SELF-MANAGEMENT INTERVENTIONS TO IMPROVE MOBILITY IN THE COMMUNITY POST-STROKE

By
Ahmad Sahely

A thesis submitted to the University of Birmingham for the degree of DOCTOR OF PHILOSOPHY

School of Sport, Exercise and Rehabilitation Sciences
College of Life and Environmental Sciences
University of Birmingham

May 2023

UNIVERSITY OF
BIRMINGHAM

University of Birmingham Research Archive

e-theses repository

This unpublished thesis/dissertation is copyright of the author and/or third parties. The intellectual property rights of the author or third parties in respect of this work are as defined by The Copyright Designs and Patents Act 1988 or as modified by any successor legislation.

Any use made of information contained in this thesis/dissertation must be in accordance with that legislation and must be properly acknowledged. Further distribution or reproduction in any format is prohibited without the permission of the copyright holder.

Abstract

Individuals' lives after stroke are affected by multiple levels of disability. Appropriate rehabilitation services can help them to regain their functions and improve their quality of life. In the UK and other developed countries, there has been a tendency toward the early supported discharge from hospital after a stroke with the aim of providing care at home after discharge. However, stroke survivors' needs after discharge from the hospital have been unmet as the health care services lack sufficient resources. Self-management strategies have been developed to help stroke survivors improve their self-efficacy and independence and play an active role in their rehabilitation process. The efficacy and appropriateness of self-management as an additional component to the current practice have been examined in several contexts, but there has been limited research around self-management strategies to improve mobility after stroke. The overarching aim of this thesis was to develop, implement, and test the feasibility of a self-management (SM) intervention to improve functional mobility for stroke survivors in the community.

Chapter 1 (the introduction) provides a background of the research problem and the knowledge to practice gap. It demonstrates the prevalence, impact, and management of stroke with focus on mobility rehabilitation as a main physical impairment. It also discusses the gap in current practice regarding the delivery of optimum amount of therapy and the role of SM in bridging the gap and facilitating the recovery of stroke survivors.

Chapter 2 demonstrates the philosophical stance taken by the researcher to select the appropriate methodology for each stage of this research work. It shows the advantages of applying different methods to address the specific objectives of the thesis. Chapter 3 includes a systematic review of the evidence about specific SM interventions that can be applied for the rehabilitation of mobility post-stroke. A new intervention was then developed in consultation

with senior clinicians and stroke patients to adapt the use of evidence to a local context of stroke rehabilitation within the West Midlands.

In study 2 (chapter 4). A qualitative exploratory study was carried out during the Covid-19 pandemic exploring needs and experiences of stroke patients and NHS therapists who worked with stroke patients with a special focus on the utility of self-management strategies post discharge. This study found four main themes that described the modifications in the care system because of the pandemic, impact on the stroke survivors at different stage, needs and priorities of stroke rehabilitation, and management strategies that have been used in stroke rehabilitation. The findings from the study contributed to the modification of the intervention developed to integrate technology and promote remote strategies for self-management.

Study 3 (chapter 5), aimed to evaluate feasibility of implementation, to explore participants' perspectives about the acceptability, practicality, and fidelity of the new intervention and to scope out methodological feasibility of a future randomised control trial of the new self-management intervention for mobility following stroke (SIMS). A mixed-methods study design was carried out including a feasibility randomised control design and focus groups to collect data. The study recruited 24 participants (14 males: 10 females; age range (36-87 years)) into both the intervention and control groups. The study findings showed that it was feasible to recruit participants from hospital and community, but the rate was low due to effects of the COVID-19 pandemic. Randomisation and blinding were successful. Retention rate was 83% at 3 months and 79.2% at 6 months assessments. Adherence to the intervention varied mainly due to post stroke fatigue, COVID-19 and the impact of mood changes. It was feasible to deliver the intervention online with no serious events related to the study. Focus groups discussed participants' motivations for joining the programme, their perspectives on the intervention (fidelity and acceptability) and methodology, perceived improvements in walking outcomes, facilitators and challenges for self-management, and suggestions for improvement. Lastly, chapter 6 provides a summary of findings and discussion points about the key findings from all three studies included in this thesis work.

Acknowledgements

All praise is due to Allah for His unlimited blessings, assistance and guidance. Only with His will and help this work has been completed.

I would like to thank everyone who participated in the success of my journey for the PhD. Starting with my supervisors Associate Prof. Sheeba Rosewilliam and Dr. Andrew Soundy, I would like to thank you very much for your continuous support, encouragement, guidance and patience in supervising my work throughout the course of PhD.

Thanks also to the senior therapists and patients (Carron Sintler, Caroline Hawkins, Brin Helliwell, Elizabeth Manuel) who kindly participated in the development of the study design and intervention. I would like to extend my thanks to clinicians at Mosely Hall Hospital (Carron Sintler, Caroline Hawkins, Maria Lee, Lisa Bennett, Kieron Chamberlain) who helped with screening and recruitment of participants for the feasibility study.

To my fellow physiotherapy students at the School of Sport, Exercise and Rehabilitation Sciences; Daniel Giles, Shara Kai Ning Hew and Yik Ka Chan, Yan So, and Maisie Soul: thank you for taking part in data collection and secondary analysis of work contained in this thesis.

I would like to thank all participants in the study for making this research possible and I hope they get utmost benefits from their participation in the study.

I am grateful to Jazan University in Saudi Arabia for funding my PhD scholarship.

To my parents, sisters, relatives and friends: thank you for your support, encouragement, prayers throughout my life journey.

Finally, my deepest thanks must go to my wife and children who have been supporting me with love, patience and positive encouragement during this intense time.

Thesis format

This thesis has been written using the alternative format for thesis presentation guidance provided by the university of Birmingham. The alternative format thesis style allows the researcher to incorporate some of the published work (or suitable for submission for publication) in peer reviewed journals as a part of the thesis chapters. This format is a combination of the traditional thesis format and the thesis by publication format in which the chapters are a series of published papers relevant to the thesis topic (appendix 1).

List of Papers and Conference Abstracts

During the course of my PhD, I have published and presented a substantial part of my research work that is related directly to this thesis in multiple conferences. Details on the use of published work within this thesis will be provided at the beginning of each chapter where applicable. As a notice, some chapters of this thesis are written verbatim from the published work and their structure and content have been replicated with addition of some changes to build the comprehensive body of the thesis manuscript. This is in accordance with the guidance for submitting an alternate thesis format presented by the University of Birmingham (Presenting your thesis (birmingham.ac.uk)).

Published Articles

1. Sahely, A., Giles, D., Sintler, C., Soundy, A., & Rosewilliam, S. (2022). Self-management interventions to improve mobility after stroke: an integrative review. Disability and rehabilitation, 1-18. **(appendix 2)**
2. Sahely, A., Kai Ning Hew, S., Ka Chan, Y., Soundy, A., & Rosewilliam, S. (2023). Exploring the experiences of people who had a stroke and therapists who managed people with stroke during the COVID-19 pandemic: An exploratory qualitative study. Plos one, 18(2), e0282325. **(appendix 3)**

Article Under Review

1. Sahely, A., Soundy, A., & Rosewilliam, S. (2023). Feasibility of a Self-Management Intervention to Improve Mobility in the Community after Stroke: A Mixed-Methods Pilot Study. **(Under Review)**

Conference Presentations

Poster presentations

1. Sahely, A., Giles, D., Sintler, C., Soundy, A., & Rosewilliam, S. (2022). Self-management interventions to improve mobility after stroke: an integrative review. European Stroke Organisation Conference 2021, Virtual.
2. Sahely, A., Giles, D., Sintler, C., Soundy, A., & Rosewilliam, S. (2022). Self-management interventions to improve mobility after stroke: an integrative review. World Stroke Congress 2021, Virtual.
3. Sahely, A., Giles, D., Sintler, C., Soundy, A., & Rosewilliam, S. (2022). Self-management interventions to improve mobility after stroke: an integrative review. The annual ESRC Midlands Graduate School Conference 2021, Virtual.
4. Sahely, A., Kai Ning Hew, S., Ka Chan, Y., Soundy, A., & Rosewilliam, S. (2023). Exploring the experiences of people who had a stroke and therapists who managed people with stroke during the COVID-19 pandemic: An exploratory qualitative study. World Stroke Congress 2022, Singapore (oral presentation).
5. Sahely, A., Kai Ning Hew, S., Ka Chan, Y., Soundy, A., & Rosewilliam, S. (2023). Exploring the experiences of people who had a stroke and therapists who managed people with stroke during the COVID-19 pandemic: An exploratory qualitative study. UK Stroke Forum 2022, Liverpool, UK (poster).
6. Sahely, A., Soundy, A., & Rosewilliam, S. (2023). Feasibility of a Self-Management Intervention to Improve Mobility in the Community after Stroke: A Mixed-Methods Pilot Study. European Stroke Organisation Conference 2023, Munich, Germany (poster).

TABLE OF CONTENTS

Contents

TABLE OF CONTENTS ..... ***viii***

LIST OF FIGURES ..... ***xii***

LIST OF TABLES ..... ***xiii***

ABBREVIATIONS ..... ***xiv***

CHAPTER 1 ..... ***15***

INTRODUCTION ***15***

1.0 Chapter overview **15**

1.1 Background **16**

1.2 Aetiology and risk factors **17**

1.3 Consequences of stroke **17**

1.4 Health care for people with stroke **20**

1.5 Gaps and challenges in services post discharge **23**

1.6 Stroke during COVID-19 pandemic **24**

1.7 Self-management and self-efficacy **26**

1.8 Role of self-management in stroke rehabilitation **29**

1.9 Overview of self-management strategies **31**

1.10 Self-management interventions for mobility following stroke **32**

1.11 The need for this thesis **33**

1.12 Research question **34**

1.13 Aim and objectives **34**

1.14 Summary of Chapter **35**

CHAPTER 2 ..... ***36***

Methodology ***36***

2.0 Overview of the chapter **36**

2.1 Outline of the stages of the study **37**

2.2 Philosophical stance and research orientation **41**

2.3 Research approaches **43**

2.4 Methodological considerations for using mixed methods **46**

2.4.1 Sampling 47

2.4.2 Data integration 48

2.5 Selection of research design and methods **49**

2.5.1 Scoping and systematic review for study 1 50

2.5.2 Individual interviews and Focus groups 53
2.5.3 Content and thematic analysis 57
2.5.4 Decision on the feasibility RCT method (study 3) 59
2.6 Reflexivity and rigour **60**
2.7 Patient and Public Involvement (PPI) throughout the research process **62**
2.8 Ethics approvals **65**
2.9 Data management **66**
2.10 Presentation of findings **66**
2.11 Chapter summary **67**
CHAPTER 3 ..... ***68***
Self-management interventions to improve mobility after stroke: an integrative review ***68***
3.1 Abstract **69**
3.2 Introduction **71**
3.2.1 Objectives 72
3.2.2 Review question 72
3.3 Methods **72**
3.3.1 Search strategy 72
3.3.2 Eligibility criteria 73
3.3.3 Study selection 74
3.3.4 Quality appraisal 75
3.3.5 Data extraction 75
3.3.6 Data synthesis 76
3.4 Results **76**
3.4.1 Study characteristics 76
3.4.2 Description of participants 78
3.4.3 Quality of evidence 79
3.4.4 Themes 96
3.5 Discussion **106**
3.6 Implications for rehabilitation **110**
3.7 Conclusion **111**
CHAPTER 4 ..... ***112***
EXPLORING THE EXPERIENCES OF PEOPLE WHO HAD A STROKE AND THERAPISTS WHO MANAGED PEOPLE WITH STROKE DURING THE COVID-19 PANDEMIC: AN EXPLORATORY QUALITATIVE STUDY ***112***
4.1 Abstract **113**
4.2 Introduction **115**
4.3 Methods **117**
4.3.1 Design 117
4.3.2 Participants 117
4.3.3 Data collection 118
4.3.4 Data analysis 119
4.4 Results **120**
4.4.1 Description of participants 120
4.4.2 Themes 121

4.5 Discussion **135**

4.6 Clinical messages **139**

4.7 Conclusion **140**

CHAPTER 5 ..... ***142***

FEASIBILITY OF A SELF-MANAGEMENT INTERVENTION TO IMPROVE MOBILITY IN THE COMMUNITY AFTER STROKE (SIMS): A MIXED-METHODS PILOT STUDY ***142***

5.1 Abstract **143**

5.2 Introduction **144**

5.2.1 Aim and objectives 147

5.3 Methodology **147**

5.3.1 Design 147

5.3.2 Participants and sampling 148

5.3.3 Setting 148

5.3.4 Sample size 149

5.3.5 Randomisation, approach and consent procedure 149

5.3.6 Intervention 149

5.3.7 Control 151

5.3.8 Outcomes 151

5.3.9 Ethics and registration 153

5.3.10 Data analysis 154

5.4 Results **154**

5.4.1 Feasibility of recruitment and validity of eligibility criteria 157

5.4.2 Feasibility of randomisation and blinding 161

5.4.3 Retention 162

5.4.4 Fidelity and acceptability of the intervention 163

5.4.5 Participants' adherence to the intervention and follow up 175

5.4.6 Feasibility of collecting outcome measures 178

5.4.7 Suggestions for improvement 180

5.5 Discussion **181**

5.6 Strengths and limitations **187**

5.7 Implications for rehabilitation: **189**

5.8 Conclusion **189**

CHAPTER 6 ..... ***190***

DISCUSSION AND CONCLUSION ***190***

6.0 Chapter overview **190**

6.1 Summary of the main findings **191**

6.1.1 SM interventions for mobility training within stroke rehabilitation literature 191

6.1.2 Conceptualisation of SM 192

6.1.3 Need and use of Self-management during COVID-19 pandemic 192

6.1.4 Experience of SM in stroke rehabilitation during the pandemic 193

6.1.5 Feasibility of implementing SM intervention in local context 193

6.2 Contribution to the literature **194**

6.2.1 Optimal period for SM 195

6.2.2 SM recommendations for rehabilitation practice 196

6.3 Contribution to methodology and theory **199**

6.4 The quality of research in the thesis in drawing conclusions 201
6.5 Strengths of the study 202
6.6 Limitations of the study 204
6.7 Implications for rehabilitation 208
6.8 Direction for future research 210
6.9 Conclusion 213
List of References 214

LIST OF FIGURES

Figure 2.1 Flow diagram of the three studies demonstrating the link between them in relation the development of the SIMS intervention. 39

Figure 2.2 Gantt Chart of thesis work (methods and timeline)..... 40

Figure 3.1 PRISMA flow diagram of study selection (Moher *et al.*, 2009) 78

Figure 4.1 Themes and subthemes derived from study's data..... 122

Figure 5.1 Flow of participants in the study 159

Figure 5.2 GAS scores for both groups 1688

Figure 5.3 steps/day for intervention and control groups 171

Figure 5.4 Collection of outcome measures at baseline, 3 months and 6 months 1790

LIST OF TABLES

Table 2.1: A summary of the characteristics of the quantitative, qualitative, and mixed methods research paradigms (Lichtman, 2012; Creswell and Creswell, 2017).....45

