Acupuncture group demonstrated higher scores on BI and BBS compared to the rehabilitation group.	Very low

Table 10- Overview of measures of physical function and immobility-related complications

Body Function	Activity	Participation	Complications
Cardiorespiratory Function Aerobic capacity Borg scale Cardiovascular response Ventilatory response **Neurological Impairment** Canadian Neurological Scale National Institutes of Health Stroke Scale **Sensorimotor Function** Active range of movement- UL* Grip strength Fugl Meyer- UL Fugl Meyer- LL^ Fugl Meyer- UL and LL Motricity Index Medical Research Council strength- UL Medical Research Council strength- LL Medical Research Council strength- UL/LL Number of upper limb movements Sensation/proprioception Sensorimotor integration test * UL- upper limb ^ LL- lower limb	**Activities of Daily Living** Barthel Index Functional Independence Measure- motor Functional Independence Measure- total Modified Rankin Scale **Balance and Postural Control** Berg Balance Scale Postural Assessment Scale for Stroke Trunk Control Test Vertical Posture Test **Gait** Continuous relative phase between UL/LL Comfortable walking speed Maximal walking speed Functional Ambulation Category Number of independent walkers Time taken to walk 50 metres independently Walking Handicap Scale Six minute walking test 10 metre walking test **General Physical Activity** Modified Bobath Scale Motor Assessment Scale Rivermead Motor Assessment Rivermead Mobility Index Stroke Rehabilitation Assessment of Movement Timed Up and Go **Upper Limb Function** Action Research Arm Test Functional Test for Hemiplegic Upper Extremity Nine-Hole Peg Test	**Instrumental Activities of Daily Living** Frenchay Activities Index Nottingham Extended ADL Scale Meal preparation **Perceived Health Status** Stroke Impact Scale General Health Questionnaire-28 **Quality of Life** EQ-5D Nottingham Health Profile Sickness Impact Profile	**Adverse Effects** Falls Pain Shoulder dislocation **Caregiver Burden** Caregiver Strain Index **Depression** Geriatric Depression Scale Hospital & Depression Scale **Mortality** Mortality **Spasticity**

For each outcome, there was usually only one study investigating the effectiveness of a specific rehabilitation intervention in each time frame post-stroke. Twenty four studies were rated as providing very low or low-quality evidence for these outcomes. The two most commonly investigated interventions in these low or very low-quality studies were treadmill gait training (n=5) and acupuncture/acupressure (n=4). However, treadmill gait training involved many variations, including the use/non-use of robotic assisted devices and body weight suspension systems. Similarly, acupuncture was applied to different body regions and delivered over a range of timeframes. This interventional heterogeneity was one reason why meta-analysis was not performed in the systematic review.

The two studies that provided high-quality evidence demonstrated that their respective treatment interventions were no more effective at improving physical function than usual care (AVERT Trial Collaboration Group, 2015; Sackley *et al.*, 2015). However, survivors of severely disabling stroke comprised a smaller sample within these larger trials. As data analyses from these subgroups may not be powered to detect changes between the usual care and treatment interventions, caution is required in interpreting the studies' findings. In AVERT (A Very Early Rehabilitation Trial), very early and frequent mobilisation commencing within 24 hours post-stroke did not result in more severely disabled stroke survivors being less dependent in activities of daily living (ADLs) or surviving at three months post-stroke compared to usual care, which traditionally started more than 24 hours post-stroke (AVERT Trial Collaboration Group, 2015). In the OTCH (occupational therapy in care home) trial, a three-month, goal-orientated occupational therapy intervention for stroke survivors living in care homes did not result in improved ADL ability, increased quality of life, or reduced depression up to one year post-intervention (Sackley *et al.*, 2015).

The two studies that provided moderate-quality evidence demonstrated that their respective treatment interventions were effective at improving different components of physical function (Kwakkel *et al.*, 1999; Rosewilliam *et al.*, 2012). In both studies, improvements were seen in the different components of physical function that were specifically trained with the treatment intervention. Kwakkel *et al.* (1999) demonstrated that, compared to usual care, a 20-week course of additional upper limb therapy resulted in improvements in upper limb function. As well, additional lower limb training resulted in improvements in upper limb function, independence in ADLs, gait speed, and gait independence. However, these improvements were not maintained after six months post-stroke once the additional therapy had discontinued. Rosewilliam *et al.* (2012) demonstrated that the addition of wrist and finger neuromuscular electrical stimulation to usual therapy care resulted in improvements in wrist extensor and grip strength but no difference in upper limb function nor independence in ADLs. Like the Kwakkel *et al.* (1999) study, improvements were only seen during the intervention period and were not evident at the nine-month follow-up.

6.6 Discussion of Systematic Review

The systematic review demonstrated a paucity of high-quality evidence to support the use of rehabilitation interventions to improve physical function and reduce immobility-related complications after severely disabling stroke. Most studies were rated as providing low or very low-quality evidence due to high or unclear risk of bias and the recruitment of small samples of stroke survivors. As such, the low quality of studies limits the ability to generalise findings from these studies to the wider stroke population. The generalisability of study findings from the larger, high-quality studies to the wider stroke population may also be affected as these studies were not powered to detect changes between the usual care and treatments interventions within each subgroup. Therefore, study findings from these high-quality studies need to be interpreted with caution.

The two high quality studies demonstrated no significant benefit of very early mobilisation or occupational therapy provision in care homes on improved ADL ability for survivors of severely disabling stroke (AVERT Trial Collaboration Group, 2015; Sackley *et al.*, 2015). In AVERT, data appeared to favour usual care practice i.e. first mobilisation performed less intensively and more than 24 hours post-stroke. Whilst this finding did not achieve statistical significance, it seems clinically sensible. It has been reported that survivors of severely disabling stroke experience high levels of fatigue and reduced exercise tolerance in the first few days to weeks post-stroke (Asplund and Britton, 1989). This would suggest that severely disabled stroke survivors may not tolerate very early and intensive mobilisation within 24 hours post-stroke. Whilst less intensive and slightly later mobilisation for survivors of severely disabling stroke may seem clinically intuitive for healthcare professionals, particularly PTs, the AVERT study’s authors did not elaborate further on the optimal timing of early mobilisation for this cohort of the stroke population. As the optimal timing to mobilise survivors of severely disabling stroke remains unknown, an exploration of the factors that guide PTs to commence mobilisation for survivors of severely disabling stroke is warranted.

In the OTCH trial, one of the reasons hypothesised by the authors for the lack of effect of a three-month course of occupational therapy on improving ADL ability was the care home residents' disability severity and cognitive impairment, which may have limited their engagement in occupational therapy. However, a content analysis of the occupational therapy intervention demonstrated that the mean number of visits by occupational therapists (OTs) over the treatment period was 5.1 (SD 3.0) and the median visit time was 30 minutes (IQR 15 – 60 minutes). ADL and mobility training, which may have directly influenced ADL ability, only constituted 15% of occupational therapy time. Although the session duration and frequency were dependent upon the care home resident's ability to engage in occupational therapy, it is feasible that a more frequent occupational therapy intervention focussing on ADL training may have resulted in improved ADL ability. This concept of training specificity on improved function was evident in the two moderate-quality studies investigating additional upper and lower limb training, and neuromuscular electrical stimulation (Kwakkel *et al.*, 1999; Rosewilliam *et al.*, 2012). In both studies, significant improvements were seen in the components of physical function that were being specifically trained. However, improvements were not maintained once the interventions ceased. The lack of carryover in both studies may highlight issues with skill retention for survivors of severely disabling stroke, suggesting the need for some form of maintenance therapy to maintain physical function.

Three observations are apparent from reviewing the included studies that may guide the direction of future research in severely disabling stroke. The first observation is that the systematic review consisted of many low-quality, single-centre RCTs that recruited small numbers of stroke survivors and investigated a broad range of interventions. In order to improve the generalisability of future research to the wider stroke population, there is a need for larger, high-quality, multi-centre RCTs investigating fewer interventions. However, RCTs, which focus on outcome evaluations, may be insufficient in themselves to understand why certain complex healthcare interventions do or do not work (Craig *et al.*, 2013; Moore *et al.*, 2015). Therefore, future research should incorporate process evaluations alongside outcome evaluations in the evaluation of rehabilitation interventions for survivors of severely disabling stroke. The second observation is that most studies were completed in the first three months after severely disabling stroke within an inpatient stroke unit or rehabilitation setting. However, survivors of severely disabling stroke may be less likely to engage and participate in therapy in the first few days to weeks post-stroke (Asplund and Britton, 1989). As such, the acute to early subacute stage post-stroke may not be the optimal time to engage survivors of severely disabled stroke in research trials that require strict adherence to intensive treatment interventions. Therefore, a greater proportion of future research should be conducted in the late subacute to chronic phase post-stroke when engagement in therapy may be higher. The third observation is that there were relatively fewer outcomes for post-stroke complications than for the components of physical function. As the primary focus of stroke rehabilitation is to optimise functional recovery (Intercollegiate Stroke Working Party, 2016; Winstein *et al.*, 2016; Stroke Foundation, 2019b; Teasell *et al.*, 2020), it may be that the primary focus of stroke rehabilitation research investigating the effectiveness of rehabilitation interventions is on improving functional recovery rather than reducing post-stroke complications. However, the high prevalence of immobility-related post-stroke complications in different phases of the stroke pathway has been reported by several authors (Langhorne *et al.*, 2000; Roth *et al.*, 2001; Sackley *et al.*, 2008; Kuptniratsaikul *et al.*, 2009, 2013). Therefore, there is merit in exploring the effect of rehabilitation interventions in the prevention and management of immobility-related post-stroke complications in severely disabling stroke.

The systematic review has several strengths that need to be reported. Firstly, this was the first systematic review to investigate rehabilitation interventions specifically for survivors of severely disabling stroke, who tend to be underrepresented in stroke rehabilitation research (Gladman and Sackley, 1998; Rodgers, 2000; Wyller, 2000; Sterr and Conforto, 2012). Due to the relatively limited amount of research involving survivors of severely disabling stroke, this systematic review may be viewed as important research in improving our understanding of effective management strategies for this cohort of the stroke population. Secondly, the outcomes of the review focussed on physical function and immobility-related post-stroke complications. Whilst improving physical function is a recognised aim of stroke rehabilitation, immobility-related post-stroke complications are known to be high in severely disabling stroke and contribute to high levels of caregiver burden (Rigby, Gubitz and Phillips, 2009). Consequently, this systematic review has identified areas for future rehabilitation research related to reducing or managing immobility-related post-stroke complications. Finally, the systematic review included studies across the whole stroke pathway and was not just confined to a particular phase post-stroke, such as the acute or subacute phases. Although most studies were conducted in the first six months after severely disabling stroke, the inclusion of research studies in the chronic phase post-stroke further improves our understanding about how to manage survivors of severely disabling stroke in the long term more effectively.

The systematic review has several weaknesses that need to be mentioned. The first weakness relates to the classification of severely disabling stroke. It has been reported by Hayward *et al.* (2014) and Peters *et al.* (2014) that defining severely disabling stroke is difficult due to different criteria used to classify severity. The use of objective scores on validated outcome measures to classify stroke severity in this systematic review was deemed necessary to ensure that participants had sustained a severely disabling stroke. In this review, the BI was the most commonly used measure to classify stroke severity, reported in 17 out of 28 studies. Using a pre-specified score on the BI to classify severely disabling stroke (≤9/20 or ≤45/100) enabled the identification of individuals with severely disabling stroke. However, the use of an alternative measure of stroke severity, such as the NIHSS, may have resulted in the inclusion of a study with participants with a slightly different clinical presentation than participants measured with the BI. Alternatively, studies that used a different scoring system to classify stroke severity may have been excluded. However, these studies were discussed in detail amongst three review authors to determine suitability for inclusion. Therefore, it is likely that the number of relevant studies excluded from the review was minimal. The second weakness relates to the use of data from subgroups within larger clinical trials. Minimum sample sizes for RCTs are often calculated in order to increase their statistical power in detecting a real difference between the arms of the RCT. Whilst specific data for severity subgroups were provided in the AVERT and OTCH trials, subgroup analyses may not be powered to detect changes between the arms of each trial. Therefore, caution is required in the interpretation of findings from these trials.

6.7 Integration with Other Research Components

In the previous chapter, an online questionnaire identified the most frequently used interventions by UK PTs and OTs in the rehabilitation of severely disabling stroke. In the current chapter, a systematic review identified the evidence for interventions used to improve physical function and reduce immobility-related complications after severely disabling stroke. Table 11 demonstrates a mismatch between the most frequently used interventions reported in the therapist survey and the available research evidence demonstrating their effectiveness. Table 12 demonstrates a mismatch between the range of interventions investigated in the systematic review and their frequency of use reported in the therapist survey.

Table 11- Research evidence for the most frequently used rehabilitation interventions after severely disabling stroke

Most Frequently Used Interventions	Available Research Evidence
Positioning	No available research
Training/education- positioning	? component of Sackley et al. study
Training/education- upper limb handling	? component of Sackley et al. study
Sitting balance practice	No available research
Bed mobility practice	No available research
Care plan- seating	? component of Sackley et al. study
Active/assisted exercises	? component of Kwakkel et al. study
Seating trials	No available research
Stretches	No available research
Training/education- seating	? component of Sackley et al. study

One possible reason for this mismatch may be due to geographical variations in clinical practice. For example, the acupuncture studies were performed in China, where this treatment modality may be more commonly used. However, use of acupuncture is not routinely performed in stroke rehabilitation within Western countries, such as the UK. Another possible reason for the mismatch is that some studies investigated the effect of a combination of interventions packaged together and labelled as “physiotherapy” or “occupational therapy”, whereas other studies investigated the effect of sole interventions. For example, the very early mobilisation intervention in AVERT consisted of sitting, standing, and walking, whereas neuromuscular electrical stimulation was the sole intervention under investigation in Rosewilliam and colleagues’ study. As a result, some of the most commonly used interventions may have formed part of a larger package of therapy provided to survivors of severely disabling stroke but were not individually investigated. Therefore, it is not possible to know whether these individual interventions are or are not effective at improving physical function and/or reducing immobility-related complications after severely disabling stroke.

Table 12- Frequency of use of interventions investigated in the systematic review

RCT Interventions	**Frequency of Use Reported in Survey**
Acupressure	Never used
Acupuncture	Never used
Bodyweight supported treadmill training	Rarely used
Cueing wristwatch	Never used
Electromyographic biofeedback	Never used
Leg cycling	Sometimes used
Neuromuscular electrical stimulation	Sometimes used
Robotic bodyweight supported treadmill training	Never used
Robotic treadmill training	Never used
Robotic verticalisation	Sometimes used
Standing frame	Sometimes used
Thermal stimulation	Never used
Upper limb training	Often used
Very early mobilisation	Sometimes used

The mismatch between current clinical practice and the available research evidence suggests that the decision to select interventions in the rehabilitation of severely disabling stroke is not based on the best available research evidence, as conceptualised within EBP. Potential factors that may guide the selection of rehabilitation interventions identified in the previous chapter included professional role differences and organisational function. However, it is not clear how these factors actually guide therapist decision making in the rehabilitation of severely disabling stroke. It is also not clear if other factors identified in previous research, such as clinical experience, training and in-service education, patient preferences, and feedback from work colleagues and family members, guide therapist decision making (Kuipers, McKenna and Carlson, 2006; Kleynen *et al.*, 2017; Sadler *et al.*, 2017). In order to understand decision making more fully, it is necessary to explore the contextual practice of therapists in more detail. This exploration will provide insight into why therapists select or do not select different rehabilitation interventions, which has direct implications on outcome after severely disabling stroke. Therefore, the next chapter will focus on an exploration of therapy practice in the rehabilitation of severely disabling stroke using ethnography.

6.8 Chapter Summary

A systematic review is a recognised method to identify, select, and critically appraise relevant research in order to address a clearly formatted research question. In this research, it has been used to investigate the effectiveness of rehabilitation interventions on improving physical function and reducing immobility-related complications after severely disabling stroke. Results from the review identified a paucity of high-quality evidence demonstrating the effectiveness of various interventions in the rehabilitation of severely disabling stroke. Combined with the findings from a survey of therapy practice, there is a mismatch between current clinical practice and the available research evidence in the rehabilitation of severely disabling stroke. This would suggest that the selection or non-selection of rehabilitation interventions by therapists is guided by factors other than the best available research evidence, as conceptualised within EBP. In order to understand therapist decision making in the rehabilitation of severely disabling stroke more fully, an ethnographic exploration of therapy practice will be presented in subsequent chapters.

Chapter 7- Setting the Scene: An Ethnographic Exploration of Therapy Practice in the Rehabilitation of Severely Disabling Stroke

7.1 Introduction

This chapter presents the third and main study of the research, which is an ethnographic exploration of therapy practice in the rehabilitation of severely disabling stroke. It will commence with a review of ethnography and an explanation of the rationale for using ethnography to understand therapist decision making in the rehabilitation of severely disabling stroke. It will continue with a discussion of the selection and recruitment of study sites and participants. It will conclude with a description of the study sites and participants, the methods used for data collection and analysis, and how trustworthiness was established during the research process.

7.2 Ethnography

7.2.1 Understanding Ethnography

Ethnography can be understood as the study or description of people and their behaviour in social settings (Madden, 2010; O'Reilly, 2012; Holloway and Galvin, 2016; Hammersley and Atkinson, 2019). Derived from the Greek words "ethnos", meaning people, and "-graphy", mean writing, ethnography translates as "a writing of people" (Holloway and Galvin, 2016; pg. 159). Accordingly, ethnography can refer to both a methodology- the research strategy- and a product- the written account of an ethnographic project (Savage, 2000, 2006). An ethnographic account investigates what people say and what people do and seeks to describe the perspectives and meanings constructed by people in their usual settings (Madden, 2010; O'Reilly, 2012). Although ethnography has its roots in early 20th century social anthropology with the exploration of small non-Western communities, modern ethnography usually involves the exploration of settings more local to the ethnographer (Hammersley and Atkinson, 2019).

Ethnographic methods have been used in healthcare for several decades and can benefit healthcare practice in several ways (Long, Hunter and Van Der Geest, 2008). In her review of the value of ethnography in healthcare, Savage (2006) suggested that ethnography can contribute to our understanding of evidence-based practice (EBP) by exploring the context in which healthcare interventions are delivered and the interaction between different forms of evidence, such as clinical guidelines and the patient's lived experience. Holloway and Galvin (2016) proposed that patient care can be improved by exploring clinical practice and identifying clinical problems through ethnography. For example, Coughlin (2013) examined nurses' and patients' perceptions of care received during main hospital events, such as hospital admission or preparation for surgery, in a hospital located in north-eastern USA. In her study, patients frequently reported poor sleep due to frequent nocturnal disruptions, which led to changes in nursing practice during night shifts. Due to the use of ethnography to understand and address healthcare problems, Savage (2006) and Holloway and Galvin (2016) have described healthcare ethnography as applied research, or research that seeks to solve practical problems.

7.2.2 Considerations in Ethnography

Like any research approach, there are several considerations and potential issues when undertaking ethnography. Firstly, ethnography primarily relies on participant observation and interviews as data collection methods. Prolonged observation of the setting under investigation, necessary to develop a deep understanding of people's behaviours, is relatively time consuming and costly compared to other data collection methods (Savage, 2000; Madden, 2010; O'Reilly, 2012). Therefore, the ethnographer needs to ensure sufficient resources are allocated when undertaking ethnography. Secondly, LeCompte (1987) highlighted the subjective nature of ethnography and the influence of researcher bias on the research process. Consequently, different researchers may interpret observations differently, resulting in multiple and possibly conflicting accounts of an observed situation. However, Creswell and Creswell (2018) argued that, in line with an interpretivist approach to social inquiry, reality is complex and may be perceived and interpreted differently by different individuals. Therefore, there may never be one singular account that fully represents the reality of an observed situation. Rather than dismissing researcher bias, Finlay (2002) reported that use of reflexivity- "where researchers engage in explicit, self-aware analysis of their own role" (Finlay, 2002, p. 531)- enables the researcher to acknowledge their influence on the research process and the reader of a written ethnography to understand how the researcher made sense of their observations. Reflexive strategies, such as use of a reflective diary, are considered essential tools for the ethnographer to demonstrate transparency in their research decisions (Finlay, 2002; Holloway and Galvin, 2016). Thirdly, ethnographic findings have been criticised as having limited generalisability to other settings due to the contextually specific nature of ethnography (Savage, 2000; Holloway and Galvin, 2016). However, in her review of ethnography in healthcare, Savage (2000) highlighted that whilst ethnography does not primarily seek to provide generalisable findings, the written ethnography should contain sufficiently detailed information for the reader to determine how applicable the findings are to other healthcare settings.

A final consideration related to the current study involves the use of insider research, where the researcher investigates their own social setting or culture (Labarre, 2002). Holloway and Galvin, (2016) defined culture as the way of life of a group- their ideas, customs, and behaviours- that is socially constructed and transmitted. Savage (2006) reported that healthcare ethnographers often investigate settings and cultures with which they are familiar or part of. Therefore, ethnography in healthcare often demonstrates varying degrees of insider research. Several authors working in health and social care have highlighted a range of benefits and challenges of insider research (Bonner and Tolhurst, 2002; Simmons, 2007; Zaman, 2008; Leigh, 2014). In terms of reported benefits, insider researchers may have easier access to a setting and are not seen as strangers but cultural members. Therefore, insider researchers may not need to spend as much time immersing themselves in the social setting as they are already based in the "field". Insider researchers also possess a deeper understanding of the culture being investigated, which may lead to the generation of greater insights. Finally, as insider researchers are more familiar with cultural processes and roles, this reduces the need for participants to explain these aspects, thereby maintaining the flow of normal social interactions. In terms of reported challenges, insider researchers may find it difficult to become "cultural strangers", questioning the familiar and normative assumptions of clinical practice. Insider researchers may also find it difficult to demonstrate sufficient objectivity in relation to their own setting and be biased in their analysis and interpretation of findings. Finally, research involving one's peers when the researcher is in a position of seniority or authority may give rise to ethical issues, such as coercion and inadvertent disclosure of sensitive information. As varying degrees of insider research was conducted during the study, including an investigation of therapy practice where I work clinically, this concept will be explored throughout the chapter.

7.3 Rationale for Ethnography

There are several reasons why ethnography is a useful approach to investigate therapy in the rehabilitation of physical function after severely disabling stroke. Understanding the decision-making process of physiotherapists (PTs) and occupational therapists (OTs) in the selection of rehabilitation interventions is one of the research's objectives. As ethnography has been previously used in healthcare research exploring the decision-making processes of healthcare professionals (Hancock and Easen, 2006; McGlinchey and Davenport, 2015; Barken, Thygesen and Söderhamn, 2016; Taylor, Jones and McKevitt, 2018; Spinnewijn *et al.*, 2020), it may be considered an appropriate research approach to achieve the research's aim.

The previous chapter identified a mismatch between the most frequently used interventions by therapists and the available research evidence investigating the effectiveness of interventions in the rehabilitation of severely disabling stroke. This finding suggests that the decision to select interventions in the rehabilitation of severely disabling stroke is not based on the best available research evidence. Potential factors that may guide the selection of rehabilitation interventions identified in previous research include clinical experience, training and in-service education, the patient's presentation, feedback from work colleagues or family members, and organisational factors (Kuipers, McKenna and Carlson, 2006; Kleynen *et al.*, 2017; Sadler *et al.*, 2017). One way to identify which factors guide the choice of interventions in the rehabilitation of severely disabling stroke is to explore the context in which they are delivered, such as the stroke service that therapists work in. This approach seems reasonable as stroke rehabilitation interventions are not delivered in isolation- they form part of a larger package of therapy provided by therapists working within a wider multidisciplinary team. Care delivered by these teams may be guided by the aims of the stroke service in which the team operates, as identified in the Survey chapter. As ethnography involves the contextual study and description of people, it may be considered a suitable approach to understand the wider contextual factors guiding therapist decision making in the rehabilitation of severely disabling stroke.

7.5 Ethnography- Methods

7.5.1 Aim

The aim of the ethnography was to understand what factors guide PTs and OTs to select particular interventions in the rehabilitation of physical function after severely disabling stroke.

7.5.2 Site Selection

Purposive sampling was used to select stroke services to investigate therapy practice. Several factors were considered in the selection of stroke services. During my PhD, I was working clinically two days per week in London. Due to the need to spend prolonged time undertaking observational fieldwork, it was not practically feasible to investigate therapy practice in stroke services outside of greater London whilst working clinically. Fortunately, the variety of stroke services located in London enabled an exploration of therapy practice within the first 12 months after severely disabling stroke. These services included hyperacute stroke units (HASUs), stroke units (SUs) and community stroke services (Figure 13).

Determining the number of different stroke services to include in the study was based on the need to capture rich, detailed data from a range of stroke services within the timescales of the PhD. Factors considered in the identification and selection of individual stroke services included:

- the average time stroke survivors spent in each type of stroke service, based on published pathway design criteria and length of stay data from SSNAP, the Sentinel Stroke National Audit Programme (Sentinel Stroke National Audit Programme, 2020)
- the likelihood that severely disabled stroke survivors would access that service, based on published pathway design criteria, eligibility criteria for post-acute stroke services, and personal knowledge of the London stroke pathway
- variations in care provided by a particular type of stroke service, based on published pathway design criteria, personal knowledge of the London stroke pathway, and stroke service performance data from SSNAP (Sentinel Stroke National Audit Programme, 2020)
- the connection between stroke services e.g. selecting an SU and then selecting a community stroke service that accepts referrals from this SU

- geographical locations of stroke services across London due to differences in sociodemographic attributes of people living in inner and outer London, such as age, ethnicity and social deprivation, which are associated with stroke prevalence and severity (Healthcare for London, 2008; Boehme *et al.*, 2014; Corso *et al.*, 2014)
- the willingness of stroke services to participate in the study

Based on consideration of these factors, five stroke services- one HASU, two SUs and two community services- were selected for the study. Details regarding these services are presented later in the chapter.

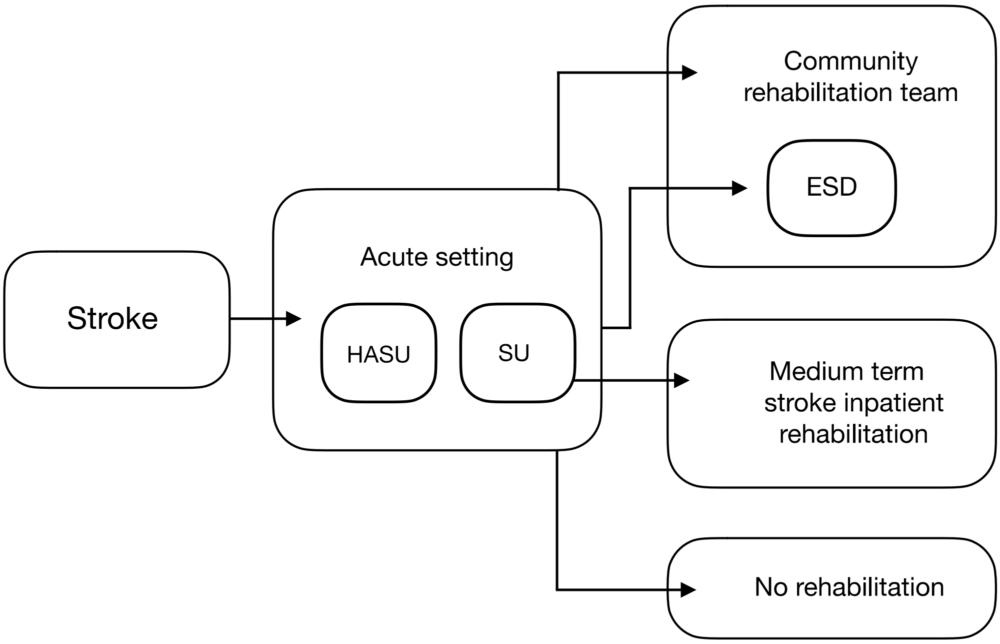


Figure 13- Overview of the London stroke care pathway

7.5.3 Ethical Considerations and Ethical Approval

As the study involved National Health Service (NHS) patients and staff, the study required ethical approval from the Health Research Authority (HRA) and research and development (R&D) approval from each participating stroke service. The nature of the study raised two key ethical issues that were detailed in the application form and discussed during the Research Ethics Committee (REC) meeting.

The first ethical issue was patient-related. Achieving the study's aim required the inclusion of severely disabled stroke survivors, some of whom lack capacity to make decisions for themselves due to the extent of their neurological impairments. Whilst the observational nature of the research was considered to pose a low risk of harm to stroke survivor participants, making decisions on behalf of a stroke survivor who lacks decision-making capacity, even with the involvement of those individuals who know the stroke survivor, contravenes their human right of self-determination and autonomy (Samanta and Samanta, 2005). However, speaking to a stroke survivor and carer group before the REC meeting highlighted the importance of recruiting stroke survivors who lack decision-making capacity. Several group members stated that it would be "unethical" not to recruit survivors just because "they can't talk for themselves". Their comments echoed the views of several researchers who have expressed concern about the underrepresentation of severely disabled stroke survivors in research (Gladman and Sackley, 1998; Rodgers, 2000; Wyller, 2000; Sterr and Conforto, 2012). After some deliberation during the REC meeting, the REC was supportive of the recruitment of stroke survivors who lack capacity provided several strategies were employed. These strategies included establishing the stroke survivor's wishes to be involved in research by seeking the opinions of individuals who know the stroke survivor; appointing an independent consultee to oversee the recruitment of every stroke survivor lacking capacity; continually assessing the decision-making capacity of these stroke survivors and re-consenting them to participate if they regained their decision-making capacity; and using the clinical team, particularly speech and language therapists, to facilitate communication.

The second ethical issue was therapist-related. Undertaking insider research as a senior therapist, particularly with therapist colleagues that I work with, introduces an asymmetrical power relationship between myself and therapist participants. Several researchers have raised concerns about power asymmetry in qualitative research studies (Clifford and Marcus, 1986; Labarre, 2002; Simmons, 2007). For example, undertaking fieldwork can be seen as problematic because it grants the researcher a power to represent and interpret the actions of others. As well, status in any variety of forms constitutes power and may be perceived as threatening by potential participants. Although I have no managerial responsibilities within the physiotherapy team, PT colleagues may feel coerced into participating in the study "for the sake of colleagueship" (Holloway and Galvin, 2016; pg. 62). Although the REC were less concerned about the use of insider research than the involvement of severely disabled stroke survivors, they agreed with the following proposed strategies to alleviate any potential issues of insider research and power asymmetry: reiterating the voluntary nature of the study to potential participants; providing as much up-front information about the study to facilitate informed consent; continually reflecting upon my effect on the research process and on the therapist participants through use of a reflective diary; and allowing a therapist to discontinue their involvement in the study for any reason and without needing to explain their reasoning. The REC also stipulated that "transcribed audio not be given to participants to check as this could cause unnecessary distress". As the process of study participants verifying the accuracy of study data, termed member checking, is one strategy to ensure the trustworthiness of qualitative research (Lincoln and Guba, 1985), the impact of the REC's stipulation will be discussed later in the chapter.

HRA and ethical approval for the research was granted in just under three months (Appendix F). Ethical approval was granted by the National Research Ethics Committee London- Queen Square (REC reference: 17/LO/1243; IRAS project ID: 218301). As the five stroke services identified for inclusion in the study were managed by three NHS Trusts, R&D approval was required from three separate NHS Trusts. R&D approval took between four to six months in each Trust. In addition, the study was accepted by the National Institute for Health Research Clinical Research Network (NIHR CRN) portfolio of studies (NIHR Portfolio Study ID 33521). Portfolio inclusion raised the profile of the study, resulting in expressions of interest from many acute stroke services across England. Consequently, portfolio inclusion facilitated the process of negotiating and gaining access to the individual stroke services.

7.5.4 Study Settings and Participants

The process of recruiting study participants was similar in each stroke service and detailed in the application form submitted to the REC. After obtaining local R&D approval, I held a face-to-face meeting with potential therapist participants in the presence of lead therapy staff. Potential therapist participants were PTs, OTs, and their assistant staff members working on the stroke service at the time of the study. The meeting involved a concise presentation outlining the study, which was followed by an opportunity to ask questions about study participation. This discussion enabled me to gauge therapists' initial response about being involved in the study. In his ethnography exploring the hospital ward culture in Bangladesh, Zaman (2008) highlighted the potential difficulty faced by qualitative researchers in gaining psychological access- developing rapport and establishing trust with study participants- in clinical settings due to two reasons. Medical professionals, particularly doctors, have historically resisted attempts of external review, which may manifest as a reluctance to being observed. Medical professionals may also be suspicious about the lack of upfront transparency characteristic of some exploratory research approaches, for fear of “doctor bashing”. Whilst Zaman’s study did not involve allied health professionals, I was aware that therapists may be similarly reluctant in being observed by another person, albeit a fellow therapist. I was also aware of the potential issues raised by conducting insider research when discussing the study with my work colleagues. Fortunately, therapists did not express any particular concerns during the discussion. Subsequently, participant information sheets were provided to all potential participants (Appendix G), who were given at least 24 hours to decide about study participation. An informal follow-up meeting occurred, usually two to three days later, to answer any outstanding questions and consent any interested therapist participants.

Once consented, study therapists identified potential stroke survivor participants. In the HASU and SUs, this was any stroke survivor with an initial National Institutes of Health Stroke Scale (NIHSS) score ≥16. In the community stroke services, this was any stroke survivor with a Barthel Index (BI) score ≤9 or Modified Rankin Scale (mRS) score ≥4. These values were chosen to be consistent with the systematic review on the effectiveness of interventions in the rehabilitation of physical function after severely disabling stroke (McGlinchey *et al.*, 2020). Therapist participants approached potential stroke survivor participants, usually in the presence of a family member, regarding study participation. If stroke survivors and/or their family member were interested in study participation, I approached the stroke survivor in the presence of their family, discussed the study with them, and provided a patient information sheet designed according to the stroke survivor’s level of comprehension (Appendix H). A similar amount of time was provided to stroke survivor participants to decide about study participation and consent was obtained from interested stroke survivors. If a stroke survivor was unable to provide informed consent themselves due to communicative or cognitive impairments, consultees (e.g. a family member or friend) or independent consultees (e.g. ward matron) were contacted to enable stroke survivor participation.

The therapist and stroke survivor participants were considered the primary study participants. In total, 79 primary study participants were recruited to the study- 30 PTs, 22 OTs, and 27 stroke survivors. It was anticipated that observed sessions involving these participants may involve other staff members, such as nurses and speech and language therapists, as well as carers of stroke survivors. In order to observe these sessions, these additional staff members and carers were invited to participate in the study as secondary study participants. Whilst observed sessions did not focus on the role of the secondary study participants, their agreement to participate in the study was required in order to capture observations involving them. As some of the secondary study participants were not known at the onset of fieldwork in each stroke service, informed consent was obtained from secondary study participants as the study proceeded. A similar informed consent process was used for secondary study participants to decide about study participation. Fortunately, all but two secondary study participants consented to participate, which enabled the observation sessions to proceed as planned. In total, 37 secondary study participants were recruited to the study- 31 staff members (nurses, doctors, and speech and language therapists) and six carers.

As ethnography can reveal contextually sensitive behaviours and practices, data that could identify individual stroke services and study participants have been anonymised. Pseudonyms have been used to refer to the stroke services and study participants, and identifying features have been modified to prevent unnecessary disclosure. Saunders, Kitzinger and Kitzinger (2015) suggested that guaranteeing complete anonymity of qualitative data may be unachievable in practice as there will always be at least one individual with access to participant information. In this study, the SU where I work clinically was included as one of the study’s stroke services. Therefore, readers of this thesis may deduce this stroke service through the accounts provided. However, consideration has been given to how findings are presented that respects confidentiality whilst maintaining the integrity of data.

An overview of each of the stroke services is presented in Table 13. An overview of the range, number, and length of sessions and meetings observed during the fieldwork is presented in Table 14. The following section will provide contextual background information on each service.

Table 13- Stroke service overview

	Anderson Stroke Unit	Fergusson Stroke Unit	Peterson Hyperacute Stroke Unit	Stephenson Community Stroke Team	Williamson Stroke Rehab Team
Location	Inner South London	North Central London	Inner North London	South East London	Outer South East London
Number of beds	22 beds	17 beds	18 beds	-	-
Catchment Area	-	-	-	640,000	330,000
Length of stay (Median, IQR)	19.1 days (9.9 – 38)	16.1 days (8.8 – 33)	2.2 days (1.3 – 4)	22 days* (4.3 – 55)	14.3 days* (9.3 – 15.3)
Therapy Staffing	1 B8 OT 0.5 B8 PT 1 B7 OT 1.5 B7 PT 1 B6 OT 1 B6 PT 1 B5 OT 1 B5 PT 1 B3 OTA 1 B3 PTA	1 B7 OT 1 B7 PT 1 B6 OT 1 B6 PT 1 B5 OT 1 B5 PT 0.5 OTA 0.5 PTA	1 B7 OT 1 B7 PT 1 B6 OT 1 B6 PT 1 B5 OT 1 B5 PT	2 B7 OT 1.8 B7 PT 3 B6 OT 3 B6 PT 2 B3 RSW 2 B3 RSW	1 B7 OT 0.8 B7 PT 2 B6 OT 2 B6 PT 1 B5 OT 1 B5 PT 0.5 B3 OTA 0.5 B3 PTA
Fieldwork Dates	December 2017 – March 2018	June – September 2019	June – September 2019	January – May 2019	February – June 2019

OT- occupational therapist, PT- physiotherapist, OTA- OT assistant, PTA- PT assistant; RSW- rehab support worker
“B” refers to banding e.g. B8 – Band 8 * ESD length of stay only- community rehabilitation length of stay not available

Table 14- Overview of participant observation sessions

	Anderson Stroke Unit	Fergusson Stroke Unit	Peterson Hyperacute Stroke Unit	Stephenson Community Stroke Team	Williamson Stroke Rehab Team
Observation Hours (Minutes)	104 (6240)	118 (7080)	56 (3360)	66 (3960)	62 (3720)
Goal setting sessions	12 sessions- 560 minutes (range 25 – 60 minutes)	10 sessions- 300 minutes (30 minutes each)	-	-	-
Team meetings	10 meetings- 690 minutes (range 35 – 120 minutes)	19 meetings- 760 minutes (40 minutes each)	11 meetings- 495 minutes (45 minutes each)	6 meetings- 300 minutes (50 minutes each)	7 meetings- 660 minutes (range 30 – 120 minutes)
Occupational therapy sessions	22 sessions- 980 minutes (range 20 – 60 minutes)	18 sessions- 820 minutes (range 20 – 80 minutes)	2 sessions- 100 minutes (range 40 – 60 minutes)	14 sessions- 920 minutes (range 20 – 80 minutes)	13 sessions- 660 minutes (range 25 – 65 minutes)
Physiotherapy sessions	29 sessions- 1390 minutes (range 20 – 60 minutes)	31 sessions- 1530 minutes (range 40 – 80 minutes)	4 sessions- 220 minutes (range 50 – 60 minutes)	12 sessions- 700 minutes (range 60 – 80 minutes)	17 sessions- 1000 minutes (range 45 – 60 minutes)
Joint therapy sessions	14 sessions- 560 minutes (range 20 – 70 minutes)	13 sessions- 740 minutes (range 40 – 70 minutes)	14 sessions- 720 minutes (range 20 – 60 minutes)	16 sessions- 1150 minutes (range 20 – 80 minutes)	6 sessions- 530 minutes (range 20 – 80 minutes)
Ward/office observation	54 observations- 2060 minutes (range 15 – 100 minutes)	65 observations- 2930 minutes (range 30 – 100 minutes)	47 observations- 1825 minutes (range 30 – 90 minutes)	23 observations- 890 minutes (range 30 – 60 minutes)	28 observations- 870 minutes (range 15 – 60 minutes)

Anderson Stroke Unit, Great Southern Hospital

Anderson SU is a 22-bedded SU located in Great Southern Hospital, a hospital based in inner South London. At the time of the fieldwork, Anderson SU provided acute and subacute stroke rehabilitation to residents local to three London boroughs. It received most of its stroke survivors from one HASU, which was also located in South London but operated by another hospital Trust. Most survivors of severely disabling stroke spent their whole inpatient rehabilitation time on Anderson SU before being discharged to the community, often with community-based therapy. Less than 10% of survivors of severely disabling stroke on Anderson SU were referred to specialist inpatient stroke rehabilitation units. This practice may have reflected adherence to the London stroke model, which was developed with significant input from one of Anderson SU's stroke consultants. Data from SSNAP suggested that Anderson SU was a high performing SU, rated as either an "A" or "B" level stroke service (Sentinel Stroke National Audit Programme, 2020). SSNAP grading is based upon adherence to process measures, such as the timely completion of assessment and discharge tasks, and the provision of regular, intensive therapy (Sentinel Stroke National Audit Programme, 2019).

Anderson SU was well-staffed in terms of therapy cover, meeting the Pan-London staff to patient ratio recommendations. However, fieldwork on Anderson SU occurred during the winter season, including the Christmas and New Year's period. Due to more staff taking annual leave over the festive period and experiencing seasonal illnesses, such as colds and flu, therapy staffing, particularly occupational therapy, was slightly lower than at other times of the year. The main reason for the relatively lower occupational therapy staffing was the different service delivery models operated by the occupational therapy and physiotherapy teams. Anderson SU was transitioning from providing therapy five days per week to seven days per week. At the time of the study, the physiotherapy team had been providing a seven-day therapy service for just over six months, whereas the occupational therapy team was planning to implement a seven-day service. Consequently, the physiotherapy team had received an uplift in staffing due to seven-day working and was able to cover staff leave more flexibly than the occupational therapy service. Despite the slightly lower therapy staffing, most therapy sessions proceeded as planned through the use of a patient timetabling system. Therapists met weekly to timetable therapy sessions for the forthcoming week, which ensured that stroke survivors received regular therapy to address their goals. However, timetables were reviewed daily to reflect any last minute changes, such as unexpected ward admissions or discharges. Therapy sessions occurred in a variety of locations, including the stroke survivor's bed space, therapy gym, patient kitchen, and ward corridors (Figure 14).

Anderson SU is also the SU where I have worked clinically as a clinical specialist PT for the past eight years. There were several reasons for including Anderson SU in the investigation. Reflecting upon my clinical practice and the practice of therapists that I have worked with over several years led me to undertake the PhD in the first instance. Therefore, understanding the culture in which I work as part of the wider culture of therapy practice was deemed appropriate to achieve the study's aim. Gaining access to the stroke service would be easier in terms of approaching key clinical and research staff members to discuss the study. Being familiar with the local ward practices meant that I could spend time developing my skills as an ethnographer- learning how to simultaneously observe and document fieldnotes, deciding how to prioritise therapy sessions to observe- in a relatively safe environment rather than spending time getting to know staff members and local practice. However, I was aware of the ethical issues of insider research previously reported in the chapter and was advised by other researchers to carefully consider my decision to research my own colleagues. Consequently, several strategies were employed to ameliorate the effect of these issues. These strategies centred on adopting a reflexive approach throughout the investigation to critically reflect upon my role and its influence on the research process, such as use of a reflective diary and debriefing with my PhD supervisors. In addition, a research advocate on the SU was appointed with whom therapist participants could talk through any concerns arising during the study.