Table 3.1 Summary table of the reviewed studies. 82

Table 4.1 Characteristics of the participating therapists. 121

Table 4.2 Characteristics of the participant stroke survivors. 121

Table 5.1 Integration of findings in relation to feasibilty outcomes. 155

Table 5.2 Participants' demographics and abseline data. 160

Table 5.3 Mean scores and standard deviations of functional outcome measures at baseline, 3 month and 6 months. 1687

ABBREVIATIONS

SM	Self-management
SIMS	Self-management Intervention for Mobility post-Stroke
ADL/ADLs	Activities in daily living/livings
ICF	International Classification of Functioning, Disability and Health
GAS	Goal Attainment Scale
FGA	Functional Gait Assessment
MoCA	Montreal Cognitive Assessment
MMSE	The Mini–Mental State Examination
GHQ	General Health Questionnaire
SE	Self-Efficacy
BCTs	Behaviour Change Techniques
GDS	Geriatric Depression Scale
PT	Physiotherapist
OT	Occupational Therapist
MLT	Motor Learning Theory
GRADE	Grading of Recommendations, Assessment, Development and Evaluations
RMI	Rivermead Mobility Index
SCT	Social Cognitive Theory
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
PROSPERO	International Prospective Register of Systematic Reviews
QoL	Quality of Life
HRA	Health Research Authority
UK	United Kingdom
NHS	National Health Services
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

1.0 Chapter overview

Individuals' lives after stroke can be affected by multiple levels of disability. Appropriate rehabilitation can help them to regain function and improve their quality of life. Rehabilitation research has been increasingly examining the most effective interventions for rehabilitation post-stroke. However, the needs of stroke survivors at the time of transfer from hospital to living at home or in the community are still not fully addressed within the current practice in the UK. Moreover, the impact of COVID-19 pandemic on health care system has limited the capacity of health care services for delivering appropriate care plans for stroke survivors. There is consistent evidence to identify the value of SM programmes to help stroke survivors take an active role in their rehabilitation process and lead to optimal outcomes of functional recovery and life adjustment. The efficacy and appropriateness of self-management strategies as an additional component to the current practice have been confirmed in several contexts, but there has been limited research around self-management strategies to improve mobility after stroke. This chapter describes stroke as a health condition, the impact of stroke on peoples' lives, the role of rehabilitation post-stroke to improve mobility in the community, the impact of COVID-19 pandemic on people with stroke focussing on rehabilitation, the current gaps in literature and practice around use of self-management strategies to improve mobility outcomes, need for the current research and research aims.

1.1 Background

Annually, stroke causes death or disability of about 14 million people and is reported as the second leading cause of death globally (WHO, 2017; Feigin *et al.*, 2022). In the UK, it is estimated that every 5 minutes a new person is affected by stroke, which leads to more than 100,000 new strokes every year (Stroke Association, 2018). The current incidence of stroke in the UK is anticipated to increase by 59% and the prevalence by 123 % by 2035 (Patel *et al.*, 2017). Moreover, studies show that around a quarter of stroke survivors will experience another stroke within five years and their chance of having a recurrent stroke is six times greater than first-ever stroke (Couillard, Poppe and Coutts, 2009; Stroke Association, 2018). Currently, there are over 1.2 million stroke survivors in the UK (Stroke Association, 2018). The increase in the incidence and prevalence of stroke is attributed to the increase in the elderly population as the age is the most important risk factor for stroke and recurrent stroke (Stroke Association, 2016b). Furthermore, the global effort to increase awareness about the early symptoms of stroke and Transient Ischemic Attack (TIA), the advancement technology for diagnosis and medical interventions that help save patients' lives at stroke onset have also contributed to increased survival rate post-stroke (Balami, Chen and Buchan, 2013; Bray *et al.*, 2013; Heart and Stroke Foundation, 2017). Recent estimates of stroke care annually in the UK is about £26 billion, which includes health care services and the reduction in economic productivity (Patel *et al.*, 2017). With the increased incidence and prevalence of stroke, these costs are bound to rise proportionately.

Stroke is defined by the World Health Organization (WHO) as "*rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin*" (WHO, 1988, p.108). This definition distinguishes stroke from the TIA which is known as a mini-stroke and in which similar symptoms of a full stroke last for less than 24 hours

(Chandratheva *et al.*, 2009). A stroke might be ischemic (85% of all strokes) when a blood vessel is blocked by a clot, or haemorrhagic, caused by a bleed in the brain (NICE, 2012).

1.2 Aetiology and risk factors

The aetiology of Stroke is associated with multiple modifiable and non-modifiable factors (O'Donnell *et al.*, 2010). The modifiable risk factors are related to people's lifestyle and can be managed or controlled by medical or behavioural change interventions. Examples of the modifiable factors are; hypertension, type 2 diabetes, hypercholesterolemia, sedentary behaviour (inactivity), smoking, drugs and excessive alcohol (O'Donnell *et al.*, 2010). Other factors such as age, gender, type 1 diabetes, and some heart diseases cannot be modifiable. Men have been found to have a higher risk of having a stroke than women at a younger age (Stroke Association, 2018; SSNAP, 2017). Reasons for the gender difference have been associated with a higher risk of diabetes or heart disease and their tendency to smoke or drink alcohol (Andersen, Andersen and Olsen, 2010; Stroke Association, 2018). However, as the women tend to live longer than men on an average scale, their risk factors for experiencing a stroke increase with age. The expected increase in risk for women is due to hormonal changes that happens later in their age, contraception, pregnancy and childbirth (Heart Health, 2014). People who live in more deprived communities are more likely to have and to experience more severe strokes (Marshall *et al.*, 2015) due to social, economic and lifestyle factors.

1.3 Consequences of stroke

Stroke has a high mortality rate; one in eight people die within a month following stroke (Bray *et al.*, 2016). In 2016, almost 38,000 people died because of stroke in the UK; two thirds of the population who are affected by stroke tend to survive with varying levels of disability (Stroke Association, 2018). People who survive a stroke will live with various levels of functional, cognitive, emotional, and psychosocial consequences and will need support to cope with the new life after stroke (Feigin *et al.*, 2008; Heart and Stroke Foundation, 2017). This increasing

rate of people surviving stroke with residual impairments will increase the demand on the National Health Services, which is deemed to already be under pressure to cover the high public demands on health services (SSNAP, 2017). Stroke not only affects people who had the stroke, but also affects their spouses and family members who might need to help them to various extents to manage life after stroke (Satink *et al.*, 2018). Thus, stroke is one of the most complex health issues in the developed countries as survivors might experience different level of disabilities based on their age, gender and previous life context (Rothwell *et al.*, 2004; Chandratheva *et al.*, 2009).

The impact of a stroke on the person depends on the type, size, number of strokes and location of the affected area in the brain and the extent of subsequent recovery (Lawrence *et al.*, 2001; Balami, Chen and Buchan, 2013). The key impact results from impairments post-stroke which might include some or all of the following (Feigin *et al.*, 2008; Wallace, Ramos and Rundek, 2012; Sun, Tan and Yu, 2014; Hatem *et al.*, 2016; Heart and Stroke Foundation, 2017; Hinkle *et al.*, 2017; Towfighi *et al.*, 2017; Chun *et al.*, 2018):

- Muscles weakness because of the (reduced power and abnormal tone) especially in the arms and legs. Weakness occurs in about 80% of cases post-stroke in forms of hemiparesis.
- Reduced joint stability.
- Reduced balance and coordination.
- Altered gait pattern and difficulty of mobility.
- Problems of sensation and proprioception.
- Fatigue (reduced energy and motivation).
- Pain and headaches.
- Aphasia, dysphagia, dysphonia and dysarthria.
- Loss of visual acuity/field deficit.

- Sleep disorders.
- Problems with consciousness, attention, or alertness.
- Bowel and bladder dysfunction.
- Sexual dysfunction.
- Change in temperament and personality.
- Executive dysfunction and cognitive decline (due to problems of memory and thinking).
- Perceptual change.

The above impairments result in the reduced physical activity associated with reduced mobility, walking ability, aerobic fitness, and reduced balance as shown in a meta-analysis of physical activity post-stroke (Field *et al.*, 2013). The reduced physical activity level was also highly associated with low mood of participants across different studies that were included in this meta-analysis. Loss of mobility and the resulting state of physical deconditioning after stroke could increase the risk of cardiovascular diseases leading to a higher mortality and morbidity rates (Ivey *et al.*, 2005). For example; coronary artery disease, which reduces the cardiovascular fitness needed for normal daily activities, is commonly reported in about two-thirds of stroke survivors (Bruce, Kusumi and Hosmer, 1973; Roth, 1993). Stroke survivors are also considered at high risk of fall at all stages post-stroke (Verheyden *et al.*, 2013). The risk of having a fall was found to be associated with the motor weakness, balance, sensory, cognitive and executive dysfunctions in addition to other fall risk factors unrelated to stroke (Baetens *et al.*, 2013). Despite multiple complex consequences following a stroke, many stroke survivors consider the physical impairment as the hardest problem to deal with as it largely affects their functions such as Activities of Daily Livings (ADLs) of walking, eating, washing, and dressing as a result of their body weakness (Lawrence *et al.*, 2001; Stroke Association, 2016b).

In a systematic review of qualitative studies that discussed stroke survivors' lived experience with physical rehabilitation, many participants considered improving mobility as the most important goal for their rehabilitation (Luker *et al.*, 2015). This perhaps reflects the importance of being mobile for people with stroke and how it affects their independence after discharge. Yet, stroke survivors living in the community walk only about 70–5800 steps/day, which is less than the recommended average (6000 steps/day) for people with physical disabilities (Michael, Allen and Macko, 2005; Tudor-Locke *et al.*, 2011).

Reduced mobility is prevalent in two-thirds of people after stroke and can lead to depression and isolation (Lawrence *et al.*, 2001; Pinter and Brainin, 2012; DePaul, Moreland and Dehueck, 2013). Consequently, depression can act as a barrier for the uptake and maintenance of physical activity after stroke as it negatively affects individual's self-efficacy, motivation, and self-determination to be physically active (Damush *et al.*, 2007; Morris *et al.*, 2012). Thus, low physical activity and reduced mobility can be both cause and consequence of weakness, fatigue, psychosocial problems, or sleep disturbance (Duncan *et al.*, 2012; Morris *et al.*, 2012; Fleming *et al.*, 2020; Fulk, Duncan and Klingman, 2020).

1.4 Health care for people with stroke

Stroke care starts when a patient is admitted to the hospital in the hyper-acute stage. Currently, stroke units are seen to be the most effective especially if they are equipped as hyper-acute stroke units (SSNAP, 2017) wherein the main goal for care is to get patients medically stable and to transfer them to post-acute settings where they can start their rehabilitation process. Rehabilitation following a stroke can help reduce the impact of impairments and promote functional recovery for most survivors (Langhorne, Coupar and Pollock, 2009; Veerbeek *et al.*, 2014). The journey of recovery might take months or years for some survivors and rehabilitation should start as early as possible to obtain optimal outcomes (Nijland *et al.*, 2010).

Rehabilitation is defined as a *"progressive, dynamic, goal-oriented process aimed at enabling a person with impairment to reach their optimal physical, cognitive, emotional, communicative and social functional level"* (Hebert *et al.*, 2016, p. 460). Post-stroke rehabilitation has shown a positive effect on functional recovery, psychological wellbeing, individual's adjustment and coping with the new role of life and reduce the risk of recurrence (Hankey *et al.*, 2002; Mehta *et al.*, 2012; Teasell *et al.*, 2012). However, the level of functional recovery during rehabilitation post-stroke is variable for individuals and is dependent on the individual's capacity (physiological and psychological) for recovery as well as the level of care (quantity and quality) a survivor might receive (Livingston-Thomas *et al.*, 2016). Further it is suggested that functional recovery reaches the peak at six months and might decline after a year following stroke (Dhamoon *et al.*, 2009). Hence to optimise recovery prospects, intensive rehabilitation must be carried out in the first six months following a stroke, because of the potential for structural and functional adaptations (neuroplasticity) in the brain (Dimyan and Cohen, 2011; Veerbeek *et al.*, 2014). Therefore, it is obvious that lack of therapy in patients post-discharge will reduce patients' chances of optimal recovery.

In the UK and other developed countries such as the USA, Canada, and Australia, the healthcare services have been underpinned by the neoliberal philosophy, which encourages the concept of individualisation of patients care (Galvin, 2002). This has been embedded in the health care systems by supporting person-centred care and self-management interventions which emphasise the role of the patient as a client instead of a passive recipient of care (NHS England, 2014; Health Foundation, 2016). Nevertheless, the health care plans in the acute care units are mainly driven by a biomedical perspective which might be gradually expanded to capture the psycho-social needs and individual preferences in the long-term care (Sadler *et al.*, 2017). Stroke survivors with mild to moderate impairments are encouraged to be discharged from hospital to an Early Supported Discharge (ESD) or community rehabilitation services

(Fearon, Langhorne and Trialists, 2012). Generally, community rehabilitation services provide rehabilitation care for stroke survivors in the community after they leave the hospital (where no Early Supported Discharge exists) (NHS West Midlands, 2019).

The ESD aims at discharging stroke survivors faster than usual from inpatient facilities and to continue their rehabilitation at home with the supervision of a multidisciplinary team (NHS West Midlands, 2019). ESD is defined as *"an intervention for adults after a stroke that allows their care to be transferred from an inpatient environment to a community setting. It enables people to continue their rehabilitation therapy at home, with the same intensity and expertise that they would receive in hospital"* (NICE, 2010, p. 25). This model of rehabilitation facilitates survivors' reintegration in their own home environment, is cost-effective, and has been promoted by policymakers and health organizations (SSNAP, 2017). Studies that evaluated the ESD's impact on patients have reported positive outcomes of increasing their self-autonomy, meeting their individual needs, and feeling more in control to carry out their own routines at home instead of being inpatients and having a passive role within healthcare (Fearon, Langhorne and Trialists, 2012). However, it is still evident that ESD is not provided to everyone across the UK (SSNAP, 2017). For example, in West Midlands (where our study is based) only 38% of stroke survivors are discharged to a specialised ESD services (NHS West Midlands, 2019). This reflects the previously reported concern of about 45% of stroke survivors who felt abandoned and unsupported after they leave the hospital (Stroke Association, 2016). Additionally, the national guideline for stroke care has also reported insufficient community stroke specialist services to support survivors with their transfer from hospital to home (Rudd *et al.*, 2016). As a result, stroke survivors' level of physical activity may stagnate or decline after they get discharged from hospitals to live at home or in the community (Michael, Allen and Macko, 2005).

1.5 Gaps and challenges in services post discharge

While two-thirds of stroke survivors in the UK are expected to discharge from hospital with a disability that requires help with their ADLs, lack of appropriate rehabilitation plans could reduce their chance for optimal recovery and increase the tendency for a sedentary behaviour (Adamson, Beswick and Ebrahim, 2004; Rimmer, Wang and Smith, 2008). Research findings, in several contexts, reported that stroke survivors might spend 75% of their daily routine alone and inactive and are considered to have the lowest level of physical activity compared to about 55% in the general population of older adults with chronic conditions (Matthews *et al.*, 2008; Rand *et al.*, 2009; Tudor-Locke, Washington and Hart, 2009; Alzahrani, Dean and Ada, 2011; Tieges *et al.*, 2015; English *et al.*, 2016).

Stroke survivors do not seem to meet the level of physical exercise recommended by the national guidelines for stroke care which recommends that more exercise can promote optimal outcomes of recovery post-stroke (Hankey *et al.*, 2002; Rand *et al.*, 2009; Mehta *et al.*, 2012; NICE, 2012; Teasell, 2012). In addition to the previous issue of lack of support after discharge from hospital, studies that discussed survivors' participation in physical rehabilitation programmes have highlighted other barriers for increasing physical activity after stroke (Rimmer, Wang and Smith, 2008; Stroke Association, 2016a). Some of these barriers are related to the lack of adequate resources such as cost, transport, poor access to or knowledge of services. Stroke sequelae (effect of stroke-related impairments) and other co-morbidities can restrain physical capability and reduce survivor's uptake and adherence to rehabilitation programmes. Other barriers could be related to the emotional and psychological status of a survivor such as depression, feeling of left out, being confused, and the fear of recurrent stroke. Sometimes, lack of survivor's confidence or knowledge regarding physical exercises and their benefits can be a barrier even if the resources are provided (Harrington *et al.*, 2010; Best *et al.*, 2012).

To address the gap in the current practice, community-based programmes have been promoted and supported by health care policymakers (Harrington *et al.*, 2010; Best *et al.*, 2012). However, many of these programmes have been criticised for their focus on physical training and giving little attention to self-management or to sustaining survivors' behaviour (Dean *et al.*, 2016). The most successful programmes for rehabilitation in the community are the ones that target the improvement of functional ability as well as self-management role of a survivor. Therefore, the national stroke guideline has recommended the addition of self-management interventions to stroke rehabilitation plans (NICE, 2012). However, the implementation of those recommendations might be challenged with some contextual barriers (Rimmer, Wang and Smith, 2008; Bayley *et al.*, 2012; Munce *et al.*, 2017; Sadler *et al.*, 2017). For instance, current clinical guidelines for stroke care are still uncertain about the description of the most effective self-management interventions (NICE, 2012; SIGN, 2023). Therefore, only half of the stroke survivors in the UK found to be assessed for most appropriate therapy options and with agreed goals for their rehabilitation at the time of discharge from hospital (Stroke Association, 2018).

1.6 Stroke during COVID-19 pandemic

The coronavirus disease 2019 (COVID-19) outbreak started in December 2019 in Wuhan, China (World Health Organization., 2020). COVID-19 is identified as an asymptomatic disease or present with clinical symptoms that range from mild (cold/flu symptoms such as fever, dry cough, dyspnea) to a life-threatening acute respiratory distress syndrome, severe pneumonia, acute kidney injury, myocarditis, eventual multi-organ failure, and death (Huang *et al.*, 2020; Inciardi *et al.*, 2020). Epidemiological studies of COVID-19 have shown a correlation between having a cerebrovascular disease (CVD) and increased severity and mortality of COVID-19 (Aggarwal, Lippi and Michael Henry, 2020; Pranata *et al.*, 2020). A systematic review of studies that discussed the association between COVID-19 and stroke indicated that COVID-19

patients who experienced concomitant stroke were older, had pre-existing CVD, had severe infection and had their strokes occurring a few days after admission to COVID-19 unit (Nannoni *et al.*, 2020). Stroke patients with COVID-19 were younger, had severe stroke, and their stroke had been caused mainly by large artery occlusions; comparing to stroke patients without COVID-19 (Nannoni *et al.*, 2020).

It has also been suggested that COVID patients are at high risk of thromboembolic complications (1.4% of COVID patients experience CVD) although the pathophysiology of cerebrovascular accidents is still unclear (Gunasekaran *et al.*, 2020; Nannoni *et al.*, 2020).

Since onset, the infection had rapidly spread globally causing a disruption in the health care services worldwide (Ferguson *et al.*, 2020; Stoecklin *et al.*, 2020). National and international health authorities had implemented social distancing measures and lockdowns to mitigate the spread of COVID-19 (Ferguson *et al.*, 2020; Sun *et al.*, 2020). In the UK, the COVID management plan in the National health system (NHS) focused on infection control and increasing capacity of care for COVID-19 patients (D'Anna *et al.*, 2021). Implemented strategies included resource allocation, workforce mobilisation, suspension of the non-urgent and outpatient services, and early discharge of inpatients from acute care (Bersano *et al.*, 2020). These measures have negatively affected the treatment and long-term care of chronic illness such as a stroke (Bersano and Pantoni, 2020; Meza *et al.*, 2020; Zhao *et al.*, 2020). An observational study showed a major reduction in the admission rate for stroke cases (about 1/3) in the UK with a significant reduction in the rate of hospitalisation for TIA and rates of thrombolysis at the beginning of the pandemic (D'Anna *et al.*, 2021). There was also a significant increase in the clinical symptoms at the time of admission of patients who experienced stroke during lockdown. A combination of factors including fear of COVID-19 infections, delayed hospitalisation, lockdown measures, advice from doctors and media to stay away from other people, reallocation of hospital staff and resources to managing people with

Covid could have resulted in the situation described above (Aguiar de Sousa, Sandset and Elkind, 2020).

Furthermore, stroke survivors' condition would have clearly worsened during the extended period of service suspension; limb pain, loss of strength, and decline in mobility were commonly observed in the survivors (Bersano and Pantoni, 2020; Meza *et al.*, 2020; Zhao *et al.*, 2020). Recent studies have called for further investigation into the long-term impact of the pandemic on the stroke care. A recent study undertaken to evaluate the quality of acute stroke care in the UK from the Sentinel Stroke National Audit Programme (SSNAP) data found that the modifications in services related to COVID-19 such as reduced staffing were still in place in 90% of stroke facilities as of October 2021 (Holloway *et al.*, 2022). As there is still no evidence to explain the potential impact of the service disruption on stroke survivor's long-term rehabilitation, this key consideration of the influence of covid pandemic on the rehabilitation of a person with stroke has been raised as a part of this thesis work.

1.7 Self-management and self-efficacy

Self-Management (SM) programmes provide stroke survivors with practical strategies, decisions and activities that can help them to manage their long-term conditions. There have been several definitions that used to describe SM most of which explain the role of an individual in the management of their chronic conditions (Corbin and Strauss, 1988; Wilkinson and Whitehead, 2009; Hinder and Greenhalgh, 2012; Parke *et al.*, 2015; Sadler *et al.*, 2017).

Based on the Expanded Chronic Care Model, SM has been defined as *"the degree to which an individual with a chronic condition is able to, and wants to, control his own daily life, by coping effectively with symptoms, treatments and lifestyle adjustments"* (Lenzen *et al.*, 2017, p. 2). This definition describes an individual's perceived and actual capability in managing daily life following the impact of their stroke on multiple levels. It does not specify aspects relevant to dealing with functional, emotional, or psychological issues; moreover, the

language of the definition seems to focus more on the medical management of chronic conditions. SM is also defined as *''the care taken by individuals towards their own health and well-being: it includes the actions people take for themselves ... to care for their long-term conditions''* (Health, 2005, p. 1). This definition is more suitable for policymakers as it seems to reflect the neoliberal philosophy which encourages individuals' role of taking care of their personal responsibilities including self-management of their own health conditions.

Encompassing more of social and environmental aspects, SM is defined as an *"individual's ability, in conjunction with family, community, and the appropriate healthcare professionals to manage the symptoms, treatment, physical, psychosocial, cultural, and spiritual consequences and inherent lifestyle changes required for living with a chronic disease"* (Wilkinson and Whitehead, 2009, p. 1145). This definition includes more of a holistic view that considers the role of family, community, and health care professional in addition to the management of various elements such as psychological, cultural, and spiritual consequences. Implementation of such a definition needs a collaboration of several stakeholders and should consider individual contexts of stroke survivors. In rehabilitation research, we can choose the definition used by the National Clinical Guideline for Stroke in the UK as the *"actions and confidence of individuals to manage the medical and emotional aspects of their condition in order to maintain or create new life roles"* (NICE, 2016, p. 28). This definition adopts a pragmatic stance focusing on the aspects that should be targeted by rehabilitation plans for stroke survivors.

There might be various conceptualisations of the SM among different stakeholders, but it is important to have a common understanding that describes the components of any definition amongst stakeholders. Having this common understanding will help effective delivery of services and choice of outcomes to be measured (Ellis *et al.*, 2017). It might be helpful to use the International Classification of Functioning, Disability and Health (ICF) model to better

understand and explain self-management within the context of post-stroke rehabilitation. The ICF classification system provides codes and measures for different personal and environmental parameters that might affect the level of function, activity, and participation of individuals with disability (Üstün *et al.*, 2003).

SM concept has been rooted in the Expanded Chronic Care Model (ECCM), which addresses the limitation of the Chronic Care Model by adding space for population health promotion (Barr *et al.*, 2003). The ECCM facilitates the efforts for prevention, recognition of the social determinants of health, and enhanced community participation to be a part of care plans for people living with chronic conditions such as stroke. Accordingly, the main principle of SM is to empower stroke survivors' autonomy by activating their role of management for their recovery. To activate engagement in SM for individuals, there is a need for increasing their knowledge, skills, and personal attitudes towards taking up SM (Warner *et al.*, 2015). Evidence shows that people who have a more active role in managing their health have better outcomes (Coulter and Ellins, 2006).

The competence of an individual for SM can be mediated by his/her level of self-efficacy, a construct of the well-established social cognitive theory (Bandura, 1989). Self-Efficacy (SE) is defined as a person's level of confidence in their capabilities toward a particular behaviour (Zimmerman, Bandura and Martinez-Pons, 1992). Self-efficacy represents four elements that can shape an individual's capability to perform a particular behaviour (Bandura, 1994). The strongest element is 'mastery experience' through successful performance of a behaviour or task. The second element is 'vicarious experience' in which the individual observes other individuals while performing that behaviour (modelling). The third reflects the influence of verbal (social) persuasion or encouragement by professionals or family, and the fourth reflects the role of the emotional and physiological status of an individual in developing and maintaining of self-efficacy (Bandura, 1994).

A systematic review of the influence of SE on the recovery of patients with stroke found that SE can improve mobility, activities of daily living, and quality of life of stroke survivors and reduce disability and depression after stroke (Korpershoek, van der Bijl and Hafsteinsdóttir, 2011). SE was significantly associated with functional mobility parameters such as balance, walking-capacity, stair climbing and chair rising in several studies (LeBrasseur *et al.*, 2006; Korpershoek, van der Bijl and Hafsteinsdóttir, 2011). SE seems to have a bidirectional relationship with SM as they both have shown a positive impact on each other (Sadler *et al*., 2017). The utility of the SE as a mediator to promote SM and improve independence after stroke has been increasingly emerging in the rehabilitation literature and recommended by the national guideline for stroke care (NICE, 2016).

1.8 Role of self-management in stroke rehabilitation

SM has shown the potential to improve the quality of life for people with chronic conditions like stroke and considered to work in parallel with the ESD programmes (Pearce *et al.*, 2015). SM has also been shown to play a role in reducing the length of stay in hospitals and other poor outcomes such as death and patient dependence (Lorig *et al.*, 1999; Parke *et al.*, 2015). The efficacy of SM interventions for rehabilitation post-stroke has been confirmed by several systematic reviews (Lennon, McKenna and Jones, 2013; Parke *et al.*, 2015; Warner *et al.*, 2015; Sahely *et al.*, 2022). For example, a systematic review of the studies that examined the effectiveness of SM programmes for stroke rehabilitation has confirmed the positive role of SM in improving function and participation outcomes in several contexts (Warner *et al.*, 2015. A review by Parke *et al.* (2015) found high-quality evidence that supports the effectiveness of SM programmes to improve basic and extended activities of daily living in several contexts where the programmes were delivered earlier post-stroke. Also, this review provided some evidence for the rehabilitation and problem-solving interventions in the facilitation of survivors' reintegration into their communities. Likewise, the findings of Lennon *et al.* review

(2013) confirmed the positive outcomes of SM programmes on measures of disability, confidence in recovery, the stroke-specific quality of life, and the physical component scale of the short form (SF-36) score. Although providing a meta-analysis was not possible in some of these reviews, it might not be a severe limitation considering the nature of stroke such as clinical manifestations, stages of recovery, and the capacity of SM programmes for individualisation of care.

In a qualitative study that explored the perspectives of stroke survivors regarding their experience with SM programmes, they alluded that SM is a useful mean for life transition after stroke (Boger, Demain and Latter, 2015). They identified some factors that can facilitate or hinder an individual's ability for SM such as an individual's capacity, support for SM, and SM environment. Individual's capacity in this context refers to an individual's ability and readiness to take the role of SM and is mainly shaped by an individual's self-efficacy. The second factor reflects the support for SM provided by health care professionals, carers, and the availability of resources. Lastly, participants suggested that individual capacity and the presence of support for SM could work more effectively in the environment that is prepared to be supportive for SM. This includes how stroke survivors can be treated by other people in their community, being recognised by policymakers, and the presence of peer support.

SM has been supported by policymakers as a response to the growing demands on healthcare services which has been increasing due to the number of people living longer with chronic conditions (Sprague, Shultz and Branen, 2006; Rudd *et al.*, 2016; Ellis *et al.*, 2017). SM support is defined as "*the support provided by healthcare professionals to enable patients to become good managers of their chronic conditions, tailored to their needs and capabilities*" (Lenzen *et al.*, 2017, p. 2).

There has been a range of SM supporting interventions that are used at multiple levels during rehabilitation post-stroke (de Silva, 2011). The identified strategies included promoting

healthy lifestyles and educating people about their conditions and how to self-manage and motivating people to self-manage by providing structured information and support. Other strategies focus on involving people in decision making and problem-solving when developing care plans with patients and health care professionals collaboratively, setting goals and following up on the extent to which the goals are achieved, encouraging people to monitor their symptoms and know when to take appropriate action. There were also some strategies for proactive follow up and providing opportunities to share and learn from other service users (de Silva, 2011).

1.9 Overview of self-management strategies

Lenzen *et al.* (2017) classified the SM strategies under five categories each of which is related to the process of goal setting and action planning. Before setting goals, patient education and reflection about their conditions might take place. Educating and increasing patients understanding of their conditions can improve their feelings of personal confidence and empowerment especially when provided with peer support (Roman, 2008). Goals for the patient's self-management can be set and actions can be planned collaboratively with their therapists based on what is important to the patient. In the process of goal setting and action planning, behaviour change theories provide useful theoretical frameworks to predict, examine, and change patient's behaviour and intention towards a certain goal or action (Lenzen *et al.,* 2017).