Anderson SU was the first stroke service investigated during the study. Sixteen therapists and seven stroke survivors were recruited as primary participants from Anderson SU. Demographic details of these study participants are shown in Table 14.

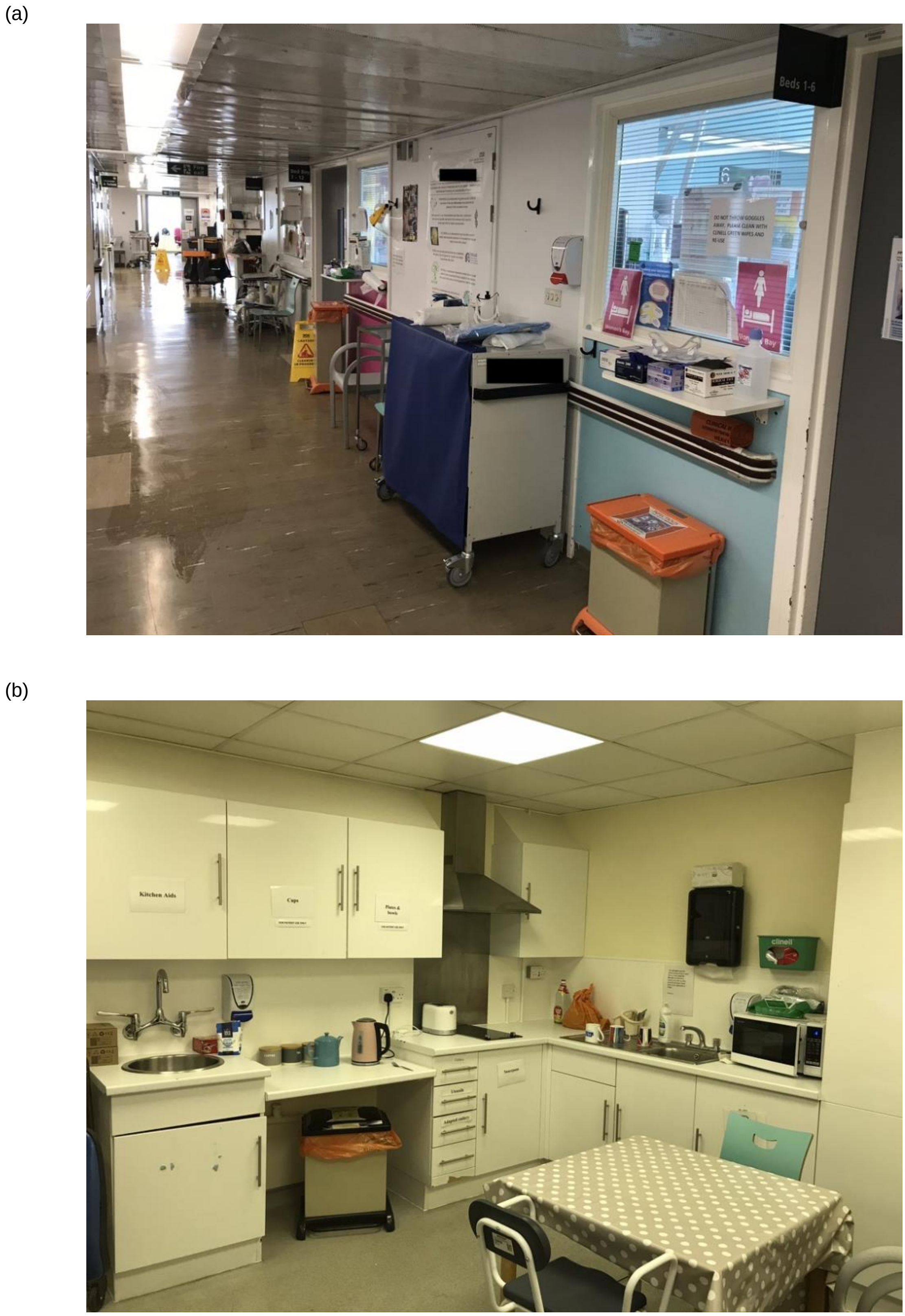


Figure 14- Anderson Stroke Unit (a) ward corridor and (b) patient kitchen

Table 15- Demographic data for Anderson Stroke Unit therapist and stroke survivor participants

Therapist Participants

Physiotherapists			Occupational Therapists		
Name	**Banding & Profession**	**Stroke Experience**	**Name**	**Banding & Profession**	**Stroke Experience**
Beth	Band 6 PT	6 months	Claire	Band 6 OT	6 years
Betty	Band 6 PT	1 year	Jane	Band 6 OT	1.5 years
Christine	Band 7 PT	4 years	Margaret	Band 5 OT	6 months
John	Band 7 PT	4.5 years	Nancy	Band 6 OT	2 months
Karen	Band 6 PT	10 months	Natalie	Band 8 OT	15 years
Lucy	Band 5 PT	6 months	Prue	Band 7 OT	2.5 years
Melanie	Band 6 PT	6 months			
Nadine	Band 6 PT	1 year			
Sally	Band 5 PT	4 months			
Tina	Band 5 PT	4 months			

Stroke Survivor Participants

Name	Age	Ethnicity	Stroke Type	Stroke Severity
Michael	56	Pakistani	R intracranial haemorrhage	NIHSS 30
Jacinta	73	Mixed British	Brainstem stroke	NIHSS 19
Brian	82	Eritrean	R intracranial haemorrhage	NIHSS 32
Morris	67	Arab British	L intracerebral haemorrhage	NIHSS 16
Paul	87	White British	L middle cerebral artery territory infarct	NIHSS 18
Irene	80	White German	L basal ganglia haemorrhage	NIHSS 26
Janice	56	Black British	R intracranial haemorrhage	NIHSS 29

PT- physiotherapist, OT- occupational therapist, NIHSS- National Institutes of Health Stroke Scale

Peterson Hyperacute Stroke Unit, Central Station Hospital

Peterson HASU is an 18-bedded HASU located in Central Station Hospital, a hospital based in inner North London. At the time of the fieldwork, Peterson HASU admitted individuals with new stroke from five London boroughs and provided care for up to 72 hours post-stroke. This care, typical of other London HASUs, involved confirmation of stroke diagnosis via clinical assessment and brain imaging, instigation of any medical management (e.g. thrombolysis), and stroke multi-disciplinary team assessment and treatment. Stroke survivors with ongoing rehabilitation needs were either discharged home with community-based therapy or repatriated to an SU for acute and subacute rehabilitation. Discharge home from a HASU was typical for survivors of mildly disabling stroke, whereas repatriation to an SU was common practice for survivors of moderately to severely disabling stroke. Repatriation to SUs was dependent upon the medical stability of stroke survivors prior to transfer and the availability of beds in the local SU. Most stroke survivors recruited to the study from Peterson HASU were repatriated within 72 hours. Consequently, due to the time taken to review the medical notes, approach, and consent stroke survivors, it was only possible to observe one therapy session of each stroke survivor participant before they were transferred to an SU. Data from SSNAP suggested that Peterson HASU was a high performing HASU, consistently rated as an “A” level stroke service (Sentinel Stroke National Audit Programme, 2020).

Whilst Peterson HASU was well-staffed in terms of therapy cover and met the Pan-London staff to patient ratio recommendations, it provided a limited physiotherapy and occupational therapy weekend service. Weekend therapy focused on new patient assessments and facilitation of discharge home rather than therapy to address rehabilitation goals. Weekday therapy, however, involved new patient assessments, rehabilitation therapy, and preparation for discharge from the HASU. Due to the highly variable nature of HASU admissions and discharges, therapists met twice daily to plan their mornings and afternoons rather than use a patient timetabling system. Due to the lack of dedicated therapy space on the HASU, therapy sessions occurred by the stroke survivor’s bed space or in the ward corridors (Figure 15).

Peterson HASU was part of the same hospital Trust as Ferguson SU, although each stroke service was located in two geographically separate acute hospitals. Recruiting and investigating both stroke services at the same time enabled an observation of stroke survivors transferring from the HASU to the SU, in addition to an exploration of therapy practice in both services. Peterson HASU and

Ferguson SU were the second and third stroke services investigated during the study. Eight therapists and nine stroke survivors were recruited as primary participants from Peterson HASU. Demographic details of these study participants are shown in Table 15.

Table 16- Demographic data for Peterson Hyperacute Stroke Unit therapist and stroke survivor participants

Therapist Participants					
Physiotherapists			**Occupational Therapists**		
Name	**Banding & Profession**	**Stroke Experience**	**Name**	**Banding & Profession**	**Stroke Experience**
Clive	Band 5 PT	5 months	Belinda	Band 7 OT	6 years
Darren	Band 6 PT	10 years	Dominic	Band 5 OT	4 months
Gareth	Band 6 PT	3 years	Samantha	Band 6 OT	2 years
Martin	Band 7 PT	4 years			
Kane	Band 5 PT	6 months			

Stroke Survivor Participants				
Name	**Age**	**Ethnicity**	**Stroke Type**	**Stroke Severity**
Carol	87	White British	L posterior cerebral artery territory infarct	NIHSS 16
Sue	55	Indian British	R middle cerebral artery territory infarct	NIHSS 16
Sharon	85	Black British	R middle cerebral artery territory infarct	NIHSS 19
Leanne	92	White Jewish	L middle cerebral artery territory infarct	NIHSS 25
Mario	72	White British	R frontoparietal haemorrhage	NIHSS 18
Roger	59	White British	R intracerebral haemorrhage	NIHSS 18
Kelsey	62	Black British	L basal ganglia haemorrhage	NIHSS 23
Daniel	68	White Italian	L pontine infarct	NIHSS 16
Albert	85	Arab British	L middle cerebral artery territory infarct	NIHSS 26

PT- physiotherapist, OT- occupational therapist, NIHSS- National Institutes of Health Stroke Scale

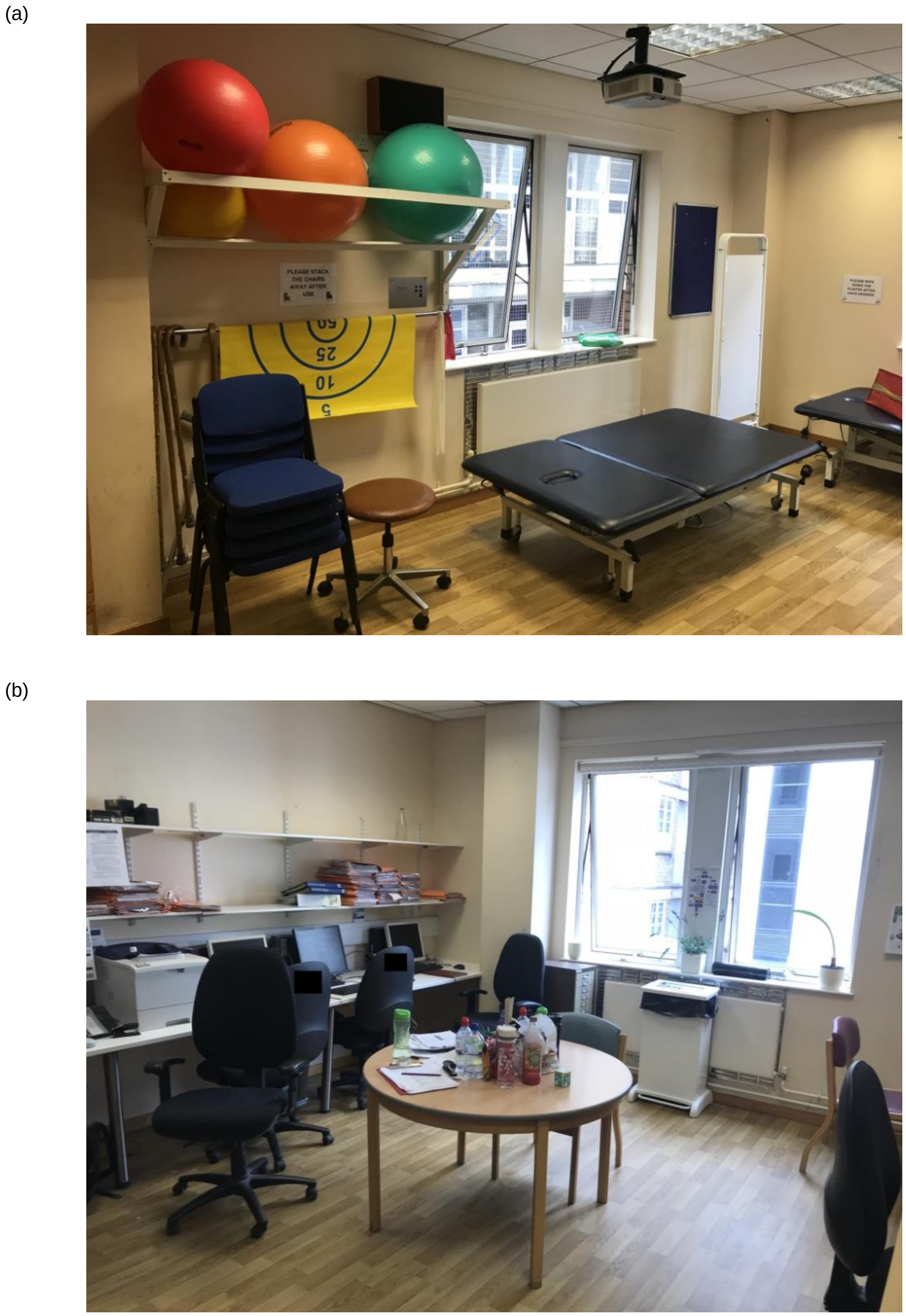
Figure 15- Peterson Hyperacute Stroke Unit

Ferguson Stroke Unit, Royal District Hospital

Ferguson SU is a 17-bedded SU located in Royal District Hospital, a hospital based in North Central London. At the time of the fieldwork, Ferguson SU provided acute and subacute stroke rehabilitation to residents local to two London boroughs. It received most of its stroke survivors from Peterson HASU and three stroke survivors recruited to the study from Peterson HASU were observed on Ferguson SU. Unlike Anderson SU, most survivors of severely disabling stroke on Ferguson SU were transferred to inpatient rehabilitation units for ongoing rehabilitation rather than being discharged to the community. This practice, atypical of the London stroke pathway for survivors of severely disabling stroke, may have reflected the local stroke pathway design, as one of London’s specialist rehabilitation units was co-located in the same hospital as Ferguson SU. Data from SSNAP suggested that Ferguson SU was a well performing SU, rated as a “B” level stroke service (Sentinel Stroke National Audit Programme, 2020).

Ferguson SU was well-staffed in terms of therapy cover and met the Pan-London staff to patient ratio recommendations. However, Ferguson SU did not have a weekend therapy service and had no immediate plans to develop a weekend service. Although geographically separate from Peterson HASU, there was a flexible working arrangement between the two stroke services. Therapists provided cross-cover during times of extended annual leave, which enabled the continuation of therapy on the understaffed SU. Ferguson SU therapists implemented a patient timetabling system to plan therapy sessions for the forthcoming week. However, therapists met daily rather than weekly to schedule therapy sessions, which offered more flexibility than the timetabling system used on Anderson SU. Therapy sessions occurred in a variety of locations, including the stroke survivor’s bed space, therapy gym, ward bathrooms, and corridors (Figure 16).

Seven therapists and five stroke survivors were recruited as primary participants from Ferguson SU. Demographic details of these study participants are shown in Table 16.



[redacted] [redacted]

Figure 16- Ferguson Stroke Unit (a) therapy gym and (b) therapy office

Table 17- Demographic data for Ferguson Stroke Unit therapist and stroke survivor participants

Therapist Participants					
Physiotherapists			Occupational Therapists		
Name	**Banding & Profession**	**Stroke Experience**	**Name**	**Banding & Profession**	**Stroke Experience**
Alicia	Band 6 PT	1.5 years	Erica	Band 5 OT	1 year
Frank	Band 6 PT	3.5 years	Kristina	Band 6 OT	3 years
Kylie	Band 7 PT	16 years	Megan	Band 7 OT	10 years
Sabrina	Band 5 PT	6 months			

Stroke Survivor Participants				
Name	**Age**	**Ethnicity**	**Stroke Type**	**Stroke Severity**
Harry	66	Japanese	L thalamic haemorrhage	NIHSS 24
Simon	84	Nigerian	L cerebellar infarct	NIHSS 30
Nigel	72	White British	L middle cerebral artery territory infarct	NIHSS 19
Ralph	79	White British	R lacunar infarct	NIHSS 18
Robert	89	American	R middle cerebral artery territory infarct	NIHSS 18

PT- physiotherapist, OT- occupational therapist, NIHSS- National Institutes of Health Stroke Scale

Stephenson Community Stroke Team

The Stephenson Community Stroke Team is a community-based rehabilitation service for stroke survivors residing in two adjacent South East London boroughs. Originally two community services providing community therapy for the two London boroughs, the Stephenson Community Stroke Team formed in 2017-2018 when these two services amalgamated. Stroke survivors referred to the service were triaged by senior therapists into one of three therapy streams according to the time post-stroke and nature of rehabilitation goals. Early supported discharge was up to eight weeks of daily multi-disciplinary therapy for stroke survivors within 28 days post-stroke who had demonstrated functional recovery and were likely to make further functional recovery. Community stroke rehabilitation was up to six weeks of thrice weekly multi-disciplinary therapy for stroke survivors within six months post-stroke who had demonstrated functional recovery and were likely to make further functional recovery. Resettlement was a service comprised of one to two therapy sessions designed to offer disability management and stroke specific advice to carers of stroke survivors. Eligible stroke survivors were those within six months post-stroke who were deemed to have no further potential for functional recovery. Consequently, most stroke survivor study participants received resettlement therapy or community stroke rehabilitation therapy. Therapy was delivered in their place of residence, which was either their own accommodation or a care home.

At the time of the study, community services in London did not participate in the same detailed performance assessment recorded by SSNAP as acute stroke services in London. Therefore, these community services were not rated in the same way as acute stroke services. Reviewing the available performance data recorded on SSNAP revealed that the Stephenson Community Stroke Team performed at a similar or slightly below average performance level compared to other London community stroke services (Sentinel Stroke National Audit Programme, 2020). For example, the time to initial assessment and patient length of stay within the service was slightly longer than other community services, whereas the amount of therapy minutes provided to stroke survivors was similar to other community services.

Anderson SU was one of Stephenson Community Stroke Team's main referral sources and both stroke services were part of the same hospital Trust. However, these stroke services were located in three geographically separate areas- Great Southern Hospital housed Anderson SU, whereas the Stephenson Community Stroke Team was based across two London boroughs in two separate buildings (Figure 17). The community stroke team's inclusion in the study was originally planned in order to observe the transition of stroke survivors between Anderson SU and the Stephenson Community Stroke Team. However, significant staffing vacancies and sickness absence in the Stephenson Community Stroke Team meant that the investigation of therapy practice in the Stephenson Community Stroke Team was not able to occur at the same time as the investigation of therapy practice on Anderson SU. Consequently, the Stephenson Community Stroke Team participated in the study 12 months after fieldwork had finished on Anderson SU and was the fourth stroke service investigated during the study. Ten therapists and four stroke survivors were recruited as primary participants from the Stephenson Community Stroke Team. Demographic details of these study participants are shown in Table 17.

Table 18- Demographic data for Stephenson Community Stroke Team therapist and stroke survivor participants

Therapist Participants					
Physiotherapists			**Occupational Therapists**		
Name	**Banding & Profession**	**Stroke Experience**	**Name**	**Banding & Profession**	**Stroke Experience**
Adrianna	Band 7 PT	6.5 years	Bernice	Band 6 OT	12 years
Chloe	Band 6 PT	2 years	Grace	Band 7 OT	6 years
Ebony	Band 7 PT	7 years	Janet	Band 6 OT	2 years
Leonie	Band 7 PT	9 years	Rita	Band 6 OT	1.5 years
Sinitta	Band 6 PT	1.5 years	Tanya	Band 7 OT	10 years

Stroke Survivor Participants

Name	**Age**	**Ethnicity**	**Stroke Type**	**Stroke Severity**
Carl	69	White British	L middle cerebral artery territory infarct	mRS 4
Daisy	84	White British	R middle cerebral artery territory infarct	mRS 5
Vernon	66	White British	Multiple L cerebral infarcts	mRS 5
Eliza	77	Nigerian	R watershed infarcts	mRS 4

PT- physiotherapist, OT- occupational therapist, mRS- Modified Rankin Scale

Figure 17- Stephenson Community Stroke Team office bases

Williamson Stroke Rehab Team

The Williamson Stroke Rehab Team is a community-based rehabilitation service based in outer South East London (Figure 18). It was the only stroke service included in the study that was not connected to another study stroke service. The inclusion of a service based in outer London was important due to sociodemographic differences of London stroke survivors in inner and outer London. Inner London tends to have greater social deprivation and a higher proportion of younger, ethnically diverse stroke survivors, whereas outer London tends to have lower social deprivation and a higher proportion of older, ethnically white British stroke survivors (Healthcare for London, 2008). As sociodemographic attributes, such as age, ethnicity, and social deprivation are associated with stroke prevalence and severity (Boehme *et al.*, 2014; Corso *et al.*, 2014), it was important to capture a diverse range of stroke survivors that reflected the reality of severely disabling stroke in a culturally diverse city such as London. Figure 19 highlights some of the architectural and topographical differences between inner and outer London.

The team was established in 2016 and provided some services not found in other London stroke services. For example, it employed a full-time clinical nurse specialist and neuropsychologist. It also employed a social services care manager to provide integrated health and social support for stroke survivors residing in the community. Reviewing the available performance data recorded on SSNAP revealed that the Williamson Stroke Rehab Team performed at a similar or slightly above average performance level compared to other London community stroke services (Sentinel Stroke National Audit Programme, 2020). For example, the time to initial assessment and patient length of stay within the service was similar to or shorter than other community services. As well, the amount of therapy minutes provided to stroke survivors was similar to or greater than other community services.

Similar to the Stephenson Community Stroke Team, stroke survivors referred to the service were triaged by senior therapists into one of three therapy streams according to the type of referring organisation and nature of rehabilitation goals. Early supported discharge was up to two weeks of daily multi-disciplinary therapy for stroke survivors discharged from a HASU and likely to improve functionally. Supported discharge was up to six weeks of daily multi-disciplinary therapy for stroke survivors discharged from an SU (or HASU patients requiring ongoing therapy) and likely to improve functionally. Targeted health management was up to six weeks of thrice weekly multi-disciplinary therapy for stroke survivors referred from a GP or specialist inpatient rehabilitation unit and likely to improve functionally. Both stroke survivor study participants recruited from the Williamson Stroke Rehab Team entered the targeted health management stream and therapy was delivered in their place of residence, which was a care home and a house.

The Williamson Stroke Rehab Team was the fifth and final stroke service investigated during the study. Eleven therapists and two stroke survivors were recruited as primary participants from the Williamson Stroke Rehab Team. Demographic details of these study participants are shown in Table 17.

Table 19- Demographic data for Williamson Stroke Rehab Team therapist and stroke survivor participants

Therapist Participants					
Physiotherapists			**Occupational Therapists**		
Name	**Banding & Profession**	**Stroke Experience**	**Name**	**Banding & Profession**	**Stroke Experience**
Bradley	Band 5 PT	2 years	Jasmine	Band 6 OT	8 months
Fabian	Band 6 PT	9 years	Kelis	Band 6 OT	10 years
Hugo	Band 5 PT	8 months	Monica	Band 7 OT	14 years
Lizzy	Band 6 PT	5 months	Nina	Band 5 OT	1.5 years
Roseanne	Band 6 PT	5 years	Susana	Band 5 OT	7 months
Sandy	Band 7 PT	8 years			

Stroke Survivor Participants

Name	Age	Ethnicity	Stroke Type	Stroke Severity
Bob	60	Black British	R lacunar infarct	mRS 4
Trevor	91	White Jewish	L middle cerebral artery territory infarct	mRS 5

PT- physiotherapist, OT- occupational therapist, mRS- Modified Rankin Scale

Figure 18- Williamson Stroke Rehab team office base

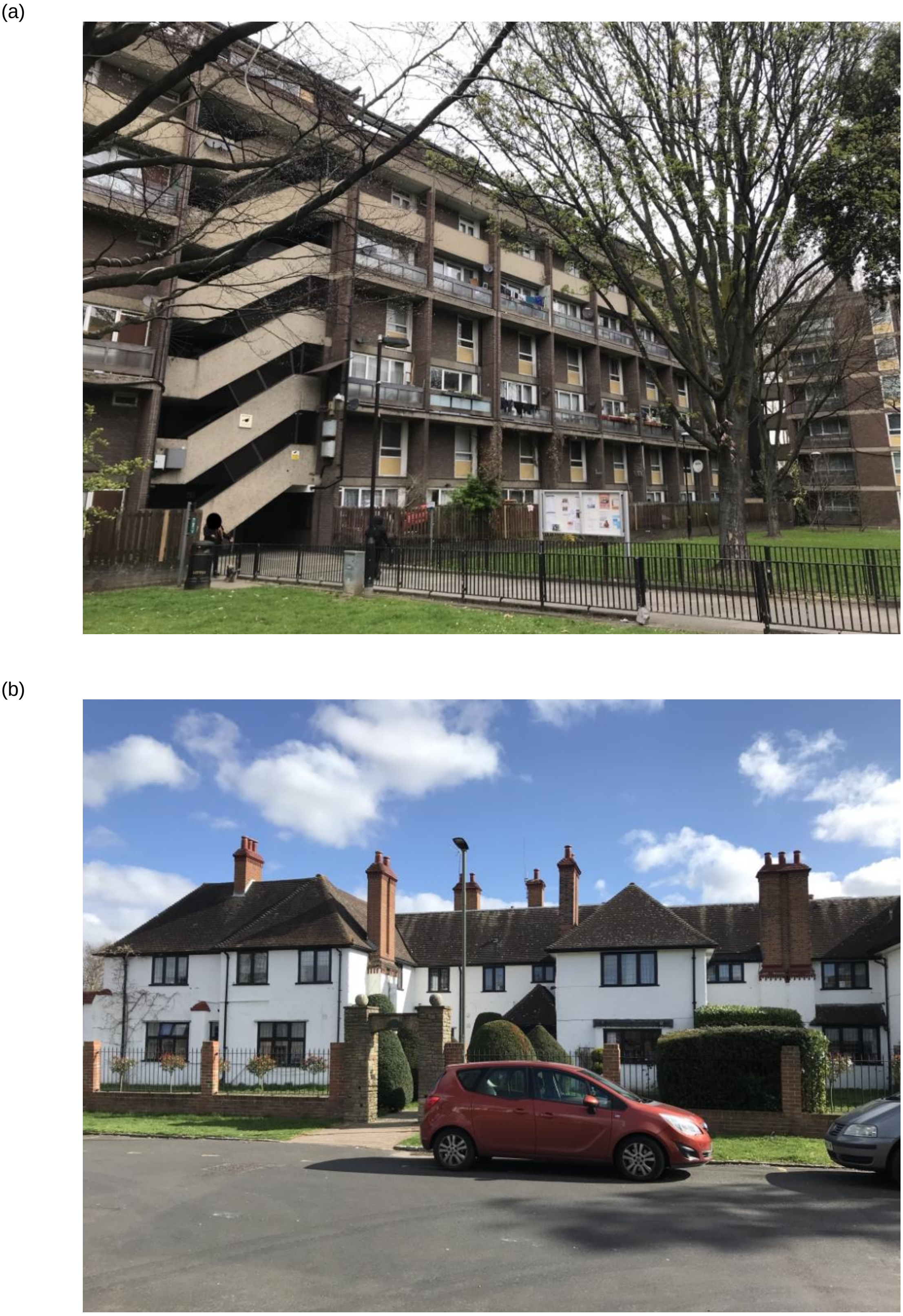


Figure 19- (a) Apartment block in inner London and (b) care home in outer London

7.5.5 Data Collection

Data was primarily gathered through participant observation of therapists and stroke survivors, as well as in-depth interviews with therapist participants. Secondary sources of data included informal discussions with therapists about therapy and goal setting sessions, therapist timetables, multidisciplinary team meeting agendas, and paper copies of stroke survivors' goals. A reflective diary was used throughout the study to record reflections of my experiences in order to understand my observations, as well as my role on the research process more fully. This section will describe how I undertook each of the primary data collection methods.

Participant Observation

Participant observation is recognised as a key data collection method in ethnography (O'Reilly, 2012; Holloway and Galvin, 2016; Hammersley and Atkinson, 2019). In his seminal article on the typology of sociological field observations, Gold (1958) described four roles of participant observation: complete observer, observer as participant, participant as observer, and complete participant. Although Gold's typology is widely cited in textbooks of qualitative healthcare research, O'Reilly (2012) has suggested that, dependent on the phenomenon being observed, participant observation may be viewed more as a continuum with full immersion at one end and detached observation at the other end. As my intention was to observe clinical practice as a clinician-researcher without actively participating in therapy sessions, goal setting sessions or team meetings, I generally adopted the role of observer as participant. My familiarity with the normal conduct of these clinical situations meant that I could position myself in the environment to observe the situation without getting in the way of staff and allow the situation to proceed as intended. Recognising that my presence was bound to have varying degrees of impact on the therapists being observed, I aimed to blend into the environment and dressed according to the fashion of the therapists in the stroke service that I was observing. As such, I wore my physiotherapy uniform in inpatient environments and smart casual clothing in community environments. As the fieldwork proceeded, it was evident that therapists became used to my presence or were not aware of my presence during some of the observation sessions, as highlighted in the therapist interviews:

> **Me: So, regarding the observation sessions, how did you find them?**
>
> Sabrina: Initially, I was nerve-wracked, like, feeling nervous about it because I was like, “Oh.” I remember my first one thinking, “Right, I’ve got it planned out exactly what I’m going to be doing. You know, he’s going to be watching me,” and so on, but it was fine.
>
> **Me: Yeah?**
>
> Sabrina: Yeah. But by the end, in the nicest way, I kind of forgot you were there which I guess is the idea that you can, kind of, sink into the background. But, no, I wasn’t too worried by it in the end.
>
> (Interview with Sabrina, Band 5 PT, Ferguson SU)

Observations of therapy sessions, goal setting sessions, and team meetings were documented in the form of ethnographic fieldnotes, which Emerson, Fretz and Shaw (2011) described as recordings of the observation collected by hand. In order to facilitate the recording of “thick” descriptions- detailed and contextual descriptions of social behaviours (Geertz, 1973)- fieldnotes were structured according to Spradley’s nine dimensions of participant observations (Spradley, 1980). These dimensions include space, object, act, activity, event, time, actor, goal, and feeling (Appendix I). Fieldnotes were recorded contemporaneously using a pen and a small notepad, which was considered to be less obtrusive than a larger notebook or laptop computer.

Across the different stroke services, there were key similarities and differences in the format of participant observation. A key similarity was the number of fieldwork days per week assigned to participation observation. As I was working clinically two days per week, I was able to commit to three full days of fieldwork per week in each stroke service. Initially, these fieldwork days were Monday, Wednesday, and Friday to coincide with pre-existing work commitments. Whilst this research pattern was transparent to the study participants and facilitated the scheduling of future observation sessions, it prevented the regular observation of inpatient therapy sessions on consecutive days and community therapy sessions on clinical work days. Although I had some flexibility in changing my fieldwork days to enable the observation of therapy sessions on consecutive days, it was not possible to do this every week. Consequently, this research pattern may have resulted in not observing pertinent therapy or goal setting sessions. Another limitation of researching part-time was the potential delay in developing rapport and gaining psychological access to the therapist participants. Both of these limitations are illustrated by the following excerpts from my reflective diary:

> Unlike Ferguson SU, fieldwork on Peterson HASU has been much slower and less productive. The eligible patient at the end of last week passed away over the weekend before the family could consent for her to participate in the study. Another patient who was initially deemed to be eligible ended up as a stroke mimic. And finally, we did manage to recruit our first HASU patient this week although her first possible observation session clashed with work day. On reflection, the short period of time that patients stay on a HASU combined with the time taken to consent patients is making observation of HASU therapy sessions very challenging.
>
> (Reflective diary entry, 20th July 2018)

> It's the end of my first full week on Ferguson SU and it has been a slower start compared to my time on Anderson SU. In addition to the slowness of recruitment, there are some other differences with this fieldwork. Firstly, gaining access. This didn't seem to be an issue on Anderson SU due to working there but gaining psychological access to the Ferguson team seems like it will take some time. I feel there is a combined element of politeness and wariness with my interactions with the team and this will hopefully change over the coming weeks. I wonder if being on the unit more often, particularly in these first few weeks where first impressions last, would result in the team getting used to me more. Or perhaps they need time to adjust and get used to me being on the unit.
>
> (Reflective diary entry, 6th July 2018)

In addition to changing my fieldwork days when possible, the main strategy to counter the part-time nature of the fieldwork was to spend prolonged time conducting fieldwork in each stroke service, guided by the attainment of data saturation- the point when no new information or themes are observed in the data (Holloway and Galvin, 2016).

A key difference in the format of participation observation was noted between inpatient and community stroke services. In the inpatient stroke services, I was usually based on a ward for several hours per day and observed several consecutive therapy or goal setting sessions. Observed sessions were selected by mutual agreement between myself and the stroke survivor's treating therapist. This discussion usually occurred in the morning after the therapists had received a nursing handover about the ward patients and planned their day accordingly. In between observed inpatient therapy sessions, I usually sat in the therapist's office or remained by the main nurses' station and either observed the ward in action or chatted with the therapy staff. The latter action enabled me to get to know the therapy staff and for the therapy staff to get to know me, which was instrumental in developing rapport with therapist participants. In the community stroke services, observed therapy sessions occurred in the stroke survivors' place of residence. Due to the geographical distances between places of residence and the time required to travel between observed sessions, it was not possible to be based in the community team's office during the day. As such, observed sessions were usually organised remotely the day before, usually via email or text messaging, and I travelled to the stroke survivor's place of residence to meet the study therapist. The limited time spent with community therapists outside of observed sessions to get to know them was addressed by spending a longer period conducting fieldwork in the community stroke services. In total, I completed just over 400 hours of participant observation in the five stroke services over a period of 18 months (Table 14). The time spent in each service varied according to the number of stroke survivor participants recruited in each stroke service and when data saturation was achieved in each service.

Whilst my intention was to observe clinical practice, there were times when therapists asked for advice or help in the delivery of sessions due to my clinical background. Dependent on the context of the situation, this resulted in me either stepping back or becoming involved in the situation. In the first example, a Band 6 PT named Alicia working on Ferguson SU was due to treat a patient on behalf of another PT who was on annual leave. As Alicia was not familiar with the patient, she asked me before an observed session whether she should practice gait re-education with the patient, as she knew I had observed the patient previously and was aware of his functional ability. Faced with a potential dilemma of unduly influencing the delivery of the session, I gently reminded Alicia that my role was just to observe therapy sessions. I then casually asked Alicia how she would normally treat another PT's patient that she was not familiar with. Alicia replied by mentioning the PT's written handover and proceeded to review the handover to decide what to practice in the therapy session. My response to Alicia’s request was designed to avoid influencing the therapy session but maintain the relationship I had developed with Alicia. Telling Alicia what to do would not be appropriate but prompting Alicia to consider how she would decide what to do was deemed sufficiently supportive without unduly influencing her decision making. In the second example, a Band 6 OT named Jane working on Anderson SU was hoisting a patient into a wheelchair with a healthcare assistant. The assistant’s inexperience and need for continual guidance throughout the session was making Jane slightly flustered. As Jane was lowering the patient into the wheelchair, the patient’s paralysed hand was about to become trapped in the armrest of the wheelchair, which was not seen by Jane or the healthcare assistant. Faced with potential harm to the patient, I quickly highlighted to Jane the position of the patient’s hand. Jane paused the hoist machine, looked at the patient’s hand, and then looked at the healthcare assistant. About to say something to the healthcare assistant, Jane sighed, turned to me, and asked me to support the patient’s arm. I obliged as Jane proceeded to lower the patient into the wheelchair. The decision to become involved in this session was made to prevent harm to the patient but also to support Jane. Not assisting Jane may have undermined Jane’s leadership of the session and negatively affected my relationship with Jane. In these examples, on-the-spot decisions to either step back or become involved in the session were made according to their potential effect on therapist decision making, patient harm, and the researcher-participant relationship. Tinney (2008) discussed similar participant observer dilemmas in her ethnographic study of nursing homes. Although performing a non-care volunteer role, Tinney made on-the-spot decisions when faced with the needs of residents, such as wiping their mouths or adjusting their clothes. She highlighted that when presented with certain situations, researchers should use their “gut feeling” to resolve arising ethical dilemmas.

Interviews

Interviews are another key data collection method used in ethnography (O’Reilly, 2012; Holloway and Galvin, 2016; Hammersley and Atkinson, 2019). Hammersley and Atkinson (2019) stated that interviews can be used to further explore the views and experiences of participants beyond that which can be obtained by participant observation. When used in conjunction with participant observation, they can be used for triangulation purposes- to complement observation findings- and for initiation purposes- to provide contradictory findings, as described by Greene, Caracelli and Graham (1989). Contradictory findings between interviews and participant observation may arise due to differences in what people say they do and what people actually do (Hammersley and Atkinson, 2019). Aday and Cornelius (2006) identified several psychological stages that interviewees go through when answering questions. These stages include comprehending the question, retrieving relevant information in the interviewee’s memory, evaluating the retrieved information with reference to the interview question, and responding to the question. In this final stage, the interviewee assesses the social acceptability or desirability of the answer before providing an answer. As such, an interviewee may provide a socially acceptable answer to an interview question which differs to the reality of what the interviewee may do in a real-life situation. Reflecting upon contradictory findings, and why contradictory findings arise, may provide further insights and a deeper understanding of the culture under investigation (Holloway and Galvin, 2016; Hammersley and Atkinson, 2019).

Interviews were semi-structured, with areas for discussion set out in advance in an interview guide (Appendix J). In line with the guided interview structure described by Holloway and Galvin (2016), an interview guide sets out broad questions derived from the research’s objectives, theory, and reflections upon concepts that require exploration. The flexibility of the semi-structured interview enabled me to cover important questions whilst being responsive to what was said by the therapist. I commenced the interviews by asking therapists general questions about their current role and work experience. I then asked more open-ended questions- about stroke rehabilitation and factors guiding decision making- for the therapists to provide more detailed and descriptive answers, including their thoughts and feelings about the subject matter.

Interviews were conducted towards the end of the fieldwork at each stroke service. There were two main benefits of interviewing therapy staff after the observation period had almost finished. Firstly, I had established rapport with the therapy staff due to prolonged immersion in each stroke service. I hypothesised that the quality of this relationship would enable therapy staff to feel comfortable to provide open and honest answers to interview questions. This may be relevant when discussing more sensitive topics, such as attitudes toward severely disabling stroke. Secondly, the interview guide would be able to accommodate questions regarding notable observed sessions. This would enable a deeper exploration of these observations than would have occurred when informally debriefing with therapy staff after these observed sessions.

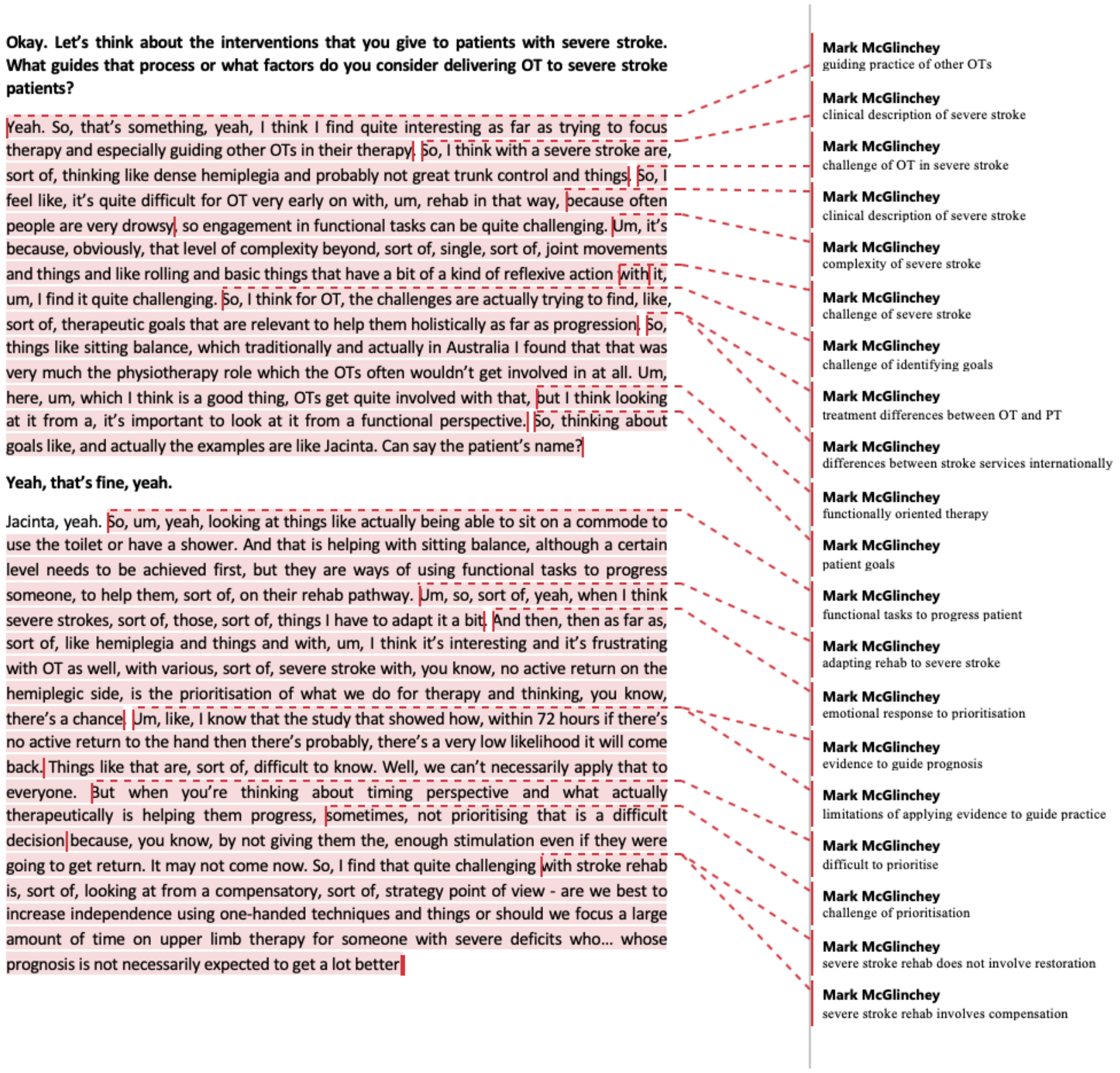
Interviews were conducted in a quiet room that was familiar to the therapist and convenient for the therapist to attend. Typical locations included quiet rooms on an SU or offices in a therapy department. Interviews were recorded on a digital voice recorder, although I used a notepad to note down pertinent therapist comments or reflections on what the therapists were saying. Several authors have highlighted a variety of advantages in tape recording interviews (Fasick, 1977; Halcomb and Davidson, 2006; Opdenakker, 2006; Rohman and Rita, 2013). Audio recording captures the words of the interview more accurately than other data collection methods, such as note writing. This may give the researcher a greater sense of what the interviewee is saying, which is important when analysing and interpreting interview data. Reference back to the audio recording provides the researcher with examples to highlight the study's findings in the context of written publications. As well, the researcher can pay attention to the interviewee's body language and maintain eye contact more consistently throughout the interview, thereby mimicking a more natural conversation. However, in his review of the effect of recording on the quality of interview data, Al-Yateem (2012) noted that some interviewees may be reluctant to be audio recorded and appear less talkative when being recorded. He proposed that prolonged engagement with the interviewee prior to the interview and "ice-breaking" questions at the start of the interview should be used to minimise the impact of recording on the interview process. These techniques were used prior to and during the interviews.