For successful formation of goals and action plans, it might be useful for therapists to start with an exploration of patients' beliefs and values so they can consider them in the process (Bodenheimer and Grumbach, 2007). Also, it is important to develop goals that are SMART (specific, measurable, achievable, realistic, and time-framed) as they can provide a powerful plan for rehabilitation post-stroke (Bovend'Eerdt, Botell and Wade, 2009; Rehman, Berry and Siddiqui, 2014). After the formulation of goals and action plans that will help to achieve their

goals, patients need to discuss coping strategies that can be used to overcome any potential barriers to their action plans. Lastly, patients need strategies for follow up. This might include self-monitoring, evaluation, and providing feedback on their plans (Lenzen *et al.,* 2017). Currently, there has been an enhancement in the use of technology for communication and follow up between patients and their therapists. Using apps, e-health, telerehabilitation and other online services can help to provide patients with useful information and connect them with their therapists remotely (Laver *et al.*, 2013; Simpson *et al.*, 2018).

Theoretically, combining more strategies in one intervention is seen to be more effective in improving recovery outcomes (Parke *et al.,* 2015). Moreover, it has been found that strategies that include behaviour change of a survivor are more effective than strategies for increasing a patient's knowledge or awareness (de Silva, 2011). Additionally, SM interventions delivered in groups in the community can be more effective in reducing the feeling of isolation felt by survivors and increasing of their self-efficacy as it allows them to share and exchange experiences and coping strategies with other stroke survivors (Pearce *et al.,* 2015). From another perspective, SM interventions can lead to better outcomes if carers are involved in the process to help stroke survivors in improving their SM skills (Kalra *et al.*, 2004). For a successful implementation of a self-management intervention, it should contain strategies that can be modifiable on the individual level based on the survivor's needs, level of recovery, self-efficacy, environment, and presence of external support (Boger, Demain and Latter, 2015). Development of comprehensive self-management programmes is a current need within stroke rehabilitation research and there is still a need for more robust interventions that target rehabilitation of specific aspects such as mobility in the community.

1.10 Self-management interventions for mobility following stroke

Although the National Stroke guidelines recommend that SM programmes should be offered to people with stroke in the community, currently, SM interventions for improving community

mobility are uncommon (Lennon, McKenna and Jones, 2013; Rudd *et al.*, 2016). It might be challenging for clinicians to implement stroke guidelines as there are still no specific SM protocols for improving mobility that has been recommended within these guidelines. A meta-review done by Parke *et al*. (2015) indicated that RCTs examining SM interventions for mobility were generally limited in stroke rehabilitation. Most of the interventions employed in these studies were criticised for their intensive resources and uncertainty about the theoretical background, as reasons that make them difficult to translate into the NHS system. For example, the BRIDGES programme, which was delivered for the patients in the community to increase their SM skills, had a limited number of participants (McKenna *et al.*, 2015). Feasibility for implementation in practice is limited due to the costs of training therapists and the programme lacked some of the self-efficacy principles such as peer-support and vicarious experiences. Another SM programme (Re-Train), focusing on mobility in the community following a stroke, was found to be feasible to integrate into community rehabilitation (Dean *et al.,* 2018). However, it was criticised for using a high number of supervised therapy sessions and lack of clarity about the theoretical construct that underpinned the SM intervention. There is a need for feasible and sustainable SM interventions that are developed to work within existing practices, be less resource-intensive, and can be adjusted for individual needs (NICE, 2016).

1.11 The need for this thesis

With the rising increase in the incidence of stroke among the elderly population in the UK, reducing the impact of post-stroke consequences and addressing patients' needs for coping with long term disability is a challenge. Stroke survivors feel neglected when they are discharged from the hospital to live in the community. There is a growing need for more effective rehabilitation services and consider the emotional and psychosocial needs of stroke survivors. Self-management interventions seem to have the potential to help in addressing this gap. Although recommended by NICE guidelines, self-management interventions that can

comprehensively address specific aspects of post-stroke rehabilitation such as mobility in the community are limited. The set of studies within this thesis try to address this gap in current practice by exploring the need for SM, identifying key components and developing a self-management intervention for mobility in the community and testing its feasibility in the local practice to improve stroke survivors' independence in their functional mobility. Functional mobility was considered as most important by many survivors for their reintegration in the community post-stroke.

1.12 Research question

The overarching research question this thesis is trying to answer was:

Is it feasible to develop and implement a self-management intervention to improve mobility in the community for stroke survivors?

1.13 Aim and objectives

The primary aim of this PhD is to develop, implement, and test feasibility of a self-management intervention to improve functional mobility for stroke survivors in the community. The specific objectives of this study are:

1) To explore current evidence around use of self-management interventions for the mobility of patients with stroke using a systematic review of the literature.

To explore clinical practice around need for self-management interventions within stroke rehabilitation.

2) To build a SM intervention based on the evidence and in collaboration with local clinicians and patient experts.

3) To implement the intervention in community stroke rehabilitation settings following which the feasibility of the new intervention will be evaluated using a mixed-methods study design. The specific feasibility objectives are to:

- explore participants' perspectives about the acceptability, practicality, and fidelity of the new intervention
- scope out methodological feasibility of a future randomised control trial

1.14 Summary of Chapter

This chapter has discussed the stroke as a complex health condition that can affect peoples' lives to various extents and the role of rehabilitation post-stroke to improve mobility in the community. It also highlighted the impact of COVID-19 pandemic on people with stroke focussing on rehabilitation, the current gaps in literature and practice around use of self-management strategies to improve mobility outcomes. The rationale for conducting this research and research aims and objectives were also explained in this chapter.

The next chapter will demonstrate the researcher's philosophical stance and methodological assumptions that can be used to address the objectives of this thesis work.

CHAPTER 2

METHODOLOGY

2.0 Overview of the chapter

This chapter outlines the three main stages of the study and the timeline for the various stages at the outset, to frame the context of the thesis work. This is then followed by a deeper discussion of the researcher's philosophical stance, research orientation, and approaches adopted to answer the research questions for this research work. The chapter provides a rationale for the use of the most appropriate methodological approaches for the set of studies included in the PhD thesis amongst other potential choices. This chapter will also demonstrate the rationale for selecting and applying specific research methods for each phase of this work in addition to describing the materials used.

2.1 Outline of the stages of the study

Overall, this study consisted of three main stages. Work carried out during stage 1 included a scoping literature review, well defined systematic review, developing the intervention, developing the protocol for the feasibility study, and applying for research passport and ethics. Stage 1 included a scoping review of literature exploring the use of self-management interventions to improve mobility for stroke survivors in the community to scope out potential for this work and guide the protocol for the main study. This scoping review for the thesis work started in February 2019 and completed in April 2019 based on which a research proposal was developed after identifying the gaps and needs that were to be targeted by this research. The research proposal included a protocol for: 1) a systematic review of evidence around the most appropriate self-management interventions to improve mobility post stroke (chapter 3) and 2) a protocol to examine the feasibility of applying these interventions in the local context. Following this a self-management intervention was then developed based on evidence from the systematic review and with the consultation of two senior stroke patients and therapists working with stroke patients in the NHS. Following the development of the self-management intervention and a proposal for testing its feasibility, an ethics application was made to the Health Research Authority (HRA) and the Research and Development (R&D) of the local NHS trust. A data management plan was also developed in this stage.

In Stage 2 from March 2020, during the COVID-19 pandemic, the experiences of people with stroke rehabilitation during the pandemic was explored using a qualitative study. Stroke care services were highly impacted and were altered because of the COVID-19 pandemic. The focus of the study evolved to understand the experiences of dealing with stroke during the pandemic period and the need for self-management in this challenging environment. Hence an objective was added to explore the experiences, needs, and challenges of stroke rehabilitation during the pandemic from patients and therapists' perspectives. Attention was

paid to the role of self-management strategies that were implemented to help patients manage their conditions during that time. Semi-structured individual interviews were conducted, and a reflexive thematic analysis approach was used to analyse data in this stage. The exploratory qualitative study in stage 2 reiterated the need for SM following stroke especially with the remote rehabilitation that had been suggested during the pandemic. Hence the previously developed SM interventions for mobility post-stroke was modified to include elements of telerehabilitation such as virtual meetings for assessment, goal setting, action planning, online group sessions and follow up. Figure 2.1 shows a flow diagram of the three studies demonstrating the link between them in relation the development of the SIMS intervention.

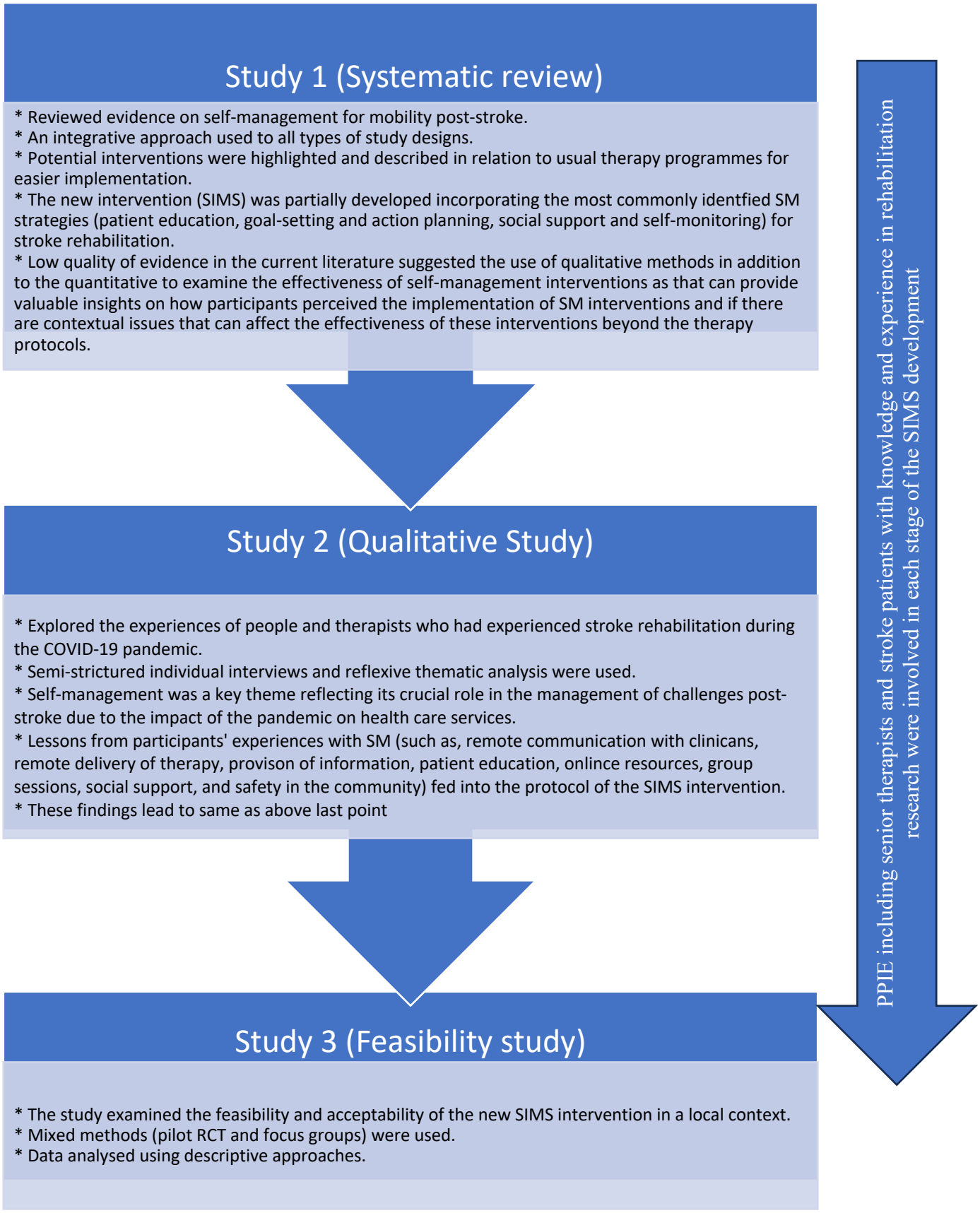


Figure 2.1 Flow diagram of the three studies demonstrating the link between them in relation the development of the SIMS intervention.

In stage 3 the feasibility and acceptability of the implementation of the new intervention was then examined in the local context of stroke rehabilitation in the West midlands in the UK (December 2021 to March 2023) using a mixed-methods approach and following the sequential explanatory design (Creswell and Creswell, 2017). The mixed methods in this study (chapter 5) included a prospective feasibility Randomized Controlled Trial (RCT) and focus groups after the delivery of the intervention. The feasibility RCT was single blinded (assessors blinded) and had two arms, one for the treatment group where the SIMS was applied and the other for the control group in which the participants had received the usual care from the NHS.

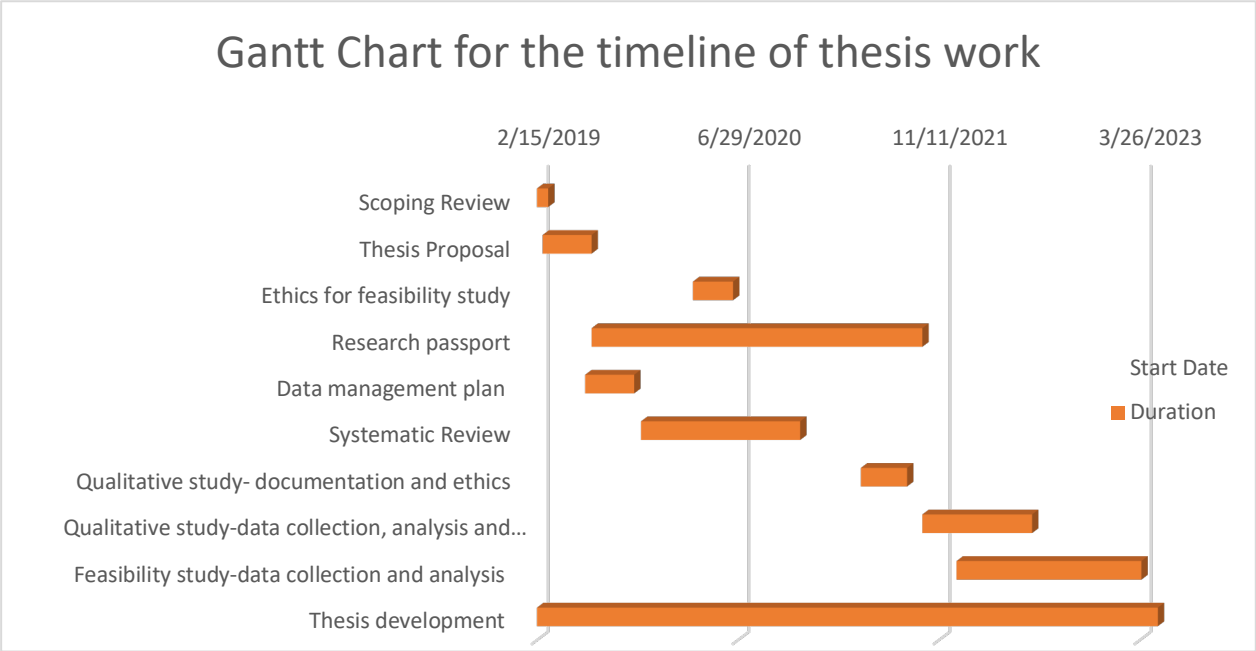


Figure 2.2 Gantt Chart of thesis work (methods and timeline)

The focus-groups (chapter 5) were undertaken to explore participants' perspectives on the effectiveness of the new intervention, their experiences and adherence to intervention protocol, identify factors affecting its feasibility and implementation for future large scale RCTs and to contribute to refinement of the intervention (Thabane *et al.*, 2010). A Gantt Chart in figure 2.2 shows the timeline of the work carried out over the period of the PhD study.

2.2 Philosophical stance and research orientation

Researchers' understanding of the truth and reality differs based on their research paradigm. Research paradigms consist of different sets of beliefs and practices that shape researchers' philosophical standpoint around the nature of knowledge and knowing (Morgan, 2007). The epistemological assumptions of each paradigm influence researchers' choice of research questions and methodologies. The area of research in this thesis explores a complex health issue (stroke) with multiple factors affecting the effectiveness/appropriateness of a complex intervention for stroke rehabilitation (Boger, Demain and Latter, 2015; Tabah *et al.*, 2020). Therefore, it was essential to apply multiple paradigmatic perspectives to answer the research question appropriately at different stages.

In stage 1, a Subtle Realist (SR) perspective was adopted while conducting an integrative review approach that allows for the combination of quantitative and qualitative data for the synthesis of evidence around self-management interventions for mobility after stroke. This SR perspective focuses on exploring the common reality experienced by different stroke survivors about self-management and assumes that we can only understand reality from our own point of view (Duncan and Nicol, 2004; Pope, Mays and Popay, 2007). In stage 2, a critical realist perspective was suitable for the qualitative study about patients and therapists' experiences with stroke rehabilitation during the COVID-19 pandemic. The premise of critical realists is that an external reality exists, and our knowledge of this reality is imperfect (much of reality happens without an awareness of it), and that to have the finest understanding of reality possible, perspectives about reality must be exposed to extensive critical examination (Archer, 2016). The aim of taking this perspective was to provide a deeper understanding through critical examination of the impact of the pandemic on individuals' experiences with stroke care, their lives and recovery.

Lastly, a pragmatic perspective was adopted for the use of mixed methods for the feasibility study of the new intervention in stage 3. Pragmatism is an evolving philosophy that support the use of Mixed-Methods Research (MMR) providing an epistemological justification for mixing approaches and methods and focusing on providing a useful knowledge about clinical interventions (Johnson, Onwuegbuzie and Turner, 2007; Morgan, 2007). The aim was to integrate data from the quantitative examination of the feasibility of intervention with qualitative data of participants' perspective on the acceptability and applicability of intervention.

The appropriateness of using quantitative versus qualitative research methodology in discovering the truth/reality has been an area of conflict between researchers from different research paradigms (Ercikan and Roth, 2006). Combining both approaches (quantitative and qualitative) in MMR entails greater methodological complexity than conducting a single method (Holloway and Galvin, 2016). Part of the complexity is related to the historical debate about the fact that quantitative and qualitative research came from different epistemological stances.

The epistemological stances of the different research approaches will be compared here to gain understanding of relevance of methods that were chosen to understand reality. Quantitative research is derived from a positivist point of view believing that the reality is objective and individuals have no impact on shaping and forming this reality. It is mainly concerned with using objective data to discover general laws between cause and effect with an emphasis on generalisability (Tariq and Woodman, 2013). Positivism reflects objectivists' belief that there is a single reality or truth which can be obtained by experimental research on objects who have no personal influence on the results. Objectivism advocates for the use of reliable and valid tools to measure the reality and contrasts with the individuals' beliefs, feelings, opinions, and assumptions driven by non-scientific approaches (Crotty, 1998).

Similarly, critical realism agrees with the existence of the objective reality as a branch of realism but assumes that knowledge is culturally, historically, and socially situated (Archer, 2016). Subtle realism is another philosophical branch of realism that believes in objective reality that is independent and argues that the knowledge of reality is shaped by researchers' cultural assumptions and use of different methods (Duncan and Nicol, 2004; Hammersley, 2018).

On the other hands, subjectivists believe that reality is what people perceive to be real and all the knowledge about reality can be obtained by exploring perspectives of different individuals (multiple reality) about it (Crotty, 1998). A constructionist perspective within this paradigm argues that the reality is shaped by the social interaction between individuals and their world in a particular social context. The constructionism is positioned between subjectivism and objectivism assuming that the humans and human world are interdependent in the construction of meanings (Crotty, 1998). According to this perspective, people from different cultures can have different interpretation for a same phenomenon (multiple interpretations) and therefore the whole reality can be socially constructed based on different interpretations of people for that reality. Qualitative elements of this research are based within this paradigm to recognise the influence of time, environment, relationships, and consciousness on human behaviour to interpretations of lived experiences (Nicholls, 2009).

2.3 Research approaches

The difference between the quantitative and qualitative approaches are not only in their ontological and epistemological assumptions. In quantitative research, the human behaviour is something that is regular and can be predictable while in qualitative research this is considered a personal, fluid, dynamic, situational, and social (Creswell and Clark, 2017; Creswell and Creswell, 2017). Moreover, the quantitative research uses very specific tools to test hypotheses or theoretical assumptions comparing to the qualitative research which uses a wider lens to

examine the breadth and depth of phenomena (Creswell and Creswell, 2017). Therefore, the results from quantitative research are proposed to be more generalisable and applicable to a wider population (Creswell and Clark, 2017; Creswell and Creswell, 2017). This diversity has led some researchers to argue that the quantitative and qualitative approaches are mutually exclusive and incompatible since they are related to different epistemological perspectives (Denzin and Lincoln, 2011). Some researchers who accepted Mixed Methods Research (MMR) for its appropriateness in certain research contexts, considered it as an independent approach and labelled it as a "third paradigm" (Johnson, Onwuegbuzie and Turner, 2007; Teddlie and Tashakkori, 2010). It has also been suggested that the two approaches are merely different and are used pragmatically based on the research question (Johnson, Onwuegbuzie and Turner, 2007; Bryman, 2015). MMR has been adopted for this thesis work as it assumes common sense, realism, and a pragmatic view of the world. This pragmatic perspective has been supported increasingly in the current literature stating that the quantitative and qualitative approaches are both valid and neither one is better than the other. Creswell (2011) ended the discussion on the benefits of using MMR by stating that combining the two approaches provides a better understanding of research issues than either the quantitative or qualitative method alone.

In this study, quantitative methods were used to generate numerical data from experimental or observational studies, the inclusion of qualitative methods in the same study helps in understanding and exploring of participants' lived experiences, behaviours, perceptions, and thoughts about the SM intervention (Harding and Gantley, 1998). MMR was considered as a useful approach to address this study's research question with multiple objectives which included complex and multiple elements such as the processes and structures in the health services people who are living with rehabilitation requirements for their stroke, (Raven *et al.*, 2011; Nicca *et al.*, 2012). Moreover, there has been an increasing use of MMR approach for systematic reviews in the recent literature in which quantitative and qualitative

literature about a research question are both systematically appraised to synthesize all types of evidence which was adopted for this work (Tariq and Woodman, 2013; Pearson *et al.*, 2015). Table 2.1 shows the characteristics of quantitative, qualitative, and mixed methods research paradigms.

Table 2.1: A summary of the characteristics of the quantitative, qualitative, and mixed methods research paradigms (Lichtman, 2012; Creswell and Creswell, 2017).

Methodological characteristics	**Quantitative Research**	**Qualitative Research**	**Mixed Methods Research**
Reality	Objective (multiple researchers can find similar observation)	Subjective (personal, and socially constructed)	Formed by subjective and objective variables
Human behaviour	Regular, predictable, and can be studied under controlled conditions	Behaviour is personal, fluid, dynamic, contextual, social, and can be studied in natural environments	Behaviour can be predictable to some extent, studied in multiple contexts
Focus	Narrow scope, testing specific hypotheses	Wide scope, examining the breadth and depth of phenomena	Multiple scopes
Research objectives	Description, explanation, and prediction	Description, exploration, discovery and theory development	Can address multiple objectives
Research methods	Deductive (hypotheses and theories are tested with data)	Inductive (new hypotheses and grounded theory can be generated from data)	Deductive and inductive
Type of data	Variables, numbers	Words, quotes, images, categories	A mix of quantitative and qualitative data
Data collection	Structured and validated measurements/ instruments	Qualitative interviews, focus groups, participant observation, the researcher can be an insider or outsider to the research process	Multiple forms
Data analysis	Descriptive and inferential statistics	Descriptive qualitative analysis, coding, categorisation,	Multiple methods done individually and then integrated

		building themes and sub-themes	
Results	Generalisable findings	Particularistic findings (multiple perspectives)	integrated findings (may be generalisable)
Presentation of data	Statistical report with numbers and graphs	Narrative report with contextual description and direct quotations from research participants	Eclectic and pragmatic

Like any other methodology, using a mixed methods design includes some challenges that researchers need to be aware of and be able to overcome, to ensure high-quality results discussed below.

2.4 Methodological considerations for using mixed methods

To obtain the advantages of combining the two methods, researchers should have a clear plan from the beginning to manage the complex process. Failure to consider and manage possible challenges might affect the quality of data collection and analysis leading to generating a poor-quality data that can be confusing, inefficient, and inappropriate for publication or in the worst-case scenario the inability to complete the project (Lieber, 2009). Below are the reasons for adopting an MMR design within this thesis:

- Initiation of new insights about the study question by comparing data from different methods which supported the integrative systematic review methodology by applying an integration of quantitative and qualitative literature as in study 1.
- Complementarity where the data obtained by one method (in this study focus groups) are used to illustrate results from another (RCT) since rehabilitation outcomes studied are mainly quantitative and influenced by factors that can be subjective and not measured using numbers in study 3.
- Expansion to get a deeper understanding of different aspects of the research question where each aspect requires a different method. For instance, a complementarity role of using MMR can allow qualitative focus group data from participants' thoughts about the intervention to explain the quantitative findings about their level of adherence to the intervention and follow up for study 3.

- Triangulation where the data from both methods are used to confirm the validity of findings. Furthermore, triangulation of results from both approaches can help draw a stronger conclusion about the feasibility of self-management interventions for stroke population or specific groups (e.g. young versus older patients) within that population (as in study 1 and study 3).

Analysis and presentation of the data from MMR requires a clear plan about how the quantitative and qualitative contents will be sequenced, prioritised, and integrated in a study (Creswell and Clark, 2017). Prioritisation indicated which study component (Quantitative/Qualitative) should take precedence or have a greater importance than the other in study 1 and 3 (Kroll, Neri and Miller, 2005). For instance, the area of self-management research had limited prior evidence, hence researchers prioritised the exploratory qualitative methods in study 2 to determine the different variables within the Covid context and the relationships between them before they were studied quantitatively in feasibility study (study 3). Conversely, priority can be given to the quantitative methods in explanatory research in which qualitative methods are used following quantitative surveys or experiments to substantiate or triangulate the identified findings as in the review for this work. In the third study, a logical sequence was followed that started with quantitative methods of measurement using standard outcome measures while participants carried out the intervention. This was then followed by qualitative focus group methods to triangulate and illustrate results of the quantitative method, get deeper understanding individuals' lived experience within the study and to suggest direction for future research.

2.4.1 Sampling

Sampling should be addressed prior to the study to increase the chance of integrating the mixed methods data and to benefit from applying various methods (Teddlie and Yu, 2007). Typically, quantitative methods focus on probability sampling to increase power and meet the

assumptions of specific analytical approaches. On the other hand, qualitative methods usually start with purposive sampling strategies to obtain a relatively smaller sample that provides rich in-depth data. In MMR, it is critical for the researchers to understand the assumptions of different sampling strategies (i.e., purposive and probability sampling) and how they compare between them in terms of sample selection, rigidity of sampling frame, and their level of generalizability. In this work, the sampling plan considered different strategies to ensure adequate representation of participants for the studies using different methods. For instance, in study one criterion-based sampling was used to select studies for the systematic review. In study two and three, probability sampling was used to include any stroke survivor with certain inclusion criteria based on self-management literature i.e., appropriateness was determined based on participants' suitability to participate in self-management interventions. In addition, purposive sampling was used to detect participants with different stroke types, gender, social status and functional ability to examine the feasibility and applicability of the intervention for survivors with different characteristics. Further justification for sampling size and strategies are provided in respective studies.

2.4.2 Data integration

The integration of different data is perhaps the most recognized challenge for using of MMR designs (Kroll and Morris, 2009; Lieber, 2009). Data integration can occur at different stages of the research process, i.e., data collection, analysis, and interpretation depending on the research question and rationale for using MMR (Kroll and Morris, 2009; Creswell and Clark, 2017). The process of successful integration of quantitative and qualitative data requires proper reduction, manipulation, and the ability to create meaningful links between different data at the stages of data analysis and interpretation (Wilkins and Woodgate, 2008; Lieber, 2009).

In our feasibility study (study 3), quantitative data (feasibility) and the focus groups qualitative data were analysed separately and then integrated at the stage of interpretation and triangulation to make meaningful links between findings from different data sources. This integration was carried out to improve the validity and transparency of the findings (Creswell & Clark, 2017). This followed a clear plan of integration that was based on and was supplemented by having the process cross checked and reviewed by two senior researchers (Driscoll *et al.*, 2007; Thomas and Harden, 2008).

Bryman (2007) believed that achieving true integration of the different types of data is difficult and so he suggested MMR researchers to reflect on the integrated findings of a study and see if their understanding of the study problem has been enriched by the combination of different types of data, if not, then this is an indicator that integration is insufficient. In this work, we found that the integrated data had helped in answering multiple aspects of the research question about the feasibility of the new intervention and that the qualitative themes helped to interpret some of the quantitative finding of feasibility outcomes. For instance, the themes of facilitators and challenges for self-management had explained the quantitative findings about the adherence of participants to the intervention and attendance at group sessions. Presentation of different perspectives (multiple reality) using MMR helped with a holistic understanding of participants' experiences coupled with the measures for feasibility.

2.5 Selection of research design and methods

This subsection will describe the methods used for the different studies, comparing these with their counterparts and critically justifying the choices made. Particularly, the decisions to select scoping vs. systematic review, individual interviews vs. focus groups, content vs. thematic analysis and the use of feasibility RCT design will be demonstrated.