I transcribed one third of interviews and the remainder were transcribed professionally. After each therapist interview had been transcribed, I listened to all interview recordings several times to confirm the accuracy of the transcription, understand what each therapist was saying more fully, and reflect upon my interview style in order to improve my interview technique. The latter aspect involved listening to the clarity of the interview question, whether I was leading therapists in their response to questions and whether I picked up on cues to explore further in the interview. As interviews were transcribed contemporaneously, the delivery of subsequent interviews was modified according to these reflections.

7.6 Ethnography- Data Analysis

Lincoln and Guba (1985) proposed that one of the principle aims of analysis in qualitative research is to make sense of the data in order to lead to a maximal understanding, or Verstehen, of the phenomenon under investigation. In ethnography, this understanding relates to what people say and do, as well as the meanings constructed by people in their usual settings (Madden, 2010; O'Reilly, 2012). Hammersley and Atkinson (2007) reported that ethnographic data analysis is not a separate phase that occurs once data collection has been completed but occurs throughout the study and is interspersed with data collection. This style of data analysis involves inductive and deductive reasoning processes as well as movement back and forth between these two reasoning approaches. Morgan (2007) described this movement between reasoning processes as abduction, or abductive reasoning. Abductive reasoning is a cyclical process where data are connected to existing theory or used to generate new theories. These theories are then assessed through further action, such as ongoing data collection and analysis. For example, during the initial stages of the fieldwork, I observed that the decision to withdraw therapy for stroke survivors making slow improvements varied considerably between therapists working in the first two stroke services. Through inductive analysis, I considered that this phenomenon could be due to therapists' previous clinical experience in severely disabling stroke as well as differences in workplace practices. These factors were related to existing theoretical frameworks on clinical decision making, stroke rehabilitation approaches, and workplace culture, and deductively analysed through further observation. However, it became apparent through further observation that therapists' beliefs and attitudes about severely disabling stroke, shaped by their previous clinical experience and knowledge about post-stroke recovery trajectories, guided decision making in this aspect of therapy. Consequently, a greater emphasis on therapists' beliefs and attitudes, as well as knowledge about post-stroke recovery trajectories, occurred in the latter stages of the fieldwork. Due to this cyclical movement between inductive and deductive reasoning, new insights into what factors guide decisions about withdrawing therapy were generated, which will be presented in the next chapter.

Formal data analysis occurred in between conducting fieldwork in the different stroke services. I used Braun and Clarke's (2006) six step approach as a guide to coding and developing themes: familiarise yourself with the data, generate initial codes, search for themes, review themes, define and name themes, and produce the report. I familiarised myself with the data by reading and re-reading fieldnotes and listening to interview recordings several times. Interview transcripts were uploaded onto NVivo and observation fieldnotes were transferred to a Word document. Initial codes, or units of meaning, were generated from both data sources, although interview transcripts were coded first. The rationale for coding interview transcripts first was that interview data covered a wider range of concepts- decision making, prognostication, attitudes and beliefs, reflections on specific observations- than observational data, which tended to focus on the immediate therapy sessions. Figure 20 presents an example of a coded interview extract, which is followed by an extract from my reflective diary. The diary extract highlights how reflection upon the interview contributed to further interpretation of data initially obtained through participant observation. Examples of coded fieldnotes from a therapy session and team meeting can be found in Appendix I.



Okay. Let's think about the interventions that you give to patients with severe stroke. What guides that process or what factors do you consider delivering OT to severe stroke patients?

Yeah. So, that's something, yeah, I think I find quite interesting as far as trying to focus therapy and especially guiding other OTs in their therapy. So, I think with a severe stroke are, sort of, thinking like dense hemiplegia and probably not great trunk control and things. So, I feel like, it's quite difficult for OT very early on with, um, rehab in that way, because often people are very drowsy, so engagement in functional tasks can be quite challenging. Um, it's because, obviously, that level of complexity beyond, sort of, single, sort of, joint movements and things and like rolling and basic things that have a bit of a kind of reflexive action with it, um, I find it quite challenging. So, I think for OT, the challenges are actually trying to find, like, sort of, therapeutic goals that are relevant to help them holistically as far as progression. So, things like sitting balance, which traditionally and actually in Australia I found that that was very much the physiotherapy role which the OTs often wouldn't get involved in at all. Um, here, um, which I think is a good thing, OTs get quite involved with that, but I think looking at it from a, it's important to look at it from a functional perspective. So, thinking about goals like, and actually the examples are like Jacinta. Can say the patient's name?

Yeah, that's fine, yeah.

Jacinta, yeah. So, um, yeah, looking at things like actually being able to sit on a commode to use the toilet or have a shower. And that is helping with sitting balance, although a certain level needs to be achieved first, but they are ways of using functional tasks to progress someone, to help them, sort of, on their rehab pathway. Um, so, sort of, yeah, when I think severe strokes, sort of, those, sort of, things I have to adapt it a bit. And then, then as far as, sort of, like hemiplegia and things and with, um, I think it's interesting and it's frustrating with OT as well, with various, sort of, severe stroke with, you know, no active return on the hemiplegic side, is the prioritisation of what we do for therapy and thinking, you know, there's a chance. Um, like, I know that the study that showed how, within 72 hours if there's no active return to the hand then there's probably, there's a very low likelihood it will come back. Things like that are, sort of, difficult to know. Well, we can't necessarily apply that to everyone. But when you're thinking about timing perspective and what actually therapeutically is helping them progress, sometimes, not prioritising that is a difficult decision because, you know, by not giving them the, enough stimulation even if they were going to get return. It may not come now. So, I find that quite challenging with stroke rehab is, sort of, looking at from a compensatory, sort of, strategy point of view - are we best to increase independence using one-handed techniques and things or should we focus a large amount of time on upper limb therapy for someone with severe deficits who… whose prognosis is not necessarily expected to get a lot better

Mark McGlinchey
guiding practice of other OTs

Mark McGlinchey
clinical description of severe stroke

Mark McGlinchey
challenge of OT in severe stroke

Mark McGlinchey
clinical description of severe stroke

Mark McGlinchey
complexity of severe stroke

Mark McGlinchey
challenge of severe stroke

Mark McGlinchey
challenge of identifying goals

Mark McGlinchey
treatment differences between OT and PT

Mark McGlinchey
differences between stroke services internationally

Mark McGlinchey
functionally oriented therapy

Mark McGlinchey
patient goals

Mark McGlinchey
functional tasks to progress patient

Mark McGlinchey
adapting rehab to severe stroke

Mark McGlinchey
emotional response to prioritisation

Mark McGlinchey
evidence to guide prognosis

Mark McGlinchey
limitations of applying evidence to guide practice

Mark McGlinchey
difficult to prioritise

Mark McGlinchey
challenge of prioritisation

Mark McGlinchey
severe stroke rehab does not involve restoration

Mark McGlinchey
severe stroke rehab involves compensation

Figure 20- Coded interview extract from interview with Prue, Band 7 OT

> Three more interviews completed- 2 OTs and 1 physio. The first OT interview, Prue, went well- like John’s interview, Prue gave a very comprehensive and holistic overview of the different issues faced by severe stroke survivors across the whole stroke pathway. The second OT interview, Margaret was not as “polished” as Prue’s interview- possibly because Margaret is a Band 5 OT with less clinical (? and life) experience than Prue. This observation may highlight what I observed during the observation sessions- therapists with more experience have a greater understanding and awareness of “the bigger picture”. They are able to see beyond the immediate effects of a few treatment sessions and consider the longer-term patient scenario, they can prognosticate more confidently and therefore select or discontinue interventions that work or don’t work. This observation is consistent with the literature exploring novice vs expert practitioners and perhaps provides evidence to support the role of the expert in the delivery of complex health-care interventions in a challenging and uncertain health-care environment.
>
> (Reflective diary entry, 22nd February 2018)

Interview and observation codes from physiotherapy and occupational therapy sessions across the different stroke services were read and cross-compared. Over 4,500 codes were grouped together to form 50 categories, or larger groups of codes. For example, codes such as “evidence guides therapy”, “lack of evidence for severe stroke”, “research not supporting early mobilisation”, and “discrepancy between research evidence and clinical problems” were grouped together to form the category “Evidence in Severe Stroke”. Appendix K presents several examples of categories with their constituent codes. Categories were then grouped together with reference to the model for evidence-based clinical decision, as presented in Chapter 3, to form five themes. Each theme comprised two to three subthemes that accurately represented the categories and their constituent codes. Examples of how codes, categories and themes relate to each other are presented in Appendix L. Thesis categories and themes are presented in Appendix M.

Whilst this linear approach to data analysis appears simple, the reality of data analysis was more complex. Using the abductive process previously described, there was constant movement backwards and forwards between coded data, categories, and themes. Some codes intuitively fitted into a particular category, such as the code “lack of evidence in severe stroke” and the category

“Evidence in Severe Stroke”. However, other codes could have been placed into more than one category or were moved to alternative categories in light of ongoing data analysis. For example, the code “allocating resources to facilitate discharge” was originally placed into the category, “Discharge Planning” but then moved to another category, “Allocating and Utilising Resources” as it became apparent through ongoing data analysis that reduced therapy staffing levels, particularly in OT, impacted heavily upon tasks such as therapy delivery and discharge planning. Whilst this code could have been placed into either of these categories, the limited practical guidance regarding category formation in thematic analysis created some uncertainty in these analytical decisions. In order to deal with this uncertainty, I frequently referred back to the raw data and the context surrounding the code in order to determine its most credible parent category. In addition, I frequently debriefed with my research supervisors regarding the formation of categories and themes to ensure that I wasn’t missing anything. Similarly, categories were initially grouped to form broader themes that related to the components of the model for evidence-based clinical decisions- clinical expertise, research evidence, patients’ preferences and actions, and clinical state and circumstances. However, it became apparent through further analysis that some therapist-related categories, such as ‘Attitudes, Beliefs, and Preferences” and “Emotional Responses in Stroke Rehabilitation” didn’t naturally fit into the “clinical expertise” component of the model for evidence-based clinical decisions. Revisiting the raw data resulted in the creation of two separate therapist-related themes, “Professional Expertise” and “Beliefs and Attitudes about Post-Stroke Recovery”, which more accurately represented the fieldwork findings.

7.7 Establishing the Trustworthiness of the Research Process

Establishing the methodological quality and rigour of any research process is paramount in order to demonstrate the truth value of the research findings and yield meaningful results (Nowell *et al.*, 2017). In qualitative inquiry, Lincoln and Guba (1985) proposed the concept of trustworthiness to establish the methodological adequacy of qualitative research. Establishing the trustworthiness of the research process is demonstrated by four key criteria: credibility, dependability, transferability, and confirmability (Rodgers and Cowles, 1993; Nowell *et al.*, 2017; Korstjens and Moser, 2018; Table 19).

Table 20- Criteria for Establishing Trustworthiness of the Research Process

Criteria	Definition	Methods to Establish Criteria
Credibility	The confidence that findings are a true, credible, and plausible interpretation of the participants' reality	Prolonged immersion Triangulation Member check Peer review Reflexivity
Dependability	The stability or consistency of findings over time	Audit trail Reflexivity
Transferability	The degree to which the findings can be transferred to other contexts or settings	Thick description Reflexivity
Confirmability	The degree to which the findings of the research study can be confirmed by other researchers	Audit trail Reflexivity Peer review

Several strategies to establish trustworthiness, such as prolonged immersion in the setting, use of thick description, and reflexivity, have been presented earlier in the chapter. Several other strategies were employed throughout the study to ensure the trustworthiness of the research process, such as member checking, triangulation, peer review, and an audit trail. Member checking involves receiving participant feedback about the researcher's understanding or interpretation of study data (Nowell *et al.*, 2017; Korstjens and Moser, 2018). Feedback ensures that the participant's reality is captured by the researcher's interpretations and prevents misunderstanding of the participant's words and actions. Unfortunately, the REC had stipulated not to provide therapists with interview transcripts. This type of member checking would have allowed the therapists to review what they said during the interviews and clarify any responses that they felt did not accurately capture what they had intended to say during the interview. In order to comply with the REC's stipulation, member checking was performed instead by paraphrasing the therapist's responses during and at the end of the therapist interviews. Whilst this process helped to clarify my understanding of their responses and confirm the representativeness of my interpretations, it was not possible to paraphrase every response during the interview. Consequently, this may have influenced the credibility of interview findings. Member checking was also performed by debriefing with therapists after observation sessions to confirm my interpretation of the session's aims and the rationale for selecting different rehabilitation interventions. However, in order to obtain the therapist's perspective of the session, care was taken not to ask leading questions about the session's aim or an intervention's rationale.

The concept of triangulation was presented in the Methodology chapter, which was described as a process in which different methods investigating the same phenomenon are combined in one study (Greene, Caracelli and Graham, 1989). Denzin (1978) described this type of triangulation as methodological triangulation and identified other types of triangulation, such as data triangulation and investigator triangulation. Data triangulation involves the use of multiple data sources obtained from different groups and settings. Investigator triangulation involves the use of more than one researcher in the research process. In the study, methodological triangulation (i.e. use of interviews, participant observation, timetable documents) and data triangulation (i.e. recruitment of PTs and OTs working in different stroke settings over time) were used to enhance the credibility of the study's findings. Investigator triangulation, such as the involvement of an additional researcher to code study data, was not employed in the study. Whilst use of multiple coders is often employed when several researchers are involved in a research project and consensus amongst researchers is required, Holloway and Galvin (2016) noted that it is less commonly used by sole qualitative researchers. Debate also exists about the appropriateness of using additional coders in qualitative research projects conducted by sole researchers, which is summarised by O'Connor and Joffe (2020). For example, using an additional coder may contravene the interpretivist agenda of qualitative inquiry, which is intrinsically related to and shaped by the researcher's unique perspective. Involving an individual who has not participated in the research process to code study data at the end of a research project may be viewed as an attempt to validate or objectify study data, thereby importing quality standards more appropriate for positivist research approaches. Consequently, another type of researcher involvement, peer review, was used during the study to enhance the credibility of the study's findings.

Peer review involves debriefing with colleagues to reflect upon study data and the researcher's interpretation of study data (Holloway and Galvin, 2016; Nowell *et al.*, 2017). Peer review can enhance the credibility of the research process in several ways. It can confirm the researcher's understanding of the study data, as well as provide alternative interpretations of the study data. It can detect researcher bias and inappropriate subjectivity, as well as challenge the researcher's assumptions or coding decisions. Throughout the study, I debriefed with my supervisors on a monthly basis to discuss and make sense of the emerging data, consider alternative interpretations of the study data, and reflect upon the impact of my role on the research process. As ethnographic analysis is an ongoing and iterative process that is not confined to the end of the fieldwork, having the ability to discuss and interpret findings throughout the study seemed more appropriate than employing an additional coder at the end of the fieldwork and more consistent with the interpretivist nature of the ethnography. Whilst having the opportunity to regularly debrief with my supervisors helped to make sense of the data, reviewing the data with other individuals, such as therapy colleagues or fellow PhD students, may have provided alternative interpretations of the study data. For example, reviewing data with therapists may have enabled a more clinically orientated discussion about study data, whereas reviewing data with fellow PhD students may have provided a more objective interpretation of study data. However, time constraints prevented the involvement of other individuals in the peer review process.

Finally, an audit or decision trail is a detailed record of the decisions made before and during the research process (Nowell *et al.*, 2017; Korstjens and Moser, 2018). Rodgers and Cowles (1993) described four types of documents that form the audit trail: contextual documents, such as excerpts from interviews or observational fieldnotes; methodological documents, that detail methodological decision making and the rationale for these decisions; analytic documents, which consist of reflections on data analysis and insights gained; personal response documents, which demonstrate the researcher's reflexivity. Appendices I, K, and L provide examples of the audit trail used throughout the study. Excerpts from interviews, observational fieldnotes, and the reflective diary are presented in the next chapter.

7.8 Chapter Summary

Ethnography is a research approach involving the study or description of people in their usual environments. In the current study, ethnography was used to investigate therapy in the rehabilitation of physical function after severely disabling stroke. Five stroke services representing different parts of the stroke pathway in London were purposively selected to explore what factors guide therapist decision making in the rehabilitation of severely disabling stroke. Physiotherapy and occupational therapy staff working in these stroke services, as well as survivors of severely disabling stroke, were recruited to participate in the study as primary study participants. As one of these stroke services was the SU where I work clinically, consideration was given to the advantages and disadvantages of insider researcher. The primary data collection methods, participant observation and semi-structured interviews, were described. Data were analysed thematically, and several strategies were employed to ensure the trustworthiness of the research process. The next chapter will present the findings from the thematic analysis.

Chapter 8- Why Do Therapists Do What They Do? Fieldwork Findings

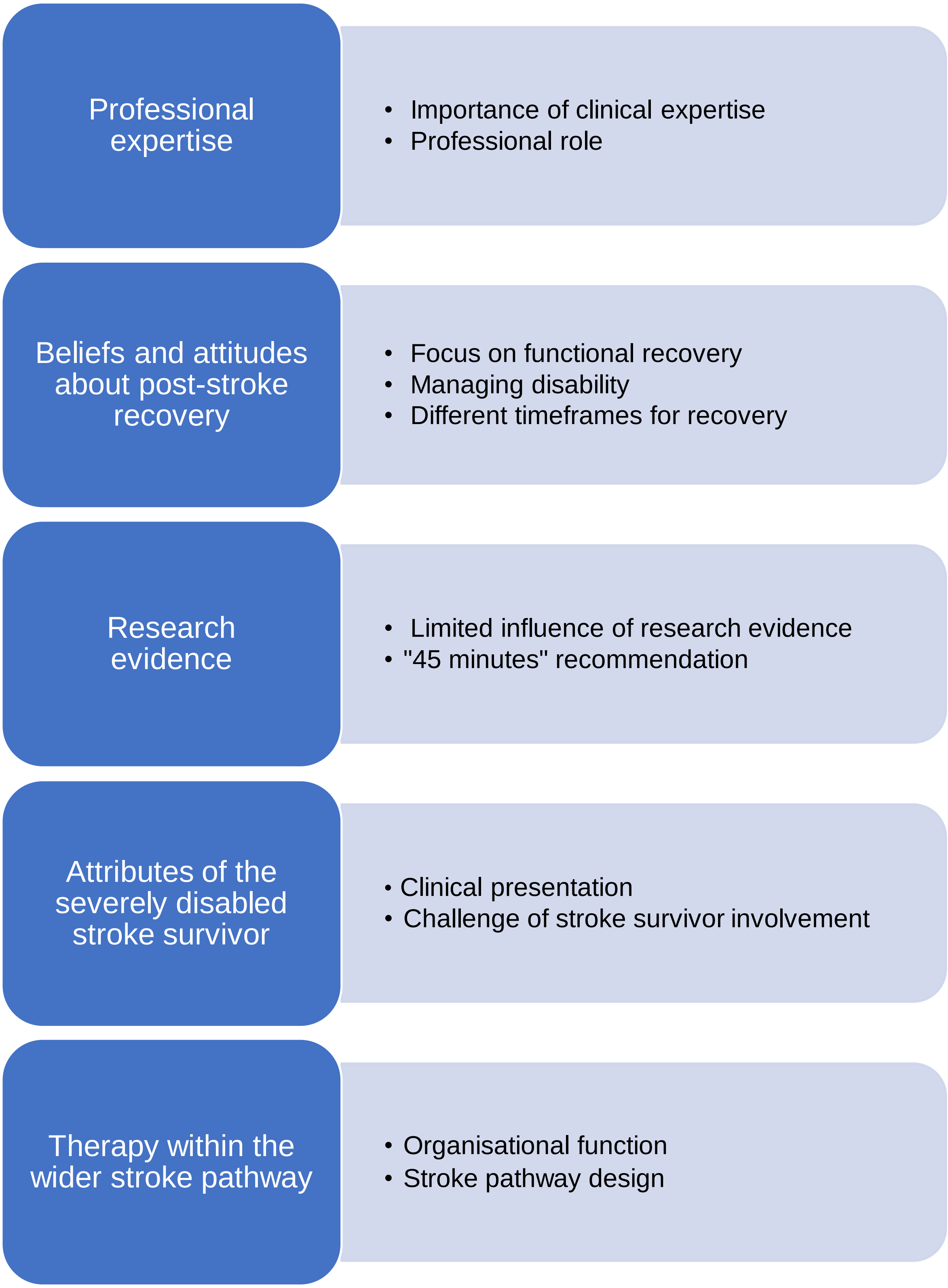
8.1 Introduction

This chapter presents the findings from the ethnographic exploration of therapy practice in the rehabilitation of severely disabling stroke. It will commence with an overview of the five themes developed through thematic analysis. It will continue with an exploration of each theme, which describe the factors that guide physiotherapists (PTs) and occupational therapists (OTs) to select particular interventions in the rehabilitation of physical function after severely disabling stroke. It will conclude with a discussion of the study's findings, including its strengths and weaknesses.

8.2 Thematic Overview

Using the theoretical framework of evidence-based practice (EBP) and its use within clinical decision making as presented in Chapter 3, five themes were developed through thematic analysis: professional expertise, beliefs and attitudes about post-stroke recovery, research evidence, attributes of the severely disabled stroke survivor, and therapy within the wider stroke pathway. Similar to the components of the model for evidence-based clinical decisions, the five themes can be divided in therapist-related ("professional expertise", "beliefs and attitudes about post-stroke recovery"), patient-related ("attributes of the severely disabled stroke survivor"), organisation-related ("therapy within the wider stroke pathway"), and research-related ("research evidence") themes. Several subthemes are contained within each theme that relate to this overarching theme (Figure 21). However, the interdependent nature of factors guiding clinical decision making meant that some subthemes are discussed in more than one overarching theme.

It is recognised that ethnographic studies can produce vast amounts of data owing to the nature of the data collection methods and the time spent in the field. For example, in this study, over 1,500 pages of raw data in the form of field notes and interview transcripts were generated. Whilst I acknowledge that I observed many interesting and valuable phenomena during the study, it is not possible to present every observation that was noted during the fieldwork. As such, I have focussed on presenting findings in accordance with the primary objective of the study- to understand what factors guide PTs and OTs to select particular interventions in the rehabilitation of physical function after severely disabling stroke.



Professional expertise

- Importance of clinical expertise
- Professional role

Beliefs and attitudes about post-stroke recovery

- Focus on functional recovery
- Managing disability
- Different timeframes for recovery

Research evidence

- Limited influence of research evidence
- "45 minutes" recommendation

Attributes of the severely disabled stroke survivor

- Clinical presentation
- Challenge of stroke survivor involvement

Therapy within the wider stroke pathway

- Organisational function
- Stroke pathway design

Figure 21- Thematic Overview

8.3 Professional Expertise

The first theme, professional expertise, comprises to two key therapist-related factors guiding decision making in the rehabilitation of severely disabling stroke: clinical expertise and professional role. Expanding upon clinical expertise, one of the components in the model for evidence-based clinical decisions, professional expertise relates to the state of a therapist's professional development and clinical practice. In this study, clinical expertise was one of the most influential factors guiding therapy practice. Notable differences were seen between less expert and more expert therapists in the selection, skilled execution, and modification of rehabilitation interventions. Guidance from more expert therapists was noted in situations characterised by high levels of uncertainty. Professional role differences between PTs and OTs resulted in the selection of different rehabilitation interventions. However, the shared focus on improving physical function resulted in the overlap of some rehabilitation interventions. Role differences also resulted in the adoption of different approaches in the delivery of rehabilitation interventions.

8.3.1 Importance of Clinical Expertise

Clinical expertise is a concept frequently referred to and defined in many ways in the clinical decision-making literature (Higgs *et al.*, 2019). Publications associated with the Evidence-Based Medicine Working Group, the collective of individuals instrumental to the modern EBP movement, defined clinical expertise as "the proficiency and judgement acquired by clinicians through clinical experience and practice" (Sackett *et al.*, 1996; pg. 71) and "the general basic skills of clinical practice as well as the experience of the individual practitioner" (Haynes, Devereaux and Guyatt, 2002; pg. 37). Skills associated with clinical practice are listed as disease diagnosis, treatment administration, and communication. These authors interpreted clinical expertise as the acquisition of practical, technical, and clinical reasoning skills as a result of clinical experience and practice. Other authors have argued that clinical expertise is more of a dynamic process or continuum of professional development guided by critical reflection, rather than a static state of skills or attributes (Higgs *et al.*, 2019; Jensen, Resnik and Haddad, 2019). According to these authors, professional development focuses on skill development, clinical reasoning, multi-dimensional knowledge, and critical reflection. Whilst the attainment of the attributes associated with expert practice, such as advanced problem-solving skills and a sound knowledge base, may be seen as a process of professional development, defining clinical expertise as a process fails to account for dictionary definitions of expertise as “expert opinion and knowledge” or “the quality or state of being expert” (Oxford English Dictionary, 2020; point 1). In addition, people often refer to possessing, acquiring, or having expertise, which suggests that expertise is state of practice rather than a process. In this study, I have drawn on both of these interpretations of clinical expertise and defined clinical expertise as an advanced and highly developed state of clinical practice composed of several aspects: skill proficiency (technical, interpersonal, and clinical reasoning); an extensive, multi-dimensional knowledge base; and metacognitive competence. These aspects are developed and refined through critical reflection upon clinical experiences.

Determining the level of clinical expertise of therapists involved in the study, and subsequently the influence of clinical expertise on decision making, was challenging for several reasons. Due to the subjective nature of clinical expertise, there is no universally accepted way to determine a healthcare professional’s level of clinical expertise. Therefore, I relied on several strategies to gauge a therapist’s level of clinical expertise. My first encounter with a therapist usually involved being told their name, their profession, and their staff grade or banding- “I’d like you to meet Bernice, who is our new Band 6 physiotherapist”. The use of a therapist’s banding during this encounter indirectly indicated their level of work experience, as higher bandings are usually associated with more work experience. Experience and expertise are related, yet different concepts. Wainwright *et al.* (2011) defined experience as exposure to patients and practice settings to apply and develop skills and knowledge. Many authors have either defined expertise in terms of years of work experience or have used these terms interchangeably when describing differences between novice and expert therapists (Strong *et al.*, 1995; Gibson *et al.*, 2000; Jensen *et al.*, 2000; Unsworth, 2001; Doody and McAteer, 2002; Edwards *et al.*, 2004; Edwards and Jones, 2007). In the model of skill acquisition by Dreyfuss and Dreyfus (1980), experience is seen as critical component in the development of expertise. This view of expertise was highlighted in the seminal work of Benner (1982), who described the transition of nurses from novice to expert practice that was guided by critical reflection upon clinical experiences. Many characteristics of expert practice were more likely to be seen in therapists with more work experience in stroke and who were graded at a Band 7 or 8 level. These characteristics include a more developed knowledge base, faster problem-solving skills, advanced communication and interpersonal skills, and technical proficiency in the execution of treatment techniques.

However, in the study, more work experience did not necessarily equate to more expertise. This finding is demonstrated by the following example involving two similarly graded PTs. Frank was a Band 6 PT working on Ferguson Stroke Unit (SU) with just over three years of work experience in stroke. During informal discussions with Frank, he mentioned that he had recently attended several evening lectures about stroke management to improve his knowledge about stroke. During several observed therapy sessions involving two stroke survivors, I observed that Frank regularly incorporated the preferences of stroke survivors to plan therapy sessions, which were frequently modified according to the stroke survivor's clinical presentation. I also observed Frank explaining to the stroke survivor and their carers about the impact of stroke and the role of physiotherapy in addressing the problems associated with stroke. Frank later confided during the interview that his father had suffered a stroke when he was studying physiotherapy, which made him more determined to consistently provide excellent patient-centred care. Frank's situation differed to Fabian' situation, a Band 6 PT working in the Williamson Stroke Rehab Team, who had over nine years of work experience in stroke. Fabian was the named PT for Bob, an individual who had sustained a large right lacunar infarct and presented with significant residual weakness but preserved communication. Fabian's delivery of physiotherapy during several observed therapy sessions with Bob appeared "formulaic"- consecutive sessions appeared to follow an identical plan and exercises were usually delivered in three sets of 10 repetitions with little deviation noticed. Apart from asking for immediate feedback about the intensity of the exercise, Fabian did not appear to ask Bob what he wanted to achieve in therapy and there was little education about stroke and its management. During informal discussions I had with Fabian, he reported that he attended in-service training at work but had little time outside of work to read articles or attend courses due to caring responsibilities. Whilst these two case studies may not be representative practice of all study therapists, the differences between Frank and Fabian highlight that work experience is not necessarily an indicator of clinical expertise. Despite having less work experience, Frank demonstrated more attributes associated with clinical expertise than Fabian. Although I used a therapist's banding and level of work experience to initially place them on a spectrum of expertise, ranging from novice to expert, or less expert to more expert, ascertaining a therapist's level of clinical expertise was made by observing their clinical practice and listening to their responses during interviews to look for the characteristics or signs of expert practice according to the definition presented earlier.

Reflecting upon over 20 years' experience working in stroke rehabilitation, I would consider myself an expert PT in stroke rehabilitation. I have undertaken an extensive range of theory and practical based learning opportunities; facilitated the professional development of many qualified PTs, physiotherapy assistants (PTAs), and undergraduate physiotherapy students; and developed stroke services at a local, national, and international level. Consequently, it was possible for me to recognise many characteristics of expert practice and the influence of clinical expertise on therapist decision making. Whilst I was conscious of the need to continually question what I was observing to prevent premature closure, I recognised the typical structure of a therapy session. Most observed therapy sessions were staffed by more than one therapist due to the dependency of stroke survivors and the need for multiple staff. As sessions were usually staffed by therapists of different staff bandings and levels of work experience, it was possible to note differences in how the sessions operated according to these staffing and experiential differences. As well, I was able to follow a therapist's clinical reasoning, the underlying cognitive processes associated with clinical practice or their "train of thought", without always having to ask the therapist why they chose certain interventions. As such, I noted several differences in clinical practice due to differences in clinical expertise.

More expert therapists appeared more decisive in selecting and confident in implementing different interventions. They also demonstrated a greater degree of fluency in the transition from one intervention- therapy sessions seemed to flow more smoothly- which was not as evident in therapy sessions led by less expert therapists. The confidence, speed, and fluency of intervention selection and delivery by more expert therapists is suggestive of the use of clinical reasoning strategies and decision-making processes characteristic of expert clinical practice, such as pattern recognition and intuitive decision making (Banning, 2008; Kahneman, 2011). In her investigation of the differences in the clinical reasoning of five novice and expert OTs, Unsworth (2001) similarly found that the ability for expert OTs to conduct therapy sessions in a seamless fashion may have been attributed to a greater capacity to reflect in action or "think on one's feet" (Unsworth, 2001, pg. 169) compared to novice OTs. Expert OTs seemed to possess "an air of quiet confidence" (Unsworth, 2001, pg. 169) acquired through prior experience of treating patients, as well as knowledge of what to do for current patients.

One situation to demonstrate this finding involved Christine, a Band 7 PT working on Anderson SU, who was treating Jacinta, an individual who had sustained a brainstem stroke and presented with a mixture of physical and cognitive post-stroke impairments. Christine was treating Jacinta for the first time because she was covering the session for Jacinta's named PT, who was on annual leave. Karl, a PTA, was supporting Christine in delivering the physiotherapy session:

> Karl arrives at Jacinta's bay with a hoist and waits for Christine. One minute later, Christine arrives at Jacinta's bay, looks at the wall clock at the cubicle and says to Karl that because time is tight, let's do something different today with the Sara steady. Karl says okay and takes the hoist away. Christine enters Jacinta's cubicle and introduces herself to Jacinta- Jacinta looks at Christine and says hi. Karl comes back with the Sara steady and says hi to Jacinta. Christine asks Jacinta if she is up for some physio- Jacinta says yes. Christine says to Jacinta that she knows what the physiotherapists are doing with her and she knows what her goals are- to get onto a commode and to go to the toilet. Christine suggests trying a different piece of equipment- not the hoist- to practice getting onto the commode, which will involve standing up. Christine asks Jacinta if that is okay- Jacinta says yes, and that standing and getting on the commode is important to her. Christine then asks Jacinta to roll to the left- Jacinta does. Jacinta says she feels scared about rolling off the bed- Christine reassures her and says she is right in front of Jacinta and Karl is behind her. Christine then asks Jacinta to bring her legs over the edge of the bed, getting Jacinta to do as much possible. Christine then raises the head of the bed and asks Jacinta to sit up. Karl is behind Jacinta and assists a little but Jacinta pushes up by herself. Karl congratulates Jacinta as this is the first time that she has actually sat up by herself- Jacinta nods and smiles but says nothing.
>
> (Extract from fieldnotes, 18th December 2017)

Grasping the whole situation- the limited remaining therapy time, Jacinta's goals, and the need to progress Jacinta towards her goals- resulted in Christine selecting the most appropriate intervention at that point in time. The decisiveness in selecting and confidence in implementing a new treatment intervention without having actually treated Jacinta before may be indicative of Christine's previous experience of treating stroke survivors with similar clinical presentations to Jacinta, and a recognition of what interventions may be appropriate to use in similar situations. Christine's awareness of Jacinta's own goals and reassuring encouragement of Jacinta to participate as much as possible suggests a personalised and patient-centred treatment approach, which, whilst not unique to clinical experts, typifies more expert practice.

Interview findings supported this interpretation of how clinical expertise influences therapy practice. Most therapists reported in the interviews that severely disabled stroke survivors were a complex and challenging group of patients who were best managed by more expert therapists. In the management of severely disabled stroke, more expert therapists were reported to possess greater knowledge and treatment ideas, which resulted in the selection of rehabilitation interventions best suited to address the needs of stroke survivors. More expert therapists were perceived to be more confident in giving advice about treatment effectiveness, and were considered to be more adept at predicting recovery:

> “I learned at university that stretching doesn’t work, that basically, what we’re taught to prevent contractures, that there’s no evidence for or there’s no clear intensity for what you should be doing. So, here I am with this person who can’t engage in anything and I’m just moving their arm. But actually, with more experience comes more sophistication in your understanding of your intervention and your ability to increase the intensity to the point where you feel like it is probably going to make a difference. And maybe there’s not an RCT, but there’s some experience that feels like you’re going to achieve something.”
>
> (Frank, Band 6 PT, Ferguson SU)

> “I particularly remember the physio, from the physical point of view, one of the Band 7s saying to me, ‘I don’t know if this patient’s going to do very well’. And I really wanted the patient to get better, like, ‘No, let’s give it another week’. But I can see now obviously she just had that experience to know. And it is hard to pinpoint what was that she knew about this patient. And I suppose that it’s the all-encompassing severe stroke, where she knew the patient had physical, communication and cognition all significantly impaired.”
>
> (Susana, Band 5 OT, Williamson Stroke Rehab Team)

On the opposite end of the expertise spectrum, differences were noted in the selection and execution of rehabilitation intervention by less expert therapists. During the observed therapy sessions, less expert therapists were more likely to replicate interventions performed in previous sessions, which sometimes were not as successfully executed compared to more expert therapists. Less expert therapists were slower and often demonstrated more hesitancy before modifying or changing interventions, which is typical of novice practice as reported by Higgs and Jones (2019). One situation to demonstrate this finding involved Clive, a newly qualified Band 5 PT normally working on Peterson Hyperacute Stroke Unit (HASU). Due to planned leave on Ferguson SU, Clive was providing cross-cover to Ferguson SU. In one observed session, Clive was treating Harry for the first time, a visiting tourist from Japan who had sustained a left thalamic stroke in the UK and spoke no English. Harry's goal was to be able to stand by himself, which was the aim of the session. Erin, a rehab support worker, was supporting Clive in delivering the session:

> Clive blocks Harry's right knee with his knees and puts his left hand on Harry's right hip. Erin is behind Harry. Clive asks Harry to lean forwards and stand up- both therapy staff guide Harry to stand up. Harry's right knee is hyperextended, and his trunk is very flexed. Clive tells Harry to "Find the middle… back tall"- Harry looks at Clive and shakes his head. Harry leans heavily to the right but Clive or Erin don't say or do anything. After 30 seconds, Clive guides Harry to sit down without saying anything to Harry. Clive says, "It's warm in here" then stands up- Erin remains behind Harry. Clive walks to the paper towel dispenser, takes a paper towel, and wipes his brow.
>
> (Extract from fieldnotes, 20th August 2018)

The lack of skilled execution in practising standing- the degree of physical effort experienced by Clive, the incomprehensible verbal commands given to a non-English speaking individual, the lack of correction of Harry's standing posture- may reflect Clive's lack of experience in treating Harry and in stroke survivors generally. Having observed many therapy sessions involving Harry, Clive appeared to be replicating the same interventions delivered in previous physiotherapy sessions without necessarily reflecting upon his skills to perform the intervention. With limited knowledge of the application of different treatment options, Clive appeared less able to modify the intervention or direct Erin throughout the session, which may have occurred with a more expert therapist performing the intervention. In addition, the slowness in modifying the intervention may be attributed to either slower and more deliberate clinical reasoning strategies, such as hypothetico-deductive reasoning, or less efficient decision making due to limited clinical experience.

Interview findings also supported this interpretation of how limited clinical expertise influences therapy practice. Less expert therapists were reported to be less confident about treating patients with profound impairments, such as global aphasia or severe spasticity. Less expert therapists themselves reported high levels of uncertainty in the effectiveness of treatment interventions, determining future prognosis, and knowing when to stop therapy completely. In these situations, it was suggested that more support was required from more expert therapists to guide decision making in these aspects of clinical practice:

> "I think probably with more junior members of staff, they're probably a little bit more anxious about going to see those sorts of patients. And what I'm noticing with students that I have on the ward at the moment, is that they keep doing the same thing and they don't know where to go on from doing the same thing. And that's maybe where they need a little bit of guidance or a little bit of support around."
>
> (Martin, Band 7 PT, Peterson HASU)

> "I think my lack of experience is always going to be a limiting factor to treat patients, because I always think that if someone's more experienced then they're going to have further ideas, further knowledge about what they could be doing or, you know, 'I wouldn't be handling it this way, I could be doing it other ways'. As well, sometimes when you're not seeing that improvement and you're thinking, 'Oh, is this something that I'm doing or is this just the way that the patient is, or should I be trying something different to optimise their rehab?' and so on."
>
> (Sabrina, Band 5 PT, Ferguson SU)

Guidance from more expert therapists was noted more frequently during therapy sessions than discussed during the therapist interviews. During the interviews, less expert therapists often emphasised the importance of their own judgement in the selection of different interventions and lessened the importance of support from more expert colleagues. Seeking advice from more expert colleagues was seen as one of many factors guiding therapy practice. However, during observed therapy sessions staffed by multiple therapists, guidance from more expert therapists was one of the most influential factors guiding therapy practice. A greater difference in expertise between therapists usually resulted in the more expert therapist taking greater leadership of the session and selecting the rehabilitation interventions. I observed this phenomenon even during therapy sessions where the less expert therapist was the stroke survivor's named therapist and may have spent more time treating the stroke survivor than the more expert therapist. Similar levels of therapist expertise usually resulted in more shared decision making between therapists in the selection of rehabilitation intervention.

As the more expert therapists were almost always of a higher banding, it is possible that I was observing the hierarchical nature of the NHS banding system and power asymmetry between therapists of different grades, which contributed to this finding. Therefore, the extent to which clinical expertise contributed to the leadership of therapy sessions and selection of rehabilitation interventions may be difficult to ascertain. However, I observed several joint therapy sessions on Peterson HASU involving Darren, a Band 6 PT and Belinda, a Band 7 OT. Despite being a lower staff grade than Belinda, Darren had more work experience in stroke than Belinda and usually led their therapy sessions. This may suggest that the leadership of their therapy sessions was due to Darren's expertise in stroke rehabilitation. However, the content of their therapy sessions, which centred on the assessment of physical tasks such as bed mobility, sitting practice, and standing practice, may suggest that other factors, such as professional role expectations, also guided therapy practice. This factor is explored in later in this theme.

Finally, critical reflection is considered to be a central component in the development of clinical expertise (Higgs *et al.*, 2019). Whilst the development of clinical expertise and the role of reflection in its development were not a focus of the study, the importance of reflection on decision making was clearly evident in the study. In his seminal work on reflective practice, Schön (1983) described two types of reflection- reflection-in-action (i.e. reflection during an event or situation) and reflection-on-action (i.e. reflection after an event or situation has occurred). In the current study, all therapists were observed to reflect during the delivery of interventions. This type of reflection manifested itself as continual reassessment during the delivery of a particular intervention, which guided the execution of the intervention and selection of subsequent interventions. As expected, more expert therapists demonstrated greater speed and fluency when executing, evaluating, modifying, and selecting interventions using this type of reflection than less expert therapists. For therapy sessions staffed by more than one therapist, there were several instances observed where therapists debriefed at the start of a therapy session to create a session plan. This plan was frequently guided by reflection upon the previous therapy session, including the outcome of delivered interventions. This deliberate and explicit planning of an impending therapy session, suggestive of the use of analytical decision making processes, was noted across all levels of clinical expertise and often performed when one or more therapists had not recently treated a stroke survivor. One situation to demonstrate this finding involved three therapy staff- Alicia, a Band 6 PT, Erica, a Band 5 OT, and Holly, a PT student- treating Robert, an individual who had sustained a large right middle cerebral artery territory infarct:

> Alicia, Holly and Erica are in the office and leave for the ward. Holly says she hasn't met Robert before, and Erica says she met Robert at the start of the week. Alicia mentions she saw Robert yesterday- they did some standing practice with him, which wasn't very successful because he was pushing a lot. The therapy staff arrive on the ward and go to the nurses' station. Alicia looks for the notes- the dietician has them. After 30 seconds, the dietician gives the notes to the therapists- Alicia takes them and they start reading through the notes. Alicia and Erica discuss possible plans for the session- standing might be too difficult therefore sitting on the edge of the bed, grooming practice might be better. Both therapists agree to get Robert sitting in his chair, take him to the gym and practice grooming tasks in sitting.
>
> (Extract from fieldnotes, 17th August 2018)

8.3.2 Professional Role

Professional role is the second aspect of professional expertise that guided therapist decision making in the rehabilitation of physical function after severely disabling stroke. Although linked with the development of clinical expertise, the development of one's professional role occurs in several different ways. Historically, the rise of professions, whereby occupations shaped themselves into self-regulated occupational groups founded upon specialist educational training and bound by codes of ethics, granted these occupational groups with a particular body of skills or knowledge unique to that profession (Colyer, 2004; Higgs, 2019). Colyer (2004) stated that ownership of these skills and knowledge created professional role boundaries, or clearly defined duties related to that professional group. This ownership of skills and knowledge also conferred power and status to these professional groups, which further established their place in society. Acquiring the skills and knowledge associated with a profession, termed professional socialisation, is a complex process involving entry education, work interactions, and ongoing learning opportunities that enables the development of professional capabilities and a sense of professional identity (Becker, 2005; Higgs, 2019). Accordingly, the development of a therapist's professional role traditionally refers to the development of the particular body of skills or knowledge unique to that profession, as well as how a therapist views themselves and identifies as a member of their own professional organisation. However, subsequent changes in recent decades have challenged traditional notions of professional role boundaries. Nancarrow and Borthwick (2005) reported that in the UK, changes in healthcare policy and shortages in the medical workforce have led to greater advocacy and role opportunities for non-medical professions, such as nursing and allied health professions. King *et al.* (2015) stated that, in many countries, the rise in an ageing population living with chronic illness and multi-morbidity has resulted in a greater need for healthcare professionals with specialist skills to work together and address a patient's multiple healthcare needs. Consequently, healthcare professionals are increasingly working within interprofessional teams and receiving training in programmes that promote interprofessional learning. As such, this close working and learning environment has the potential to influence the roles of existing professional groups. Therefore, a therapist's professional role is shaped by their membership of a particular profession and its traditions of professional socialisation, a response to changes in population demographics, local healthcare policy, and the social context in which the therapist works.

The influence of a therapist's professional role on therapy practice was first identified in the therapist survey. In the survey, similarities and differences in intervention use were noted between OTs and PTs working in different stroke services. The most similar practice, in terms of the similarity of interventions delivered, occurred between community PTs and OTs. The most diverse practice, in terms of the variety of interventions delivered, occurred between SU PTs and OTs. In the current study, this workplace distinction was less clear- PTs and OTs generally performed different interventions irrespective of their workplace. As explained during one therapy session on Ferguson SU by Megan, a Band 7 OT, to Nigel, an individual who had sustained a large left middle cerebral artery territory stroke, "the physio's job is to get you moving but my job is to get you doing". Whilst Megan's role description is not completely accurate, in the sessions I observed, PTs predominantly performed:

- transfer practice, such as transferring from lying in bed to sitting and from the bed to a chair
- balance tasks in sitting and standing
- mobility tasks, such as stepping and walking practice

OTs predominantly performed:

- self-care tasks, such as grooming, washing, and dressing
- upper limb splinting
- task-specific object use, such as using cutlery during feeding or making a hot drink

Having worked alongside OTs for almost 20 years and spending part of a previous job role managing a team OTs and PTs, I approached the fieldwork conscious of professional role differences between OTs and PTs. As such, the finding that OTs and PTs performed different interventions in the rehabilitation of physical function after severely disabling stroke was not surprising. Several observational studies comparing the content of physiotherapy and occupational therapy sessions during stroke rehabilitation have similarly identified differences in intervention use between these professional groups (Ballinger *et al.*, 1999; Bode *et al.*, 2004; De Wit *et al.*, 2006). In these studies, PTs were more likely to practice walking, transfers, standing balance, and active movements, whereas OTs were more likely to practice washing and dressing, leisure activities, sensory tasks, and perceptual training. Although these studies included stroke survivors of differing levels of stroke severity and did not specifically report intervention use for severely disabled stroke survivors, they support the current study's finding that professional role influences therapy practice. In the current study, I also noted several differences between PTs and OTs in their communication style and the manner in which interventions were delivered. For example, PTs tended to adopt a more directive communication style with greater use of commands before and during the performance of task. This was particularly noticeable during tasks when stroke survivors were finding a task difficult to perform or when safety was comprised, such as standing practice. One situation to demonstrate this finding involved Sandy, a Band 7 PT working in the Williamson Stroke Rehab Team. Sandy was practising standing with Trevor, an individual who had sustained a large left middle cerebral artery territory stroke. Hugo, a Band 5 PT, was helping Sandy to deliver the session:

> Sandy asks Trevor to stand- Trevor stands up with the therapists' support. Sandy puts Trevor's hand on the commode and reminds Trevor to tuck his bottom in and lift his head up- Trevor does and Sandy says, "Well done". Sandy asks Trevor to straighten his right knee- Trevor does. Sandy says, "Good job" and then tells Trevor to move his weight side to side- Trevor leans to the left towards Hugo and then to the right towards Sandy. Sandy explains to Trevor that she is looking at his knee control when he does this exercise. Trevor moves his weight side to side four times in each direction and then stops and starts to lean back. Sandy tells Trevor, "Stand up straight and lean forwards"- Trevor straightens his back.
>
> (Extract from fieldnotes, 8th April 2019)

Sandy's directive style of communication, characterised by several short instructions and motivational statements, is similar to the findings from several observational studies exploring the communication style of PTs working in stroke rehabilitation (Talvitie, 1996; Talvitie and Reunanen, 2002; Parry, 2005; Durham *et al.*, 2009). Whilst the relearning of motor tasks, a key aim of physiotherapy in stroke rehabilitation, is enhanced by the provision of feedback about motor performance (van Vliet and Wulf, 2006; Schmidt and Wrisberg, 2007), Talvitie (1996) and Durham *et al.*, (2009) found that PTs in their studies generally provided very limited feedback about motor performance during physiotherapy sessions. In these studies, communication mostly consisted of verbal instructions and motivational statements. In light of their findings, Durham suggested that PTs need to consider the effectiveness of their communication approach if motor relearning is the primary aim of physiotherapy. However, Parry (2005) suggested that the use of motivational statements form part of the routine aspects of physiotherapy practice and encourage the stroke survivor to participate in physiotherapy. Therefore, they may contribute to motor relearning in a different way compared to feedback on motor performance.

OTs tended to adopt a more facilitatory communication style, with less verbal commands during therapy sessions. This was particularly noticeable when OTs were trying to get the stroke survivor to problem solve errors during the performance of a task. OTs focused not just on whether the stroke survivor could perform the task but also assessed various aspects of cognition, such as visual perception, object recognition, and praxis during task performance. This finding may reflect the additional role of OTs in the assessment and management of cognitive dysfunction after stroke. The following situation involving Erica, a Band 5 OT, treating Simon, an individual who sustained a left cerebellar infarct, demonstrates this finding:

> Simon is sitting in front of the basin and mirror. Erica asks Simon if he wants to brush his teeth- Simon nods and picks up a comb. Erica pauses for a few seconds and then asks Simon what would he use to brush his teeth. Simon stops and points to the toothbrush. Erica nods- Simon then picks up the toothbrush and brushes his teeth. Erica holds up the toothpaste and smiles- Simon stops, smiles back, and holds out his toothbrush. Erica then puts toothpaste on the toothbrush- Simon continues to brush his teeth with the toothpaste on the toothbrush.

(Extract from fieldnotes, 11th July 2018)

Another professional role difference was the range and continuity of interventions delivered in therapy sessions over time. PTs tended to deliver a relatively smaller number of interventions designed to improve physical function, such as transfers, balance, and mobility practice, over a course of physiotherapy. The content of sequential physiotherapy sessions was quite similar and the main change from physiotherapy session to session was the progression of these selected number of interventions related to the survivor’s pattern of recovery, such as sitting to standing practice or standing to stepping practice. However, OTs tended to deliver a larger range of interventions over a course of occupational therapy. These interventions were designed to improve physical and cognitive function, such as washing and dressing, grooming, meal preparation and feeding. As well, OTs performed several discharge planning tasks, such as home visits, referrals to social services, and equipment provision.

Interventions performed in one occupational therapy session were not consistently performed in subsequent sessions due to the need to deliver other interventions within the available time. A potential advantage of performing a smaller number of interventions more consistently is that each task can be performed more repetitively, which is more likely to promote functional recovery (Kwakkel, 2006). As well, stroke survivors may understand a professional's role more clearly if the professional performs a set of tasks more regularly. The following situation involving Prue, a Band 7 OT working on Anderson SU, assessing Morris, an individual who sustained a left intracerebral haemorrhage, highlights this concept:

> Prue enters the bay and approaches Morris- Morris is resting in bed. Prue asks how the day leave was. Morris talks about how the day leave went- no issues, he was able to get on/off the toilet without problems. Prue asks Morris what he would like to do now. Morris says, "Physio?" Prue says, "No, I'm the OT- the occupational therapist". Morris says, "What's that?" Prue says that occupational therapist works on everyday tasks, such as washing, dressing, or making a cup of tea. Morris says, "Oh". Prue asks Morris about his arm and whether he remembers what they were doing last week. Morris says practising with the cones. Prue says, "No, that was with the physios". Prue says they practised pulling up the trousers- "Remember?" Mo pauses and replies, "Not sure".
>
> (Extract from fieldnotes, 27th December 2017)

Morris was one of the few stroke survivors recruited to the study who, despite having significant motor impairments, had minimal cognitive impairment. Consequently, Morris was able to recall quite accurately how much therapy he had received, as well how much therapy he had missed out on when therapy sessions were cancelled or postponed. Therefore, Morris' difficulty in recalling the content of occupational therapy sessions may have been due to receiving less occupational therapy than physiotherapy, or not practising dressing as frequently as performing upper limb exercises with the PTs. Morris' lack of understanding of occupational therapy may also reflect the finding by Booth and Hewison (2002), who suggested that a lack of role clarity between PTs and OTs may arise due to role overlap between these professions. In their study, both groups of therapists reported that the role of occupational therapy was less well understood by stroke survivors and other health colleagues than the role of physiotherapy.

Whilst there were differences in intervention use and communication style due to professional role differences, both professions performed similar interventions, such as positioning and seating, upper limb exercises, and training and education of other staff or carers. Training and education were more commonly observed in community settings, where the therapist's role was to inform carers about safe moving and handling principles, and interventions to manage different clinical problems. Although there was some shared content in the training and education provided by both professions, such as upper limb handling and positioning, PTs tended to focus on manual handling methods during transfers, whereas OTs tended to focus on monitoring safety during self-care tasks. Due to my previous experience working alongside OTs, the finding that OTs and PTs performed similar interventions in the rehabilitation of severely disabling stroke was foreseeable. Booth and Hewison (2002) similarly identified the existence of role overlap between occupational therapy and physiotherapy in stroke rehabilitation. In their study, therapists reported that role overlap was inevitable considering the multi-disciplinary nature of stroke rehabilitation. The performance of the same treatment approach by multiple therapists was seen as beneficial to patient care. However, some therapists in their study expressed concern that too much role overlap threatened professional identity and caused role insecurity due to the crossing of professional boundaries. However, therapists in the current study did not raise this phenomenon, possibly due to a relatively clear delineation of physiotherapy and occupational therapy roles observed in the current study.

The shared focus on improving physical function and the normative practice of multi-disciplinary working meant that many observed sessions were delivered by both physiotherapy and occupational therapy staff. In most instances, I observed mutual negotiation before and sometimes during the joint therapy session about the aims of the session, which resulted in the selection of interventions designed to achieve the session's aim. The session lead was usually the most expert therapist, as previously reported, although individual interventions were usually led by the professional traditionally responsible or more experienced in delivering that intervention. For example, standing and walking practice were led by PTs, whereas grooming practice and meal preparation were led by OTs. I did not observe any joint therapy session where PTs or OTs disagreed in determining the session's aim or deciding who would deliver each intervention. Some therapists reported in the interviews that joint working between occupational therapy and physiotherapy staff provided an opportunity to support and learn from each other:

> "So, I suppose some of it is what you're confident with doing. So, I wouldn't necessarily go down an FES [functional electrical stimulation] route on my own. I'd, obviously, I would ask the physios to come in and support me with that. But it might be that I would look at those kind of tasks."
>
> (Nina, Band 5 OT, Williamson Stroke Rehab Team)

> "I certainly use joint working with my junior staff because I usually don't have a lot of time to provide one-on-one support, because they've just got to take their caseload and I've got to take mine. Otherwise we're just not going to get through the day and we're not going to keep the service running. So, if I know there's a senior physio going with a junior OT, that senior physio might come to me afterwards and say, 'It might be a good idea if you talk through this or check this, just because I'm not sure why they did that or why that decision was made'."
>
> (Belinda, Band 7 OT, Peterson HASU)

Belinda's comment about the nature of multi-disciplinary working on Peterson HASU highlights a practical benefit of PTs and OTs working together, in terms of sharing supervisory responsibilities of less expert staff. Belinda felt that she could trust the senior PT to inform her of any issues with her junior staff, which suggests that both she and the senior PT possessed a shared understanding of the roles and responsibilities associated with each other's profession and knew when to escalate any issues associated with clinical practice. Although there was a general separation of intervention use by PTs and OTs during joint sessions, Belinda's quote highlights that multi-disciplinary working may result in role blurring of some aspects of professional practice.

8.4 Beliefs and Attitudes about Post-Stroke Recovery

The second theme, beliefs and attitudes about post-stroke recovery, is another therapist-related theme that comprises therapists' perspectives on the focus of therapy and the timeframes for recovery after severely disabling stroke. A clinician's beliefs and attitudes were not originally considered factors guiding decision making within the model for evidence-based decisions proposed by Haynes, Devereaux and Guyatt (2002). As such, I felt that these factors were separate to the factors associated with professional expertise, resulting in the generation of a different theme.

The conceptualisation and development of this theme stemmed from reflection upon the survey and systematic review findings, analysis of direct fieldwork observations, and reflection on my own beliefs and attitudes about recovery after severely disabling stroke. As previously reported in Chapter 6, there was a discrepancy noted between the most frequently used rehabilitation interventions identified by the survey and the available research evidence for these rehabilitation interventions identified by the systematic review. However, another discrepancy in therapy practice was noted by reflecting upon the survey and systematic review findings- the differential focus of therapy to optimise recovery versus therapy to manage post-stroke complications after severely disabling stroke:

> Another emerging finding from both the systematic review and the survey interview analysis relates to contradiction. Most trials have focussed on physical recovery in severe stroke, yet the literature states that functional recovery in severe stroke is not always possible or incomplete. Very few trials focussed on reducing post-stroke complications after severe stroke, but these are known to be high in this group. Therapists reported in the survey interviews that they focus on functional tasks, yet patients are discharged because they don't meet their functionally orientated goals. It's not clear why these contradictions arise and why there seems to be a lack of rehabilitation (and research) focus on some of the poor outcomes after severe stroke, such as post-stroke complications or carers' burden. The fieldwork will hopefully provide more insight into this under-researched and under-investigated area of stroke rehabilitation.
>
> (Reflective diary entry, 22nd November 2017)

Whilst awareness of this differential therapy practice influenced the focus of observation sessions, it was not immediately clear during the initial stages of the fieldwork why this practice occurred. However, as the fieldwork progressed, it became apparent that a therapist's beliefs and attitudes guided therapist decision making in the rehabilitation of severely disabling stroke. For example, the normative expectation of functional recovery early after severely disabling stroke by most therapists resulted in less focus on managing residual disability and less long-term therapy provision. A preference expressed by many therapists to treat less disabled stroke survivors may have contributed to this differential focus of therapy practice. Consequently, there were instances when therapy did not always address the needs of this cohort of the stroke population.

Awareness of the influence of a therapist's beliefs and attitudes on decision making also made me question my existing beliefs and attitudes about recovery after severely disabling stroke. These beliefs and attitudes had been shaped mostly by years of reflective clinical experience working in stroke rehabilitation, as well as more recent immersion in the stroke rehabilitation literature. Emerging observations from the fieldwork both supported and refuted my existing beliefs and attitudes, leading to new insights into why therapists manage survivors of severely disabling stroke the way they do. Due to the influence of my beliefs and attitudes about post-stroke recovery on the development of this theme, some of these beliefs and attitudes will be discussed throughout this section.

8.4.1 Focus on Functional Recovery

It was apparent from observing therapy practice in different settings, particularly in the acute phase post-stroke, that the focus of therapy was to restore as much function and independence as possible within the parameters of the stroke service and within the constraints of severe brain damage. Function was understood by most therapists as the ability to perform specific tasks or activities, such as transfers, walking, and grooming. As such, these activities were referred to as functional tasks. Functional recovery, therefore, referred to a recovery in the ability to perform functional tasks. In the interviews, many therapists recognised that some aspects of recovery for survivors of severely disabling stroke differed to recovery for those less affected by stroke. For example, the recovery process was slower, took longer, and was often less complete. Severely disabled stroke survivors were also considered less likely to resume their previous social roles, such as hobbies or work. These differences in recovery were highlighted by Jane, a Band 6 OT working on Anderson SU:

> "I certainly think, I mean at the end of the day, it's similar in that you're dealing with patients who have had a stroke and a lot of it is improving function and trying to get them back to their baseline as close as possible. But I think with the severe strokes, you're a lot more mindful that they might not get back as quickly or back to the same level."
>
> (Jane, Band 6 OT, Anderson SU)

Despite literature reviews highlighting uncertainty about the effect of inpatient stroke rehabilitation and early supported discharge on improving independence in activities of daily living for survivors of severely disabling stroke (Pereira *et al.*, 2012; Langhorne, Baylan and Trialists, 2017), the overall philosophy of stroke rehabilitation across all stroke services was to optimise the ability to perform tasks as independently as possible, similar to that of less disabled stroke survivors:

> "I think I'd probably still treat people relatively similarly-ish from outset. And by the outset, I mean, days to a week. But then as those impairments become a little bit more apparent in a functional way, then I'd want to start to change how I approach them. Almost like giving patients the benefit of the doubt. Treating everybody as if they can do something or giving them an opportunity to see what they can do. For example, you might want to get everyone sitting on the edge of the bed to start with. And if it becomes apparent that this is not the way that we're going with, then maybe reassessing that."
>
> (Kylie, Band 7 PT, Ferguson SU)

Kylie's quote also highlights the widespread view amongst acute stroke therapists that in situations where functional recovery was very slow and prognosis of functional abilities was uncertain, it was better to provide regular therapy in the hope that a severely disabled stroke survivor regained some ability to perform tasks, rather than provide limited therapy and risk the chance of a stroke survivor not recovering. Conversely, many therapists also believed that because functional recovery was synonymous with the overall philosophy of stroke rehabilitation, a lack of functional recovery was a key indication to stop providing therapy. Betty, a Band 6 PT on Anderson SU, highlighted these sometimes conflicting views:

> “I think stopping can be a really difficult decision to make and it has to be an MDT [multi-disciplinary team] discussion. And I think it goes back to potential, you know, that there may be improvements- you can’t guarantee it- but you can be fairly certain that, over time, there will be some gains but they’re likely to be very small gains. And, I suppose, then you have to weigh up, with those gains, what are you likely to achieve? Or will the eventual outcome still be the same? And, in an ideal world, we would rehab everyone for as long as we could, but we don’t have that funding and we don’t have those really long stay beds. But then if they’re not making those gains, you have stop at some stage.”
>
> (Betty, Band 6 PT, Anderson SU)

The primacy of a functionally-orientated focus of stroke rehabilitation, even for survivors of severely disabling stroke, is a belief that I held for many years based upon my work experience in stroke rehabilitation. This belief, shared by most therapists in the study, is consistent with the conceptual understanding of stroke rehabilitation reported in many international clinical guidelines on stroke rehabilitation (Intercollegiate Stroke Working Party, 2016; Winstein *et al.*, 2016; Stroke Foundation, 2019b; Teasell *et al.*, 2020). In a therapy approach that focussed on functional recovery, I commonly observed that interventions were delivered in a sequential and progressive manner. Therapists commenced with practising more basic functional tasks, such as rolling, grooming in bed, or sitting independently, before progressing to more difficult functional tasks, such as standing, stepping, or washing in a bathroom. I also noted that therapists initially adopted a restorative approach when improving function. In this approach, therapists focussed on the restoration of impaired body functions, such as muscle power and sensation, during the performance of a specific task. Therapists practiced tasks based on normal movement patterns, such as standing up with the trunk in extension and weight evenly distributed through both lower limbs, or reaching forwards with shoulder flexion and elbow extension. One situation to demonstrate this finding involved Sally, a Band 5 PT, and John, a Band 7 PT working on Anderson SU. Sally was the named PT for Jacinta, an individual who had sustained a brainstem stroke and described earlier in the chapter. Prior to the therapy session, Sally had highlighted some concerns to John about Jacinta's lack of independence in standing. John, as a more expert PT, was using the therapy session to guide Sally in different ways to practise standing with Jacinta:

> John asks Jacinta to stand- Jacinta stands up. John and Sally discuss quietly between them where Jacinta's weight is and if there is any activation in her trunk and leg. Jacinta looks ahead, not really paying attention to the conversation. John asks Sally what her aim regarding Jacinta's stand is- Sally pauses for a few seconds and then says to get activity in the leg. John explains to Sally that at the moment the way Jacinta is standing, it's good for her trunk extension and she is getting some activation in her gluts, but it's not that good for her quads as she is standing with her knee hyperextended and pelvis forward. Sally suggests maybe trying some squats- John says that is a good idea. John asks Jacinta to put her right hand on his left shoulder- Jacinta does and her posture is straighter (less laterally flexed to the right). John says, "That's better" and says to Sally that Jacinta has more weight on her left leg.
>
> (Extract from fieldnotes, 5th January 2018)

If restoration of impaired functions was slow or limited, I frequently observed therapists shifting to a compensatory, or adaptive, approach. In this approach, therapists focussed on the performance of a task as independently as possible, with less concern about the type of movement pattern executed during the task. The transition from a restorative to a compensatory approach varied considerably between therapists and stroke services and was influenced by therapist preference and workplace philosophy as much as the rate of restoration of impaired body functions:

> "But when you make that total change towards being more adaptive is probably, I don't know if I could put a timeline on it, but when the comorbidities are feeding into it, when you've tried the restorative things again and again and again and again and you're still not getting activity in the hand or, activity in the leg. Then I would work toward, more towards the adaptive things at that point."
>
> (Megan, Band 7 OT, Ferguson SU)

> "But it also made me really think about whether I should be impairment-based training someone or should I be function-based training them. I think you always end up doing a mix of the two, don't you, to keep it interesting because impairment-based training alone is mind numbing for the patient, I'm sure. But the second we got him [Harry, a stroke survivor] doing repetitive movements, sit to stand from a plinth, we got more consistent activity as well carry over. So, whilst it wasn't pretty, and it wasn't exactly what I wanted, and he wasn't necessarily activating the muscles at the right time in the right way, we were getting function. And I suppose that, maybe, I was bringing my personal assumptions into it and not what the patient should be doing."
>
> (Alicia, Band 6 PT, Ferguson SU)

Upon clarification, Alicia's reference to impairment-based training was synonymous with a restorative approach to improving function that did not specifically involve the repeated practice of certain tasks. In several therapy sessions involving Alicia and her colleagues treating Harry, impairment-based training involved attempts to activate Harry's paretic lower limb muscles in different positions, such as supine, side-lying, and standing. Alicia's view that impairment-based training can be "mind numbing" or boring for the patient was astute- Harry often appeared disinterested after several minutes of PTs using this training approach. However, Harry appeared much more engaged when PTs practised more functionally orientated tasks, such as stepping practice or walking.

The initial approach adopted by therapists to optimise functional recovery may not be consistent with the literature on functional recovery after severely disabling stroke. Several authors have reported that post-stroke recovery is a complex process that occurs through a combination of spontaneous and learning-dependent processes (Kwakkel, Kollen and Lindeman, 2004; Bayona *et al.*, 2005; Langhorne, Bernhardt and Kwakkel, 2011; Teasell and Hussein, 2018). Kwakkel, Kollen and Lindeman (2004) and Bayona *et al.* (2005) stated that these processes include restitution, involving the repair of the lesioned area with its function assumed by adjacent cortical and subcortical structures, as well as substitution, involving behavioural compensation by the stroke survivor. Cortical reorganisation is more likely in smaller strokes due to the preservation of adjacent cortical structures that can assume the function of the damaged area. Therefore, restoration of impaired body functions is more likely in smaller, milder strokes compared to larger, more severe strokes. As larger, more severe strokes involve more cortical and subcortical damage, compensatory strategies are likely to play a greater role in functional recovery after severely disabling stroke. Consistent with this view is the finding from a prospective observational study conducted by Roth *et al.* (1998), who found a weak relationship between residual neurological impairment and activity performance in 402 stroke survivors undergoing stroke rehabilitation in the USA. They found that stroke survivors were still able to perform functional activities despite having residual neurological impairment, which highlights the importance of compensatory strategies in post-stroke recovery.

In this study, I was not evaluating the effect of different rehabilitation interventions or approaches on functional recovery. Therefore, it was not clear how much a restorative or a compensatory approach contributed to improvements in functional recovery seen in the stroke survivors participating in the study. Regardless of the approach used, the performance of tasks as independently as possible was a fundamental aim of therapy sessions in inpatient and community stroke services. Attainment of goals, which usually centred on a stroke survivor becoming more independent in specific tasks, enabled the continued provision of inpatient therapy. For some community services, such as the Williamson Stroke Rehab Team, only stroke survivors who had demonstrated functional recovery in hospital and had the potential for further functional improvements were accepted by the community team. This aspect of therapy practice is explored later in the chapter.

8.4.2 Managing Disability

Although most therapists adopted an approach to optimise function and independence, I observed that some stroke survivors on the SUs made very slow or limited progress even when adopting a compensatory approach to recovery. In this instance, therapists shifted to an approach designed to maintain the stroke survivor’s current level of functioning, as well as prevent functional deterioration and the development of post-stroke complications. Therapists frequently referred to this approach as disability management:

> “But if it looks like, actually, they’ve given it a good go and they’ve not achieved things, I’m looking more of a disability management perspective. So, trying to reduce the risk of secondary complications. So, contractures, pressure sores, just general comfort. Making sure people are positioned well in bed and can get seated.”
>
> (Christine, Band 7 PT, Anderson SU)

Some interventions designed to manage disability, such as positioning and resting splints, were performed alongside therapy designed to improve functional recovery. However, the focus on functional recovery in the early stages post-stroke meant that there was less emphasis on managing disability over a 24-hour period. Although I noted that therapists positioned stroke survivors in bed or in a chair at the end of a therapy session with limbs well supported by pillows, blankets or resting splints, monitoring a stroke survivor’s body position and alignment outside of therapy sessions was not consistently performed. Despite the visible placement of positioning charts detailing recommended body postures on the walls surrounding the stroke survivor’s bed space, I frequently observed many stroke survivors spending most of the day in bed with incorrect placement of pillows or inconsistent use of resting splints. Despite overhearing therapists handing over to nurses when a stroke survivor should return to bed after sitting out, I regularly noted many stroke survivors slouched in chairs and looking visibly tired after sitting out for longer than recommended by therapists. During the fieldwork, I found it challenging not to intervene in these situations for two reasons. Firstly, my automatic instinct as a PT would have been to correct a stroke survivor’s posture or reposition a pillow under their upper limb if I was walking past them and they appeared to be uncomfortable or in distress. Secondly, continued reading about the high prevalence and impact of immobility-related complications after severely disabling stroke during the fieldwork altered my beliefs about the focus of stroke rehabilitation-preventing complications was just as important as improving functional recovery for this cohort of the stroke population. Therefore, I felt that interventions designed to manage disability should be given a similar level of priority by therapists as interventions designed to optimise functional recovery.

Despite my views on the importance of disability management and the role of therapy in its delivery, several therapists suggested that it was the nurses’ responsibility to ensure that interventions designed to manage disability were executed, particularly outside of therapy sessions:

> “And then optimal positioning. So, making sure that they’re sitting upright, making sure they’ve got good positioning of their affected limb, making sure that they’re regularly turned and pressure care and that sort of thing. So, that’s more from the nursing side of things.”
>
> (Karen, Band 6 PT, Anderson SU)

> “I’ve noticed that some nursing assistants are really good as they often sit with some patients and talk to them about things to try and engage them and keep an eye on them at the same time. You know, if the patient were sat in the chair to do that, then that would be beneficial.”
>
> (Kristina, Band 6 OT, Ferguson SU)

Whilst therapists developed positioning programmes and seating recommendations for nurses to perform, I did not observe any instances where therapists addressed any mismatch between recommended and actual positioning practice with nurses. The difference in what interventions therapists wanted nurses to perform and what interventions nurses actually performed may be attributed to a lack of understanding of the nursing role in stroke rehabilitation, as identified by Pryor (2008) and Kearney and Lever (2010). In the current study, despite therapists’ desire to engage nurses in a stroke survivor’s rehabilitation programme, therapists recognised that nurses had many work tasks to complete and that monitoring a stroke survivor’s positioning was another task for the nurses to complete:

> “If one person is a severe stroke, they might be incontinent and need hoisting. If a nurse or a HCA [healthcare assistant] has put a lot of time into that patient already in that morning, constantly repositioning them or prompting the patient to engage in exercises outside of therapy might be lower down the list. Because, they are very overstretched, they are very overworked.”
>
> (Susana, Band 5 OT, Williamson Stroke Rehab Team)

In his systematic review and meta-ethnography of nursing practice in stroke rehabilitation, Clarke (2014) similarly identified the challenges that nurses face in balancing direct care tasks and rehabilitation activities, which were perceived to be dependent upon sufficient staffing levels. As direct care and monitoring of stroke survivors are essential tasks to prevent harm and maintain safety, and rehabilitation techniques are perceived to take more time, Clarke (2014) stated that nurses may prioritise monitoring and direct care tasks over rehabilitation activities. This deprioritisation of rehabilitation activities may explain why I observed many stroke survivors sitting in a chair for longer than recommended or positioned with incorrect placement of pillows and resting splints.

Once it was decided by therapists to shift from a functional recovery approach to a disability management approach, therapists reported that they provided informal teaching or verbal handovers to nurses about safe limb handling, positioning plans, and seating regimes. Although not directly observed, the frequency of performing interventions for disability management was reported to be much lower than the usually daily frequency of therapy sessions to improve functional recovery:

> "I think disability management is less frequent because we're not expecting to see changes… because it's more preventative, it's more of the monitoring, so, putting things in place. So, going to assess someone's positioning in bed, maybe taking photos with their permission or family's consent, and educating the nurses on the best regime for that patient. So, that's something that's not going to change from day-to-day. So, I'd say that's much lower intensity."
>
> (Melanie, Band 6 PT, Anderson SU)

If a stroke survivor remained in hospital for several days beyond the transition to disability management, therapists stated that the stroke survivor was usually discharged from their caseload, with the caveat that nurses could inform the therapist if there were changes in the stroke survivor's clinical presentation requiring further therapy assessment. However, I did not observe any instances where stroke survivors were referred back to therapy staff.

Although therapists highlighted the importance of disability management in preventing complications, disability management was not perceived as "regular" rehabilitation, which focussed on functional recovery. Disability management was also viewed as less rewarding than "regular" rehabilitation:

> "I know I said that physios want to fix people and I think we do hold restoration of function in higher regard than we do management of disability. And I think, especially in neurology, I think that is the case. And no one I've ever met aspires to want to, unless you've got a really big interest in it, no one aspires to want to go and work in a disability unit at Jordanville, to passively range people and tilt table, like, GCS [Glasgow Coma Scale] 3 patients. And I think there is an element of job satisfaction you want- you want to work with patients because you like building that relationship with patients and therefore all of a sudden you don't have that because someone's GCS is very low. You don't get any reward."
>
> (John, Band 7 PT, Anderson SU)

The preference for therapy to optimise functional recovery rather than manage disability, as highlighted by John, reflected a wider preference amongst therapists to treat stroke survivors that were able and motivated to engage in therapy and demonstrated faster functional recovery. These stroke survivors were usually those less affected by stroke. Reflecting upon my own preferences, I understood the satisfaction that John was referring to, which was derived from developing a therapeutic relationship with a stroke survivor and seeing them recover after a stroke. It was recognised by many therapists that, although personal preferences should not influence clinical practice, a preference to treat those less affected by stroke may influence the provision of therapy to those severely disabled by stroke:

> "I think some people probably don't like treating the more severe stroke. So, you kind of go into one session and you see, or you compare to a patient that you saw two months ago that was the same who didn't progress. So, you, kind of, make that expectation."
>
> (Monica, Band 7 OT, Williamson Stroke Rehab Team)

Previous research has investigated the influence of stroke care professionals' attitudes and beliefs on clinical decision making (Maclean *et al.*, 2002). In their study, Maclean *et al.*, (2002) explored SU professionals' concept of patient motivation and how they used this concept in their clinical practice. Stroke survivors with a proactive demeanour, such as asking questions or engaging in exercises outside of scheduled therapy sessions, were deemed to be motivated by stroke care professionals. Stroke survivors were described as unmotivated if they displayed a passive demeanour, demonstrated limited interaction with therapy staff, or demonstrated little interest in rehabilitation. Some professionals in their study preferred to treat more motivated stroke survivors and were less likely to push unmotivated stroke survivors, particularly if they were elderly. In the current study, it is possible that some therapists who preferred to treat less disabled stroke survivors or held less positive attitudes towards more disabled stroke survivors were inclined to treat these stroke survivors differently. Upon reflection on the interviews, several therapists appeared more uncomfortable and demonstrated greater hesitancy when answering questions about personal preferences. Potentially, these therapists may have felt threatened by this line of questioning, as revealing one's personal preferences, particularly if they contravene the normative expectations of clinical practice, may be considered unprofessional. Whilst no therapist stated in the interviews that they would treat a severely disabled stroke survivor less favourably based on their personal preferences, the recognition by many therapists that personal preferences may influence therapy is suggestive that attitudes towards severe disability indirectly guide therapist decision making.

Some stroke survivors discharged from SUs were referred to their corresponding community stroke service to continue with disability management. However, only Stephenson Community Stroke Team provided a service, albeit limited, specifically for disability management. The aim of the service, termed resettlement, was to provide training and education to carers about strategies to prevent post-stroke complications. Therapists reported that the resettlement service involved one to two sessions and then stroke survivors were discharged. However, therapists in this team highlighted several issues with such a short period:

> "And then our third stream is our resettlement stream, which is for those people that, on the surface, may just need disability management and help in their transition from an acute unit, to home to maybe a nursing home, but with an increased package of care. So, there's not necessarily rehabilitation goals, but we find that actually these patients sometimes change and also have the most complex needs. So, where we initially thought this stream would be one or two sessions to touch base to see everything has been transitioned well, the reality of it is that it is actually a lot more input, a lot more coordination."

(Ebony Band 7 PT, Stephenson Community Stroke Team)

> "It feels like with some of these complex patients that you're just firefighting and almost case managing and then rehab ends up going on the back burner. And then by the time you've sorted out issues- like, we had a patient who doesn't have the right medications, or his carers aren't turning up or the fridge is broken, and now the window's broken and it's really cold. And you end up firefighting all these kinds of almost case management issues and then you get to the point that your time is up and you go, 'Oh'."
>
> (Tanya, Band 7 OT, Stephenson Community Stroke Team)

These quotes from Ebony and Tanya highlight that disability management is not a simple nor straightforward aspect of therapy practice that can be easily handed over to other staff groups or carers in a short period of time or within a few therapy sessions. The relatively limited time that therapists devoted to disability management in hospitals or that community services were commissioned to provide disability management corroborates the preferential focus on functional recovery over disability management held by many therapists in the rehabilitation of severely disabling stroke. This preferential focus on functional recovery may also be influenced by a preference to treat less disabled stroke survivors, as well as less favourable attitudes towards severe disability.

8.4.3 Different Timeframes for Recovery

During the interviews, therapists demonstrated different understandings about the timeframe for recovery after a severely disabling stroke, which influenced the selection and timing of different interventions. In line with the normative expectation of recovery post-stroke, many therapists reported that most recovery occurred in the first three months after a severely disabling stroke. Accordingly, these therapists felt that most therapy should be provided in the acute inpatient phase, which usually comprised once daily therapy sessions focussing on functional recovery. Therapists also felt that there was limited benefit in referring stroke survivors not demonstrating early functional recovery to community services to monitor for further signs of improvement. Similarly, community therapists were less likely to reassess functional tasks or perform task-specific practice for stroke survivors who had not improved functionally in the acute inpatient phase, as it was felt that further recovery was limited or not possible. In these instances, interventions focussed more on disability management:

> "What we don't do, if someone has come out of hospital, and they haven't managed to get sitting balance, is that we don't go into doing a complete sitting balance assessment. So, with the lady we saw, she had a stroke, I think it was four months, and she never managed to get sitting balance and she never progressed beyond hoist. So, the first time we saw her, we did a full assessment and then got her positioned out into the chair. There was no point focussing on sitting balance or exploring standing with the standing hoist."
>
> (Leonie, Band 7 PT, Stephenson Community Stroke Team)

This timeline of recovery after severely disabling stroke reported by these therapists is contrary to observational studies that report a much slower and longer recovery period after severely disabling stroke (Wade and Hewer, 1987; Duncan *et al.*, 1992; Jorgensen *et al.*, 1995a; Jorgensen *et al.*, 1995b; Ancheta *et al.*, 2000; Sackley and Dewey, 2001; Douiri *et al.*, 2017). In two of these observational studies, survivors of severely disabling stroke continued to demonstrate improvements in functional recovery between 6 - 12 months post-stroke (Sackley and Dewey, 2001; Douiri *et al.*, 2017). However, these studies did not clearly report whether stroke survivors received any type of therapy during this timeframe. Therefore, the contribution of therapy towards improvements in functional recovery is not known. Despite this uncertainty, findings from these studies suggest that limiting therapy to the first three months after severely disabling stroke may have negative consequences on longer-term recovery for this group of stroke survivors.

A smaller number of therapists believed that functional recovery was possible in the chronic phase post-stroke. These therapists were usually more expert and had direct experience of treating stroke survivors in the chronic phase post-stroke. Reflecting upon my own clinical experiences, this was a belief that I similarly developed after working with stroke survivors in outpatient settings and who were seeking treatment several months post-stroke. In the study, therapists recalled instances where stroke survivors demonstrated improvements in function months and sometimes years post-stroke, despite making variable gains in the acute and subacute phase:

> "The rehab centre where I worked in was easily the best rehab centre I've worked in, even compared to here. It's on another level. And we used to see really severe strokes, really, really severe strokes and we used to see them quite far down the line, where they had lots of secondary complications because they could wait up to a year to come to us. And we used to get a lot of them up walking in the end. But if you don't know, if you haven't maybe seen beyond the HASU, beyond the stroke unit, beyond the outpatients, if you haven't seen their whole spectrum, you may not know how far to push someone or, maybe, when less is more at that certain time. So, I guess it comes back to experience."
>
> (Darren, Band 6 PT, Peterson HASU)

Therapists who believed in later recovery highlighted the limitations of early decision making regarding future prognosis and advocated for stroke survivors to have access to community therapy or therapy "further down the line." The focus of latter stage therapy was to monitor for signs of engagement, optimise functional recovery, as well as enable societal participation:

> "But, you know, these patients still may have the potential to improve in the community six months down the line. I think we pin too much decision making sometimes on this acute stage. And I think the decision making for the longer term needs should be made six, nine months down the line. Not at six weeks post stroke, in an acute hospital, when they've been medically unwell, they've gone through a massive life event where family are stressed, where the transition into the community is very stressful from the hospital. Actually, when things have settled down six months down the line, it would be interesting to see how these patients actually do."
>
> (Natalie, Band 8 OT, Anderson SU)

> “I would say again this is where I really struggle with any sort of resettlement, because even if someone’s got a severe stroke that they may not be able to gather any sort of independence from a physical or a functional point of view. But there are still creative ways that people can participate and have a sense of control, an ownership over their lives. So, even thinking a bit more outside the box… okay, this patient is never going to walk again or they’re never going to be doing a standing transfer again, but is there any component of their life that they can have some form of participation in or someone can support them to feel part of the community or feel that they have a role of, you know, maybe just turning up to a group?”
>
> (Ebony, Band 7 PT, Stephenson Community Stroke Team)

The limitation of early decision making after stroke has been identified in several observational studies investigating the accuracy of therapists’ prediction of functional recovery post-stroke (Kwakkel, Van Dijk and Wagenaar, 2000; Eghidemwivbie and Schneeweis, 2010; Nijland *et al.*, 2013). In these studies, PTs and OTs were asked to assess stroke survivors at two different time point post-stroke and predict tasks such as walking ability, upper limb function and dexterity, and activities of daily living at six months post-stroke. The first time point was 72 hours (Eghidemwivbie and Schneeweis, 2010; Nijland *et al.*, 2013) or two weeks post-stroke (Kwakkel, Van Dijk and Wagenaar, 2000), whereas the second time point was hospital discharge (Eghidemwivbie and Schneeweis, 2010; Nijland *et al.*, 2013) or five weeks post-stroke (Kwakkel, Van Dijk and Wagenaar, 2000). Therapists were more accurate in predicting function on the second time point compared to the first time point. One major implication of the inaccuracy of early decision making is that severely disabled stroke survivors may be less likely to access ongoing rehabilitation based on perceived lack of future functional recovery. This situation arose during the study with Trevor, a stroke survivor seen by the Williamson Stroke Rehab Team:

> "So, Trevor wasn't initially referred to us. So, he had a stroke but wasn't referred to our team because he was deemed as having no rehab potential in hospital. He had a past medical history diagnosis of dementia which I think perhaps impacted peoples' thinking about why he may not be able to participate and relearn skills. Also, in hospital, he was in bed 23 hours a day, he wasn't participating in sessions. He was very low in mood and not even sitting out of bed regularly. So, he was discharged home without referral to us. And his daughter initiated the referral to us saying he was very keen for us to get involved. And that's how he come to our team."
>
> (Sandy, Band 7 PT, Williamson Stroke Rehab Team)

Trevor's situation highlights the importance of giving severely disabled stroke survivors opportunities for therapy in the longer term. Residing in a care home, Trevor initially required a standing hoist to transfer due to moderate weakness and reduced exercise tolerance. The Williamson Stroke Rehab Team were understandably reluctant to accept his referral. Due to the persistence of Trevor's daughter, Carolina, and regular physiotherapy, Trevor was able to transfer and walk using a rollator frame with the assistance of one person after six weeks of therapy. Whilst all his therapists commented upon his successful recovery and the need to "give patients a chance", only one therapist acknowledged the limitation of premature decision making in the absence of having a patient advocate:

> **Me: Do you think if Carolina wasn't there, he might not have had the same input?**
>
> Lizzy: Um, yeah. If she wasn't there, we might have pulled out sooner. But because she was there and really involved, I guess we continued to see Trevor. And it was really nice that she was involved and wanted to see him improve and maybe that rubs off on him and, you know, it's that whole psychological support from her as well. But I think, if she wasn't there, we probably would have pulled out sooner, because although he was making gains, they were very small gains.
>
> (Lizzy, Band 6 PT, Williamson Stroke Rehab Team)

8.5 Research Evidence

The third theme, research evidence, relates to the influence of research evidence and clinical guideline recommendations on decision making in the rehabilitation of severely disabling stroke. Whilst EBP has been defined as the integration of best research evidence with clinical expertise and patient values (Haynes, Devereaux and Guyatt, 2002), it was noted that there was limited awareness of the available research evidence underpinning rehabilitation for survivors of severely disabling stroke. Many interventions delivered during observed therapy sessions had no research evidence supporting their use in clinical practice, a finding that was similarly noted in Chapter 6 when comparing the results of the therapist survey to the systematic review. As well, interventions with known effectiveness were not consistently observed across all stroke services. These findings suggest that research evidence was a less influential factor guiding therapist decision making in the rehabilitation of severely disabling stroke. Conversely, a key guideline recommendation to provide stroke survivors with at least 45 minutes of each appropriate therapy daily was more influential in guiding therapy practice. Its impact was noted in the length and frequency of therapy sessions, which shaped the nature and content of therapy sessions.