2.5.1 Scoping and systematic review for study 1

Literature review is a key step in the research process to explore knowledge around any topic of interest. Traditionally, it can be used to summarise evidence about a topic presenting different aspects such as conceptual, theoretical, or historical development of the topic or issue. Systematic and scoping reviews have been suggested as approaches using a structured process for evidence synthesis and providing high quality findings (Munn, Peters, *et al.*, 2018). The decision on the appropriateness of certain methods depends on the area of research, research question and type of evidence required (Munn, Stern, *et al.*, 2018). question/objectives (Munn, Peters, *et al.*, 2018). A scoping review was carried out at the beginning of this thesis work to identify the type of evidence available around the use of different self-management interventions to help stroke survivor's recovery of mobility post stroke. It also helped the decision on the selection of the specific methods (design, inclusion and exclusion criteria, data collection and analysis) for the systematic review and the intervention that was developed eventually based on evidence. For instance, the scoping review confirmed the feasibility of implementing self-management interventions in the community for the prevention and management of different aspects of life post stroke. The scoping review revealed that there was a need for focusing on specific rehabilitation outcomes such as mobility that can be targeted by self-management. Scoping review had also shown that meta-analysis could not be performed because of the heterogeneity in the outcome measures used within current literature. The inclusion and exclusion criteria were identified based on the scoping review to allow for the inclusion of a wider range of relevant studies.

The scoping review was followed by a systematic review. Systematic reviews are more specific in summarising, evaluating, and synthesising evidence against specific criteria have been effectively used in health care research to inform policy and practice (Chalmers, Hedges and Cooper, 2002; Bastian, Glasziou and Chalmers, 2010; Jordan *et al.*, 2015). It differs from

the scoping review in that it considers the quality of studies included in the review unlike a scoping review. In addition, the use of systematic reviews can help to discover the international evidence about a topic, compare and contrast between findings of different studies, guide future research, and provide statements for the development of practice guideline or policy (Pearson, 2004; Liberati *et al.*, 2009; Aromataris and Pearson, 2014; Munn, Peters, *et al.*, 2018).

Systematic reviews have been recommended to examine the effectiveness of clinical interventions by critical evaluation of the methods and findings of randomised controlled trials (RCTs) and providing meta-analysis if possible (Pearson, 2004; Munn, Tufanaru and Aromataris, 2014). However, it has been argued that in rehabilitation research not all questions about the appropriateness of an intervention can be answered by assessing effectiveness alone (Pearson, 2004; Pearson *et al.*, 2005). In many cases, there can be a need for a combination of multiple types of reviews to answer a research question. For instance, for successful development of an intervention or evidence-based practice guidelines, systematic reviews should cover other aspects such as cost effectiveness, feasibility and acceptability of the implementation of an intervention by rehabilitation stakeholders (patients, health care professionals, and policy makers) and contextual factors affecting their uptake.

Inclusion of individuals' perspectives has been advocated as important in the health research especially for the evaluation of interventions for the care of long-term conditions such as stroke (Evans and Pearson, 2001). In our work, we have taken these factors into consideration during the planning for the systematic review and hence decided to choose a review design that can allow for the combination of both effectiveness (quantitative) and experiential (qualitative) literature to synthesis evidence about the most appropriate self-management interventions for mobility training in the community. Therefore, an integrative review of relevant studies was conducted (Whittemore and Knafl, 2005; Pope, Mays and Popay, 2007).

The integrative review's strength lies in the combination of evidence from studies with diverse methodologies (experimental/non-experimental or empirical/theoretical) to draw a wider conclusion about a phenomenon or intervention; however, concerns have been raised about the rigour and accuracy of the combining process (Beck, 1999; O'Mathuna, 2000). Analysing and synthesising data from different sources has been considered as the most challenging step in conducting integrative reviews. To enhance the quality of conducting an integrative review, published guidance was used to guide the process (Conn and Rantz, 2003; Whittemore and Knafl, 2005; Garrard, 2020). Following Whittemore and Knafl (2005) guidance, we have used the findings of the scoping review to identfy the research problem and development of literature search strategy using the PICOS (Population, Intervention, Comparison, Outcomes and Study) (Amir-Behghadami and Janati, 2020). To maximise the number of eligible studies, we have used a comprehensive strategy for data search and a wide inclusion criteria so we can capture any literature discussing the efficacy of self-management for mobility, lived experiences of stroke survivors, functional and psychosocial outcomes, conceptual and theoretical constructs underpinning self-management. The protocol of this systematic review including the plan for data collection, analysis and synthesis was reviewed and registered with the International Prospective Register of Systematic Reviews (PROSPERO) (see appendix 4).

Evaluation of the quality of data is a complex process in integrative review. A proper decision should be made whether to use a single comprehensive criterion that can evaluate the quality of data from different primary sources or using multiple quality appraisal tools suitable for each study design included in the review. As there has not been any gold standard for quality evaluation and interpertation in research review, we sought to use different tools suitable for each study design considering that specific tools can enable a more thorough evaluation than using a broader critria. Details on tools used for data evaluation, anlysis and synthesis are

provided in chapter 3.

2.5.2 Individual interviews and Focus groups

In qualitative research, data collection may include different forms and techniques based on how the researcher can reach the level of data richness that can help answer the study questions. Qualitative researchers can decide whether they need to use focus groups (FGs) or individual interviews to collect their data. A critical question here is to decide which method is the most appropriate for the particular study. Apparently, the choice depends on the study objective context and skills of the researcher (Azzara, 2010; Straus, 2010; Guest *et al.*, 2017).

a. Study objectives and context guide the decision

Typically, one-to-one interviews are deemed to be a powerful method of data collection when the objective of a study is to explore a range of individuals' behaviours, experiences, or responses about particular issue and to compare/contrast them to build a clear understanding of the issues (Holloway and Galvin, 2016). It allows obtaining the essence of the participant's personal thoughts without any external influences. On the other hand, FGs might be the best if the objective is to understand participants' responses in relation to social context or interaction with other individuals with shared experience (Powell and Single, 1996). FGs are necessary when consensus or debate are part of the process needed to explore various perspectives. The strength of FGs lies in the stimulation of participants' thoughts and reminding them of feelings and perceptions about the topic through the dynamic interaction between participants (Stewart and Shamdasani, 2014).

There has been evidence that the two methods are complementary and using them together in a single study can give the best of their worlds where individual interviews provide depth of questioning and personal perspectives and FGs help understand the social context of issues (Straus, 2010; Dilshad and Latif, 2013).

For this thesis work, both methods were employed in different phases. In stage two of this study, it was crucial to collect individual experiences of different stakeholders in stroke rehabilitation during COVID-19, using one-to-one interviews. Since life post-stroke is complicated, needs are personalised, challenges and support provided for each individual can vary; a decision of using individual interviews was made to capture wider perspectives of peoples' lived experiences with the phenomenon. This part of the study discusses a highly sensitive, personal, and detailed information about participants' illness or disability. Hence FG was avoided since; participants might have some concerns to disclose or discuss in front of other people (Holloway & Galvin, 2016; Azzara, 2010).

In stage three of the study, when a consensus about the feasibility, applicability, and acceptance of the self-management intervention was sought, focus groups were suggested to discuss further details about shared experiences towards same intervention. Although a level of discrepancies could occur between participants regarding their experiences with the intervention, focus groups can help identify how the intervention can be adjusted/tailored to address needs of a wide range of participants. Also, as most of participants were elderly stroke survivors who might have cognitive or memory issues, focus groups were considered to facilitate a recall of events and proper evaluation of the intervention by group members (Holloway & Galvin, 2016; Azzara, 2010). Moreover, as Kitzinger (2005) argues that FGs can empower participants to discuss sensitive topics as they encourage group members to feel more comfortable to discuss these topics as a group, this method would be helpful to critique the acceptability and feasibility aspects in the 3rd study (chapter 5).

b. Sampling considerations for interviews and focus groups

Sampling strategy for the two methods should consider the variability in the individuals' level of education, lifestyle, socioeconomic, and personality type and it is worth asking some participants if they prefer to discuss the sensitive topic individually or in a group. In chapter 4

and 5, we have used a purposive sampling to meet the main objectives of the two studies with applying a broader inclusion criterion for other variables. While purposive sampling is a commonly useful strategy in qualitative research to help careful selection of a wide range of participants, a clear plan to eliminating bias is required. For instance, in the qualitative study about individuals' experiences with stroke rehabilitation during the pandemic (chapter 4), participants who experienced their strokes or cared for people with stroke during the pandemic period were purposively sampled. Other criteria such as functional and psychosocial status post stroke were not restricted to capture a wide range of lived experiences. To eliminate selection bias, the study advertisement was made publicly throughout the websites of the different strokes, stroke association, and GP clinics.

In the feasibility study (chapter 5), participants were purposively recruited from a single NHS site to manage the geographical distancing to the study identification centre.

c. Consideration of practical issues for data collection for FGs and interviews

Novice researchers need to be aware of practical challenges in the data collection as some challenges might wave the decision on the method selection. This subsection outlines the practical issues considered (time, resources, skill set, location and context) and how they were dealt with during the course of the work.

The selection of data collection method must be planned with appreciation of time and resources that a researcher has. One of the main reasons to choose FGs by many researchers is that they are quicker and cheaper than interviews in collecting data. In contrast, Individual Interviews are considered by other researchers because they are an easier and more practical method to manage (Holloway & Galvin, 2016). In our context, it was the appropriateness of methods that led the decision for the selection of methods at different stages rather than time especially since the research team members were familiar and experienced in both methods.

The student researcher was supported by senior researchers to deal with any conflict between the participants that might occur during the discussions.

Researchers also need to use their skills to eliminate potential bias that might occur as a result of group effect or when some members in the group tend to dominate the discussion (Carey and Smith, 1994). While data from FGs can be collected in shorter time in comparison to individual interviews, they are much more complex and difficult to transcribe and analyse (Carey & Smith, 1994; Holloway & Galvin, 2016). The complexity of data in this case is related to the nature of FGs process in which participants' voices vary and more than one may speak at the same time especially if there is a debate or conflict. During the qualitative data collection in the two studies, the main researcher attempted to record field notes to report and acknowledge any periods of conflict and to familiarise himself with data content (Halkier, 2010).

Location is another practical issue that researchers need to consider before deciding on the method of data collection. From an ethical perspective, participant's privacy could be threatened in community settings. An example from our study was a participant who did an interview online for the qualitative study (chapter 4) and she was reluctant to share some thoughts about depression while having her kids around in the house. If some participants cannot be physically available for participation and can use the telephone or any other electronic media, individual interviews can be more reliable in this case (Straus, 2010). An additional ethical consideration in this situation is to ensure the confidentiality and security of collected data and obtaining informed consent by mail or electronically from the participants (Holloway & Galvin, 2016). Researchers also need to be more careful when analysing data collected by this method as they are not accompanied by any gestures or facial expression. As our research took place during the COVID-19 restrictions, most of the FGs and interviews were collected remotely through video conferencing or phone calls. For the latest study (chapter 5),

participants were giving the choice to meet at our school for their focus groups or to meet online and only one participant attended in person. Others were familiar with online meetings which was a part of the self-management intervention. and they alluded to the notion of saving time and efforts for travelling to the school while they can easily meet online from home.

2.5.3 Content and thematic analysis

Content analysis and thematic analysis are two methods used to analyse qualitative data and have been commonly used in health and nursing research (Vaismoradi, Turunen and Bondas, 2013). Content analysis is commonly used to analyse textual or visual material by counting the occurrence of certain words, phrases, or concepts (Graneheim and Lundman, 2004). This approach can be used quantitatively to identify trends or patterns in large datasets, or qualitatively to gain a deeper understanding of the meaning behind the data.

Thematic analysis, on the other hand, is a more interpretive approach to data analysis that seeks to identify and interpret patterns of meaning within qualitative data. This method involves identifying themes, patterns, and relationships within data that can be organized into broader categories (Braun & Clarke, 2006). Thematic analysis can be useful for understanding subjective experiences, perceptions, and attitudes, as well as for exploring the complexity of social phenomena. Nevertheless, the process of data analysis in both approaches is similar to some extent. Initially, researchers should familiarise themselves with the data and then conduct coding for the dataset. In content analysis, the researchers start with coding data and then create categories and subcategories. In thematic analysis, the researchers should systematically code all data and then start to arrange the codes with consideration to similarities and differences, put them in bigger categories which may develop a hierarchical structure of code, subtheme, and theme (Braun & Clarke, 2006; Graneheim & Lundman, 2004; Vaismoradi et al., 2013). While content analysis focuses on the surface level of language, thematic analysis aims to

identify more high-level themes and patterns. In this thesis, both of these approaches were applied at different stages (Vaismoradi, Turunen and Bondas, 2013).

In the systematic review (study 1), as the self-management is a complex behaviour that has multiple factors influencing individual's ability for carrying out this role, thematic analysis was used to get in-depth understanding of what makes a successful self-management and how stroke survivors can manage their mobility rehabilitation. Later, in study 3, for the examination of the feasibility and acceptability of the SIMS, content analysis approach was undertaken to summarises participants' experiences and perspectives on the feasibility and acceptability of the intervention with minimal input from researchers about the process. This is to avoid any possibility of researcher bias or influence the researchers might have on the findings of the study.

Another form of the thematic analysis is the Reflexive Thematic Analysis (RTA). RTA was developed by Braun and Clarke involving data analysis of qualitative data to identify patterns and themes in people's experiences, views, and perceptions using the researcher's subjectivity and position as tools in the research process (Braun & Clarke, 2019). RTA is not a neutral process, as all analysis is influenced by the researcher. Themes are defined by the researchers and not necessarily to be solely driven by data (Braun & Clarke, 2021).

The RTA approach was used with a critical realist's perspective in the qualitative study (chapter 4) to better describe the explored lived experiences of stroke survivors and therapists with rehabilitation during the pandemic. The decision was based on the study objectives to explore participants perspectives through critical questioning about their experiences in order to explore challenges, needs, and strategies used to manage the situation. Also, as there were no previous theoretical assumptions about the research question, it was crucial to use researcher's subjectivity and position in trying to connect the dots and making connections between experience of people from different contexts to better explain the situation. The

subjectivity of the researcher in the RTA has been suggested as integral to the analysis process in the qualitative health research (Campbell *et al.*, 2021).

2.5.4 Decision on the feasibility RCT method (study 3)

Proof of concept for SM has been confirmed by multiple studies for the rehabilitation of stroke population (Lennon, McKenna and Jones, 2013; McKenna *et al.*, 2015; Van Den Berg *et al.*, 2016; DePaul *et al.*, 2019). Based on the available evidence and to address study's objectives, an intervention was developed integrating self-management components suitable for mobility training in the community. Hence, a feasibility study to assess of the feasibility, acceptability and practicality of the proposed intervention was required (Thabane *et al.*, 2010).

Feasibility studies are commonly called pilot studies and considered as the best way to test the feasibility of large and expensive full-scale studies as it can provide valued information about the various aspects such as feasibility of recruitment, randomization, retention, process evaluation, implementation of novel interventions and reporting of safety and adverse events (Lancaster, Dodd and Williamson, 2004). It can be used for further purposes such as evaluation of time, resources and international collaboration between research facilities and other more (Van Teijlingen & Hundley, 2001; Van Teijlingen et al., 2001). Feasibility studies usually are not used for hypothesis testing or examination of the effectiveness of an intervention (Leon, Davis and Kraemer, 2011). Therefore, our study did not aim for the examination of effectiveness of the intervention and hence was not powered enough to detect significant clinical changes in the performance outcomes.

The Randomised Control Trials (RCTs) have been considered as the gold standard for determining a treatment's efficacy in clinical research. The most important virtue in using RCTs is that all eligible participants have an equal chance of receiving all treatments, which minimises biases due to selection criteria like disease severity or a history of prior treatment.