8.5.1 Limited Influence of Research Evidence

During the interviews, research evidence was not a commonly reported factor contributing to decision making in the selection of different rehabilitation interventions. Some therapists mentioned that there was good evidence for repetitive, task-specific practice in promoting neuroplasticity and functional recovery. However, these comments were in response to introductory interview questions asking therapists to define stroke rehabilitation generally and list some of the key principles guiding its practice. It is possible that therapists were demonstrating their knowledge of the available research evidence investigating post-stroke recovery, which has mostly involved less disabled stroke survivors, and applied it to survivors of severely disabling stroke. Some expert therapists mentioned prognostic indicators reported in the literature, such as the presence of incontinence, severe cognitive impairment, or initial limb weakness. Reference to these factors occurred when discussing rehabilitation potential, which therapists usually defined as the potential for functional recovery. The presence of these factors in a stroke survivor indicated less rehabilitation potential and a greater likelihood in not providing therapy to promote functional recovery:

> “There are some indicators that when we assess patients at that acute stage that would indicate whether the patient has less rehab potential versus patients that have more rehab potential. So, low arousal levels, severe cognitive impairment, dense upper limb weakness, obviously the emergence of spasticity can be poor prognostic indicator. Severe trunk impairments and things such as Pusher Syndrome, poor midline awareness, are obviously going to have an impact. And with time, if we identify that some of those factors or impairments don’t improve, patients have less of a potential to physically rehabilitate.”
>
> (Natalie, Band 8 OT, Anderson SU)

Only one therapist, a HASU PT, specifically referred to findings from AVERT, a randomised controlled trial (RCT) investigating the effect of very early mobilisation post-stroke, and their impact on clinical practice in the rehabilitation of severely disabled stroke:

> “I guess one of the difficulties is the AVERT trial that came out saying that early mobilisation led to worse outcomes with some of the more severe strokes and it’s difficult… I think it was quite a shocking piece of research because from when I started as a Band 5, I always thought the first thing you do is get them up and out. And it has made me question more what I do and whether that early mobilisation is really necessary that day or whether it’s better to leave them for a bit.”
>
> (Martin, Band 7 PT, Peterson HASU)

Martin’s view highlighted one way in which research evidence guides clinical decision making- to question the effectiveness of standard clinical practice in order to guide the future selection and delivery of rehabilitation interventions. This role of research evidence in guiding clinical practice may stem from the historical practice of physiotherapy and occupational therapy, which lacked a coherent theoretical basis underpinned by research evidence, as reported by Turner (2001) and Turner and Knight (2015). Whilst research is conducted for a variety of reasons, one possible aim of physiotherapy and occupational therapy research conducted in recent decades is to address this paucity in the evidence base underpinning clinical practice. The AVERT trial was a seminal stroke rehabilitation trial that sought to determine the effectiveness of very early mobilisation, a commonly used intervention that was poorly defined and not based upon robust research evidence. The findings from AVERT suggested that stroke survivors undergoing very early mobilisation (i.e. within 24 hours post-stroke) were less likely to have a favourable outcome, in terms of functional recovery, than stroke survivors mobilised more than 24 hours post-stroke. The findings were seen as surprising to the AVERT research team, as well as clinicians, as they challenged the prevailing view that very early mobilisation was beneficial in augmenting recovery post-stroke.

In addition to Martin's comments on research evidence, two PTs suggested that there was limited evidence in severely disabling stroke, although there was a degree of uncertainty in their responses:

> "I think the evidence out there for severe strokes isn't quite there, which I guess is why you're conducting this study."
>
> (Clive, Band 5 PT, Peterson HASU)

> "I think, evidence-wise, maintaining range by passive stretching doesn't have a huge evidence base. It'd be more 24-hour positioning and with the nurses, because we're wanting to maintain range in the longer term rather than just get an improvement in that session. So, yeah, I think there is quite limited evidence in severe stroke, from my understanding anyway, as to what is the most effective option."
>
> (Melanie, Band 6 PT, Anderson SU)

These quotes from Martin, Clive, and Melanie suggest that therapists interpreted research evidence as studies evaluating the effectiveness of different rehabilitation interventions, such as RCTs. No therapist referred to alternative research approaches, such as qualitative research, when discussing research evidence. Equating research evidence with RCTs may reflect therapists' awareness of the hierarchy of research evidence (Akobeng, 2005a), which places systematic reviews and RCTs at the top of the hierarchical pyramid. Two systematic reviews by Scurlock-Evans, Upton and Upton (2014) and Upton *et al.* (2014) explored OTs' and PTs' attitudes, knowledge, and use of EBP. Both reviews identified low and inconsistent use of research evidence investigating intervention effectiveness by therapists in clinical decision making. Upton *et al.* (2014) found that OTs raised concerns about the relevance and applicability of research evidence to actual clinical problems, which further limited its use in clinical decision making. Despite the generally low citation of research evidence during the interviews, I expected more expert therapists would have referred to research evidence more frequently than less expert therapists, even if to venture an opinion about the applicability of research evidence to clinical practice. My expectation arose from the view that expert therapists possess a greater multi-dimensional knowledge base than novice therapists and this knowledge base includes theoretical, or propositional, knowledge, derived through reading articles and textbooks, as well as practical, or experiential, knowledge, derived from clinical practice (Higgs and Jensen, 2019). As well, several more expert therapists were undertaking or had recently undertaken master's degrees. As such, I expected them to be more familiar with, and therefore more likely to discuss, the research evidence base underpinning clinical practice. Although an awareness of the prognostic factors for functional recovery was more evident amongst more expert therapists, there appeared to be little difference between less and more expert therapists in the frequency of citation of research evidence as a factor guiding decision making in the use of rehabilitation interventions.

During the therapy sessions, therapists did not explicitly discuss research findings before or during therapy sessions amongst themselves, with stroke survivors, or with their carers. Therefore, I inferred the extent to which findings from research evidence were applied into clinical practice by noting the types of interventions delivered during therapy sessions and comparing these interventions to the findings from my systematic review. Many interventions delivered during observed therapy sessions had no research evidence supporting their use in the rehabilitation of severely disabling stroke. Examples of these interventions include positioning, passive stretches, sensory stimulation, and seating trials. However, some interventions supported by research evidence, such as task-specific practice and electrical stimulation, were noted during the therapy sessions. One situation to demonstrate this finding involved Roseanne, a Band 6 PT working in the Williamson Stroke Rehab Team, who was treating Bob, an individual who had sustained a large right lacunar infarct and presented with significant residual weakness but preserved communication. Roseanne was assisting Jasmine, Bob's OT, in the delivery of functional electrical stimulation (FES). FES is a treatment modality designed to stimulate paretic muscles to increase their strength and has documented evidence of its effectiveness in increasing wrist and finger strength (Rosewilliam *et al.*, 2012):

> Roseanne asks Bob does he understand what FES is- Bob pauses for several seconds and then says, “Functional electrical stimulation”. Roseanne says yes and that it is giving the muscles electrical signals to help them contract. Roseanne goes through the list of contraindications to FES- pacemaker, metal in the arm, epilepsy, cancer treatment, broken skin. Bob says he has none of these. Roseanne asks if sensation is okay- Jasmine says yes. Roseanne asks if Bob can tell the difference between hot and cold- Bob says he can. Roseanne explains to Bob that the aim of the FES is to strengthen the movement of the wrist and fingers and that it can reduce the tone in the arm. Roseanne stresses that it will only work if Bob does it lots of times- at least four to five times a day- as there is no point doing it if Bob only does it twice a week- Bob says, “Oh”. Roseanne asks if this frequency would be okay- Bob pauses and says yes. Bob asks if he can do it by himself- Roseanne adds that it would be helpful if Tamara [Bob’s wife] or family help as you need two hands to apply the electrodes as they are quite sticky.

(Extract from fieldnotes, 7th March 2019)

The use of evidence-based interventions in therapy sessions was similarly found by Tyson, Woodward-Nutt and Plant (2018) in their observational study describing the content and dose of physiotherapy sessions in four English SUs. The authors reported that PTs treating balance and mobility problems post-stroke focussed on functional tasks known to have strong evidence, such as walking and sit to stand practice. However, stroke survivors included in their study presented with a range of stroke disability levels and included stroke survivors less disabled than the current study. As most research trials of stroke rehabilitation interventions have generally recruited survivors with mild to moderate stroke severity (Legg, Drummond and Langhorne, 2009; Pollock *et al.*, 2014; Veerbeek *et al.*, 2014), the delivery of evidence-based interventions to individuals less disabled by stroke may be easier to apply due to the greater applicability of findings to this cohort of the stroke population. One disadvantage of the limited evidence based in severely disabling stroke is that most interventions used in clinical practice have no documented research evidence to support their use. Therefore, the decision to deliver these interventions is not based upon research evidence because no or very little research evidence supporting their use exists. Consequently, factors other than research evidence appeared to be more influential in guiding therapist decision making in the rehabilitation of severely disabling stroke.

In the current study, the mismatch between the low citation of research evidence during interviews and the more frequent use of therapy interventions with documented effectiveness may have arisen for several reasons. It is possible that therapists may have previously read an article or several articles about an intervention and incorporated the findings into clinical practice. Yet, they may have forgotten the article’s details and therefore not discussed the article during the interview. However, in this instance, it seems plausible that a therapist would have at least highlighted the existence of research investigating the intervention during the interview. It is also possible that therapists may not be familiar with the original research evidence but have learned about the intervention during undergraduate training, clinical practice, and discussion with therapy colleagues. In support of this reason was the observation of clinical practice in the two SUs and differences in how certain interventions were delivered in these units. Although PTs in both units regularly performed gait practice, PTs working on Anderson SU frequently used ankle-foot orthoses and four-point walking sticks to enable the early mobilisation of stroke survivors. I also observed PTs demonstrate to nurses how to practise walking with some stroke survivors, as well as nurses walk with these stroke survivors outside of therapy sessions. However, PTs working on Ferguson SU tended to focus on achieving standing symmetry and muscle activation of the hemiparetic leg before commencing gait practice. Very few stroke survivors used orthotic supports and I observed no nurses practice walking with stroke survivors outside of therapy sessions. Upon reflection, the different ways that PTs practised gait, a commonly used evidence-based intervention, appeared to be due to the established practice of the more expert therapists working in these units, which influenced the practice of less expert therapists through joint sessions and in-service training.

8.5.2 "45 minutes" recommendation

Whilst research evidence was not frequently cited by therapists during the interviews, every HASU and SU therapist and most community therapists referred to guidance from the UK's National Clinical Guideline for Stroke recommending the daily provision of at least 45 minutes of each appropriate therapy (Intercollegiate Stroke Working Party, 2016). The recommendation to provide a daily minimum of 45 minutes of each appropriate therapy in the UK was first published in the 3rd edition of the National Clinical Guideline for Stroke in 2008 (Intercollegiate Stroke Working Party, 2008). This recommendation was made on the basis of contemporaneous research suggesting that the provision of more therapy led to better outcomes post-stroke (Langhorne, Wagenaar and Partridge, 1996; Kwakkel *et al.*, 1997; Slade, Tennant and Chamberlain, 2002; Bhogal, Teasell and Speechley, 2003). This recommendation was also created on the basis that comparative studies highlighted that face-to-face therapist to patient contact time in the UK was shorter than other European countries (De Wit *et al.*, 2005; Putman *et al.*, 2006). Subsequently, the "45 minutes" recommendation was incorporated into other aspects of healthcare governance, such as the Sentinel Stroke National Audit Programme (SSNAP) audit. SSNAP is the national stroke register of England, Wales, and Northern Ireland which been operational since 2013 (Sentinel Stroke National Audit Programme, 2019). SSNAP prospectively records care processes and outcome data of patients treated in hospital with acute ischaemic stroke or primary intracerebral haemorrhagic stroke. In terms of therapy, SSNAP records several metrics that include the applicability of therapy, the number of days on which therapy is delivered, and the number of therapy minutes provided (McGlinchey *et al.*, 2019; Gittins *et al.*, 2020). SSNAP also calculates the adherence of patients receiving 45 minutes of therapy, five days per week (Sentinel Stroke National Audit Programme, 2019, 2020).

Whilst providing a minimum amount of therapy is important to deliver rehabilitation interventions designed to promote functional recovery post-stroke, it also serves the purpose of adhering to the expected audit targets detailed in SSNAP. Therapists across all stroke services highlighted the importance of achieving the SSNAP targets, as it was perceived to influence commissioning decisions regarding therapy staffing:

> "SSNAP in itself refers to the whole monitoring and auditing of the HASU and that's linked into the funding of it. But the way it affects us is we have targets. So, all patients should receive an assessment from a therapist, whether it's speech and language or physio within 24 hours and all therapists, all specialities that should be seeing a patient should have assessed them within 72 hours."
>
> (Martin, Band 7 PT, Peterson HASU)

> "So, we're very much indoctrinated into the 45-minute SSNAP target which is the fundamental reason why we're here and why we're so well staffed as a therapy service. Although I've come from a system that didn't work with SSNAP before, so sometimes I find that I'm thinking more about the overall day and the enriched therapeutic environment and that kind of thing."
>
> (Megan, Band 7 OT, Ferguson SU)

Megan was a Band 7 OT who had been working on Ferguson SU for just under one year. Having spent most of her career working overseas, her observation about therapy delivery in the UK, which partly focussed on the adherence to SSNAP, highlighted a potential dilemma in therapy delivery- providing therapy for the benefit of the patient versus providing therapy to satisfy audit requirements. In their exploration of how the audit of therapy intensity influenced inpatient stroke rehabilitation in three English SUs, Taylor, Jones and McKevitt (2018) identified that therapists expressed mistrust about auditing practices, as it did not reflect the quality of the services they provided. Quality of therapy was interpreted by how well it addressed the individual needs of patients rather than how well it adhered to performance targets. Therapists in their study similarly perceived that audit results informed commissioning decisions and revealed concerns that services could be decommissioned if SSNAP targets were not met. Whilst the accuracy of this latter statement was not substantiated by any evidence, it highlights the mixed perceptions of therapy performance targets and the influence of performance targets on therapy practice.

In the current study, the influence of the "45 minutes" recommendation on therapy decision making was clearly visible. In Peterson HASU, stroke survivors were prioritised to be seen based on the number of days post-stroke. Priority was given to stroke survivors within 72 hours post-stroke, who were classified as “SSNAP patients”, to ensure that they received regular therapy for the first three days post-stroke. In Anderson and Ferguson SUs, therapists used a timetable system to plan their day and allocate therapy sessions to stroke survivors. Most therapy sessions were listed as 45 or 60 minutes on the timetables. The longer, 60-minutes session length incorporated time to prepare the stroke survivor for the session, such as hoisting them into a wheelchair and completing documentation of the session after its completion. Timetabling stroke survivors was seen as beneficial by therapists to ensure the equitable delivery of therapy consistent with the needs of stroke survivors:

> “I think our team is very good in that we do our timetable every day… it makes sure that everyone gets seen regularly. So, aiming for, if we can, six times a week. It also means that the national guidelines tend to be met.”
>
> (Beth, Band 6 PT, Anderson SU)

> “And then it was more of a case of working out how we can improve her engagement levels with therapy. And we did that through adding in a timetable and things like that, which then really helped with her arousal levels and level of engagement. It allowed her to have a snooze in between OT and physio. So, providing that structure really helped.”
>
> (Sally, Band 5 PT, Anderson SU)

Sally’s comment about structuring a stroke survivor’s day with timetabling reinforces the benefits of timetabling from the stroke survivor’s perspective. In their multi-centre, mixed-methods case study evaluation exploring therapy provision in English SUs, Clarke *et al.* (2018) reported that timetabling led to more stroke survivors being available for therapy and more therapy minutes being provided. As therapists did not have to compete with others for the same time slot, Clarke *et al.* (2018) also noted that fewer stroke survivors missed therapy sessions. As such, timetabling benefited all stroke survivors by ensuring the allocation of therapy to as many stroke survivors as possible.

In the interviews, most therapists felt that a singular, 45-minutes therapy session was not always appropriate for survivors of severely disabling stroke. SU therapists suggested shorter and more regular sessions may be preferable due to the stroke survivor’s reduced ability to physically and cognitive engage for an extended period:

> “But realistically, with a lot of these patients, they don’t have the attention span for it. And a lot of them suffer from fatigue, which means that they can’t tolerate those kinds of sessions. So, for patients, I often feel that short bits throughout the day would be more appropriate.”
>
> (Claire, Band 6 OT, Anderson SU)

> “So, if a patient gets shattered because of our 45-minute time block, cutting that down to 30 minutes or seeing them twice a day might be better.”
>
> (Lucy, Band 5 PT, Anderson SU)

However, therapists highlighted that this frequency was not always feasible due to difficulties in coordinating multiple therapy staff and ensuring the availability of specialist seating. Community therapists reported that fatigue was less prevalent once stroke survivors were residing in the community compared to the acute inpatient environment. Community therapists suggested that session length should be determined by the purpose of the session and the time required to perform interventions related to the session’s purpose:

> “Once you see someone in their own home, that guides you with what you need to do. You can see how their environment influences your session. So, if they need to be able to do stairs and it take 10, 15 minutes, then that’s what it takes. If they need to get to their bathroom and it takes just as long, then so be it. So, I’m guided by what they need to achieve and however long it takes to achieve it. For some clients, it can be 60 minutes or an hour and a half. But then, it might be once a week that is required.”
>
> (Keely, Band 6 OT, Williamson Stroke Rehab Team)

8.6 Attributes of the Severely Disabled Stroke Survivor

The fourth theme, attributes of the severely disabled stroke survivor, comprises two patient-related factors guiding decision making in the rehabilitation of severely disabling stroke: the stroke survivor's clinical presentation and their ability to express their preferences and wishes. Therapy was tailored according to the range and extent of post-stroke impairments. Severely disabled stroke survivors experienced various levels of engagement in therapy sessions, which guided current therapy provision and suitability for future therapy. Severely disabled stroke survivors were also more likely to experience communication or cognitive impairments limiting their ability to express their preferences, which presented unique challenges for therapists. In situations where stroke survivors were unable to express their preferences, alternative sources of information, such as family and friends, were inconsistently used in decision making.

8.6.1 Clinical Presentation

In addition to clinical expertise, the stroke survivor's clinical presentation was one of the most influential factors guiding the selection of interventions for survivors of severely disabling stroke. Noted during the therapy sessions and reported during the interviews, the stroke survivor's clinical presentation was determined following an initial therapy assessment, which focussed on determining the stroke survivor's impairments and activity limitations. Therapists assessed these aspects of function in a logical and sequential process, which guided the formulation of a treatment plan at a level appropriate for the stroke survivor. The manner of collecting and evaluating clinical data during the assessment to formulate treatment plans, which were sometimes similar to other stroke survivors and based upon prior experience of treating severely disabled stroke survivors, suggest the use of both analytical and intuitive decision making processes in the selection of treatment interventions.

> "So, I would do a full physiotherapy, neurological assessment. And then I would make a problem list. I would make an impairment activity participation, so an ICF type problem list, to identify and separate the impairments, the activities that are impaired, and the participating patient elements. And then I would make a treatment programme to address those things."

(Sandy, Band 7 PT, Williamson Stroke Rehab Team)

> “And then from there, our assessments are all about essentially finding the deficits. The doctors are looking at the medical side of things, we’re looking at what the patient is actually experiencing, what’s going to limit them. And obviously with stroke, the majority of patients have a cognitive impairment. So, it’s teasing out exactly what they’re experiencing. But you need to really identify what is their limiting factor, so you can work around it and get the right level of activity with them.”
>
> (Dominic, Band 5 OT, Peterson HASU)

In therapy sessions, I noted that most interventions were selected to address specific problems arising from the assessment at an appropriate level for that stroke survivor. For example, Mario was an individual who was initially admitted to Peterson HASU after sustaining a large right frontoparietal haemorrhage. Mario was then transferred to Ferguson SU for ongoing rehabilitation. Initially presenting with marked limb and trunk weakness as well as left-sided inattention, Mario required maximal assistance to sit on the edge of his bed. His safety when sitting was sometimes compromised as he demonstrated significant pushing behaviour whenever he was sat on the edge of his bed. In order to address his lower limb weakness, his PTs initially practised lower limb strengthening exercises when Mario was lying in bed due to his difficulty in maintaining his sitting posture whilst performing lower limb strengthening exercises. As Mario regained the ability to sit more independently, his PTs practised standing with manual support and equipment to progress his lower limb strengthening exercises. Mario’s situation highlights the provision of rehabilitation interventions tailored to a stroke survivor’s clinical presentation and progressed as the clinical presentation changes over time.

Whilst therapists selected interventions to address specific assessment findings, some assessment findings were not addressed during subsequent therapy sessions. For example, I observed that almost all stroke survivors in the SUs and most stroke survivors in the community had difficulty with bed mobility and transferring from lying in bed to sitting on the edge of the bed. Although therapists would sometimes assist a stroke survivor to roll in bed during repositioning or changing bed sheets, I did not observe any therapist practise bed mobility in any therapy session with the aim of getting the stroke survivor to become more independent in bed mobility. A similarly low amount of therapy time devoted to practising bed mobility was found by Tyson, Woodward-Nutt and Plant (2018). In their observational study of SU physiotherapy practice, bed mobility was only practised in 3% of physiotherapy sessions. It was not clear from their study what proportion of stroke survivors had limitations in bed mobility as all their stroke survivors had a Rivermead Mobility Index score ≥3, which indicates the ability to sit for 10 seconds without holding on to the bed. However, their study highlighted a large variation in the frequency of intervention use by PTs. In the current study, it appeared that therapists tended to deliver some interventions, such as sitting practice, early mobilisation, and seating, more frequently than other interventions, such as bed mobility practice.

As the primary aim of therapy was to enable the patient to become more independent in tasks, setting functionally orientated goals provided focus for therapy sessions. As such, goal setting further guided the selection of interventions:

> "Usually, we are a very goals-orientated team and we would help the patient to identify their goals that they want to achieve in the time with us. And I would focus on these patient goals and help them to achieve these goals. So, trying to combine functional tasks with impairment-based treatment to work towards achieving their goals basically."
>
> (Bradley, Band 5 PT, Williamson Stroke Rehab Team)

Upon reflection of the goal setting and therapy sessions, I noted that most goals were related to assessment findings and most interventions delivered within therapy sessions were related to the stroke survivor's goals. For example, Janet, a community OT working in the Stephenson Community Stroke team, was treating Eliza in her home. Eliza had sustained right sided watershed infarcts and presented with moderate upper limb weakness and spasticity, which affected her ability to use her upper limb. As Eliza used to work as a tea sommelier, her primary goal was to be able to make and drink a cup of tea. In order to achieve this goal, Janet performed a variety of interventions commencing with stretches to Eliza's wrist and longer finger flexor muscles before practising reaching and grasping of a cup, and then supporting Eliza to drink from the cup. The close relationship between assessment findings, goal setting, and treatment plans was also noted in Plant and Tyson's multi-centre observation of goal setting in stroke rehabilitation (Plant and Tyson, 2018). Although the authors found that goals were not connected to treatments plans in two SUs, between 90 and 100% of goals were related to treatment plans in the study's three other SUs.

In addition to assessment findings and identified goals, the stroke survivor's ability to actively engage and participate in a session determined the type of interventions delivered. More passive interventions, such as bed positioning, splinting, and sitting in a recliner chair, were delivered if a stroke survivor was drowsy or not following commands. More active interventions, such as task-specific practice, were delivered if a stroke survivor was alert and able to follow some commands. Within each intervention, therapists made smaller decisions based upon the stroke survivor's immediate response to the intervention. Smaller decisions included aspects such as the number of repetitions and the length of time to perform an intervention. Continual reflection upon these interventions, or reflection-in-action as described by Schön (1983), led the therapist to modify or change the intervention. Fatigue, determined by therapists as a stroke survivor becoming visibly tired or demonstrating reduced movement quality, was reported to be a sign to change the intervention to something easier or to stop the session completely. One situation to demonstrate this finding involved two therapists working on Ferguson SU-Kristina, a Band 6 OT, and Sabrina, a Band 5 PT. Both therapists were treating Simon, an individual who had sustained a left cerebellar infarct. Simon's rehabilitation was complicated by numerous post-stroke complications, including a cardiac arrest, several respiratory tract infections, and urinary tract infections. Consequently, Simon presented with reduced levels of engagement in therapy:

> Kristina asks Simon to give the washcloth to Sabrina- Kristina facilitates the movement with Simon's arm to the left. Sabrina holds the washcloth and asks Simon to open his hand first- Simon does. Sabrina takes the washcloth and puts it in the washbag. Kristina gets some moisturising cream from the washbag and asks Simon to turn his right palm upwards- Simon's eyes close and then open. Kristina applies the cream to Simon's right palm and fingers and then asks Simon to put the cream on his left forearm- no response is seen from Simon. Kristina guides the movement, applying the cream from Simon's left fingers and along his left forearm in long stroking movements. Simon's wife says, "Looks like he's falling asleep"- both therapists agree. Simon closes his eyes and keeps them closed for more than 15 seconds- Kristina suggests to Sabrina that they apply the boxing glove splint and finish the session there- Sabrina says yes. (Extract from fieldnotes, 13th July 2018)

The stroke survivor’s ability to actively engage and participate in therapy also determined other aspects of therapy provision, such as the frequency of therapy sessions and how much therapy was provided overall. In addition to goal attainment, active participation in therapy sessions led to continued therapy provision. SU therapists reported that stroke survivors in hospital who were actively participating in therapy would benefit from daily therapy sessions in order to optimise functional recovery. Therapists advocated for stroke survivors who were attaining goals and actively participating in therapy to remain in hospital for longer in order to receive more therapy. Stroke survivors who demonstrated variable or less engagement in therapy sessions over time experienced a reduction in the frequency of therapy sessions. Therapists highlighted in interviews that reasons for reduced engagement would be identified and addressed prior to reducing the frequency of therapy. Potential reasons that could be more easily addressed were medical illnesses, such as urinary tract or respiratory tract infections. Therapists frequently identified low mood as a factor resulting in reduced engagement in therapy. Various strategies were reported to be employed to address low mood, such as medication, psychological input, and possessing a motivating disposition. A survey of 199 PTs and OTs working in rehabilitation facilities in the USA similarly identified these barriers impacting upon patient engagement in therapy sessions (Lequerica, Donnell and Tate, 2009). In this survey, low mood and impaired cognition were two of the most commonly cited barriers to patient engagement. Making therapy more enjoyable, providing patient education, and allowing more patient control were reported to be key facilitators of patient engagement. However, it is not clear if all these facilitators would be applicable for survivors of severely disabling stroke in the presence of communication and cognitive impairments.

Differences in active participation and engagement were also noted by therapists working in the community stroke services. Therapists expected that stroke survivors engaging in therapy on an SU would continue to engage in the community. Therapists also expected that stroke survivors not engaging in therapy on an SU would not engage in the community and therefore not be eligible for community therapy. However, several community therapists noted that the clinical presentation of some stroke survivors did not follow these expectations:

> "Yeah, I've certainly seen it go both ways, to be honest. I've seen people massively plateau or not do well in hospital just because the environment was so unfunctional to them, and they were just very low in mood, low in morale, and were desperate to get home. But actually, when they've gone home, it's been their own home, it's much more meaningful, their goals, their rehab, you know. They actually want to get out of bed and I've seen people then massively improve when they were deemed not to be able to or have the potential to. But then I've also seen the opposite where people were doing really well in the ward, progressing daily or progressing weekly. And then they've gone home and suddenly, that has massively affected their mood, because they've actually realised their deficits much more than when they were in hospital. And these people almost go backwards."
>
> (Sandy, Band 7 PT, Williamson Stroke Rehab Team)

Lack of engagement by a stroke survivor in the community led to their discharge. However, new engagement by a stroke survivor residing in the community sometimes created issues due to the lack of available resources to provide therapy:

> Yeah. It's really tough. So, it's good that you saw Carl [stroke survivor] because I think he's someone that we do get faced with quite often where patients were referred for resettlement but we feel that they actually need more than that. But it's tricky because, we struggle to go out in pairs because of our staffing and resources. And we tried to provide rehab for him as we were able to and then we referred him into a 2B bed [specialist inpatient rehabilitation bed] which we felt would be a more appropriate setting for him. But unfortunately, that referral was declined. And I think that's one of the challenges once someone has come out of an acute ward into the community- it is always a lot harder than to try and get them back into rehab."
>
> (Tanya, Band 7 OT, Stephenson Community Stroke Team)

In this situation, Tanya highlighted several issues with therapy practice and community rehabilitation for survivors of severely disabling stroke previously reported. These issues include the incorrect belief that functional recovery in the chronic phase post-stroke is not possible and the limited amount of time devoted to managing longer-term disability. This situation also highlights the difficulty in re-accessing inpatient rehabilitation once stroke survivors are discharged to the community, which Tanya reported was common due to the linear design of the stroke pathway- stroke survivors move from inpatient services to the community environment and not vice versa. It is not known how common this situation was, as most severely disabled stroke survivors referred for resettlement were discharged within two to three sessions. Consequently, any opportunity to see an improvement in engagement levels may have been missed as stroke survivors were no longer being seen by the community service. However, it does highlight a pathway design issue that may negatively affect the longer-term recovery of survivors of severely disabling stroke.

8.6.2 Challenge of Stroke Survivor Involvement

The second patient-related factor guiding decision making in the rehabilitation of severely disabling stroke was the stroke survivor's ability to express their views and preferences. The importance of involving stroke survivors in aspects of their care is recommended in all major international stroke clinical guidelines (Intercollegiate Stroke Working Party, 2016; Winstein *et al.*, 2016; Stroke Foundation, 2019b; Teasell *et al.*, 2020). A study by Kristensen *et al.* (2016) that surveyed 63 Danish stroke survivors found that involving stroke survivors in treatment decisions was associated with having their health needs met in six areas: fatigue, falls, emotion, memory, reading, and speaking. However, 80% of stroke survivors who participated in this survey were classified as having a mild stroke. It is not clear if findings would be similar for survivors of severely disabling stroke, who may have different health needs and may be less able to articulate their views.

In the current study, it was recognised by therapists that involving severely disabled stroke survivors in decision making was challenging due to communication and cognitive impairments. Most therapists reported that stroke survivors with aphasia limited the therapist's ability to inquire about the stroke survivor's preferences and for the stroke survivor to express their preferences. Some therapists highlighted that the presence of anosognosia meant that the stroke survivor may not realise that therapy was required to address their problems. In these situations, the selection of interventions was made almost exclusively by the therapist following an initial assessment of the stroke survivor:

> "And especially with the severe stroke patients…the fact that a lot of them can't communicate or they might not have the cognitive ability to make a goal or have the insight into their deficits and so on. So, I guess decisions can be led more by therapists or care staff."
>
> (Sabrina, Band 5 PT, Ferguson SU)

Therapists highlighted strategies to modify their communication for stroke survivors presenting with communication and cognitive impairments in order to understand their preferences or involve them in decision making:

> "I think just giving them, if it's somebody who has got dysphasia and just it takes them for ever to get the words out, then just giving them the time of day for that."
>
> (Tina, Band 5 PT, Anderson SU)

> "Well, there are different ways to communicate if they can't express themselves verbally. We can communicate through writing, through a communication booklet, or with pictures. Or signs like thumbs up and thumbs down."
>
> (Bradley, Band 5 PT, Williamson Stroke Rehab Team)

During the therapy sessions, I observed that these and other strategies were employed to facilitate communication with stroke survivors presenting with communication and/or cognitive impairments. Speech and language therapists participated in some therapy sessions to assess and facilitate communication in stroke survivors with aphasia. More expert therapists appeared more confident in modifying their communication compared to less expert therapists. As well, OTs tended to use fewer complex instructions than PTs when communicating with stroke survivors presenting with impaired cognition or communication. The latter finding may reflect OTs' greater understanding of the impact of post-stroke cognitive impairments due to their role in the management of cognitive dysfunction post-stroke. However, in most observed therapy sessions, the aim of communicating with a stroke survivor presenting with communication and/or cognitive impairments seemed to be more about obtaining feedback about an intervention, rather than involving the stroke survivor in selecting an intervention.

Alternative sources of information to understand the stroke survivor's perspective, such as family members, were sometimes used. This usually involved a therapist asking a family member about the stroke survivor's previous level of function, as well as their hobbies and interests. I observed that family members were physically less present in hospitals compared to community environments. Consequently, I noted more dialogue between therapists and family members in community settings compared to hospital environments. However, family members were rarely involved in the selection of different interventions in any setting. Some therapists felt that this was a decision to be made by therapists based upon assessment findings and identified goals. Some therapists recognised that family involvement in decision making was variable and should occur more often:

> "I think it's quite easy as a therapist when you're in somebody's home and they're telling you what they want for the patient, it can be quite easy to be swayed by what the family want. But I think it's just about trying to keep the patient at the centre and thinking, actually, what does patient want? And it doesn't really matter what the family want, it's about the patient and it's trying to work cohesively with both the patient and the family to make sure that it's the best outcome for the patient based on my assessment and my clinical reasoning as a therapist. And actually, you are the therapist and you do know what's best."
>
> (Jasmine, Band 6 OT, Williamson Stroke Rehab Team)

> "I don't actually think we engage family members that much in that decision making. I think it's the therapists telling the family members that this is what's happening, or the medics telling the family members, rather than it being a two-way decision making. I think it's probably a bit medical model, kind of, 'This is where they're at. This is what's happened.' And I think there's probably some need to be better at engaging family members in decision making, which may help with that understanding of rehab progress and as a means for them adjusting to the disability as well."
>
> (Natalie, Band 8 OT, Anderson SU)

Another area of clinical practice requiring the involvement of stroke survivors was goal setting. Similar to the therapy sessions, therapists employed various strategies to enable stroke survivors to participate in goal setting. Timetabling was used in both SUs to plan therapy and goal setting sessions, meetings, and training. However, only Anderson SU therapists formally met with stroke survivors to discuss goals, whereas Ferguson SU therapists discussed goals as a wider therapy team. Coming from an SU where discussing goals with stroke survivors was common practice, I found the method of goal setting adopted by therapists on Ferguson SU strange and contrary to a patient-centred approach expected of therapists. For example, more time for goal setting was allocated on Anderson SU if a stroke survivor was able to participate in goal setting but demonstrated mild communication impairments that could slow down the conversation. This extra time was designed to ascertain the stroke survivor’s preferred goals. In one goal setting session on Anderson SU, I observed a speech and language therapist using pictures of walking aids, different foods, and clothing to facilitate the identification of goals to address in subsequent therapy sessions. Similar facilitators to goal setting were described by Plant *et al.* (2016) in their systematic review identifying the barriers and facilitators to goal setting during stroke and acquired brain injury rehabilitation. In their review, the authors identified several barriers to goal setting, such as the stroke survivor’s communication and cognitive impairments, lack of dedicated time for goal setting, and coordination of staff to meet for goal setting. The practice of therapy goal setting, particularly on Anderson SU, appeared to address these known barriers to goal setting.

Whilst there were different approaches to goal setting in the SUs, I noted that therapists in both services generated most goals themselves as opposed to the stroke survivor generating the goal. On Ferguson SU, therapists discussed and generated goals amongst themselves, whereas on Anderson SU, therapists usually presented goals to stroke survivors and sought agreement from stroke survivors. The exception to this observation was during goal setting sessions involving stroke survivors who were able to express their preferences. For example, I observed only one goal setting session on Anderson SU where Morris, a stroke survivor able to articulate his preferences, was asked what goals he wanted to work on in future therapy sessions. Plant and Tyson (2018) described goal setting in five English inpatient SUs and found that 60% of goals were set by therapists, and stroke survivors were rarely involved in goal setting. The authors also found that 48% of goals were never reviewed and new goals were often documented without any relationship to previously set goals. Whilst the limited stroke survivor involvement in goal setting reported by Plant and Tyson (2018) is similar to the current study, I observed therapists on both SUs routinely discussing the attainment of previously set goals and progress goals in relation to these previously set goals with stroke survivors or other therapists.

8.7 Therapy within the Wider Stroke Pathway

The fifth and final theme, therapy within the wider stroke pathway, refers to the influence of organisational factors and pathway design on therapist decision making in the rehabilitation of severely disabling stroke. Individual rehabilitation interventions were selected by therapists as part of a wider package of therapy to address specific clinical problems. As therapists worked closely with one another in teams across a range of interconnected stroke services, the context in which therapy was delivered shaped therapy practice. Generally, there was alignment with the use of therapeutic interventions and the function of each stroke service. The interconnected nature of stroke services within a particular stroke pathway generated an awareness of the role of other stroke services in the stroke pathway, which similarly guided therapy practice.

8.7.1 Organisational Function

As identified in the therapist survey, the type and function of the stroke service in which a therapist worked guided the selection of rehabilitation interventions. In the current study, each stroke service had a specific role or function within the London stroke pathway. The selection of interventions and therapeutic approach adopted by therapists tended to align with this role. My understanding of these roles was derived from literature pertaining to the London stroke pathway, as well as involvement in Pan-London initiatives to develop stroke rehabilitation services, such as seven-day therapy working (Healthcare for London, 2008; Fitzpatrick, 2013; McGlinchey, Cutting and Fenwick-Elliott, 2015; NHS London Strategic Clinical Networks, 2015).

The role of a HASU is to assess, medically manage, and triage stroke survivors into the different rehabilitation services. These options were home with support or ongoing inpatient stroke rehabilitation. During the therapy sessions on Peterson HASU, I observed that therapists usually assessed stroke survivors within 24 hours of HASU admission using a paper proforma, which listed key assessment procedures to perform. Therapists then commenced therapy for survivors of severely disabling stroke, which usually consisted of sitting practice on the edge of a bed; task-specific upper limb practice in sitting, such as dressing and grooming; and transferring the stroke survivor into a supportive chair with manual handling equipment. Most initial assessments on the HASU were conducted jointly with an OT and PT to reduce overlap of assessment procedures and to provide double handed therapy support due to the dependency of severely disabled stroke survivors:

> "And that's why I certainly think I try to rely more on the physios at that stage with those sorts of patients because, well, for a few different factors really. One is that time factor and needing two people. But then you might not get so much out of them if you went to see them straight after they've just had physio. And I think when it's the physical side of things, we would be having similar goals, in terms of get them sitting out or have them positioned well. And I think the physios would be on the same page there. And maybe with transfers too. So, I think all that comes into it."
>
> (Samantha, Band 6 OT, Peterson HASU)

The need for a timely assessment and prompt decision for ongoing rehabilitation reflects the very short length of stay (LOS) expected of stroke survivors on a HASU. In their qualitative study exploring clinical decision making in discharge planning, Jette, Grover and Keck (2003) similarly found that therapists working in an acute care setting in the USA often had to make recommendations for patient discharge during their initial assessment because of the organisational operative of reducing hospital LOS. A PT in their study reported that early decision making was often difficult due to having incomplete information about a patient's situation. However, in the current study, all severely disabled stroke survivors were expected to be discharged to an SU for ongoing rehabilitation. Therefore, HASU therapists were less likely to be involved in discharge planning to other settings, such as care homes. Complying with organisational practice was also highlighted by McGlinchey and Davenport (2015) in their ethnographic exploration of decision making by PTs working in two London SUs. In their study, adherence to local policies, such as patient timetabling, guided decisions regarding the length and frequency of therapy sessions. In the current study, adhering to the use of a paper proforma guided the selection of assessment procedures performed by HASU therapists.

The role of an SU is to provide multi-disciplinary stroke rehabilitation until such time that a stroke survivor can safely continue their rehabilitation in a community environment, plateaus in their recovery, or requires longer-term rehabilitation in a non-acute, inpatient environment. The latter situation may arise as some stroke survivors making slow but consistent improvements in recovery may still benefit from rehabilitation in an inpatient environment. However, due to the location of London SUs in acute hospitals and the widespread drive to reduce hospital LOS, remaining on an SU may counteract the organisational demands of reducing LOS. Although I have reported differences in the therapeutic approach adopted by Anderson and Ferguson SU therapists in the delivery of evidence-based rehabilitation interventions, the organisational function of the two SUs was similar. During the therapy sessions, I observed that therapists in both SUs assessed stroke survivors within 24 hours of SU admission and continued to provide therapy to optimise functional recovery at a level appropriate to their clinical presentation as previously described. Therapists also set goals with stroke survivors within five days of SU admission to further refine the content of therapy sessions. As the five-day time frame for initial goal setting was an organisational requirement of SUs in the London stroke pathway, complying with organisational policy also guided the practice of SU therapists. If functional recovery plateaued, therapy shifted to a disability management approach and more emphasis was placed on discharge planning. Discharge planning interventions included referrals to onward services, such as social services, community stroke teams, and inpatient stroke rehabilitation units. Other interventions included informing family members about the transition from hospital to home, assessing the suitability of the community environment for discharge, and ordering equipment to enable the stroke survivor to be managed in the community. In line with their professional role, more discharge planning tasks were performed by OTs than PTs. OTs frequently highlighted the competing demands of discharge planning and therapy provision:

> “But I think possibly as OTs as well, we tend to have a lot of other discharge planning as well. Like, in terms of equipment and paperwork for different wheelchairs or for access visits. So, there’s a lot of other things that get chucked in in that time as well. And I find the discharge planning then overtakes all the rehab from the OT.”
>
> (Claire, Band 6 OT, Anderson SU)

> "And I think from an OT role, even though we're there predominantly for the rehab side of things, I think that a lot of the time, our time is taken up for discharge planning. So, if we don't do it, people don't go home and other people who have had strokes can't come in to have rehab. So, it's a bit of a vicious circle."
>
> (Margaret, Band 5 OT, Anderson SU)

The role of a community stroke service is to reintegrate a stroke survivor into their community. For survivors of severely disabling stroke, community reintegration involves becoming as independent in specific tasks, such as walking indoors or accessing local shops in a wheelchair. Community integration also involves enabling carers to manage stroke survivors in their environment, as carers are responsible for the longer-term management of stroke survivors. As the two community services operated different eligibility criteria for stroke survivors, I noted the selection of interventions and therapy approaches differed between these services. The Williamson Stroke Rehab Team only accepted stroke survivors who had demonstrated functional recovery and were likely to continue to functionally improve. Therefore, therapists in this team provided interventions designed to improve functional recovery, such as task-specific practice of functional tasks. The Stephenson Community Stroke Team provided a limited disability management service in addition to functional restoration. Therefore, therapists in this team provided more carer training and education, positioning and splinting regimes, and referrals to additional services, such as tissue viability nurses and spasticity clinics, than therapists in the Williamson Stroke Rehab Team. The time limited nature of both services, up to six weeks, meant that some therapists changed their treatment approach within this period:

> "So, we obviously have six weeks. And in the first two weeks, it's more about developing a stroke relationship with the patient and working towards specific goals. However, as you get to the end of the six weeks, it's more about making sure that you can hand over things to people, that there is some form of continuation- whether it's a community team, whether it's private physio, whether it's outpatient physio- that there's things that they can still continue to work on. But also decreasing your visits as you get towards the end, so it suddenly doesn't go from three to four times a week to nothing. But making sure that- we do a lot of videos and laminated instructions and manuals for carers and family. Prompt sheets, transfer guidelines, anything like that, to try and encourage and hand over what we've been doing for them to continue on with."
>
> (Roseanne, Band 6 PT, Williamson Stroke Rehab Team)

Each community stroke service had developed different pathway streams for stroke survivors referred to their service. Access to these different pathway streams was dependent upon the time post-stroke, the type of referring stroke service, and the nature of community goals. The most intensive pathway streams were usually reserved for stroke survivors discharged from HASUs, whereas the least intensive streams were usually reserved for stroke survivors making much slower progress. I noted that most stroke survivors recruited to the study were accepted into the least intensive streams, which was confirmed by therapists during the interviews. The time limited nature of the different pathway streams caused some consternation amongst therapists:

> "I suppose from my view, I don't see why we have an ESD [early supported discharge] pathway, a supported discharge pathway and a THMT [targeted health management] pathway, because I think it makes it unfair for patients. And I think actually, as a therapist, my clinical judgement as to how often I need to see somebody should be taken more into account than, 'Right, because it's a THMT, they can only be seen three times' or 'Because they're an ESD, they've got to be seen five times for two weeks'. So, I would say, take all the pathways out, assess the person and see what their tolerance is and how much they can be seen."
>
> (Kelis, Band 6 OT, Williamson Stroke Rehab Team)

Another way in which the type of stroke service influenced therapists' decision making was the demand and capacity of the stroke service, which was related to the number and dependency of stroke survivors in the service and the available staffing resources. Whilst I observed this phenomenon in all stroke services, it was particularly apparent in the inpatient stroke services. SU therapists used timetabling to determine when each stroke survivor was seen and how long to treat each stroke survivor for. As most severely disabled stroke survivors were dependent for most activities, many therapy sessions were staffed by at least two therapy staff members. In the event of short periods of staff sickness or annual leave, therapists prioritised stroke survivors to be seen with the remaining therapy staff. Priority was usually given to those stroke survivors newly admitted, making faster improvements in functional recovery, or those that could be seen with one therapist. Consequently, I observed that survivors of severely disabling stroke were frequently prioritised out when staffing levels were reduced. If staffing levels were reduced for a prolonged period, survivors of severely disabling stroke were treated but at a reduced frequency compared to survivors of less disabling stroke. Prioritisation of stroke survivors as a method to plan therapy schedules was also identified by McGlinchey and Davenport (2015). In their study, higher priority stroke survivors, deemed as those making improvements and compliant with physiotherapy, were often treated at a time of day that enabled maximal participation in physiotherapy sessions. Lower priority stroke survivors, deemed as those making limited progress or requiring maintenance therapy, were more likely to be seen less frequently and possibly for a shorter length of time, especially if there were higher priority stroke survivors perceived to need more therapy. In the current study, the rationing of therapy and allocation of resources to stroke survivors perceived to benefit from therapy may have been guided by the therapists' belief in the normative expectation of stroke rehabilitation as a process to optimise functional recovery. Stroke survivors that presented differently to this normative expectation were deprioritised.

Whilst the reality of deprioritising out survivors of severely disabling stroke was frequently observed, therapists often lamented during the interviews about the unfairness of deprioritising, or "writing off", severely disabled stroke survivors and not giving them a chance for recovery:

> "But my fear with these larger strokes, is that they are written off too early. And then do not have time and then access to maybe the support that they need a little bit further down the line"
>
> (Adrianna, Band 7 PT, Stephenson Community Stroke Team)

> "But if it's constantly happening, then I think that has to be really looked at, you know. If this is their window, then it's really unfair if they keep being de-prioritised."
>
> (Kylie, Band 7 PT, Ferguson SU)

However, only one therapist connected the consequences of reduced therapy frequency on the likelihood of functional recovery and that therapists themselves were primarily responsible for the deprioritisation of severely disabled stroke survivors:

> "I think most of the time if they're prioritised out, it's normally if they've hit a bit of a plateau. And if they're not making the gains each day… But if anybody's going to improve, the three months is the most important part. So, not seeing them as often means they might not then hit the same level they might have done if they were seen as much as the patients that were higher functioning who weren't prioritised out."
>
> (Karen, Band 6 PT, Anderson SU)

8.7.2 Stroke Pathway Design

The range of stroke services that a stroke survivor traversed through during the rehabilitation process, as well as the therapeutic approach delivered in these stroke services, was another factor that guided therapist decision making. This factor was particularly noticeable in the interface between SUs and community stroke services and once stroke survivors were discharged from the community stroke services. As Anderson SU and the Stephenson Community Stroke Team formed part of one stroke pathway and Peterson HASU and Ferguson SU formed part of another pathway, the relationship between services in their respective stroke pathway also influenced therapist decision making.

Although my clinical role is based upon Anderson SU, it predominantly focuses on the provision of expert advice and guidance to the rest of the physiotherapy team on the SU. Consequently, my role involves no direct discharge planning interventions and therefore very little contact with therapists working in the community services, such as the Stephenson Community Stroke Team. I make reference to this fact because my observations, particularly about the interface between Anderson SU and the Stephenson Community Stroke Team, are based more as an informed outsider rather than an insider possessing local knowledge of potential issues associated with the transition of care from hospital to home. These issues include communication breakdown between inpatient and community services, lack of support services on discharge, and difficulties experienced by stroke survivors in adjusting to a new environment (Connolly and Mahoney, 2018).

Anderson SU was part of a stroke pathway that referred most of its severely disabled stroke survivors to the community, such as the stroke survivor’s home or a care home. Less than 10% of severely disabled stroke survivors were referred for further inpatient stroke rehabilitation. Consequently, I observed that Anderson SU therapists initially adopted a restorative approach before shifting to a compensatory approach to improve functional recovery. Disability management was interspersed throughout a stroke survivor’s length of stay, particularly when functional recovery had plateaued. Discharge planning then commenced, and many stroke survivors were discharged to the Stephenson Community Stroke Team. This community service frequently in-reached onto Anderson SU, whereby community therapists introduced themselves to stroke survivors and their families and explained the role of community therapy. Stephenson Community Stroke Team therapists noted what therapy a stroke survivor received on Anderson SU, which guided the selection of community interventions:

> “In terms of severe stroke, I would expect that if someone’s been in hospital, they would have explored all the options to improve their functional trajectory. And also, they should ensure a lot the things are in place when they get home, such as equipment and level of support that’s required. And I think the emphasis in the community is either continuing those treatment strategies from the acute, such as transfer practice or walking, or it might be more of a resettling type of approach if progress was slow to make sure that things have been followed through. So, it would be the appropriate positioning for a limb or pressure care management.”
>
> (Sinitta, Band 6 PT, Stephenson Community Stroke Team)

Community therapists usually continued working on the stroke survivor's inpatient goals. However, goals were often modified, discarded, or created to account for the new environment in which the stroke survivor resided and any changes in the stroke survivor's clinical presentation:

> "I know that things can change significantly in quite a short space of time when people transition home. So, if the referral came through for resettlement, are there still disability management, goals or have things changed, such as their level of engagement? So, I've learned that you don't take the referral with a pinch of salt- that's not downgrading the referral. But you have to take it in context to what you see. And quite often, I've then fed back to the referrers and said, 'Do you know what, this is what I'm seeing, is that different?' And they go, 'Yeah. That's different.' And it guides your treatment."
>
> (Rita, Band 6 OT, Stephenson Community Stroke Team)

Clarke and Forster (2015) highlighted the importance of multi-disciplinary team working in improving post-stroke recovery at key stages of the stroke pathway. In their review, they provided an evidence-based summary of the effectiveness of different interventions, including interdisciplinary team working. Whilst the current study's findings demonstrate the working relationship between stroke teams in different stroke services, there is a paucity of literature evaluating team working or communication across the stroke pathway. In his editorial review of rehabilitation, Wade (2016) described the range of rehabilitation services supporting individuals with disability as a "meta-team", or a team of teams. A meta-team comprises a lead team working with the patient at a particular point in time, as well as more peripheral teams that contribute to the patient's rehabilitation. The different stroke multi-disciplinary teams within a particular stroke pathway could be viewed as a meta-team, with each stroke service that a stroke survivor traverses through taking the lead team role at a particular point in time. Some of the principles of effective stroke multi-disciplinary team working may be applicable to meta-team working, such as the employment of specialist healthcare professionals, patient-centred and goal-directed therapy, and open communication (Wade, 2016). However, other principles of effective stroke multi-disciplinary team working may be more challenging to implement or less appropriate for meta-teams, such as a sharing a team base or regularly reviewing team working processes. In the current study, there was some acknowledgement by therapists of inter-team pathway issues. For example, some Anderson SU therapists mentioned that there were delays in accepting referrals by the Stephenson Community Stroke Team due to their limited capacity. Some Stephenson community therapists reported that referral forms completed by Anderson SU therapists did not always identify pertinent issues, such as a stroke survivor's risk of falls. Despite these acknowledgements, there appeared to be an effective working relationship between Anderson SU and the Stephenson Community Stroke Team. Therapists in these services highlighted many benefits of community therapists in-reaching onto the SU. These benefits included developing an understanding of each other's roles more clearly and being aware of any challenges affecting the flow of stroke survivors across the stroke pathway, such as staff shortages. Therapists also highlighted that stroke survivors and their carers liked meeting the community therapists before discharge to familiarise themselves with the community therapists and to discuss any concerns about discharge.

The time limited nature of community stroke services meant that stroke survivors were discharged from the service once their allotted time with the service had finished or, less commonly, once all goals were achieved. Community therapists reported a paucity of longer-term rehabilitation services for survivors of severely disabling stroke. The consequence of limited ongoing rehabilitation services, which usually had long waiting lists and provided substantially less therapy, meant that some interventions were handed over to the stroke survivor's carers to continue, whereas some interventions were discontinued. Many community therapists expressed a range of emotions, including frustration and distress, about the lack of ongoing therapy for severely disabled stroke survivors:

> "I suppose the difficultly with the severe strokes are the ones that are changing when we come to the end of our length of stay. They're really tricky to discharge because morally you feel that they need more input. But realistically the resources aren't there to give them more input. And sometimes, I go back to management, because I really struggle with discharging someone that is continuing to make change."
>
> (Adrianna, Band 7 PT, Stephenson Community Stroke Team)

Peterson HASU and Ferguson SU comprised the first two stroke services of their respective stroke pathway in North London. Although the same hospital Trust operated both services, they were located in geographically separate hospitals. Despite this separation, therapists in each service provided cross-cover when there were significant therapy shortages due to sickness or annual leave. This reciprocal arrangement enabled continuity of therapy provision in each service, which supported the organisational requirements of moving stroke survivors through the stroke pathway. The cross-cover arrangement also provided an opportunity for therapists to gain experience in each setting, of which most therapists were supportive. Whilst Anderson SU discharged most of its severely disabled stroke survivors to the community, I observed a different discharge pathway for stroke survivors on Ferguson SU. Unless severely disabled stroke survivors previously resided in a care home, Ferguson SU referred most of their severely disabled stroke survivors for further inpatient stroke rehabilitation. These inpatient stroke rehabilitation units included a Level 1 specialist inpatient neurological rehabilitation unit located in the same hospital as Ferguson SU, as well as a Level 3 rehabilitation unit geographically separate from Ferguson SU. Consequently, Ferguson SU therapists adopted a restorative approach to improve function, interspersed with some disability management, for most of the stroke survivor's length of stay. Ferguson SU therapists rarely shifted to a compensatory approach to improve function, as there was a strong workplace philosophy on targeting therapy to reduce impairments and a belief that a compensatory approach could be explored once the stroke survivor was undergoing further inpatient rehabilitation:

> "We have a very much a restorative approach philosophy in the hospital here. So, sometimes I find that I will be working on someone's stronger hand to be able to get them to do more things and I feel like, maybe, I'm a little bit more of a lone soldier doing that because everyone else is working on the impaired side, working on trying to regain some function in the impaired side."
>
> (Megan, Band 7 OT, Ferguson SU)

Due to the extent of neurological impairment in most survivors of severely disabling stroke and the focus on a restorative approach to improve function, functional recovery appeared much slower for stroke survivors on Ferguson SU than Anderson SU. As most survivors of severely disabling stroke were not discharged directly into the community, Ferguson SU therapists performed different discharge planning interventions to Anderson SU therapists. These interventions included referrals to inpatient stroke rehabilitation units and informing family members about the transition from hospital to the inpatient stroke rehabilitation unit. These interventions were performed similarly by OTs and PTs on Ferguson SU.

8.8 Discussion

This ethnographic exploration of therapy practice in five London stroke services has demonstrated that many factors guide decision making in the use of interventions in the rehabilitation of physical function after severely disabling stroke. Using Haynes and colleagues' model for evidence-based clinical decisions as a framework to conceptualise therapist decision making (Haynes, Devereaux and Guyatt, 2002), the exploration revealed differing contributions of the model's components to therapist decision making. In the selection of different rehabilitation interventions, more emphasis was placed on the therapist's clinical expertise and the stroke survivor's clinical presentation, whereas less emphasis was placed upon research evidence and the stroke survivor's treatment preferences. The exploration also revealed that therapists' professional roles, as well as beliefs and attitudes on recovery after severely disabling stroke, guided therapist decision making. These factors were not originally conceptualised in the model for evidence-based decisions. The interdependent nature of specific interventions within a larger package of therapy meant that therapists often described their practice in terms of treatment approaches- restoration versus compensation, functional recovery versus disability management- rather than specific interventions. As this larger package of therapy was provided by therapists working in teams across a range of different stroke services, organisational function and the stroke pathway design also guided therapist decision making.

One of the most influential factors guiding clinical decision making was the therapist's level of clinical expertise. Clinical expertise was defined as an advanced and highly developed state of clinical practice, which is composed of several components. Developed through critical reflection upon clinical experiences, these components include skill proficiency; an extensive, multi-dimensional knowledge base; and metacognitive competence. Several differences in the practice of therapists with varying levels of clinical expertise were identified, such as the speed of selection and confident, skilled execution of rehabilitation interventions. Greater use of faster clinical reasoning strategies and intuitive decision making processes were seen in more expert therapists. Therapy practice by less expert therapists was more likely to be guided by and reliant upon the clinical expertise of more expert therapists. This reliance may stem from the uncertainty of clinical practice in the rehabilitation of severely disabling stroke and the perception that more expert therapists know what to do in these situations. This reliance may also stem from the paucity of research evidence supporting the use of particular interventions in the rehabilitation of severely disabling stroke. However, reliance on the clinical expertise of more expert therapists is contrary to the opinion that EBP should place less emphasis on the authority of experts, as suggested by the Evidence-Based Medicine Working Group (1992). Although Jensen, Resnik and Haddad (2019) proposed that expert practice is the hallmark of professional practice, reliance on expert opinion to guide decision making may pose issues. It is recognised that cognitive biases can negatively affect decision making (Kahneman, 2011; Saposnik *et al.*, 2016; O'Sullivan and Schofield, 2018). Expert decision making may be prone to cognitive biases such as overconfidence- the overestimated opinion of one's clinical ability- and confirmation bias- the interpretation of information to fit a preconceived hypothesis (Saposnik *et al.*, 2016; O'Sullivan and Schofield, 2018). These cognitive biases could lead to the selection of incorrect treatments or inaccurate prognostication, although this was not directly investigated in the current study. However, until there is a larger research evidence base of studies investigating the effectiveness of interventions in the rehabilitation of severely disabling stroke, clinical expertise is likely to remain as one of the most influential factors guiding therapist decision making in the management of this cohort of the stroke population.

Another of the most influential factors guiding therapist decision making was the stroke survivor's clinical presentation. Therapists used both analytical and intuitive decision making processes to guide this aspect of therapy practice. Interventions were selected according to assessment findings and modified based upon the stroke survivor's response to the intervention. This "reflection-in-action" (Schön, 1983), or reflection upon clinical data derived from assessment tests and observations, has been described by Higgs and Turpin (2019) as one of the forms of evidence required by healthcare professionals to practice in an evidence-based manner. Higgs and Turpin posited that reliance on research evidence as the sole form of evidence in treatment prescription fails to acknowledge the complexity of individuals' responses to illness and their proposed treatments (Higgs and Turpin, 2019). Continual reflection upon clinical experience, such as whether a particular intervention works for a particular stroke survivor, may provide more real evidence about an intervention's effectiveness than data from a research trial conducted in a foreign healthcare setting. Even if there were a larger number of studies investigating the effectiveness of interventions in the rehabilitation of severely disabling stroke, therapists need to be judicious in the application of a study's findings to the management of a particular stroke survivor (Sackett *et al.*, 1996). This application requires skills in critical appraisal of research evidence, clinical reasoning to determine the suitability of a study's findings to the clinical situation, and continual monitoring of the effect of an intervention on a stroke survivor's clinical presentation (Evidence-Based Medicine Working Group, 1992). Consequently, it seems logical that the stroke survivor's clinical presentation is an important factor guiding therapist decision making within an EBP framework.

The reliance on these clinically orientated factors in therapist decision making over other factors described in the EBP model, such as patient preferences and research evidence, may have also arisen for other reasons. The study's findings highlighted the challenge of involving stroke survivors in decision making due to communication and cognitive impairments. In the study, 74% of stroke survivors had an impairment of communication or cognition limiting their ability to express their preferences. The high prevalence of these impairments in the study cohort demonstrates the reality faced by therapists in determining what severely disabled stroke survivors want, which may be not possible or very difficult to achieve. Despite attempts by therapists to modify their communication or involve family members in these instances, these strategies were not consistently implemented. As well, the lack of research investigating the effectiveness of rehabilitation interventions in severely disabling stroke may reflect the origins of physiotherapy and occupational therapy. These practically oriented professions have historically lacked a structured theoretical basis underpinned by research evidence guiding clinical practice (Turner, 2001; Turner and Knight, 2015). For example, one of the most common therapy approaches in neurophysiotherapy, the Bobath concept, developed in the mid-20th century from observations of handling stroke survivors with reference to contemporaneous theories of motor control (Lennon, 1996; Pollock *et al.*, 2014). However, these early observations were not corroborated through any form of systematic evaluation. As well, trials evaluating the effectiveness of the Bobath concept did not occur until the end of the 20th century (Kollen *et al.*, 2009; Díaz-Arribas *et al.*, 2020), by which time the Bobath concept was firmly entrenched in clinical practice (Sackley and Lincoln, 1996; Lennon, Baxter and Ashburn, 2001). Early stroke rehabilitation trials have encountered methodological issues in their execution, such as unclear outcome reporting, recruitment of small sample sizes, and lack of patient blinding (McIntyre *et al.*, 2014; Mayo *et al.*, 2016). Consequently, these methodological issues may limit the utility of research findings from early stroke rehabilitation trials. Several authors have also suggested that relatively less research has been conducted in investigating the effectiveness of rehabilitation after severely disabling stroke due to negative attitudes towards recovery after severely disabling stroke (Gladman and Sackley, 1998; Rodgers, 2000; Wyller, 2000; Sterr and Conforto, 2012). Consequently, the evidence base for physiotherapy and occupational therapy in the rehabilitation of severely disabling stroke is limited in size and quality. This limitation further reduces the potential contribution of research evidence to guide therapist decision making in the rehabilitation of severely disabling stroke.

The identification of two factors guiding therapy practice not originally conceptualised in the original model for evidence-based clinical decisions- professional roles and beliefs and attitudes- highlights a limitation of the applicability of the model to therapy practice. However, evidence-based medicine (EBM), the precursor to EBP, was originally designed as a model of medical teaching and practice for the medical profession. As such, it was not intended to consider the influence of professional role differences on decision making, as it only focused upon one healthcare profession. Apart from a revision of the model reported by Haynes, Devereaux and Guyatt (2002), uptake of the principles of EBM by other healthcare professions, such as physiotherapy and occupational therapy, did not result in any significant change to the model's components. Use of the term "professional expertise" in this chapter- a hybrid of professional role and clinical expertise- rather than "clinical expertise" may account for the influence of one's professional role on evidence-based decision making. Beliefs and attitudes were also not included in the original model due to the desire to create a new model of medical teaching and practice deemphasising the biases associated with a clinician's personal beliefs on clinical decision making (Evidence-Based Medicine Working Group, 1992). It was clear in the current study that a therapist's beliefs and attitudes, at times inconsistent with the literature, resulted in the provision of therapy that did not always address the needs of severely disabled stroke survivors. This may suggest that the Evidence-Based Medicine Working Group was correct in deemphasising a clinician's beliefs and attitudes on clinical decision making. However, their presence in the current study suggests a need for therapists to be more critical of their beliefs and attitudes, as well as any potential bias that these beliefs and attitudes may cause, on therapist decision making. In light of the identification of these two additional factors guiding therapist decision making, a revised diagrammatic model of therapy decision making in the rehabilitation of physical function after severely disabling stroke is presented in Figure 21.

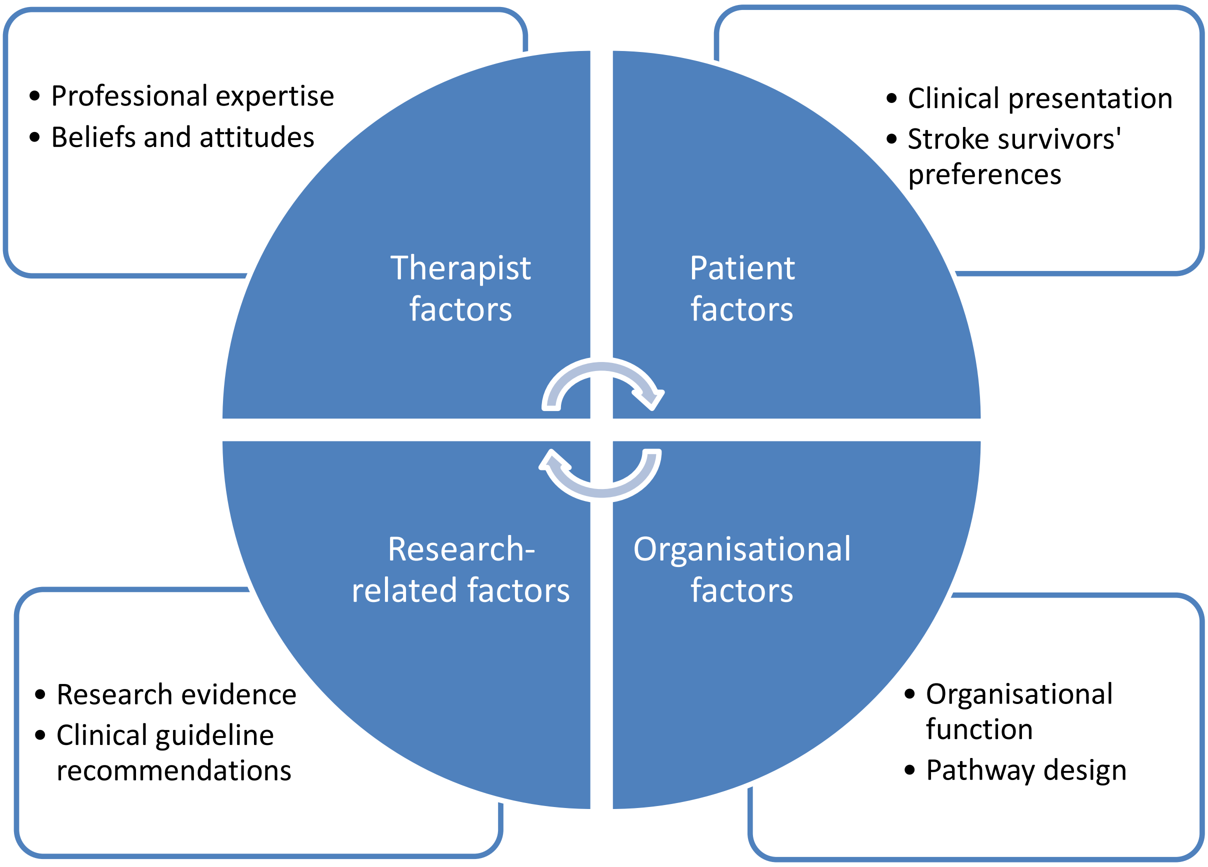


Figure 22- Model of therapy decision making in the rehabilitation of severely disabling stroke

This ethnographic exploration of therapy practice has several strengths that need to be mentioned. Firstly, due to my in-depth knowledge of the London stroke pathway, I was able to identify and select the appropriate type and number of stroke services that reflected the transition of severely disabled stroke survivors across the London stroke pathway. The study's inclusion on the NIHR portfolio of studies facilitated the recruitment of these stroke services to the study. Secondly, undertaking research whilst adopting varying degrees of “insiderness” was advantageous for several reasons. Being a PT working in stroke rehabilitation, my clinical expertise and familiarity with the clinical setting allowed me to immerse myself in each stroke service relatively quickly and appreciate some of the more hidden and unspoken aspects of therapy practice, such as clinical reasoning and interprofessional relationships. Adopting a critically reflexive approach throughout the fieldwork, particularly when investigating my own SU, enabled me to compare and contrast rehabilitation practice in my own SU to other stroke services. Through this reflection, my views on rehabilitation practice after severely disabling stroke, which were mostly critical and slightly pessimistic, were tempered by positive examples of clinical practice. These examples include the advocacy of therapists to ensure that stroke survivors receive as much therapy as possible to facilitate recovery and the shared belief by a small number of more expert therapists that latter recovery after severely disabling stroke is possible. As such, it has given me a renewed sense of hope that more can be done to improve outcomes after severely disabling stroke. Finally, I adhered to several key aspects of the ethnographic tradition. I spent prolonged time in each stroke service until data saturation was achieved. I generated a thick description of the settings under investigation, as exemplified by producing over 1,500 pages of raw data. I combined data obtained from semi-structured interviews and participant observation to enable triangulation of fieldwork findings. Triangulation resulted in a deeper and more representative understanding of therapy practice. For example, many therapists considered rehabilitation for survivors of severely disabling stroke as a process of optimising functional recovery as well as managing residual in the therapist interviews. However, the additional use of participant observation clearly demonstrated how much therapist time is devoted to functional recovery and how little therapist time is devoted to managing residual disability. In some instances, I noted contradiction between what therapists did during therapy sessions and what therapists reported they did in the interviews. For example, many therapists emphasised the importance of giving stroke survivors a chance for rehabilitation during interviews. However, the same therapists were observed to deprioritise or cancel their planned therapy session during times of reduced staffing. This contradiction, described as initiation by Greene, Caracelli and Graham (1989), provided alternative insights into therapy practice than would have been obtained if only one data collection method was used.

This ethnographic exploration of therapy practice also has several weaknesses that need to be reported. Ethnography is a research approach that is often used to provide a detailed exploration of a particular culture. In healthcare research, this exploration usually involves a selection of different healthcare settings. It is possible that different findings may have been generated if I recruited alternative services to the study or investigated therapy practice in other towns and cities. Whilst the aim of ethnography is not to generate generalisable findings, the detailed description of the different stroke services and study participants should enable the reader of this ethnography to understand the context of the stroke services and determine the transferability of study findings to other stroke services. As well, my role as an insider researcher may have presented several challenges throughout the study. It is possible that I did not obtain sufficient critical distance when interpreting and analysing emerging findings, particularly from my own SU or regarding physiotherapy practice. I may have also relied on my position of seniority to coerce therapists, particularly my therapist colleagues, into participation. Their inclusion in the study not only raises ethical concerns about the manner of their recruitment but may have affected the type and quality of emerging data, due to a desire to please a more senior therapist by presenting themselves in a certain way (Bonner and Tolhurst, 2002; Simmons, 2007). However, it is hoped that by adopting a critically reflexive approach throughout the study and regular debriefings with my supervisors, these issues may have been ameliorated. In addition, the ethical concern of coercion of my colleagues was addressed by appointing a research advocate on the SU with whom therapist participants could talk through any concerns arising during the study. Fortunately, no therapist reported any concern about study participation. Finally, whilst there were several benefits of combining data from different data collection methods for the purposes of triangulation and initiation, analysing such a large amount of data as a sole researcher was challenging and time consuming.

8.9 Chapter Summary

Guided by the theoretical framework of EBP and its use within clinical decision making, an ethnographic exploration of therapy practice in the rehabilitation of severely disabling stroke occurred in five London stroke services. Five themes were developed through thematic analysis: professional expertise, beliefs and attitudes about post-stroke recovery, research evidence, attributes of the severely disabled stroke survivor, and therapy within the wider stroke pathway. Clinical expertise and the stroke survivor’s clinical presentation were two of the most influential factors guiding decision making in the use of interventions in the rehabilitation of physical function after severely disabling stroke. Research evidence and the stroke survivor’s treatment preferences were less influential factors guiding decision making. Other factors guiding therapist decision making were also identified, including professional role, the therapist's beliefs and attitudes about post-stroke recovery, organisational function, and the stroke pathway design. The next chapter will present a discussion of the mixed methods investigation of therapy practice in the rehabilitation of physical function after severely disabling stroke. The next chapter will also present a summary of the implications of the mixed methods investigation and suggestions for future research in this area.

Chapter 9- Discussion

9.1 Introduction

The aim of this thesis was to investigate therapy in the rehabilitation of physical function after severely disabling stroke. Using a mixed methods research (MMR) approach, three studies were undertaken to understand this aspect of stroke rehabilitation more fully. This chapter presents a discussion of this MMR thesis. It will revisit the rationale for undertaking the research and present a summary of the findings from the three studies. It will continue with a discussion of the thesis' findings and how they may explain the poor outcomes experienced by survivors of severely disabling stroke. It will position the thesis' findings within the context of stroke rehabilitation policy and suggest recommendations for future research and clinical practice. It will conclude with a discussion of the thesis' strengths and weaknesses.

9.2 Rationale for the Research

In the Introduction chapter of the thesis, I presented a personal account of some of the clinical challenges faced in the rehabilitation of severely disabling stroke, the mainstay of managing stroke. These challenges included the physically demanding and emotionally draining nature of physiotherapy provision to a cohort of the stroke population that are more likely to die or be discharged with high levels of dependency. I highlighted the lack of longer-term rehabilitation support in managing residual disability and preventing secondary complications associated with severely disabling stroke. I also questioned whether current rehabilitation practice was actually making a difference to the lives of those individuals who had experienced a severely disabling stroke. Consequently, I proposed that there was merit in exploring current rehabilitation practice further to determine if anything could be done differently to address these clinical challenges.

Despite research suggesting that stroke rehabilitation can reduce mortality, hospital length of stay, and the likelihood of institutionalisation compared to general medical ward care for individuals with severely disabling stroke, there was a lack of clarity about the constituent components, or interventions, delivered within this stroke rehabilitation. Whilst several observational studies reported the range of interventions delivered by physiotherapists (PTs) and occupational therapists (OTs) during stroke rehabilitation therapy sessions, it was not clear which interventions were delivered to survivors of severely disabling stroke. If clinical practice needs to change to address the clinical challenges associated with severely disabling stroke, it is important to know what clinical practice actually entails. Therefore, research was required to understand what interventions are currently provided in the rehabilitation of severely disabling stroke.

Alongside the lack of clarity regarding what interventions are provided to survivors of severely disabling stroke, there was a lack of clarity regarding the effectiveness of rehabilitation interventions on improving physical function and reducing immobility-related complications after severely disabling stroke. Many systematic reviews investigating the effectiveness of rehabilitation interventions on improving physical function post-stroke did not recruit survivors of severely disabling stroke nor provide results specifically for survivors of severe stroke. Additionally, there were no published systematic reviews investigating the effectiveness of rehabilitation interventions on reducing immobility-related complications after severely disabling stroke. Therefore, research was required to investigate the effectiveness of rehabilitation interventions on improving physical function and reducing immobility-related complications specifically for survivors of severely disabling stroke.

As stroke rehabilitation can alter outcomes after severely disabling stroke and rehabilitation is composed of sets of interventions, understanding why therapists decide to use certain interventions in the rehabilitation of severely disabling stroke, which has direct implications on post-stroke outcomes, is important to know. The expectation in current healthcare practice is to incorporate patients' treatment preferences in decision making and base clinical decisions on robust research evidence, termed evidence-based practice (EBP). However, adopting EBP in the rehabilitation of severely disabling stroke may be challenging for two reasons. Firstly, there is uncertainty regarding the effectiveness of rehabilitation interventions used in the management of severely disabling stroke. Secondly, severely disabled stroke survivors may experience difficulty when expressing themselves due to communication and cognitive impairments. Therefore, research was required to understand what factors guide therapists to decide upon certain interventions in the rehabilitation of severely disabling stroke within an EBP framework.

Using the theoretical framework of EBP and its use in clinical decision making, MMR involving three studies was adopted to investigate these research questions. These studies included a national survey of therapy practice in the first 12 months after severely disabling stroke, a systematic review investigating the effectiveness of rehabilitation interventions on improving physical function and reducing immobility-related complications after severely disabling stroke, and an ethnographic exploration of therapy practice in the rehabilitation of severely disabling stroke.

9.3 Summary of Study Findings

The thesis has presented new knowledge generated from three studies. The national survey of therapy practice identified the use of a range of interventions and outcomes measures in the rehabilitation of severely disabling stroke. Whole body positioning, upper limb handling and positioning training, and sitting balance practice were the most frequently used interventions across all therapists. Interventions were delivered to achieve particular aims as part of goal-directed therapy. Intervention use varied between PTs and OTs across the stroke pathway, which suggested that professional role and organisational function guide the selection of interventions. For example, PTs performed sitting balance practice, bed mobility practice, and active/assisted exercises more frequently than OTs. OTs performed washing and dressing practice, grooming practice, and referred to social services more frequently than PTs. Active and passive interventions were more frequently performed in inpatient settings, which aligned with the goals of inpatient therapy- optimising functional recovery and preventing secondary complications. Developing care plans and carer training and education were more frequently performed in community settings, which aligned with the goals of community therapy- ensuring carers were safe and competent in delivering longer-term management interventions. The Barthel Index (BI), Modified Rankin Scale (mRS) and National Institutes for Health Scale (NIHSS) were the most frequently used outcome measures across all therapists. Outcome measure use was generally low across both professional groups and was more likely to be completed during the initial assessment phase. Therapists reported that lack of time prevented ongoing outcome measure use during the rehabilitation of severely disabling stroke. Some outcome measures, such as the mRS and NIHSS, were performed more to comply with national audit rather than to guide clinical practice. Therapists also reported that most existing outcome measures lacked sensitivity to detect meaningful clinical change in survivors of severely disabling stroke, further limiting the utility of existing outcome measures.

The systematic review investigating the effectiveness of rehabilitation interventions on improving physical function and reducing immobility-related complications after severely disabling stroke included 28 randomised controlled trials (RCTs). These trials investigated 20 different interventions, most of which were delivered in the acute and early subacute phase post-stroke. The systematic review demonstrated a paucity of high-quality evidence supporting the use of rehabilitation interventions to improve physical function and reduce immobility-related complications after severely disabling stroke. Many potential RCTs were excluded because they provided insufficient information to determine stroke severity or presented no results specifically for survivors of severely disabling stroke. Twenty four included studies were rated as providing low or very low-quality evidence due to high or unclear risk of bias and the recruitment of small samples of stroke survivors. As such, the low quality of studies limits the ability to generalise findings from these studies to the wider stroke population. There was high-quality evidence from two studies that very early mobilisation and occupational therapy in care homes were no more effective than usual care. There was moderate-quality evidence from one study supporting short-term benefits of wrist and finger neuromuscular electrical stimulation on improving wrist extensor and grip strength. There was also moderate-quality evidence from one study supporting short-term benefits of additional upper limb training on improving upper limb function, as well as additional lower limb training on improving upper limb function, independence in activities of daily living, gait speed, and gait independence. The most commonly used outcome measures across the studies assessed independence in or performance of activities of daily living. There were relatively fewer outcome measures assessing the occurrence of immobility-related complications.

Integrating the findings from the national survey of therapy practice and the systematic review demonstrated that the rehabilitation interventions most frequently used by survey respondents have either no or limited research evidence demonstrating their effectiveness when used for survivors of severely disabling stroke. For example, there were no trials included in the systematic review that explored the effectiveness of whole body positioning, upper limb handling and positioning training, and sitting balance practice specifically for survivors of severely disabling stroke. It was also found that many interventions investigated in the systematic review were never or infrequently used by survey respondents. For example, acupuncture and treadmill training were investigated in nine studies but were rarely or never used by survey respondents. In an era of EBP, it is expected that healthcare decisions are based upon the integration of the best available research evidence, clinical expertise, and patients' values and preferences. The mismatch between current clinical practice and the available research evidence identified by integrating study findings suggested that the decision to use particular interventions in the rehabilitation of severely disabling stroke is based on factors other than the best available research evidence. These factors may include other components in the model for evidence-based clinical decisions, such as clinical expertise and patients' values and preferences. However, the contribution of these and other factors to decision making in the rehabilitation of severely disabling stroke was not clear. Consequently, ethnography was used to identify and explore the factors that guide the selection of interventions by PTs and OTs in the rehabilitation of severely disabling stroke.

Over an 18-month period, an ethnographic exploration of therapy practice occurred in five London stroke services. These stroke services included one hyperacute stroke unit, two stroke units, and two community stroke rehabilitation services. Services were selected based on the survey finding that therapy practice varied according to type of stroke service. Using participant observation and semi-structured interviews, five themes were developed through thematic analysis: professional expertise, beliefs and attitudes about post-stroke recovery, research evidence, attributes of the severely disabled stroke survivor, and therapy within the wider stroke pathway. Clinical expertise and the stroke survivor's clinical presentation were two of the most influential factors guiding therapist decision making. More expert therapists demonstrated more confident and skilled execution of therapy interventions and their clinical expertise guided therapy practice of less expert therapists. The reliance on the clinical expertise of more expert therapist may stem from the uncertainty of clinical practice in the rehabilitation of severely disabling stroke and the perception that more expert therapists know what to do in these situations. As well, interventions were selected at a level appropriate to the stroke survivor's clinical presentation and modified according to the stroke survivor's response to the intervention. Continual reflection upon this response provided therapists with real-world evidence of an intervention's effectiveness in the absence of definitive research evidence. Two notable components of the model for evidence-based clinical decisions, research evidence and the stroke survivor's treatment preferences, were less influential factors guiding therapist decision making. It was observed that that there was reduced awareness of the available, albeit limited, research evidence underpinning rehabilitation for survivors of severely disabling stroke.

Many interventions delivered during observed therapy sessions had no research evidence supporting their use in clinical practice and interventions with reported effectiveness were not consistently observed across all stroke services. In addition, most severely disabled stroke survivors recruited to the study had an impairment of communication or cognition limiting their ability to express their preferences. Despite attempts by therapists to modify their communication or involve family members in these instances, these strategies were not consistently implemented.

The identification of factors not considered within the model for evidence-based clinical decisions proposed by Haynes, Devereaux and Guyatt (2002) suggested a possible limitation of the applicability of the model to therapy practice. These factors included the therapist's beliefs and attitudes about post-stroke recovery and the therapist's professional role. Accordingly, a revised model of therapy decision making in the rehabilitation of severely disabling stroke was proposed, which comprised four key factors:

- therapist factors- professional expertise, beliefs and attitudes
- patient factors- clinical presentation, stroke survivors' preferences
- research-related factors- research evidence, clinical guideline recommendations
- organisational factors- organisational function, pathway design

9.4 Contribution to Poor Outcomes after Severely Disabling Stroke

The previous chapter identified several positive aspects of therapy practice in the rehabilitation of severely disabling stroke. These aspects included the modification of therapy sessions according to the stroke survivor's presentation, inter-team communication strategies to facilitate the smooth transfer of stroke survivors across the stroke pathway, and the advocacy of therapists to ensure that stroke survivors receive as much therapy as possible to facilitate recovery. However, the rationale to explore current therapy practice was to determine if anything could be done differently to address the poor outcomes experienced by survivors of severely disabling stroke. Consequently, the findings from the thesis revealed three aspects of therapy practice in the rehabilitation of physical function after severely disabling stroke that may contribute towards the poor outcomes experienced by survivors of severely disabling stroke:

- the mismatch between the needs of severely disabled stroke survivors and the current rehabilitation pathway design
- deficiencies in the evidence base underpinning current clinical practice
- biases associated with clinical decision making

9.4.1 Mismatch Between Stroke Survivors' Needs and Current Practice

Contrasting the literature with the thesis' findings demonstrates a mismatch between the needs of severely disabled stroke survivors, current therapy practice, and the rehabilitation pathway design. This mismatch may be one reason why survivors of severely disabling stroke experience poor outcomes. Several observational studies have demonstrated that survivors of severely disabling stroke experience a much slower and longer pattern of functional recovery compared to less disabled stroke survivors (Wade and Hewer, 1987; Duncan *et al.*, 1992; Jorgensen *et al.*, 1995a; Jorgensen *et al.*, 1995b; Ancheta *et al.*, 2000; Sackley and Dewey, 2001; Douiri *et al.*, 2017). As well, improvements in functional recovery in some of these studies were seen between 6 – 12 months after severely disabling stroke. However, the majority of multi-disciplinary rehabilitation is provided in the first few months post-stroke (Intercollegiate Stroke Working Party, 2016; Winstein *et al.*, 2016; Stroke Foundation, 2019b; Teasell *et al.*, 2020), at a time when severely disabled stroke survivors may demonstrate reduced ability to actively engage in rehabilitation (Asplund and Britton, 1989). Relatively less rehabilitation is provided in the longer-term (Sentinel Stroke National Audit Programme, 2019), at a time when severely disabled stroke survivors may continue to demonstrate improvements in functional recovery that may be augmented by the provision of additional therapy. The relatively limited provision of longer-term rehabilitation also coincides when survivors of severely disabling stroke experience high levels of immobility-related complications, such as falls, contractures, pain, and pressure sores (Sackley *et al.*, 2008; Kuptniratsaikul *et al.*, 2009, 2013). These immobility-related complications may be alleviated by greater access to therapy.

The study's findings supported this mismatch in the optimal timing and focus of rehabilitation after severely disabling stroke. Survey respondents reported that the aim of therapy in the acute post-stroke phase was to optimise functional recovery and prevent secondary complications. However, therapists involved in the ethnographic exploration of therapy practice working in the acute stroke services prioritised the restoration of functional recovery over the management of post-stroke complications. Therapy sessions were frequently modified or cancelled to accommodate for a range of issues that affected the stroke survivor's ability to engage in therapy sessions, such as fatigue and incontinence. Survey respondents reported that the aim of therapy in community stroke services was to ensure that carers looking after stroke survivors were able to implement longer-term management interventions. However, the ethnographic exploration of therapy practice found that access to ongoing community therapy was largely dependent upon attainment of functionally orientated goals in the inpatient environment and the likelihood of further functional improvements. Only one community service provided a very time-limited service to specifically train and educate carers to look after survivors of severely disabling stroke. Therapists involved in the ethnographic exploration of therapy practice working in community stroke services frequently reported very limited longer-term rehabilitation options, which tended to provide therapy for individuals less disabled by stroke.

This mismatch in the optimal timing and focus of rehabilitation after severely disabling stroke suggests that alternative models of rehabilitation should be considered to better meet the needs of survivors of severely disabling stroke and ultimately improve outcomes after severely disabling stroke. This mismatch also suggests that therapists need to critically reflect upon the aims of their therapeutic input at different stages of the stroke pathway to ensure that therapy provision matches the needs of survivors of severely disabling stroke.

9.4.2 Deficiencies in the Evidence Base

Integrating the findings from the therapist survey and systematic review revealed that current clinical practice in the rehabilitation of severely disabling stroke has insufficient research evidence supporting its use in improving physical function and reducing immobility-related complications. Fieldwork findings demonstrated that clinical decisions made by therapists were inconsistently based upon research evidence, due to reduced awareness of a small research evidence base that is characterised by low-quality research evidence. Using Sackett and colleagues' definition of EBP- "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (Sackett *et al.*, 1996, pg. 71), these findings suggested limited uptake of EBP in the rehabilitation of severely disabling stroke. Consequently, delivering rehabilitation interventions with unknown or limited evidence of effectiveness or not delivering rehabilitation interventions with demonstrable evidence of effectiveness may be contributing to the poor outcomes experienced by survivors of severely disabling stroke.