Randomisation tends to create groups that are comparable on both measured and unmeasured factors that could affect prognosis or treatment response as the sample size grows (Friedman *et al.*, 2015). Considering this, an RCT design was used for the feasibility study including two groups, a treatment group who receive the new intervention (SIMS) in addition to the usual care provided by the NHS and a control group who will only receive the usual NHS care. The inclusion of comparison/control group in feasibility testing of conducting a future large study has been suggested to provide more realistic examination of recruitment and retention, randomisation and blinding and implementation of interventions (Leon, Davis and Kraemer, 2011). Elaborate details on the methods on data collection and analysis for the feasibility study are provided in chapter 5.

2.6 Reflexivity and rigour

My intention as a researcher is to consider reflexivity through each step in my research process as it has been suggested to be a contentious process in qualitative research (Berger, 2015). I believe research creditability increases when the reflexivity of the researcher has been clearly identified. Being insider or outsider to the research context both have advantages and disadvantages based on the study context (Berger, 2015). In my study context, I am interested in examining the effect of self-management-based interventions on mobility outcomes for stroke survivors. I have had some experience of working with this population for a couple of years when I was working as a physiotherapist. Based on my clinical background as a therapist, I noticed that patients might have a hard time after they are discharged from hospital, and they need support to improve their recovery post discharge. In some cases, the services are exhausted that they cannot offer an appropriate support for every survivor. Moreover, when the COVID-19 pandemic happened (in the middle of my PhD journey), the service delivery was hugely affected by social distancing measures including complete stop of therapy in some cases.

Survivors' recovery might also be affected by other comorbidities and stroke sequalae which might affect their participation in any form of therapy. I have had exposure to different issues affecting rehabilitation post-stroke based on my experience working with this population in different contexts including Saudi Arabia (my home country) and Canada (where I did my MSc). However, I was not familiar with services in the UK where this study took take place. As a plan to get more familiar with the UK context, I engaged in multiple discussion with the local rehabilitation therapists and senior patients who helped me and the research team in the development of the intervention. I also had a chance to work with physiotherapists, prior to data collection, to develop an understanding about their context and practice. I gained knowledge and deeper understanding of the context for engagement and transferability.

To reduce researcher biases the data transcription and analysis were done by a team of researchers to increase the rigor of the study. Data analysis of each study was carried out by two independent researchers and checked by a third (senior researcher). The research team selected performance outcome measures that are commonly used in stroke rehabilitation and well known for their reliability and validity in different contexts. Triangulation of findings was used at multiple stages during this research. For instance, in the qualitative study, findings from therapists' interviews were triangulated with perspectives of patient participants to increase the creditability credibility of findings. It was also used to triangulate the findings of quantitative with qualitative data in the integrative review and feasibility study. To eliminate bias and ensure the confirmability of findings based on participants' responses and without any influence or personal motivations from the researchers; blinding, reduction of contamination, using standardised tools for reporting and appraising of studies, periodical presentation and discussion of the findings with research team and reporting of any potential biases were adopted.

To increase the transferability of our findings, eligibility criteria of participants were made broader to include participants from different clinical, social, economic and ethnical groups (Connelly, 2016). The aim was to provide evidence that can be applicable in different contexts such as survivors who live alone or with a family member, able to physically attend therapy sessions or receive remote rehabilitation or can walk independently or with assistive device. In the qualitative study (chapter 4), including participants from different geographical areas helped to better describe the disruption in services and challenges faced by survivors in different circumstances.

Lastly, as this study involved other stakeholders (patients, clinicians, researchers and ethics and organisational bodies) in the planning and development of the study protocol, a level of dependability should be assumed. This work also included involvement of some of the stakeholders in the evaluation of study reports to ensure consistency of our findings and that the study can be repeated (Connelly, 2016).

2.7 Patient and Public Involvement (PPI) throughout the research process

This study involved different stakeholders in the planning of an appropriate protocol. Stroke therapists and patient-experts helped refine the intervention, study design, methodological aspects of recruitment and assessment. Two patient-experts (BH and PEW) who had a stroke several years ago and who have experience of working with other research protocols agreed to be a part of the PPI group for this study. In addition, thirty people who had chronic stroke from Northfield stroke association community club were consulted regarding this study. Therapists (physiotherapists and occupational therapists) from the NHS site where the study recruited from were consulted as stakeholders and contributed to the study design and documentation. The therapists and senior patients were both invited to meet with the researchers every six months to discuss the progress of the work including the recruitment issues and challenges faced during the delivery of intervention. Taking into consideration safety, protocol breeches,

and adverse events, these meetings provided useful insights to the implementation of the programme from an end users' perspectives.

PPI and stakeholders' input for this project was gained through:

a) two meetings with patient-experts (BH and PEW),

b) presentation and discussion with 30 people with stroke in a community club and

c) presentation and discussion with doctors, physiotherapy, occupational therapy, nursing and SALT clinicians.

These meetings were helpful to refine the intervention, study design, methodological aspects of recruitment and assessment.

The community stroke-club members could not recollect any explicit self-management strategy, they had limited early supported discharge help and hence felt this intervention will be a good step forward. They queried whether people with more severe walking deficits could be included and whether we needed to consider the cognitive ability of patients to participate in self-management. The above queries were also raised by the clinicians in their stakeholder meeting. The changes made in the protocol based on these two meetings are:

• To include slightly more disabled participants (FAC 2) and to invite carers or family to involve in the self-management intervention to improve adherence and safety.

• Cognitive ability will be discussed with the referring clinician at the point of recruitment. Montreal Cognitive Assessment will be administered to assess cognitive ability.

• Clinicians also suggested an objective measure of walking such as using a pedometer which will be given to participants.

• Due to the extent of the geographical area, clinicians suggested having another community centre for the group sessions which was negotiated during the study set up. However, due to Covid we amended study to take place on zoom.

The following changes were made based on patient-experts' views:

• To have 5 group sessions instead of the originally planned two sessions since they highlighted that we often undervalue the use of group sessions,

• To have information sheets in Punjabi and Urdu due to the diversity in the geographical location of this study.

• To add the General Health Questionnaire-12 to assess psycho-social well-being in participants since Mr.BH stated that we tend to ignore the psychological aspects following discharge.

• To carry out focus groups instead of interviews for this study since participants will support each other if we collect data in focus groups and might be reluctant to speak openly in individual interviews.

• Exercises around balance, speed and distance along with positive feedback to the participants on their performance will be added.

• To deliver education, safety advice and feedback from measurements for both the control and treatment groups and

• To record routine therapy that participants get from NHS.

In response to COVID-19 measures of safety and health, the clinicians and the two patient experts were consulted for the new plan of implementing the same protocol of intervention. They were a part of the study steering group that met every 6 months. Recommendations from clinicians included adding the remote communication/delivery of intervention as an option to reduce the physical meeting with participants. Patient experts suggested providing participants with a printed safety tips brochures as a part of patient education to ensure safety of training at home or in the community.

2.8 Ethics approvals

This thesis required two different ethics approvals. One was obtained for the feasibility study from the Health Research Authority (HRA) at the National Health Services (NHS) as it involved participants from NHS community services. Ethics approval for this study was initially obtained in June 2020 (IRAS project ID: 269079); however, due to the situation of the COVID-19 pandemic, the research team applied for an amendment to the approved protocol and a final approval was received in June 2021 (appendix 5). The R&D access was granted by the NHS in October 2021. The amendment included the addition of remote delivery of the SIMS to comply with the national safety and social distancing measures applied during the time of recruitment of participants for this study. It also included a plan to extend the recruitment of participants from community through local GP practices in addition to relying on the NHS community hospital site for the study, as this patient identification centre was affected by the impact of the pandemic in term of research activities.

For the qualitative study, another approval was obtained separately from the Science, Technology, Engineering and Mathematics (STEM) ethics committee at the University of Birmingham (reference: ERN_21-0775) (appendix 6).

Throughout every step in this research work, participants safety and privacy have been the top priority while addressing the research objectives. There was two stage consenting process. Participants were asked to provide permission to contact form at the initial contact through their formal therapists before they were referred to the research team. We also ensured that every participant received study information sheet prior to signing their consent to participate in the study and they were given time to consider their participation and ask questions for clarification. This thesis work was supervised by two senior clinicians who were responsible for research in the trust and monitored by R&I managers ensuring the study fulfilled the British legal and ethics requirements.

2.9 Data management

A Data Management Plan was created using DMPonline (appendix 7) at the beginning of the programme in 2020. The plan was created in consultation with the academic supervisors for this project. The plan clearly stated that the study principal investigator (PI) and the other researcher are responsible for the process of data collection and will ensure that the participants' anonymised data and information will be saved on a database held securely at the School of Sport, Exercise, and Rehabilitation Sciences in the University of Birmingham, UK. The plan also explained how the data will be archived and deleted/destroyed 10 years after the study completion.

2.10 Presentation of findings

It was planned that the findings of this research work will be disseminated throughout multiple methods. For the academic purposes of the PhD degree, the findings of each study will be presented in a separate chapter, each of which will be linked to the findings of other chapters in drawing together the whole story. Publicly, these findings are crucial to be disseminated to a wide range of audience who are involved in the field of self-management and stroke survivorship to share insights and inform research and practice. The impact of this research will be demonstrated through different approaches:

a. for specialist audiences

This will include presenting of the research findings in relevant conferences nationally and internationally, publishing papers in high impact journals, and presenting reports to clinicians and researchers including NHS staff.

b. for non-specialist audiences

The research findings will be published publicly through summary online for organisations such as Stroke Association and Different Strokes websites and the NHS trust's website and social media pages. In addition, they will be presented to stroke survivors through different

stroke social clubs as a part of public engagement activities. Participants in the study will also be provided with a report of the research findings.

2.11 Chapter summary

Considering options for the methodological approaches to help answer the research questions for this thesis work, the decisions on using the selected approaches were made considering the philosophical stance of the researcher and epistemological and ontological basis of the knowledge explored. This included applying multiple paradigmatic perspectives to answer the research question sufficiently at different phases, using multiple methods. A critical realist perspective was adopted for the integrative review, a subtle realist perspective for the qualitative study, and a pragmatic constructive perspective for the feasibility study. The use of mixed methods in the feasibility study will help obtain a deeper understanding of peoples' experiences with the SIMS, the assessment of functional improvement, and efficacy of delivering such intervention in the community. More details about the sample size, sampling, recruitment and the procedures for data collection and analysis are discussed in each of the following chapters. Finally, the use of the alternative format thesis style has helped to publish the work earlier and add these published articles to the final thesis. The next chapter includes the details of the integrative systematic review that was carried around the use of SM interventions that improve mobility post-stroke.

CHAPTER 3

SELF-MANAGEMENT INTERVENTIONS TO IMPROVE MOBILITY AFTER STROKE: AN INTEGRATIVE REVIEW

This chapter represents a full content of a published paper by the PhD student as a first author (Sahely *et al*., 2022). It contains verbatim text from the published paper in addition to some changes made for the purposes of thesis writing.

Publications and Presentations

1. **Sahely, A.,** Giles, D., Sintler, C., Soundy, A., & Rosewilliam, S. (2022). Self-management interventions to improve mobility after stroke: an integrative review. Disability and rehabilitation, 1-18. **(appendix 2)**

2. **Sahely, A.,** Giles, D., Sintler, C., Soundy, A., & Rosewilliam, S. (2022). Self-management interventions to improve mobility after stroke: an integrative review. European Stroke Organisation Conference 2021, Virtual.
3. **Sahely, A.,** Giles, D., Sintler, C., Soundy, A., & Rosewilliam, S. (2022). Self-management interventions to improve mobility after stroke: an integrative review. World Stroke Congress 2021, Virtual.
4. **Sahely, A.,** Giles, D., Sintler, C., Soundy, A., & Rosewilliam, S. (2022). Self-management interventions to improve mobility after stroke: an integrative review. The annual ESRC Midlands Graduate School Conference 2021, Virtual.

3.1 Abstract

Self-management based interventions can help stroke survivors to manage several aspects of their rehabilitation post stroke. There is a need for the examination of most effective self-management interventions that can be used for physical rehabilitation in this population. This chapter aimed to review the evidence around self-management interventions used to improve mobility post-stroke.

An integrative review was carried out in this chapter to synthesis evidence from quantitative and qualitative data that discussed self-management interventions for mobility training after stroke. Eight databases were searched from 1992 to July 2021 using keywords based on the PICOS strategy. Two reviewers independently screened and extracted the relevant data. Quality of studies was assessed and a quantitatively led narrative synthesis of data, supported by qualitative evidence, was then completed.

Twenty-four studies with 823 participants were reviewed. Self-management strategies such as patient education, providing information, goal setting, problem solving, action planning, self-monitoring, and social support were integrated with rehabilitation therapy to improve mobility post-stroke. The reviewed studies showed improvements in functional

mobility and walking ability, self-efficacy, participation in physical activity, and quality of life to various extent. Participants in qualitative studies considered the self-management interventions as a valuable addition to their therapy and perceived the improvement in their mobility following them.

There is some evidence that self-management interventions help to improve mobility outcomes post-stroke. However, these interventions were resource intensive and not completely applicable in community practice. Heterogeneity of data in the studies made meta-analysis impossible. Future work should focus on developing interventions that are directly transferable to community practice, that are less resource intensive and based on the relevant theoretical constructs.

3.2 Introduction

As discussed in the introduction (Chapter 1), promoting patients' role of self-management can help them to cope better with the consequences of stroke and achieve their priority goal of improving mobility post stroke. The main principle of Self-Management (SM) is to empower individuals with knowledge, skills, and confidence that can increase survivors' capabilities for functional rehabilitation and reintegration into the community (Warner *et al.*, 2015). Supporting strategies are taught to enable patients to overcome challenges after discharge from hospital care (Barr *et al.*, 2003; Health, 2016). SM was defined by the National Clinical Guideline for Stroke in the UK as the *"actions and confidence of individuals to manage the medical and emotional aspects of their condition in order to maintain or create new life roles"* (Rudd *et al.*, 2016, p. 28). SM can support rehabilitation efforts during early sup- ported discharge from acute care and has been positively associated with functional and psychosocial outcomes of rehabilitation during both subacute and chronic stages of stroke recovery (Pearce *et al.*, 2015; Warner *et al.*, 2015). Therefore, it has been recommended by clinical guidelines as a considerable part of therapy planning (Rudd *et al.*, 2016). Based on the above evidence, increasing patients' SM skills might positively influence functional mobility outcomes post-stroke, hence, there is a need to explore the characteristics of the most effective SM strategies relevant to functional mobility.