However, it could be argued that alternative forms of evidence guide clinical decision making in the rehabilitation of severely disabling stroke. Evidence can be defined as “the available body of facts or information indicating whether a belief or proposition is true or valid” (Oxford English Dictionary, 2020, point 6). Higgs and Turpin (2019) identified several sources of evidence available to clinicians that can inform decision making. These sources of evidence include clinical data derived from assessment procedures and observations, as well as experience-based knowledge about a patient’s clinical condition. The ethnographic exploration of therapy practice revealed that clinical expertise and the stroke survivor’s clinical presentation, particularly their response to an intervention, were key factors that guided decision making. These factors provided therapists with immediate, real-world, and context-specific evidence that some interventions work and some interventions don’t work in the rehabilitation of severely disabling stroke. Rycroft-Malone *et al.* (2004) recognised that knowledge acquired through clinical experience was one of four key sources of evidence that could be used to inform individualised clinical decision making. Acknowledging that more personalised sources of evidence may be viewed as being less robust than research evidence, Rycroft-Malone and colleagues identified several strategies to improve the credibility of these personalised sources of evidence. These strategies include the systematic gathering and documentation of clinical experiences, as well as the analysis and verification of clinical experiences by multiple sources. As such, these alternative forms of evidence may provide a credible source of additional evidence to guide decision making and address the complexity of clinical practice.

As well, it could also be argued that alternative forms of research evidence exist that could contribute more fully towards clinical decision making. Guidance from the Medical Research Council recommends the use of alternative methodologies beyond outcome evaluations in the evaluation of complex interventions, such as process evaluations (Craig *et al.*, 2013; Moore *et al.*, 2015). Process evaluations are used to understand how an intervention works by investigating its implementation and mechanisms of impact (Moore *et al.*, 2015). Process evaluations are also used to identify contextual factors associated with variations in outcomes (Craig *et al.*, 2013). As process evaluations can provide insight into why an intervention succeeds or fails, as well as how a successful intervention can be optimised, they provide useful research evidence that can guide the selection of interventions.

In stroke, the recent rise of process evaluations in the evaluation of stroke rehabilitation interventions highlights the increasing availability of this form of research evidence to guide the selection of different rehabilitation interventions (Masterson-Algar *et al.*, 2014; Luker *et al.*, 2016; Liu *et al.*, 2019).

The lack of high-quality RCTs demonstrating the effectiveness of interventions in the rehabilitation of severely disabling stroke may be a contributing factor to the limited uptake of EBP in this area of stroke rehabilitation practice. However, it is unlikely that every currently used intervention in the rehabilitation of severely disabling stroke will have at least one well-designed RCT investigating its effectiveness. As individual interventions are packaged together in different combinations by therapists during stroke rehabilitation, it is even less likely that each of these different packages of therapy interventions will have RCT-level evidence supporting their use. Consequently, it may be an opportune time to reconsider the acceptable forms of evidence that can guide clinical decision making within an EBP framework.

9.4.3 Biases in Clinical Decision Making

The updated model for evidence-based clinical decisions proposed by Haynes, Devereaux and Guyatt (2002) comprises four components involved in clinical decision making: clinical expertise, research evidence, patients' preferences and actions, and clinical state and circumstances. However, the range of identified factors that guide decision making in the rehabilitation of severely disabling stroke suggests that clinical decision making may be more complex than Haynes and colleagues' EBP model. The identification of attitudes and beliefs as a factor guiding clinical decision making introduces potential bias in the selection of rehabilitation interventions and allocation of therapy to severely disabled stroke survivors. In the ethnographic exploration of therapy practice, the incorrect belief shared by many less experienced therapists that most functional recovery occurs within the first three months after severely disabling stroke influenced the focus of hospital-based therapy and reduced access to community-based therapy. As well, most therapists generally preferred to treat less disabled stroke survivors and recognised that this preference may influence the amount of therapy provided to survivors of severely disabling stroke. As the amount of therapy delivered post-stroke is associated with a range of outcomes, such as hospital length of stay, mortality, disability, and institutionalisation (Gittins *et al.*, 2020), this bias could be a contributing factor to the poor outcomes experienced by this cohort of the stroke population.

Another factor guiding decision making that may introduce bias in the selection of rehabilitation interventions is the reliance on clinical expertise in decision making. Jensen, Resnik and Haddad (2019) proposed that expert clinical practice is the goal to which all healthcare professionals should aspire. Whilst knowledge generated through advanced critical reflection upon clinical practice can provide immediate, real-world evidence of the effectiveness of specific rehabilitation interventions, clinical decision making by expert therapists may be prone to several cognitive biases. Some of these biases identified by Saposnik *et al.* (2016) and O'Sullivan and Schofield (2018) include overconfidence (the overestimated opinion of one's clinical ability), confirmation bias (interpretation of information to fit a preconceived hypothesis), and availability bias (more recent and readily available solutions are preferentially favoured because of ease of recall). These cognitive biases can potentially lead to clinical errors, such as incorrect treatment decisions or inaccurate prognostication (Saposnik *et al.*, 2016; O'Sullivan and Schofield, 2018). In the ethnographic exploration of therapy practice, the confident delivery of some interventions with uncertain effectiveness by several more expert therapists and the instruction of less expert therapists in the execution of these interventions highlighted these biases in action. Whilst this finding was not observed in every stroke service, it demonstrates that biases in clinical decision making are not restricted to therapists with less clinical expertise. The influence of cognitive biases on clinical decision making suggests a need for therapists to acknowledge the existence of cognitive biases and their potential impact upon clinical decision making.

9.5 Research Findings within the Context of Stroke Rehabilitation Policy

In the previous two decades, there has been an increasing global drive to develop high-quality stroke rehabilitation in the management of stroke (Mendis, 2013). In the United Kingdom, several key healthcare policies have been instrumental in improving stroke rehabilitation service nationally. These policies include the NHS Plan (Department of Health, 2000), which highlighted the importance of intensive rehabilitation services, and the National Stroke Strategy (Department of Health, 2007), which provided a 10-year quality framework in the planning, development, and monitoring of stroke services. More recently, the National Health Service (NHS) Long Term Plan was published in 2019 and described the ambitions for the NHS over the next 10 years (Department of Health and Social Care, 2019). In the NHS Long Term Plan, stroke was identified as a clinical priority and the National Stroke Programme was jointly developed by NHS England and the Stroke Association in order to achieve the stroke-related aims set out in the Plan. These aims include improved post-hospital stroke rehabilitation for stroke survivors, increased use of thrombolysis and mechanical thrombectomy, and consultant training to deliver thrombectomy in more hospital sites.

Whilst the focus on improving stroke rehabilitation is promising, it is unclear how the rehabilitation of severely disabling stroke aligns with the aims of the NHS Longer Term Plan. In order to further improve stroke rehabilitation, service specifications for inpatient stroke rehabilitation and community stroke services, or integrated community stroke services, have been drafted as part of the National Stroke Programme (FutureNHS, 2021). In both specifications, there is very limited reference to stroke survivors with more severe or complex needs. In the inpatient stroke rehabilitation service specification, there is a greater focus on early functional recovery than on the prevention of post-stroke complications. This differential focus is not consistent with the optimal timing and focus of rehabilitation after severely disabling stroke as previously discussed. The integrated community stroke services specification states that rehabilitation can be provided for up to six months post-stroke. However, it is unclear whether severely disabled stroke survivors demonstrating new functional improvements beyond six months will have access to community-based rehabilitation and what level of therapy intensity they can expect.

Despite these limitations, there is some hope that improvements in the rehabilitation of severely disabling stroke may occur as part of the National Stroke Programme. The inpatient stroke rehabilitation service specification refers to a small number of patients that may require longer term slow stream rehabilitation. Whilst no further details are provided regarding the nature of slow stream rehabilitation or eligibility criteria for slow stream rehabilitation, it is likely that this model of rehabilitation would align with the pattern of recovery after severely disabling stroke. Therefore, there is hope that survivors of severely disabling stroke may have greater access to longer term rehabilitation than currently provided. The integrated community stroke services specification identifies a number of different care pathways for stroke survivors. One of these pathways involves the provision of therapy to stroke survivors residing in care homes, which includes training care home staff to manage the sequalae of disabling stroke. As such, survivors of severely disabling stroke residing in care homes may have greater access to appropriately trained staff to deal with their specific needs. These opportunities are further discussed in the next section.

9.6 Recommendations for Future Practice and Research

Based on the three aspects of therapy practice that may contribute to the poor outcomes experienced by survivors of severely disabling stroke and the direction of current NHS policy for stroke rehabilitation, there are several recommendations for future practice and research. These recommendations will require the collective efforts of healthcare professionals, researchers, commissioning bodies, and policy makers, as well as input from stroke survivors and their carers. Accordingly, the term "we" will be used to refer to this collective community of individuals and organisations interested in improving outcomes after severely disabling stroke.

We need to reconceptualise the aims of rehabilitation for survivors of severely disabling stroke. The current focus of stroke rehabilitation is on functional recovery and function is often narrowly defined in terms of activity performance. Some of the most commonly used stroke rehabilitation outcome measures, such as the BI and Functional Independence Measure, focus on independence or ability to perform activities of daily living (ADLs) (Mahoney and Barthel, 1965; Keith *et al.*, 1987). However, there are other important rehabilitation aims for survivors of severely disabling stroke that have received less clinical and research attention. These aims include reducing post-stroke complications, improving quality of life, reducing caregiver burden, and improving societal participation. Dependent upon the stroke survivor's clinical presentation and time post-stroke, the priority of these rehabilitation aims will vary over time. Consequently, the effectiveness of rehabilitation after severely disabling stroke should be assessed according to how well it addresses these aims. This reconceptualisation of the aims of stroke rehabilitation will require the identification or development of outcome measures that assess the attainment of these aims, rather than existing outcome measures that primarily focus on independence or ability to perform ADLs.

We need to develop and evaluate different models of delivering rehabilitation to survivors of severely disabling stroke that consider the needs and incorporates the preferences of stroke survivors and their carers more fully. Based on the recovery pattern of severely disabling stroke, there is merit in altering the intensity and frequency of acute and sub-acute therapy to match the stroke survivor's clinical presentation more closely. For example, it may be appropriate to provide less intensive therapy focussing on functional recovery in the acute and sub-acute phases post-stroke if active engagement and participation in therapy is limited. In these situations, it may be more appropriate to focus more on preventing post-stroke complications, such as contractures and pressure sores, until such time that the stroke survivor is more able to actively engage in therapy. Consistent with the argument proposed by Enderby *et al.* (2017) about regular reassessment of a stroke survivor's longer term rehabilitation needs, there is also merit in providing multi-disciplinary rehabilitation in the longer term if a stroke survivor's clinical presentation changes over time. One such model could be slow stream inpatient rehabilitation, which provides less intensive inpatient therapy for a longer time period. This model of rehabilitation aligns more closely to the pattern of functional recovery after severely disabling stroke than the current rehabilitation model, which delivers intensive therapy in the initial post-stroke phase and limited therapy in the longer term. In situations where inpatient rehabilitation is not considered appropriate or stroke survivors do not want to wish to receive therapy as an inpatient, another rehabilitation model could be the more regular provision of therapy to care home residents or stroke survivors residing in their home at an intensity sufficient to address their specific needs.

Whilst these rehabilitation models could feasibly be developed in line with current NHS policy for stroke rehabilitation, there are several factors that need to be considered before altering current practice. Adopting an alternative model of rehabilitation will require guidance and input from survivors of severely disabling stroke and their carers. Research using qualitative methods will be required to understand their concerns about the current stroke pathway and ascertain their preferred model of stroke rehabilitation. Different models of stroke rehabilitation will require different resources, such as staffing and infrastructure. These resources may be funded by different mechanisms, such as general taxation or private insurance, dependent upon the local context in which the rehabilitation model operates. Both of these factors will influence how much rehabilitation can actually be provided in any alternative rehabilitation model. As there are advantages and disadvantages in providing rehabilitation in different settings and via different funding mechanisms, the clinical and cost effectiveness of these different models will need to be investigated.

We need to evaluate the effectiveness of interventions used in the rehabilitation of severely disabling stroke. Effectiveness will be determined according to the proposed aim of the intervention. Therefore, effectiveness could refer to improvements in functional recovery and quality of life, and reductions in post-stroke complications and caregiver burden. Priority should be given to the most frequently used interventions in current clinical practice, such as whole body positioning, sitting balance practice, and training and education. However, it is not known if survivors of severely disabling stroke respond to interventions in the same manner as other stroke survivors. Differences in post-stroke cortical reorganisation have been identified between smaller and larger strokes (Kwakkel, Kollen and Lindeman, 2004; Teasell and Hussein, 2018). Therefore, it is feasible that survivors of severely disabling stroke respond to interventions differently compared to survivors of less disabling stroke. As such, there may be a need to undertake more proof of concept studies to understand the mechanisms of recovery more fully after severely disabling stroke. Due to the complexity of rehabilitation interventions, it is recommended that process evaluations are conducted alongside outcome evaluations (Craig *et al.*, 2013). Therefore, future trials of the most frequently used rehabilitation interventions should be guided by more proof of concept research and involve both outcome and process evaluations.

We need to understand potential biases associated with clinical decision making and their impact on patient outcomes more fully. Personal beliefs and attitudes about post-stroke recovery can influence the allocation of therapy resource and amount of therapy that survivors of severely disabling stroke receive. As the amount of therapy delivered post-stroke has a direct effect on post-stroke outcomes (Gittins *et al.*, 2020), understanding the negative impact of beliefs and attitudes on clinical decision making is important. Such an understanding may be obtained through qualitative forms of inquiry, such as therapist interviews or participant observation. Similarly, it is accepted that clinical expertise is the goal to which all healthcare professionals should aspire (Jensen, Resnik and Haddad, 2019). However, the relationship between expert practice and improved patient outcomes is less clear. As well, expert decision making may be prone to several cognitive biases that lead to clinical errors. Therefore, understanding the benefits and limitations of expert decision making, particularly their impact upon outcomes in stroke rehabilitation, is warranted. This understanding may be obtained through observational studies examining the relationship between level of expertise and patient outcome, as well through documentary analysis of patient records.

Finally, we need to reconceptualise EBP by considering alternative forms of evidence that can guide clinical decision making within an EBP framework. Several authors have reported that all research methods have inherent strengths as well as weaknesses (Greene and Caracelli, 1997; Johnson and Onwuegbuzie, 2004; Johnson, Onwuegbuzie and Turner, 2007). One of the reported benefits of MMR is that use of different research approaches capitalises on their strengths and minimises their weaknesses. Consequently, evidence derived from these different research approaches can be integrated to understand the phenomenon under investigation more fully. In terms of understanding whether a rehabilitation intervention might work for a particular stroke survivor, a therapist might combine findings from a randomised controlled trial with a qualitative study about stroke survivors' treatment expectations about the intervention. This information can be integrated with a therapist's level of clinical expertise and awareness of contextually specific factors, as well as the stroke survivor's clinical presentation, to decide whether the intervention may work for that particular patient. Incorporating evidence derived from multiple research approaches as part of the best available research evidence may enhance the quality of evidence-based practice in stroke rehabilitation.

9.7 Strengths and Weaknesses of the Thesis

The strengths and weaknesses of the individual studies have been presented in their respective chapters. In this section, the strengths and weaknesses of the thesis as a whole will be discussed. A key strength of the research in the thesis was the use of mixed methods to investigate therapy practice in the rehabilitation of severely disabling stroke. In MMR, the concept of the centrality of the research question posits that the most appropriate research method is selected to answer the proposed research question (Tashakkori and Teddlie, 2010). In this thesis, an a-paradigmatic stance was adopted to select three different research approaches in order to address three epistemologically different research objectives. The normative conventions of each research approach were followed to address these objectives and achieve the thesis' aim. The advantage of using MMR was that a broader and deeper understanding of therapy practice emerged by comparing and contrasting the findings from the three different research approaches using the processes of triangulation and initiation. Triangulation enabled corroboration of research findings and initiation highlighted contradiction within research findings. For example, there was corroboration between survey findings and fieldwork findings in the influence of professional role and organisational function on the selection of rehabilitation interventions. A mismatch between the most commonly investigated interventions in the systematic review and the most frequently used interventions in clinical practice suggested factors other than research evidence guide therapy practice, which were subsequently identified during the fieldwork. These processes facilitated the development of new insights than would have been obtained if the studies were conducted and analysed separately.

Another strength of the research in the thesis was the exploration of therapy practice across the wider stroke pathway. Recent ethnographic studies exploring therapy practice in stroke rehabilitation have focussed more on acute or inpatient stroke rehabilitation services (Clarke *et al.*, 2018; Taylor, Jones and McKevitt, 2018). Whilst exploring therapy practice in these settings is important to further our understanding of these settings, the range of issues experienced by survivors of severely disabling stroke in different phases post-stroke required an exploration of therapy practice across the wider stroke pathway. In addition, exploring therapy practice across the stroke pathway has been relatively under investigated in stroke rehabilitation research.

A final strength of the research in the thesis was the opportunity to undertake insider and outsider research. The rationale for undertaking the PhD was to contribute to wider clinical and research efforts designed to improve outcomes after severely disabling stroke. Years of clinical practice and critical reflection upon rehabilitation practice for survivors of severely disabling stroke provided the foundation for becoming an insider researcher. Having the opportunity to balance varying degrees of insider research with research involving other clinical settings and professional groups enabled a broader, deeper, and more critical investigation of therapy practice in the rehabilitation of severely disabling stroke.

One weakness of the research in the thesis was the subjective way in which severely disabling stroke was defined and classified. In the absence of an existing definition, severely disabling stroke was defined using clinical descriptions and cut-off scores on existing outcome measures. Using cut-off scores to classify a phenomenon that does not have clear boundaries and the lack of interchangeability between different outcome measures may have resulted in the misclassification of severely disabling stroke. This may have excluded some research studies in the systematic review or stroke survivors in the ethnographic exploration of therapy practice. As well, the definition of severely disabling stroke used in the research was determined from a healthcare professional perspective. A different definition of severely disabling stroke may have arisen if the perspectives of stroke survivors or carers were considered.

Another weakness of the research was the focus on physiotherapy and occupational therapy in the rehabilitation of severely disabling stroke. Whilst the systematic review investigated rehabilitation interventions delivered by therapists and nurses, the therapist survey and ethnographic exploration of therapy practice focussed on PTs and OTs in the rehabilitation of severely disabling stroke. The decision to focus on these professions was based upon my role as a PT and a desire to understand therapy practice more deeply in improving physical function after severely disabling stroke. This desire was guided by personal reflections on the key personnel delivering rehabilitation interventions to improve physical function after severely disabling stroke. It is possible that different findings would have been obtained if other personnel involved in the rehabilitation of physical function after severely disabling stroke were surveyed or recruited, such as nurses and care home staff.

9.8 Conclusions

Survivors of severely disabling stroke experience poor outcomes overall and compared to less disabled stroke survivors. MMR was used to investigate therapy practice in the rehabilitation of physical function after severely disabling stroke. Findings from this investigation demonstrated that current therapy practice for survivors of severely disabling stroke is infrequently based upon a limited and low-quality research evidence base. Findings from this investigation also demonstrated that current therapy practice is guided by a variety of factors, some of which may negatively influence how therapists select interventions in the rehabilitation of severely disabling stroke. Consequently, current therapy practice does not always address the needs of severely disabled stroke survivors, which may contribute to the poor outcomes experienced by this cohort of the stroke population. Accordingly, alternative aims and models of stroke rehabilitation, as well as ways of therapist working, should be considered to address the needs of severely disabled stroke survivors more fully. There is a need to conduct more research evaluating the effectiveness of rehabilitation interventions to improve physical function and reduce secondary complications using outcome and process evaluations. The potential for different forms of evidence guiding therapist decision making needs to be considered to enhance the quality of clinical decision making.

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Appendix A. Therapist Questionnaire

Survey of physical rehabilitation interventions used in the management of severe stroke

Introduction

Thank you for agreeing to take part in this survey. The survey should take between 10 – 15 minutes to complete.

This survey has two aims. The primary aim of the survey is to establish what types of **physical rehabilitation interventions** are currently used in the first 12 months post-stroke for patients with **severe stroke**. The secondary aim of the survey is to establish what **outcome measures** are currently used in the first 12 months post-stroke for patients with **severe stroke**.

For the purposes of this survey, severe stroke can be defined by a patient's:

- clinical signs- a patient with severe physical and cognitive and/or communicative impairments (e.g. severe paresis, reduced level of consciousness, aphasia)
- functional presentation e.g. dependent for washing and dressing, requires a hoist for transfers, can only sit in specialist seating, may need a modified diet or alternative ways to feed, such as a PEG
- performance or score on a standardised assessment tool e.g. NIHSS score > 16, Modified Rankin Scale 4 or 5, Barthel score < 10/20

Returning the questionnaire

Please complete and return the questionnaire in the envelope provided to:

Mark McGlinchey
Room 6.10, Addison House
Division of Health and Social Care Research
Guy's Campus
King's College London
London, SE1 1UL

If you need any additional help to complete the questionnaire, or have any questions about the study, please contact Mark McGlinchey at:

mark.p.mcglinchey@kcl.ac.uk

Online version of the questionnaire

An online version of this questionnaire is available from the following web link:

https://www.surveymonkey.co.uk/r/severestroke

Part A

In order to understand who is completing the survey, please answer the following:

1. a) Have you treated or worked with stroke patients in the past 12 months?

Yes ☐

No ☐

b) Do you work with stroke patients in the first 12 months post-stroke?

Yes ☐

No ☐

If you have answered 'NO' to either of these questions, **please do not answer any more questions**. We only wish to survey therapists who have worked with stroke patients within the past 12 months and in the first 12 months post-stroke. **Thank you for your time.**

2. What is your profession? *(please tick one box only)*

Occupational therapist ☐

Physiotherapist ☐

3. What is your current grade or banding?

4. Where is your main place of work? If you work in more than one place, please describe where you work.

Hyperacute stroke unit ☐

Acute stroke unit ☐

Neurosurgical unit ☐

Stroke or neuro rehabilitation unit ☐

Early supported discharge ☐

Community neuro service ☐

Neuro outpatient department ☐

Residential home ☐

Nursing home ☐

Hospice ☐

Private practice ☐

Combined unit/service (please describe) ☐

Other (please describe) ☐

5. How long have you worked in your main place(s) of work? *(please provide your answer in months and/or years)*

6. How long have you been working as an occupational therapist/physiotherapist? *(please provide your answer in months and/or years)*

7. In which town or city do you work?

Please proceed to Part B (next page)

Part B- Physical rehabilitation interventions in severe stroke

In this section, we would like to establish what types of **physical rehabilitation interventions** are currently used in the **first 12 months post-stroke** for patients with **severe stroke**. For the purposes of this survey, physical rehabilitation interventions are those interventions used to manage the physical problems due to having a stroke. They include:

- **passive interventions** e.g. positioning, fabrication of splints and casts
- **active rehabilitation tasks** e.g. functional task practice
- provision of **aids, equipment, and seating** e.g. tilt-in-space wheelchairs
- **training and education** e.g. advising carers on safe upper limb handling
- **recommendations and care plans** e.g. 24-hour positioning programme
- **onward referrals** e.g. social services for environmental adaptations

8. Please select how often you use or provide the following different types of **passive interventions** for patients with **severe stroke**.

	Always	**Often**	**Sometimes**	**Rarely**	**Never**
Air splinting	☐	☐	☐	☐	☐
Injecting a patient with botulinum toxin	☐	☐	☐	☐	☐
Oedema massage	☐	☐	☐	☐	☐
Passive ranging exercises	☐	☐	☐	☐	☐
Pillow wrapping	☐	☐	☐	☐	☐
Positioning	☐	☐	☐	☐	☐
Soft and scotch splinting	☐	☐	☐	☐	☐
Stretches/stretching programme	☐	☐	☐	☐	☐
Taping	☐	☐	☐	☐	☐
Thermoplastic splinting	☐	☐	☐	☐	☐
Other (please list): ______________________	☐	☐	☐	☐	☐
Other (please list): ______________________	☐	☐	☐	☐	☐
Other (please list): ______________________	☐	☐	☐	☐	☐
Other (please list): ______________________	☐	☐	☐	☐	☐

9. Please select how often you use the following different types of **active rehabilitation tasks** patients with **severe stroke**.

	Always	Often	Sometimes	Rarely	Never
Bed mobility practice	☐	☐	☐	☐	☐
Body weight support +/- treadmill	☐	☐	☐	☐	☐
Electrical stimulation (FES/NMES)	☐	☐	☐	☐	☐
Facilitated or active/assisted exercise	☐	☐	☐	☐	☐
Feeding practice	☐	☐	☐	☐	☐
Gait practice +/- gait aids	☐	☐	☐	☐	☐
Grooming practice	☐	☐	☐	☐	☐
Hydrotherapy	☐	☐	☐	☐	☐
Meal preparation	☐	☐	☐	☐	☐
Repetitive task practice	☐	☐	☐	☐	☐
Robotics	☐	☐	☐	☐	☐
Seating trials	☐	☐	☐	☐	☐
Sensory stimulation	☐	☐	☐	☐	☐
Sit to stand practice	☐	☐	☐	☐	☐
Sitting balance practice	☐	☐	☐	☐	☐
Standing frame	☐	☐	☐	☐	☐
Standing transfer aids	☐	☐	☐	☐	☐
Strengthening exercises	☐	☐	☐	☐	☐
Tilt tabling	☐	☐	☐	☐	☐
Toileting practice	☐	☐	☐	☐	☐
Transfer practice (bed – chair – toilet)	☐	☐	☐	☐	☐
UL/LL cycling machines	☐	☐	☐	☐	☐
Washing and dressing practice	☐	☐	☐	☐	☐
Wheelchair skills	☐	☐	☐	☐	☐
Other (please list): ______________________	☐	☐	☐	☐	☐
Other (please list): ______________________	☐	☐	☐	☐	☐

10. Please select how often you use or provide the following different types of **aids, equipment, or seating** for patients with **severe stroke**.

	Always	Often	Sometimes	Rarely	Never
Adapted cutlery	☐	☐	☐	☐	☐
Armchair	☐	☐	☐	☐	☐
Bed lever	☐	☐	☐	☐	☐
Commode	☐	☐	☐	☐	☐
Eye patch	☐	☐	☐	☐	☐
Helmet	☐	☐	☐	☐	☐
Manual wheelchair	☐	☐	☐	☐	☐
Oedema gloves	☐	☐	☐	☐	☐
Orthosis	☐	☐	☐	☐	☐
Palm protector	☐	☐	☐	☐	☐
Pre-fabricated splint	☐	☐	☐	☐	☐
Powered wheelchair	☐	☐	☐	☐	☐
Prism glasses	☐	☐	☐	☐	☐
Shoulder brace/sling	☐	☐	☐	☐	☐
Specialist static chair	☐	☐	☐	☐	☐
Specialist wheelchair	☐	☐	☐	☐	☐
T-roll	☐	☐	☐	☐	☐
Other (please list): ______________________	☐	☐	☐	☐	☐
Other (please list): ______________________	☐	☐	☐	☐	☐

11. Please select how often you provide the following different types of **training or education** to carers (paid or unpaid) or other members of the multi-disciplinary team for patients with **severe stroke**.

	Always	Often	Sometimes	Rarely	Never
Bed mobility	☐	☐	☐	☐	☐
Fatigue management	☐	☐	☐	☐	☐
Feeding	☐	☐	☐	☐	☐
Gait practice	☐	☐	☐	☐	☐
Grooming	☐	☐	☐	☐	☐
Hoist use	☐	☐	☐	☐	☐
Oedema massage	☐	☐	☐	☐	☐
Positioning	☐	☐	☐	☐	☐
Post-stroke shoulder pain	☐	☐	☐	☐	☐
Seating	☐	☐	☐	☐	☐
Splinting/orthosis use	☐	☐	☐	☐	☐
Stretches	☐	☐	☐	☐	☐
Toileting	☐	☐	☐	☐	☐
Transfers	☐	☐	☐	☐	☐
UL care/handling	☐	☐	☐	☐	☐
UL/LL exercises	☐	☐	☐	☐	☐
Washing and dressing	☐	☐	☐	☐	☐
Other (please list): ______________________	☐	☐	☐	☐	☐
Other (please list): ______________________	☐	☐	☐	☐	☐

12. Please select how often you devise the following different types of **care plans** for patients with **severe stroke**.

	Always	Often	Sometimes	Rarely	Never
Positioning	☐	☐	☐	☐	☐
Fatigue management	☐	☐	☐	☐	☐
Feeding	☐	☐	☐	☐	☐
Grooming	☐	☐	☐	☐	☐
Mobility	☐	☐	☐	☐	☐
Seating	☐	☐	☐	☐	☐
Splinting/orthosis use	☐	☐	☐	☐	☐
Toileting	☐	☐	☐	☐	☐
Transfers	☐	☐	☐	☐	☐
Washing and dressing	☐	☐	☐	☐	☐
Other (please list): _______________________	☐	☐	☐	☐	☐
Other (please list): _______________________	☐	☐	☐	☐	☐

13. Please select how often you refer to the following different types of **services** for patients with **severe stroke**.

	Always	Often	Sometimes	Rarely	Never
Community rehabilitation	☐	☐	☐	☐	☐
GP	☐	☐	☐	☐	☐
Inpatient rehabilitation	☐	☐	☐	☐	☐
Private sector	☐	☐	☐	☐	☐
Social services (care package)	☐	☐	☐	☐	☐
Social services (home adaptations)	☐	☐	☐	☐	☐
Spasticity clinic	☐	☐	☐	☐	☐
Splinting/orthotic service	☐	☐	☐	☐	☐
Voluntary sector	☐	☐	☐	☐	☐
Wheelchair service	☐	☐	☐	☐	☐
Other (please list): _______________________	☐	☐	☐	☐	☐
Other (please list): _______________________	☐	☐	☐	☐	☐

We are interested in understanding what factors may influence your decision to discharge a patient with severe stroke from your care/caseload.

14. Please select which factor(s) influence your decision to discharge a patient with severe stroke from your care/caseload. *(please tick all that apply)*

The patient has achieved all of their goals and there are no more appropriate interventions to provide ☐

The patient has achieved some of their goals- there are more interventions to provide but these will be provided by someone else in the stroke pathway ☐

The patient has demonstrated limited or no achievement of their goals and there are no more appropriate interventions to provide ☐

The patient has ongoing goals to work towards but the patient is being discharged sooner than I would like ☐

I can only see patients for a set period of time before I have to discharge them from my caseload ☐

I can only see patients for a set number of sessions before I have to discharge them from my caseload ☐

My line manager/supervisor tells me when I have to stop ☐

Other (please list): ______________________________ ☐

15. If a patient is being discharged sooner than you would like but they still have ongoing goals to work towards, please write down why they are being discharged sooner than you would like.

16. If you are only allowed to see a patient for a set period of time or set number of sessions, please write how long you are able to see the patient for before having to discharge them from your care/caseload.

Please proceed to Part C (next page)

Part C- Outcome measures used in severe stroke

In this section, we would like to establish what **outcome measures** are currently used in the **first 12 months post-stroke** for patients with **severe stroke**. For the purposes of this survey, an outcome measure is a standardised assessment tool used to objectively evaluate the effect of an intervention. We are only interested in outcome measures related to the **physical management** of severe stroke.

17. Please select how often you use the following **outcome measures** for patients with **severe stroke**.

	Always	Often	Sometimes	Rarely	Never
Ashworth/Modified Ashworth Scale	☐	☐	☐	☐	☐
Arm Activity Measure	☐	☐	☐	☐	☐
Barthel Index	☐	☐	☐	☐	☐
Fugl-Meyer Assessment	☐	☐	☐	☐	☐
Functional Independence Measure	☐	☐	☐	☐	☐
Glasgow Coma Scale	☐	☐	☐	☐	☐
Goal Attainment Scale	☐	☐	☐	☐	☐
Modified Rankin Scale	☐	☐	☐	☐	☐
Motor Assessment Scale	☐	☐	☐	☐	☐
Motricity Index	☐	☐	☐	☐	☐
National Institutes for Health Stroke Scale	☐	☐	☐	☐	☐
Nottingham Assessment of Somatosensation	☐	☐	☐	☐	☐
Orpington Prognostic Scale	☐	☐	☐	☐	☐
Postural Assessment Scale for Stroke Patients	☐	☐	☐	☐	☐
Rivermead Somatosensory Assessment	☐	☐	☐	☐	☐
Rivermead Motor Assessment	☐	☐	☐	☐	☐
Stroke Rehabilitation Assessment of Movement	☐	☐	☐	☐	☐
Tardieu/Modified Tardieu Scale	☐	☐	☐	☐	☐
Trunk Control Test	☐	☐	☐	☐	☐
Trunk Impairment Scale	☐	☐	☐	☐	☐
Other (please list): ______________________	☐	☐	☐	☐	☐
Other (please list): ______________________	☐	☐	☐	☐	☐

18. If you have never used an outcome measure, please state why you have not used an outcome measure.

If there is anything that has not been covered in the survey and you would like to add or if you have any further comments, please write in the below section:

This is the end of the survey. However, we would like to further explore key aspects of the physical rehabilitation interventions and outcome measures. These aspects include the aims of the interventions and outcome measures, the dosage of the interventions and the frequency of completing outcome measures.

If you would like to be contacted to participate in this exploration, please provide your contact details below:

Thank you for completing the survey.

Appendix B. Ethical Approval- Therapist Survey

Mark McGlinchey

20 January 2017

Dear Mark

LRS-16/17-3911 - Survey of physical rehabilitation interventions used in the management of severe stroke

Thank you for submitting your application for the above project. I am pleased to inform you that your application has now be approved with the provisos indicated at the end of this letter. All changes must be made before data collection commences. The Committee does not need to see evidence of these changes, however supervisors are responsible for ensuring that students implement any requested changes before data collection commences.

Ethical approval has been granted for a period of **three years** from 20 January 2017 . You will not be sent a reminder when your approval has lapsed and if you require an extension you should complete a modification request, details of which can be found here: http://www.kcl.ac.uk/innovation/research/support/ethics/applications/modifications.aspx

Please ensure that you follow the guidelines for good research practice as laid out in UKRIO's Code of Practice for research: http://www.kcl.ac.uk/innovation/research/support/conduct/cop/index.aspx

Any unforeseen ethical problems arising during the course of the project should be reported to the panel Chair, via the Research Ethics Office.

Please note that we may, for the purposes of audit, contact you to ascertain the status of your research.

We wish you every success with your research.

Yours sincerely,

BDM Research Ethics Panel REP Reviewer

Major Issues (will require substantial consideration by the applicant before approval can be granted)

N/A

Minor Issues related to application (the reviewer should identify the relevant section number before each comment)

N/A

Minor Issues related to recruitment documents

Initial recruitment documents - Where appropriate, please explain how you obtained the potential participants contact details and why they are being contacted. This is particularly relevant where contact details for physiotherapists and occupational therapists are being obtained through a therapy contact.

Advice and Comments (do not have to be adhered to, but may help to improve the research)

N/A

Page 1 of 1

Appendix C. Survey Interview Guide

1) General introduction
- aims of interview
- summary of main questionnaire findings

2) Therapist introduction
- work experience in stroke
- current place of work

3) Aims of rehabilitation in severely disabling stroke
- general aim(s)
- aims in stroke setting where therapist works

4) Aims of most frequently used interventions
- aims of most frequently used interventions overall
- aims of most frequently used interventions where therapist works

5) Timing and frequency of outcome measure use
- when outcome measures first used
- how often outcome measures are performed

6) Issues with using outcome measures
- any issues with existing outcome measures
- any reasons for low outcome measure use

7) Any final comments
- thank therapist
- explain next stages

Appendix D. Thesis Publications

McGlinchey *et al. Systematic Reviews* (2018) 7:197
https://doi.org/10.1186/s13643-018-0870-y

Systematic Reviews

PROTOCOL **Open Access**

The effect of rehabilitation interventions on physical function and immobility-related complications in severe stroke—protocol for a systematic review

Mark P. McGlinchey[1,2*], Jimmy James[2], Christopher McKevitt[1], Abdel Douiri[1], Sarah McLachlan[1] and Catherine M. Sackley[1]

Abstract

Background: Stroke rehabilitation aims to optimise function and reduce complications post-stroke. Rehabilitation to optimise physical function post-stroke has beneficial effects for survivors of mild to moderate stroke. However, little is known about the effectiveness of interventions to rehabilitate physical function or manage immobility-related complications for survivors of severe stroke. The systematic review aims to evaluate the effectiveness of rehabilitation interventions on physical function and immobility-related complications in severe stroke and identify topics for future research in this area.

Methods: A systematic review of relevant electronic databases (MEDLINE, Embase, CINAHL, AMED, PEDro, DORIS and CENTRAL) between January 1987 and July 2017 will be undertaken to identify eligible published randomised controlled trials (RCTs) in any language. Ongoing RCTs will be identified by searching health-care trial registers (Stroke Trials Registry, ClinicalTrials.gov). Hand searches of identified study reference lists will also be performed. The PRISMA statement will be used to guide the systematic review. Two reviewers will screen search results, select studies using pre-defined selection criteria, extract data from and assess risk of bias for selected studies. Studies comparing the effect of one type of rehabilitation intervention to another or usual care on physical function and immobility-related complications for patients with severe stroke will be included. Studies may include participants with all levels of stroke severity but must provide sub-group analysis based on stroke severity. Studies will focus on any phase of the stroke rehabilitation pathway and will be grouped and analysed according to their timeframe post-stroke into acute and early sub-acute (up to 3 months post-stroke), early sub-acute to late sub-acute (from 3 to 6 months post-stroke) and chronic (greater than 6 months post-stroke). If sufficient studies demonstrate homogeneity, a meta-analysis will pool results of individual outcomes. The GRADE approach will be used to assess the evidence strength.

Discussion: The results of this systematic review will summarise the strength of evidence for rehabilitation interventions used in the rehabilitation of physical function and immobility-related complications in severe stroke and identify gaps in evidence.

Systematic review registration: The systematic review was registered with the International Prospective Register of Systematic Reviews (PROSPERO)—registration number CRD77737.

Keywords: Stroke, Stroke rehabilitation, Physical therapy speciality, Physical therapy modalities, Occupational therapy, Nursing, Recovery of function, Activities of daily living, Complications

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* Correspondence: mark.p.mcglinchey@kcl.ac.uk
[1] School of Population Health and Environmental Sciences, Faculty of Life Sciences and Medicine, King's College London, Addison House, Guy's Campus, London SE1 1UL, England
[2] Physiotherapy Department, St Thomas' Hospital, Guy's and St Thomas' NHS Foundation Trust, London, England

Open access Original research

BMJ Open

The effect of rehabilitation interventions on physical function and immobility-related complications in severe stroke: a systematic review

Mark P McGlinchey, [1,2] Jimmy James, [2] Christopher McKevitt, [1] Abdel Douiri, [1] Catherine Sackley [1]

To cite: McGlinchey MP, James J, McKevitt C, *et al*. The effect of rehabilitation interventions on physical function and immobility-related complications in severe stroke: a systematic review. *BMJ Open* 2020;**10**:e033642. doi:10.1136/bmjopen-2019-033642

► Prepublication history and additional material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2019-033642).

Received 14 August 2019
Revised 02 December 2019
Accepted 20 December 2019

[1] Department of Population Health Sciences, School of Population Health and Environmental Sciences, King's College School, London, UK
[2] Physiotherapy Department, Guy's and Saint Thomas' NHS Foundation Trust, London, UK

Correspondence to
Mark P McGlinchey;
mark.p.mcglinchey@kcl.ac.uk

ABSTRACT

Objective To evaluate the effectiveness of rehabilitation interventions on physical function and immobility-related complications in severe stroke.

Design Systematic review of electronic databases (Medline, Excerpta Medica database, Cumulative Index to Nursing and Allied Health Literature, Allied and Complementary Medicine Database, Physiotherapy Evidence Database, Database of Research in Stroke, Cochrane Central Register of Controlled Trials) searched between January 1987 and November 2018.

Methods The Preferred Reporting Items for Systematic Reviews and Meta-Analysis statement guided the review. Randomised controlled trials comparing the effect of one type of rehabilitation intervention to another intervention, usual care or no intervention on physical function and immobility-related complications for patients with severe stroke were included. Studies that recruited participants with all levels of stroke severity were included only if subgroup analysis based on stroke severity was performed. Two reviewers screened search results, selected studies using predefined selection criteria, extracted data and assessed risk of bias for selected studies using piloted proformas. Marked heterogeneity prevented meta-analysis and a descriptive review was performed. The Grading of Recommendations Assessment, Development and Evaluation approach was used to assess evidence strength.

Results 28 studies (n=2677, mean age 72.7 years, 49.3% males) were included in the review. 24 studies were rated low or very low quality due to high risk of bias and small sample sizes. There was high-quality evidence that very early mobilisation (ie, mobilisation with 24 hours poststroke) and occupational therapy in care homes were no more effective than usual care. There was moderate quality evidence supporting short-term benefits of wrist and finger neuromuscular electrical stimulation in improving wrist extensor and grip strength, additional upper limb training on improving upper limb function and additional lower limb training on improving upper limb function, independence in activities of daily living, gait speed and gait independence.

Conclusions There is a paucity of high-quality evidence to support the use of rehabilitation interventions to improve physical function and reduce immobility-related complications after severe stroke. Future research investigating more commonly used rehabilitation interventions, particularly to reduce poststroke complications, is required.

PROSPERO registration number CRD42017077737

Strengths and limitations of this study

- This is the first systematic review to investigate rehabilitation interventions specifically to survivors of severe stroke.
- The review included outcomes on physical function and immobility-related poststroke complications, of which the latter contribute to high levels of caregiver burden and are less commonly reported outcomes in stroke rehabilitation research.
- Marked heterogeneity of included studies prevented meta-analysis.
- Most included studies were rated as low or very low-quality evidence due to unclear or high risk of bias as well as recruitment of very small samples.

INTRODUCTION

Despite advances in stroke management over recent decades, stroke remains one of the most common causes of death and disability globally.[1 2] The mainstay of treating stroke is stroke rehabilitation, which aims to enable a person to achieve their optimal physical, cognitive, communicative, emotional and social level of function.[3–5] Rehabilitation of physical function comprises a large component of stroke rehabilitation programmes delivered by healthcare professionals, such as physiotherapists and occupational therapists.[6–8] While several systematic reviews support the use of rehabilitation interventions to improve aspects of physical function, such as motor function, balance, walking speed and activities of daily living (ADLs),[9–11] it is not clear from these reviews if these

BMJ McGlinchey MP, *et al*. *BMJ Open* 2020;**10**:e033642. doi:10.1136/bmjopen-2019-033642 1

Appendix E. Example of Systematic Review Search Strategy (Medline)

1. exp Stroke/
2. severe stroke.mp.
3. stroke severit*.mp.
4. stroke disabilit*.mp.
5. exp Physical Therapy Modalities/
6. exp Occupational Therapy/
7. exp Nursing Care/
8. physical rehabilitation.mp.
9. exp Stroke Rehabilitation/
10. exp Patient Positioning/
11. exp Posture/
12. exp Exercise/
13. exp Exercise Therapy/
14. passive exercise.mp.
15. exp “Range of Motion, Articular”/
16. manual technique.mp.
17. active exercise.mp.
18. Resistance Training/
19. exp Muscle Stretching Exercises/
20. exp Electric Stimulation/
21. exp Electric Stimulation Therapy/
22. exp Wheelchairs/
23. seat?.mp.
24. exp “Equipment and Supplies”/
25. exp Teaching/
26. exp Education/
27. exp Motor Skills/
28. exp Movement/
29. motor function.mp.
30. motor recovery.mp.
31. exp “Recovery of Function”/
32. exp “Activities of Daily Living”/
33. functional independence.mp.
34. physical independence.mp.
35. complicatio*.mp.
36. exp Pain/
37. exp Contracture/
38. exp Pressure Ulcer/
39. exp Respiratory Tract Infections/
40. Muscle Spasticity/
41. Venous Thrombosis/
42. exp Pulmonary Embolism/
43. exp Urinary Tract Infections/
44. exp Accidental Falls/
45. exp Fatigue/
46. exp Depression/
47. 1 or 2 or 3 or 4
48. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26
49. 27 or 28 or 29 or 30
50. 31 or 32 or 33 or 34
51. 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46
52. 47 and 48 and 49
53. 47 and 48 and 50
54. 47 and 48 and 51
55. limit 52 to (“all adult (19 plus years)” and randomized controlled trial)
56. limit 53 to (“all adult (19 plus years)” and randomized controlled trial)
57. limit 54 to (“all adult (19 plus years)” and randomized controlled trial)

Appendix F. HRA and REC Approval

NHS
Health Research Authority

Email: hra.approval@nhs.net

Professor Catherine Sackley
Division of Health and Social Care Research
Addison House, Guy's Campus
King's College London, London
SE1 1UL

14 September 2017

Dear Professor Sackley

Letter of HRA Approval

Study title:	**Investigating physical rehabilitation for survivors of severe stroke**
IRAS project ID:	**218301**
REC reference:	**17/LO/1243**
Sponsor	**King's College London**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details

Health Research Authority

London - Queen Square Research Ethics Committee
HRA NRES Centre Manchester
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

<u>Please note</u>: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

14 September 2017

Professor Catherine Sackley
Division of Health and Social Care Research
Addison House, Guy's Campus
King's College London, London
SE1 1UL

Dear Professor Sackley

Study title:	**Investigating physical rehabilitation for survivors of severe stroke**
REC reference:	**17/LO/1243**
IRAS project ID:	**218301**

Thank you for your correspondence of 6 September 2017, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and one other Committee member, Dr Scott Hill.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further

Appendix G. Therapist Participant Information Sheet

Participant Information Sheet (Occupational therapy staff)

Study Title- Investigating physical rehabilitation for survivors of severe stroke

Invitation to participate in the above study
I would like to invite you to take part in a research study. Before you decide whether you would like to do so or not, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and talk to others about the study if you like. **I will be happy to go through the information sheet with you and answer any questions you have.**

What is the purpose of the study?
This study is being conducted by Mark McGlinchey, PhD student. Research suggests that specialist stroke rehabilitation improves outcomes and reduces mortality post-stroke. Physical rehabilitation, provided by occupational therapists and physiotherapists, is a key component of specialist stroke rehabilitation. Whilst previous research has suggested that physical rehabilitation has a beneficial effect on motor function and functional recovery post-stroke, there is no published research on how to deliver physical rehabilitation most effectively to patients with different levels of stroke severity. This is particularly true for patients with severe stroke, who demonstrate worse outcomes compared to patients with milder stroke. The purpose of the study is to understand what physical rehabilitation is provided to patients with severe stroke by occupational therapy and physiotherapy staff and why this rehabilitation is given. I plan on observing therapy staff treat patients with severe stroke to understand what rehabilitation they provide to these patients. I am also going to interview therapy staff to understand why they provide these types of rehabilitation treatments.

Why have I been asked to take part?
You have been chosen to participate in the study because you are currently working on Anderson Stroke Unit. You are being informed of the study to see if you would like to take part in the study.

Do I have to take part?
No. It is up to you to decide whether you would like to participate. The details of the study will be explained to you and then this information sheet will be yours to keep and look at, at any time. You can discuss whether to take part or not with any friends or colleagues. Whether you choose to take part is completely up to you. You will have a minimum of 24 hours and a maximum of seven days to decide whether or not you want to take part in the study. If you do decide to take part, you will be asked to sign a written consent form. If you decide not to take

part, the working relationship between you and I will not be affected in any way. If you do decide to take part but want to withdraw at any stage, you are free to do so and no questions will be asked about your reasons for making that decision.

What will participation involve?

It is anticipated that you will be involved in the study for up to three months. You will be observed for two to four hours per week treating your patients with severe stroke. These patients will be selected though mutual agreement between you and I. These observed sessions will take place on Anderson Stroke Unit and I will purely observe the session and document the proceedings of the session on paper. You will also be observed discussing how you plan and deliver occupational therapy for patients with severe stroke with your multi-disciplinary colleagues and with your patients. These observations will occur during goal setting sessions and any discussions you have with your colleagues. These observations will also be documented on paper by myself. You will not need to do anything special or different during these observation sessions.

You will also be asked to participate in a face-to-face interview with me. The aim of the interview will be to investigate which factors you consider when you provide occupational therapy to patients with severe stroke. This interview will take place shortly after the observation occupational therapy sessions begin. This interview will last anywhere from 30 - 45 minutes and will be recorded on both paper and using a tape recorder. Light refreshments will be made available during the interviews, which will be conducted during normal work hours.

Will you keep my information confidential?

Yes. All collected data will be confidential. A code name will be used instead of your real name to make sure everything about you is anonymous**.** No personal information about you will be held by Mark or the research team. Recordings and transcripts will be kept securely, and you will not be identified in the study report.

Expenses and payments

Taking part will not cost you anything, and we will not be able to pay you for your time.

Are there any possible disadvantages or risks?

We do not anticipate any disadvantages or risks from taking part. It is recognised that the methods used in the study may seem intrusive. As well, the process of verbalising your clinical reasoning process may be quite challenging. However, you will have the opportunity to discuss your feelings/any anxieties with either Mark or a trusted colleague. The results of the study will hopefully provide information as to the reality of occupational therapy practice in today's NHS and contribute to the evidence base of decision making amongst occupational therapists. The results of the study will also inform future clinical trials evaluating the effectiveness of physical rehabilitation interventions in severe stroke.

What will happen if I don't want to carry on with this study?

You may withdraw from the study at any time. If you withdraw after the interview has taken place, it might be difficult to remove any data you contributed from the study report. Therefore, data collected before your departure may still be used.

What if there is a problem?

Questions and Concerns

If you have a concern about any aspect of this study, you should ask to speak to me as the researcher and I will do my best to answer your questions. Please contact: Mark McGlinchey (PhD student), mark.p.mcglinchey@kcl.ac.uk, 0207 188 8679.

Complaints

If you have a complaint, you should talk to me and I will do my best to answer your questions. If you remain unhappy, you can contact the chief investigator of the study, Professor Catherine Sackley, catherine.sackley@kcl.ac.uk, at Addison House, Guy's Campus, King's College London, London, SE1 1UL.

Harm

This study is co-sponsored by King's College London and Guy's and St Thomas' NHS Foundation Trust. The sponsors will at all times maintain adequate insurance in relation to the study independently.

What happens when the study ends?

I will give you a summary of the findings if you wish. Results will be widely disseminated through conference presentations and publication.

Who is funding this work?

This project is funded by The Dunhill Medical Trust.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by London- Queen Square Research Ethics Committee.

Who do I contact for more information?

Mark McGlinchey (PhD student)
Contact Address: Room 6.10, Addison House, Guy's Campus, King's College London, SE1 1UL
Email: mark.p.mcglinchey@kcl.ac.uk
Tel: 0207 188 8679

Appendix H. Stroke Survivor Information Sheets

Guy's and St Thomas' NHS
NHS Foundation Trust

KING'S College LONDON

University College London Hospitals NHS
NHS Foundation Trust

Study: Therapy for Patients with Severe Stroke

What is the purpose of this project?

Rehabilitation by specialist **therapists** is recommended after a stroke

Therapy can help you

- Get better
- Do more for yourself
- Manage at home

We don’t know what type of therapy patients with severe stroke receive

We also don’t know how well it works

We would like to know

- What **therapy** patients with **severe stroke** receive
- Why they get this type of **therapy**

Why have I been asked to take part?

You have had a **stroke** and you are being treated by therapists involved in the study

Your experiences will help us to understand what therapy patients with severe stroke receive after a stroke

What happens if I take part?

You will be visited on the stroke unit by Mark, a PhD student. This study forms part of his PhD.

He will watch some of your therapy sessions. He will write down what he watches.

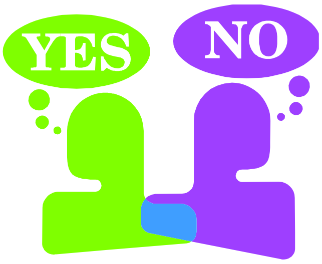
You don’t have to do anything different or special in your therapy sessions

All collected data will be **confidential**

It will be made **anonymous**

It will be stored for **5 years**

Do I have to take part?



No. The **choice** is yours.

If you are interested:

Tell

Mark (the PhD student) will **contact you**

He will visit you **on the stroke unit**

He will **answer your questions**

He will ask you to sign a **consent form**

If you are not interested:

You will not be contacted by Mark again

You can withdraw at any time

You **do not** have to give a reason

Your care **will not** be affected

Is there a cost to me?

Taking part will **not cost you anything**

We will not pay you for your time

Are there any possible benefits?

We want to better understand how to **care for people with severe stroke**

Understanding what people want or need **may help stroke survivors and their families** in the future

Are there any possible risks?

We do not expect any risks / side effects from taking part

What if there is a problem?

Questions and **concerns**:

Speak to Mark, the PhD student, on (0207 188 8679)

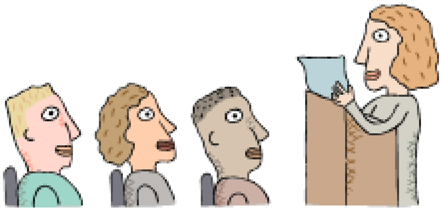
If you remain unhappy and wish to complain formally, you can do this through the Guy’s and St Thomas’ Patients Advice and Liaison Service (PALS) on 020 7188 8801, pals@gstt.nhs.uk. The PALS team are based in the main entrance on the ground floor at St Thomas’ Hospital and on the ground floor at Guy’s Hospital in the Tower Wing.

In the event that something does go wrong and you are harmed during the research you may have grounds for legal action for compensation against Guy’s and St Thomas’ NHS Foundation Trust and/or King’s College London but you may have to pay your legal costs.

What happens when the study ends?

I will **give you** a **summary** of the findings if you wish

What will we do with the results?



We will **present the results** at conferences

We will **write up** the results for publication

We will understand more about what therapy patients with severe stroke receive after a stroke

Who is funding this work?

This project is funded by The Dunhill Medical Trust

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by London- Queen’s Square Research Ethics Committee.

Who do I contact for more information?

Mark McGlinchey
(PhD student)

Contact Address:
Room 6.10, Addison House, Guy’s Campus
King’s College London
SE1 1UL
Email: mark.p.mcglinchey@kcl.ac.uk
Tel: 0207 188 8679

Patient Information Sheet

Study Title- Investigating physical rehabilitation for survivors of severe stroke

Invitation to participate in the above study

I would like to invite you to take part in a research study. Before you decide whether you would like to do so or not, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and talk to others about the study if you like. **I will be happy to go through the information sheet with you and answer any questions you have.**

What is the purpose of the study?

This study is being conducted by Mark McGlinchey, PhD student. This study forms part of Mark's PhD. Research suggests that patients who receive specialist stroke rehabilitation make a better recovery after stroke. However, very little is known about how to best provide this rehabilitation to patients with different levels of stroke severity. This is particularly true for patients with severe stroke, who do not recover as well as patients with less severe stroke. The purpose of the study is to understand what rehabilitation treatments are provided to patients with severe stroke by physiotherapy and occupational therapy staff and why these treatments are given. I am going to observe therapists treat patients with severe stroke to understand what treatments they provide to these patients. I am also going to interview therapists to understand why they provide these types of treatments.

Why have I been asked to take part?

You have been chosen to participate in the study because you have had a stroke and are currently being treated by therapists involved in the study.

Do I have to take part?

No. It is up to you to decide whether you would like to participate. The details of the study will be explained to you and then this information sheet will be yours to keep and look at, at any time. You can discuss whether to take part or not with any friends or family or other staff. Whether you choose to take part is completely up to you. You will have a minimum of 24 hours and a maximum of seven days to decide if you want to take part in the study. If you decide not to take part, the care that you will receive will not be affected in any way. If you do decide to take part but want to withdraw at any stage, you are free to do so and no questions will be asked about your reasons for making that decision.

What will participation involve?

If you are interested in participating, let me or know. I will come and see you on the stroke unit. I will answer your questions, and if you still want to participate I will ask you to sign a consent form. It is expected that you will be involved in the study for up to 6 weeks. You would be observed for up to four hours per week being treated by your regular physiotherapist or occupational therapist. These observed sessions would take place on the stroke unit and I would purely observe your normal session and make a few notes on paper about the proceedings of the session. You would not need to do anything special or different during these sessions.

Will you keep my information confidential?

Yes. All collected data will be confidential. A code name will be used instead of your real name to make sure everything about you is anonymous. No personal information about you will be held by Mark or the research team. Notes from the observation session and any related documents will be stored securely. Anonymised data will be kept for 5 years in line with guidance from King’s College London.

Expenses and payments

Taking part will not cost you anything, and we will not be able to pay you for your time.

Are there any possible benefits?

We want to better understand how to care for people with severe stroke. Particularly, we want to know how therapists make decisions about what treatments to give to patients with severe stroke. Understanding this decision-making process may help stroke patients and their families in the future.

Are there any possible risks?

We do not anticipate any risks or side effects from taking part.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to me as the researcher and I will do my best to answer your questions. Please contact: Mark McGlinchey (PhD student), mark.p.mcglinchey@kcl.ac.uk, 0207 188 8679.

If you remain unhappy and wish to complain formally, you can do this through the Guy's and St Thomas' Patients Advice and Liaison Service (PALS) on 020 7188 8801, pals@gstt.nhs.uk. The PALS team are based in the main entrance on the ground floor at St Thomas' Hospital and on the ground floor at Guy's Hospital in the Tower Wing.

In the event that something does go wrong and you are harmed during the research you may have grounds for legal action for compensation against Guy's and St Thomas' NHS Foundation Trust and/or King's College London but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

What happens when the study ends?

I will give you a summary of the findings if you wish. I will present the results at conferences. I will write up the results for publication.

Who is funding this work?

This project is funded by The Dunhill Medical Trust.

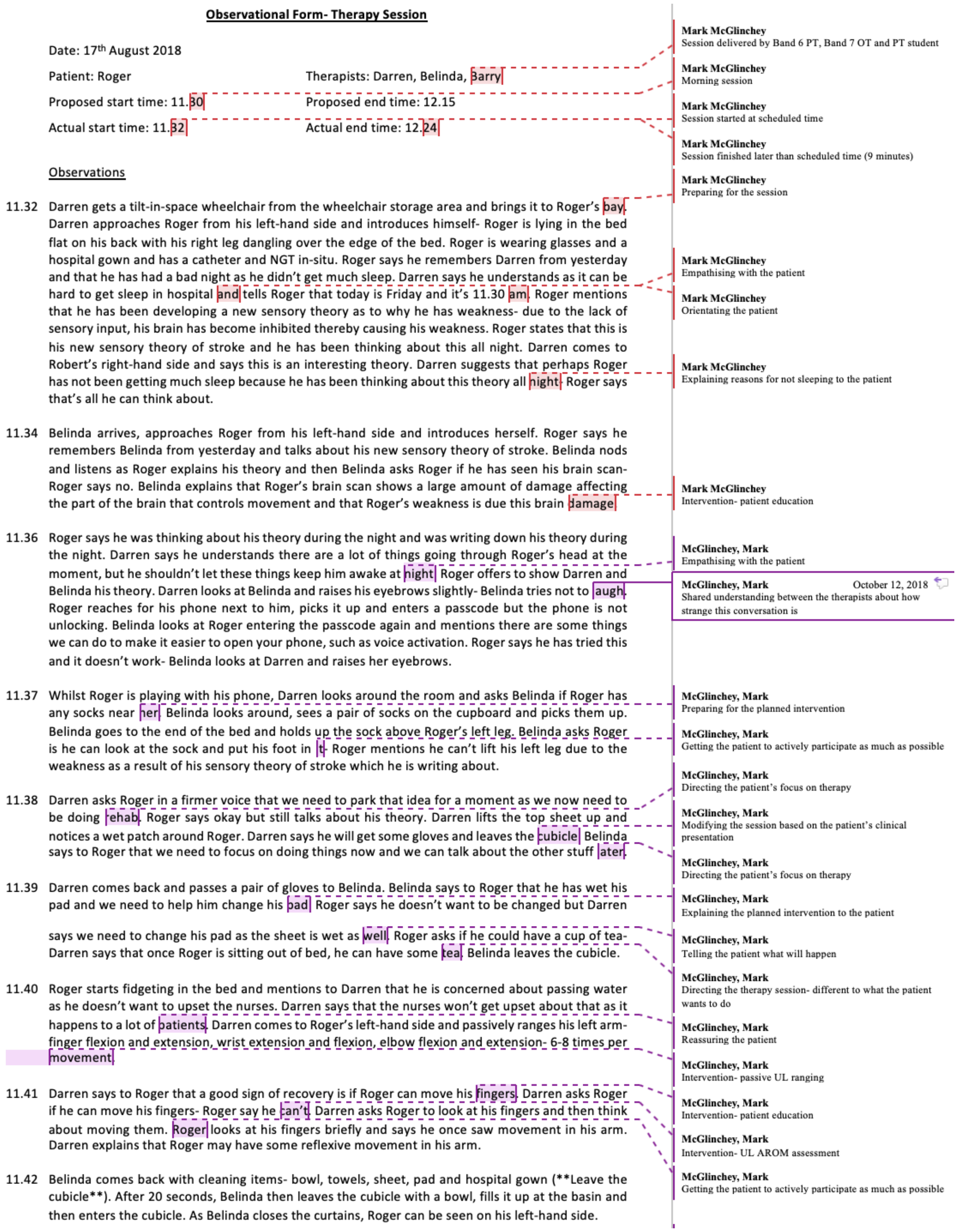
Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by London- Queen’s Square Research Ethics Committee.

Who do I contact for more information?

Mark McGlinchey (PhD student)
Email: mark.p.mcglinchey@kcl.ac.uk
Tel: 0207 188 8679

Appendix I. Fieldnote Extracts (Coded with Post-Session Reflection)



Observational Form- Therapy Session

Date: 17th August 2018

Patient: Roger   Therapists: Darren, Belinda, Barry

Proposed start time: 11.30   Proposed end time: 12.15

Actual start time: 11.32   Actual end time: 12.24

Observations

11.32 Darren gets a tilt-in-space wheelchair from the wheelchair storage area and brings it to Roger's bay. Darren approaches Roger from his left-hand side and introduces himself- Roger is lying in the bed flat on his back with his right leg dangling over the edge of the bed. Roger is wearing glasses and a hospital gown and has a catheter and NGT in-situ. Roger says he remembers Darren from yesterday and that he has had a bad night as he didn't get much sleep. Darren says he understands as it can be hard to get sleep in hospital and tells Roger that today is Friday and it's 11.30 am. Roger mentions that he has been developing a new sensory theory as to why he has weakness- due to the lack of sensory input, his brain has become inhibited thereby causing his weakness. Roger states that this is his new sensory theory of stroke and he has been thinking about this all night. Darren comes to Robert's right-hand side and says this is an interesting theory. Darren suggests that perhaps Roger has not been getting much sleep because he has been thinking about this theory all night. Roger says that's all he can think about.

11.34 Belinda arrives, approaches Roger from his left-hand side and introduces herself. Roger says he remembers Belinda from yesterday and talks about his new sensory theory of stroke. Belinda nods and listens as Roger explains his theory and then Belinda asks Roger if he has seen his brain scan- Roger says no. Belinda explains that Roger's brain scan shows a large amount of damage affecting the part of the brain that controls movement and that Roger's weakness is due this brain damage.

11.36 Roger says he was thinking about his theory during the night and was writing down his theory during the night. Darren says he understands there are a lot of things going through Roger's head at the moment, but he shouldn't let these things keep him awake at night. Roger offers to show Darren and Belinda his theory. Darren looks at Belinda and raises his eyebrows slightly- Belinda tries not to laugh. Roger reaches for his phone next to him, picks it up and enters a passcode but the phone is not unlocking. Belinda looks at Roger entering the passcode again and mentions there are some things we can do to make it easier to open your phone, such as voice activation. Roger says he has tried this and it doesn't work- Belinda looks at Darren and raises her eyebrows.

11.37 Whilst Roger is playing with his phone, Darren looks around the room and asks Belinda if Roger has any socks near her. Belinda looks around, sees a pair of socks on the cupboard and picks them up. Belinda goes to the end of the bed and holds up the sock above Roger's left leg. Belinda asks Roger is he can look at the sock and put his foot in it- Roger mentions he can't lift his left leg due to the weakness as a result of his sensory theory of stroke which he is writing about.

11.38 Darren asks Roger in a firmer voice that we need to park that idea for a moment as we now need to be doing rehab. Roger says okay but still talks about his theory. Darren lifts the top sheet up and notices a wet patch around Roger. Darren says he will get some gloves and leaves the cubicle. Belinda says to Roger that we need to focus on doing things now and we can talk about the other stuff later.

11.39 Darren comes back and passes a pair of gloves to Belinda. Belinda says to Roger that he has wet his pad and we need to help him change his pad. Roger says he doesn't want to be changed but Darren says we need to change his pad as the sheet is wet as well. Roger asks if he could have a cup of tea- Darren says that once Roger is sitting out of bed, he can have some tea. Belinda leaves the cubicle.

11.40 Roger starts fidgeting in the bed and mentions to Darren that he is concerned about passing water as he doesn't want to upset the nurses. Darren says that the nurses won't get upset about that as it happens to a lot of patients. Darren comes to Roger's left-hand side and passively ranges his left arm- finger flexion and extension, wrist extension and flexion, elbow flexion and extension- 6-8 times per movement.

11.41 Darren says to Roger that a good sign of recovery is if Roger can move his fingers. Darren asks Roger if he can move his fingers- Roger say he can't. Darren asks Roger to look at his fingers and then think about moving them. Roger looks at his fingers briefly and says he once saw movement in his arm. Darren explains that Roger may have some reflexive movement in his arm.

11.42 Belinda comes back with cleaning items- bowl, towels, sheet, pad and hospital gown (**Leave the cubicle**). After 20 seconds, Belinda then leaves the cubicle with a bowl, fills it up at the basin and then enters the cubicle. As Belinda closes the curtains, Roger can be seen on his left-hand side.

Mark McGlinchey
Session delivered by Band 6 PT, Band 7 OT and PT student

Mark McGlinchey
Morning session

Mark McGlinchey
Session started at scheduled time

Mark McGlinchey
Session finished later than scheduled time (9 minutes)

Mark McGlinchey
Preparing for the session

Mark McGlinchey
Empathising with the patient

Mark McGlinchey
Orientating the patient

Mark McGlinchey
Explaining reasons for not sleeping to the patient

Mark McGlinchey
Intervention- patient education

McGlinchey, Mark
Empathising with the patient

McGlinchey, Mark October 12, 2018
Shared understanding between the therapists about how strange this conversation is

McGlinchey, Mark
Preparing for the planned intervention

McGlinchey, Mark
Getting the patient to actively participate as much as possible

McGlinchey, Mark
Directing the patient's focus on therapy

McGlinchey, Mark
Modifying the session based on the patient's clinical presentation

McGlinchey, Mark
Directing the patient's focus on therapy

McGlinchey, Mark
Explaining the planned intervention to the patient

McGlinchey, Mark
Telling the patient what will happen

McGlinchey, Mark
Directing the therapy session- different to what the patient wants to do

McGlinchey, Mark
Reassuring the patient

McGlinchey, Mark
Intervention- passive UL ranging

McGlinchey, Mark
Intervention- patient education

McGlinchey, Mark
Intervention- UL AROM assessment

McGlinchey, Mark
Getting the patient to actively participate as much as possible

17th August 2018

- Setting and participants
  - the session occurred within the patient's cubicle
- the session was delivered by a Band 7 OT, Band 6 PT and PT student
  - the aim of the session was not explicitly stated before the session but involved practising sitting, washing and dressing, sit to stand, standing and seating
- Reflections
  - the session started on time
  - the aim of the session was not explained to the patient in advance of the session, but it appeared that the therapists understood what to do during the session (? communicated beforehand)
  - the more experienced PT led and directed the session, although the slightly less experienced OT led some interventions that she was more experienced in delivering (e.g. washing and dressing)
  - despite the PT's experience, the PT could have simplified his communication based on the patient's cognitive ability e.g. not giving explanations prior to a planned intervention as the patient did the intervention when the PT spoke the words
  - the session finished slightly later than scheduled: it seems like the main aim was to get the patient into the chair and due to the therapists having to wash and dress the patient, this may have caused the session to overrun (? highlights the impact of incontinence in the acute phase, ? lack of nursing staff to assist in personal care)

Observational Form- MDT Meeting

Date: 8th March 2019

Present: Madeleine (B8 SLT), Connie (Contract Manager), Orla (B7 SLT), Nina (B5 OT), Monica (B7 OT), Derrick (B3 RSW), Bradley (B5 PT), Fabian (B6 PT), Kelis (B6 OT), Rowena (B6 NS), Kassandra (Case Manager), Roseanne (B6 PT)

> **McGlinchey, Mark**
> Full range of MDT staff

Proposed start time: 9.00 Proposed end time: 10.30

Actual start time: 9.03 Actual end time: 10.42

> **McGlinchey, Mark**
> Meeting started at scheduled time

> **McGlinchey, Mark**
> Meeting finished later than scheduled time (12 minutes)

Observations

9.02 The therapists enter the meeting room. Madeleine circulates the patient list to the therapists.

9.03 Madeleine suggests the team introduce themselves to the new contract manager- the team members state their name and their job role.

> **McGlinchey, Mark**
> Most senior staff member (B8 SLT Team Lead) leading the meeting

9.04 Madeleine explains to the contract manager that the team first discusses the ESD patients. Madeleine explains what ESD is to the contract manager- intense therapy for 2 weeks for patients to achieve their goals. where patients. The first ESD patient is DW- seen by Kelis and Roseanne.

> **McGlinchey, Mark**
> Explaining the format of the MDT meeting to a new staff member

> **McGlinchey, Mark**
> Explaining terminology to a new staff member

9.07 The last ESD patient is AM- seen by Kelis, Fabian and Derrick.

9.09 Madeleine explains to the contract manager that the team next discusses the SD patients, who are patients that receive slightly less intensive therapy for up to 6 weeks. The first SD patient is KH- seen by Nina, Fabian and Orla.

> **McGlinchey, Mark**
> Explaining terminology to a new staff member

9.11 Next SD patient is CJ- seen by Monica and Bradley.

> **McGlinchey, Mark**
> The format of the meeting is that the Team Lead asks the keyworker for feedback first and then asks for feedback from each of the different disciplines. Staff members feedback on how many times they have seen the patient in the previous week, provide a summary of assessment findings (including OM feedback e.g. Berg, MOCA), goal attainment and any future plans (which is usually to continue with current goals until end of LOS or discharge from caseload).

9.14 Next SD patient is MR- seen by Fabian and Rowena.

> **McGlinchey, Mark**
> The staff member discussing the patient usually speaks to the Team Lead directly when giving feedback although they sometimes talk amongst themselves; sometimes a (usually) more senior staff member adds to the discussion or asks for clarification

9.17 Next SD patient is JS- seen by Kelis, Bradley, Derrick and Rowena.

9.23 Next SD patient is DB- seen by Roseanne, Dahlia (Orla provides feedback)

> **McGlinchey, Mark**
> If a staff member is absent, a staff member from the same discipline feeds back information

9.24 Next SD patient is MM- seen by Dahlia (Orla provides feedback), Nina, Rowena and Hugo (Derrick provides feedback). Madeleine asks Nina to explain apraxia to the contract manager- Nina states that it is a problem with motor planning and sequencing.

> **McGlinchey, Mark**
> Explaining terminology to a new staff member

9.27 Next SD patient is Bob. Madeleine says that Jasmine is the keyworker, but she is not here. Nina says that Jasmine is on a visit and reads Jasmine's handover. Nina says that they have tried FES over the past few days and will refer Bob to the upper limb clinic. Madeleine looks at Roseanne- Roseanne says she knows how this is going to turn out. Roseanne adds that she saw Bob with Jasmine for the past two visits and tried FES. Madeline asks Roseanne to explain what FES is to the contract manager. Roseanne states that FES stands for functional electrical stimulation, which is a machine that gives electrical signals to the muscles to enable a weak muscle to contract. Roseanne states that it will only work if the patient continually uses it and practises exercises all the time. Roseanne says that with Bob, the electrodes are too big for Bob's arm as his wrist is quite small. Madeleine suggests that they order some smaller electrodes as it is the end of the financial year and they have money that they can spend. Roseanne proceeds by saying that with the FES, they get good wrist and thumb extension but not finger extension Roseanne adds that it took them at least 20-25 minutes yesterday to find good movement and at the moment, it is too complex to handover to Bob and his wife. Roseanne says that they will try the smaller electrodes to see if it is successful. Roseanne says she is not convinced that the electrodes are not going to do it.

> **McGlinchey, Mark**
> OT providing an overview of the patient's current treatment plan

> **McGlinchey, Mark**
> Meeting lead seeking feedback from a more experienced therapist (PT)

> **McGlinchey, Mark**
> PT (more experienced therapist) contributing to the patient discussion

> **McGlinchey, Mark**
> Explaining terminology to a new staff member

> **McGlinchey, Mark**
> PT highlighting issues with the current treatment plan

> **McGlinchey, Mark**
> Meeting lead identifying solutions to the current treatment issues

> **McGlinchey, Mark**
> PT providing an overview of the patient's current treatment plan

8th March 2019

- Setting and participants
    - the meeting occurred in the meeting room
    - the meeting was attended by SLT (Band 7 and 8), PTs (Band 5 and 6s), OT (Band 5, 6 and 7), nurse (Band 6), RSW (Band 3), and managers (contract and case managers)
- Reflection
    - the meeting started on time
    - the meeting was facilitated by the Team Lead (Band 8 SLT), who clinically manages the stroke team
    - the meeting had representation from all disciplines working within the team (although there is no dietician within the team)
    - the format of the meeting was that patients were discussed in groups based upon their classification within the service (ESD, SD, THMT- higher priority to lower priority) and ordered according to their position on the patient list
    - for each patient, the Team Lead asked the patient's keyworker for feedback first and then asked for feedback from each of the different disciplines; staff members fed back on how many times they saw the patient in the previous week, provided a summary of assessment findings (including OM feedback e.g. Berg, MOCA), goal attainment and any future plans (which is usually to continue with current goals until end of LOS or discharge from caseload)
    - the staff member discussing the patient usually spoke to the Team Lead directly when giving feedback (thereby reinforcing her role as meeting lead), although they sometimes talked amongst themselves when discussing the patient; sometimes a (usually) more senior staff member added to the discussion or asked for clarification
    - the Team Lead performed multiple roles in the meeting, including information gatherer, clinical expert and time-keeper, which may have been facilitated by her expertise in facilitating team meetings and the staff members' awareness of the format of the team meeting
    - the meeting finished later than scheduled

Appendix J. Interview Guide- Stephenson Community Stroke Team

1) Introduction
- explain the format of the interview e.g. semi-structured, tape recorded, 30 – 45 minutes

2) Introductory questions about their work experience in stroke rehabilitation & definition/understanding of stroke rehabilitation

3) Factors considered when providing rehabilitation
- deciding what intervention(s) to use
- deciding on the delivery of rehabilitation (length, frequency)

4) Factors considered when stopping rehabilitation
- deciding when to stop interventions
- thoughts and feelings about reducing or stopping rehabilitation

5) MDT or patient/carer involvement in decision-making

6) Preference for treating milder/more severe stroke patients

7) Transition from hospital to community

8) Questions related to the observation sessions

9) If there was anything you could change about the stroke pathway for patients with severe stroke, what would it be?

10) Any other questions they may have and paraphrase key aspects

11) Conclusion
    - thank the therapist
    - explain the next stages e.g. data analysis

Appendix K. Examples of Categories with Constituent Codes

Clinical Experience

able to see clear steps to progress patient
adapting clinical reasoning as necessary
allowing patients to tell their story influenced by personal experience of stroke
being aware of others' impact on clinical reasoning
best practice guides therapy
changing practice as not in line with colleagues
clinical experience guides learning
clinical experience guides patient prioritisation
clinical experience guides preference for different levels of stroke severity
clinical experience guides prognostication
clinical experience guides stopping therapy
clinical experience guides therapy
clinical experience guides therapy frequency
clinical experience suited to help more severe stroke patients
clinical reasoning guides rehab
clinical wisdom guides practice
dealing with therapists not sure what to do
doing things my own way
doing what you can
experience in communicating with family
hard to explain clinical reasoning
having access to experienced therapists
having more patient centred approach due to work experience
having to learn new skills to treat patients with communication and cognitive problems
hospital staff with no community experience don't appreciate community challenges
learning through experience
learning to accept the limitations
learning ways to be more efficient
limited experience in severe stroke
limited experience in stopping severe stroke SU rehab
limited experience of patients further down the line
limited experience of complications
limited experience of stroke
limited experience with patients declining therapy
limited experience with resettlement patients
limited time working with stroke patients
more experience of severe stroke in the acute setting than the community
need for education of less experienced staff
new OTs not having much experience with complex UL problems
not being aware of less experienced therapist's skills influences patient allocation
pattern recognition guides therapy
PTA learning through experience
PTA learning through training
PTA understanding of therapy sessions
previous experience guides therapy
quality of community therapy depends on therapist experience
range of skills across therapy team
rehab guided by clinical reasoning
senior support guides reducing therapy
senior support guides stopping therapy
senior support guides therapy
senior support to improve knowledge and skills
senior support to progress sessions
some experience of post-stroke complications
some therapists not treating patients as not certain of benefits
some therapists not treating patients as not sure what to do
sound clinical reasoning improves outcomes
therapist training influences therapy role
training guides therapy
training leads to confidence
wanting to work in neuro
wasting skills seeing patients with no stroke therapy need

work experience
working in neuro

Evidence in Severe Stroke

being aware of limited research evidence
discrepancy between research evidence and clinical problems
evaluating research to guide therapy
evidence based pathway guides therapy
evidence for shorter therapy session
evidence guides decision making about rehab potential
evidence guides therapy
evidence has changed clinical practice
evidence supports rehab after Botox
evidence to guide prognosis
evidence to guide prognosis not always beneficial
evidence to support therapy
hoping for recovery despite the evidence
importance of severe stroke research
inquiring about aim of research
lack of evidence enables innovative practice
lack of evidence for severe stroke therapy taught at university
lack of evidence informing guidelines
lack of evidence means treatment based on patient response
lack of evidence to support severe stroke rehab
limitations of applying evidence to guide practice
limited evidence for passive stretching
limited evidence in severe stroke
receiving training to know evidence-base treatment
research disseminated by supervisors
research findings go against established clinical practice
research for rehab outcome
research guides therapy
research guides therapy frequency
research not supporting early mobilisation of severe stroke patients
research supporting self-management
research supports repetitive practice to promote recovery
research to filter out what doesn't work
research to focus more on what works
shocked by research findings not supporting established clinical practice
stronger evidence for 45 minutes of therapy would lead to greater adherence
using research to guide prediction of future recovery

Patient Involvement and Preferences

allowing the patient to express themselves
alternative ways to communicate with patients
balancing therapy to progress and patient choice
being comforted by religion
being influenced by the patient
building rapport to establish what is important to patients
challenging if patient and therapist ideas don't match
challenge of involving patients with communication problems
challenging to deal with unrealistic expectations
considering the patient's best interest to guide rehab
considering the patient's interests for the long-term
deciding therapy for patient unable to express themselves
deciding what's best for the patient
decisions in community rehab more patient led as able
decisions more therapist led for patients with cognitive impairment
difficult to ascertain what severe stroke patients want
difficult to discuss poor prognosis with patients
difficult to educate patients with cognitive impairment

difficult to know patient wishes if medically unwell
discussing assessment findings with the patient
discussing patient progress with patients
discussing suitability of home environment for patients with significant needs
easier if patients can communicate their needs
ensuring patient has confidence to know how to access services
ethical concerns about therapy for patients with limited cognition
fast progress once relationship with patient developed
feeling better once toileted
finding out what's important to patients
finding out why patients decline therapy
forgetting to involve severe stroke patients in decision making
getting to know patient's wishes
getting to know the patient once home
giving advice once developed rapport
giving feedback about progress
giving positive feedback about performance in therapy
giving realistic feedback about performance in therapy
having unrealistic expectations
important to spend time building rapport
improving insight as building rapport with patients
interested in patient's views on activity post-stroke
interpreters helpful to understand patient
involving patients in developing exercise programmes
involving patients with capacity in decision making
involving patients with communication impairment in therapy
keeping the patient at the centre of decision-making
knowing patient's wishes to achieve best outcomes
knowing what the patient needs to function
letting the patient decide what they want to do
level of cognition enables understanding of patient
limitations of giving patient choice to decide which SU to go to patient wishes guide therapy
making patients comfortable at the end of their life
meaningful tasks to guide therapy
not always considering patient's preferences
not always considering spiritual or social needs
not realising patient's wishes
not wanting to damage therapeutic relationship by contradicting patient
not wanting to do self-care tasks
patient choice about rehab options
patient choice guides discharge home
patient choice guides stopping therapy
patient choice guides therapy
patient choice guiding therapy
patient involvement in goal setting
patient involvement in therapy
patient not always happy about set goals
patient perspective matters first
patient preferring physio goals
patient wishes guide therapy goals
patient wishes to stop therapy
patients giving up as realise there's limited chance of recovery
patients giving up as unable to do much for themselves
patients not accepting poor prognosis
patients not always aware of how difficult life will be at home
patients would prefer more therapy with the hope of improvement
practising tasks important to the patient
receiving feedback to understand recovery
providing more therapy if patient asks for more therapy
respecting patient wishes for discharge
ruining rapport with communication discrepancy
showing patients their gains
shared understanding of patient's disease
some patients don't want further rehab once home
some patients may not be mentally ready for rehab
some patients may not be ready for early rehab
staff should know patient before the stroke

staff should know patient's wishes about rehab
trusting the patient's safety awareness
understanding cognitive and communication barriers
understanding cognitive deficits challenging
understanding life before stroke
understanding the patient
understanding the patient to guide therapy
using the patient to generate treatment ideas
variable patient involvement in decision making

Issues with Acute Stroke Unit Rehabilitation

being interrupted limits providing intensive therapy
being occupationally deprived on the ward
difficult to recreate patient's environment in the hospital
difficult to set up patients at home from non-local SU
hospital staff need to consider appropriateness of referral
hospital staff may benefit from more education around ESD eligibility
inpatient environment quite limiting
issue of early decision making
issue of reduced therapy if not making gains
issue of sitting out for too long
issue with not providing daily inpatient rehab
issues with patients receiving complex equipment in a timely manner
lack of space on SU
limitation of lack of interim rehab between hospital and home
limitations of acute environment
limitations of early decision making
limited scope of rehab in hospital
limited time to provide rehab
making decisions too soon due to busy acute environment
more distracting factors in the acute setting
more limitations in DGH
never used to refer independent patients to ESD
no weekend therapy on SU
not enough importance placed on preventing deterioration while waiting for community rehab
not getting the intensity whilst waiting for inpatient rehab
not managing complications in ICU
not sure why hospital staff are referring independent patients to ESD
patients can wait longer than 72 hours before repatriated
patients not being repatriated creates difficulties
patients spend too much time in bed
poor SU physical environment
some patients don't do well in hospital as desperate to get home
some patients don't do well in hospital due to low mood
some patients don't do well in hospital environment
some patients low in mood due to hospital environment
some patients referred to community as hospital staff are risk averse
some units slow to accept HASU patients
toileting impacts upon other interventions
toileting not a great intervention
too much focus on the acute stage

Appendix L. Example of Code – Category – Thematic Development

Interview Data	Code	Category	Theme
"And I think it's just, kind of, weighing it all up and taking in the whole picture and doing what you can"	doing what you can	Clinical Experience	Professional Expertise
"They only time I've really seen pressure sores was when the patient has come into hospital with one… yeah, I don't think I've seen any that have happened whilst they've been in hospital"	limited experience of complications		
"I think one of the reasons I wanted to do neuro, as a Band 5 rotation choice, was because it's the one rotation thing that's almost kept from you on all the other rotations"	wanting to work in neuro		
"So, if it's somebody who's really complex and I'm not just sure, then I may would always seek advice from my Band 7"	senior support guides therapy		
"I'd say probably after a week of working with somebody you'd have a relatively good idea of how well they're going to do"	predicting recovery	Uncertainty and Prognostication	
"I mean it's hard to know who's going to be the person that doesn't regain a lot ability and who's the person that could regain a lot of ability"	difficult to prognosticate in severe stroke		
"Maybe we're not sure what interventions will work yet… I guess that's why you're doing the study"	not sure if therapy effective		
"But yeah, I think it's difficult to know how much time to keep on going with someone who's not getting any better"	uncertainty about stopping therapy		

Appendix M. Ethnography Categories and Themes

		Themes		
Professional Expertise	**Beliefs and Attitudes about Post-Stroke Recovery**	**Research Evidence**	**Attributes of the Severely Disabled Stroke Survivor**	**Therapy in the Wider Stroke Pathway**
		Categories		
Clinical experience	Attitudes, beliefs, and preferences	Adherence to clinical guidelines	Allocating and utilising resources	ASU rehabilitation
Level of therapist experience	Differences with milder stroke patients	Evidence in severe stroke	Assessing patients	Care homes
Physiotherapy role	Disability management	Session length	Carer burden	Community stroke rehabilitation
Occupational therapy role	Emotional responses in stroke rehabilitation	Therapy frequency	Family and carer involvement	Discharge planning
Stopping therapy and rehabilitation	Post-stroke complications		Giving patients a chance for rehabilitation	HASU rehabilitation
Therapist knowledge	Quality of life		Goal setting and attainment	Inpatient SU rehabilitation
Therapy role	Severe stroke patients		Outcome measurement	Issues with ASU rehabilitation
Uncertainty and prognostication	Severe stroke rehabilitation		Patient involvement and preferences	Issues with care homes
	Stroke rehabilitation		Patient participation and engagement	Issues with community stroke rehabilitation
	Treatment approaches		Patient presentation	Issues with HASU rehabilitation
			Prioritising stroke patients	Issues with inpatient SU rehabilitation
			Rehab potential	MDT working
			Treating patients	Stroke pathway design
				Ways to address pathway issues
				Working across the pathway