In the rehabilitation literature, strategies used to enhance self-management behaviours range from providing patients with information or education about their conditions to more complex strategies such as involving a patient in goal setting, decision making, problem-solving, or self-monitoring during their rehabilitation process (de Silva, 2011; Parke *et al.*, 2015). Theoretically, incorporating multiple strategies in an intervention can be most effective especially when behaviour change needs to be targeted (Parke *et al.*, 2015; Warner *et al.*, 2015). Previously, reviews have evaluated the effectiveness of SM as a holistic approach that

explores aspects of rehabilitation such as functional ability, participation, self-efficacy, and quality of life (Parke *et al.*, 2015; Warner *et al.*, 2015); yet there has been no review of SM interventions for improving mobility post-stroke. This review aims to provide an evidence synthesis of the SM-based interventions that can be used by rehabilitation professionals to improve patients' mobility post-stroke.

3.2.1 Objectives

To collect, review, synthesise evidence around self-management interventions to improve mobility and the relevant outcomes that were studied within stroke rehabilitation.

3.2.2 Review question

What are the effects and outcomes of self-management interventions related to the rehabilitation of mobility post-stroke?

3.3 Methods

An integrative review of relevant studies was undertaken (Whittemore and Knafl, 2005). A subtle realist perspective was assumed for this review that focuses on the common reality experienced across individuals. This perspective supports the combination of different methodologies to explore participants' perceptions of reality (Duncan and Nicol, 2004; Pope, Mays and Popay, 2007). The study protocol was registered on the International Prospective Register of Systematic Reviews (PROSPERO Registration # CRD42019151051).

3.3.1 Search strategy

A systematic search was undertaken on the following electronic databases from January 1992 until July 2021: PubMed, MEDLINE, EMBASE, PsycINFO, AMED, CINAHL, Cochrane Database of Systematic Reviews, and Web of Science. The search terms included: 'stroke', 'rehabilitation', 'self-management', 'walking', and 'functional mobility. These terms were exploded using synonyms from relevant literature and identification of MeSH terms from PubMed (see Supplementary Appendix 8 for a detailed list). Further, searching was undertaken

using electronic search engines including Google Scholar and ScienceDirect. We used limiters to search for the articles that were published in English, related to humans, and when keywords were found within abstracts. References from shortlisted articles and a search of grey literature including publications from conference proceedings were also conducted as a secondary search. If the initial search had returned any PhD theses, we searched for articles published from this work. We wrote to authors of theses and conference abstracts to check for any relevant publications.

3.3.2 Eligibility criteria

The following eligibility criteria for studies were identified using the PICOS (Participants, Intervention, Comparison, Outcome, Study design) acronym. The eligibility criteria have been set out below based on the PICOS.

3.3.2.1 ***Participants***

Studies that included results detailing separate (if mixed samples) and identifiable analysis of stroke survivors with any type or severity of a stroke, who have received any form of self-management support interventions to improve their mobility at any time after stroke. Studies were excluded if they recruited stroke survivors under 18 years of age or used self-management specifically for stroke prevention.

3.3.2.2 ***Interventions***

The review included studies that used self-management strategies that targeted improved mobility either individually or in clusters. Studies were excluded if they involved psychosocial and/or behavioural interventions in isolation without targeting self-management behaviour. For example, (tele) rehabilitation or cognitive therapy that did not encourage self-management behaviourswere excluded.

3.3.2.3 ***Comparison groups***

Articles were included whether they had a comparator, usual care or no comparator intervention. We did not specify any inclusion criteria for the comparator treatments (all types) provided to the control groups of participants.

3.3.2.4 ***Outcomes***

Studies were included if they provided qualitative or quantitative data related to functional mobility (individual's physiological ability to move independently and safely to perform ADLs in a different environment (Forhan and Gill, 2013)) outcomes, in addition to other self- management-related outcomes such as psychological, social, or general well-being measures.

3.3.2.5 ***Study designs***

There was no restriction on the types of study design for inclusion in this review.

3.3.3 **Study selection**

The identified results from the databases search were transferred and saved into the RefWorks reference management software (ProQuest LLC, 2020). The duplicates were removed and an initial screening of titles was done by a reviewer (AS). This was followed by a screening of abstracts which was done independently by reviewers (AS, SR and DG). Irrelevant studies were excluded at this stage based on the inclusion criteria. The full-text screening was done by two independent reviewers (AS and DG). Conflicts between the two reviewers were resolved by a third reviewer (SR) at each stage of screening. A PRISMA Flow Diagram was used to summarise the results of the screening.

3.3.4 Quality appraisal

To assess the risk of bias in the selected studies, the Cochrane's Risk of Bias Tool (the updated version) was used to critically appraise the randomised controlled trials (Sterne *et al.*, 2019). The Risk Of Bias In Non-Randomised Studies of Interventions (ROBINS-I) was used to evaluate the non-controlled trials (Sterne *et al.*, 2016). The Mixed Methods Appraisal Tool (MMAT) was used for the quality assessment of the mixed-methods studies (Hong *et al.*, 2018). The Critical Appraisal Skills Programme (CASP) was used for the critical appraisal of studies with other designs (CASP, 2003). Studies with poor quality were not excluded from the review as we planned to describe all possible effects of self-management interventions on the stroke population. The Grading of Recommendations, Assessment, Development and Evaluations (GRADE) framework was used to rate the overall strength of evidence around outcomes, based on the quality of the reviewed quantitative studies (Schünemann *et al.*, 2013). Two reviewers (AS and DG) assessed the quality of the included studies independently and a third reviewer solved the discrepancy between their results (SR).

3.3.5 Data extraction

A data extraction template was adopted from the Cochrane Data Extraction and Assessment Template for each study and a summary table of the extracted information from all studies was created. This was done independently by two reviewers (AS and DG) and checked by a third reviewer (SR). The extracted data included information about participants' characteristics, study methods, interventions, outcomes and findings. Specific details about the strategies and protocols of self-management interventions used in the studies were extracted. Ten study authors were contacted for any missing data relevant to the review question.

3.3.6 Data synthesis

The data analysis process is suggested to follow the steps of data reduction, data display, data comparison, conclusion drawing, and verification (Miles and Huberman, 1994; Whittemore and Knafl, 2005). Step 1 data reduction: Data from articles were reduced to a manageable format by initially classifying them into two main groups, quantitative and qualitative. Step 2 data display: The key elements of the studies were extracted using tabulation techniques (see Table 1 and Supplementary Appendix 9). The articles were presented within the data extraction table in alphabetical order. Step 3 data comparison: Identified themes from step 2 were compared using a constant comparison method to identify the similarities and differences in the contents of the included studies. The data was organised under key sections that served as overarching themes. Qualitative findings were independently analysed by AS and SR using thematic analysis (O'Connor and Gibson, 2003) (see Supplementary Appendix 9). Findings were compared and conflicts were discussed between the reviewers until they reached a consensus. Each theme included subthemes that covered different aspects of participant's perspectives regarding that theme (see Supplementary Appendix 9). Conclusions were presented by integrating the thematic analysis with the quantitative data sections supported by the qualitative findings under the themes.

3.4 Results

3.4.1 Study characteristics

A total of 1903 studies were found from the databases searched. Secondary searches resulted in 45 articles. After screening, twenty-four studies conducted between January 1999 and July 2021 were included in this review (Figure 1 PRISMA flow diagram). Nine studies were randomised controlled trials (Baskett *et al.*, 1999; Olney *et al.*, 2006; Kendall *et al.*, 2007; Haworth, Young and Thornton, 2009; Chumbler *et al.*, 2012; Treger *et al.*, 2014; Malagoni *et*

al., 2016; Van Den Berg *et al.*, 2016; Vloothuis *et al.*, 2019), two quasi-experimental studies (Mansfield *et al.*, 2016; Paul *et al.*, 2016), one single group longitudinal study (Ezeugwu and Manns, 2018), five pre-post designs (Taylor *et al.*, 2009; Sullivan *et al.*, 2014; Kanai *et al.*, 2017; Preston, Catherine M Dean, *et al.*, 2017; Scrivener *et al.*, 2021), and two case reports (Broetz and Birbaumer, 2013; Richardson *et al.*, 2015). Five studies used mixed-methods designs to examine the feasibility of different SM interventions (Huijbregts, McEwen and Taylor, 2009; White *et al.*, 2013; Dean *et al.*, 2018; Portz *et al.*, 2018; DePaul *et al.*, 2020).

Studies were conducted in different countries: Canada (7 studies), Australia (5 studies), UK (3 studies), USA (3 studies), Netherlands (1 study), Japan (1 study), New Zealand (1 study), Israel (1 study), Italy (1 study) and Germany (1 study). Participants were recruited from various settings involving various stages of recovery defined as acute (less than 2 weeks after stroke), sub- acute (within 6 months from the onset of stroke) and chronic (more than 6 months after onset). Eleven studies were recruited from acute and subacute stages (Baskett *et al.*, 1999; Kendall *et al.*, 2007; Haworth, Young and Thornton, 2009; Chumbler *et al.*, 2012; Treger *et al.*, 2014; Mansfield *et al.*, 2016; Van Den Berg *et al.*, 2016; Preston, Catherine M Dean, *et al.*, 2017; Ezeugwu and Manns, 2018; Vloothuis *et al.*, 2019; DePaul *et al.*, 2020), ten studies from the chronic stage (Olney *et al.*, 2006; Huijbregts, McEwen and Taylor, 2009; Broetz and Birbaumer, 2013; White *et al.*, 2013; Sullivan *et al.*, 2014; Richardson *et al.*, 2015; Malagoni *et al.*, 2016; Paul *et al.*, 2016; Portz *et al.*, 2018; Scrivener *et al.*, 2021), one study recruited only from the acute stage (3 ± 1 days from stroke onset) (Kanai *et al.*, 2017), and two studies recruited participants including both subacute and chronic stage of recovery (Taylor *et al.*, 2009; Dean *et al.*, 2018).

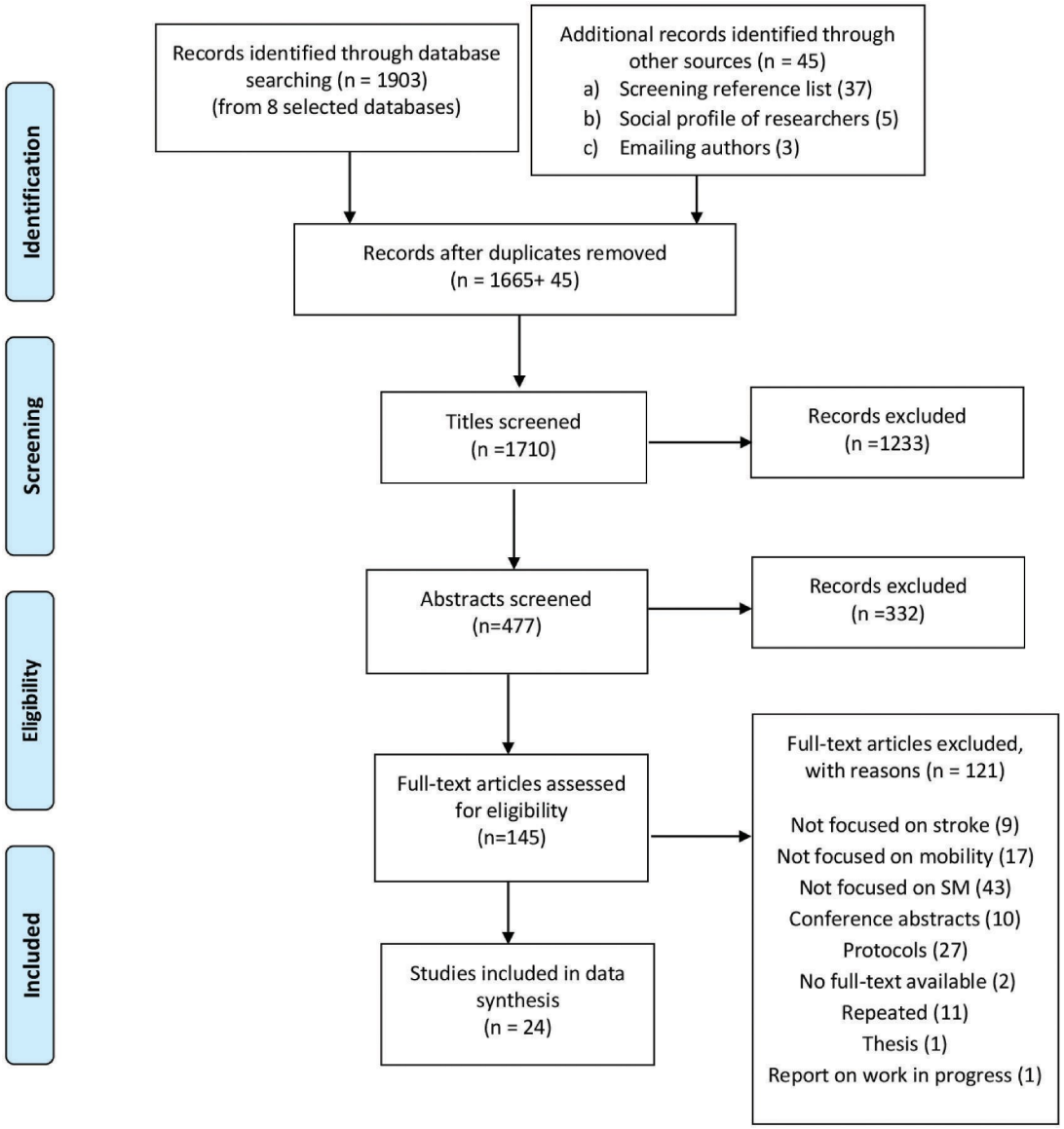


Figure 3.1 PRISMA flow diagram of study selection (Moher *et al.*, 2009)

3.4.2 Description of participants

A total of 823 participants (523 men and 300 women) with a mean age of 63.7 years (age range: 40.9-73.2 years) were included in the selected studies. Nineteen studies indicated that participants had to have mild to moderate impairments ((FIM 40) or were able to walk independently or with minimal assistance (FAC < 5)) to be eligible for participation in the selected studies (Baskett *et al.*, 1999; Olney *et al.*, 2006; Haworth, Young and Thornton, 2009; Chumbler *et al.*, 2012; Broetz and Birbaumer, 2013; Sullivan *et al.*, 2014; Treger *et al.*, 2014;

Richardson *et al.*, 2015; Paul *et al.*, 2016; Van Den Berg *et al.*, 2016; Malagoni *et al.*, 2016; Preston, Catherine M Dean, *et al.*, 2017; Kanai *et al.*, 2017; Portz *et al.*, 2018; Dean *et al.*, 2018; Ezeugwu and Manns, 2018; Vloothuis *et al.*, 2019; DePaul *et al.*, 2020; Scrivener *et al.*, 2021). Three studies had recruited survivors with ischemic stroke (Treger *et al.*, 2014; Richardson *et al.*, 2015; Kanai *et al.*, 2017), six studies had a mix of ischemic and haemorrhagic (Chumbler *et al.*, 2012; Malagoni *et al.*, 2016; Van Den Berg *et al.*, 2016; Dean *et al.*, 2018; Ezeugwu and Manns, 2018; Vloothuis *et al.*, 2019) and one study had only one participant with haemorrhagic stroke (Broetz and Birbaumer, 2013). Other studies did not specify the stroke type of their participants.

The availability of a caregiver was an eligibility criteria for inclusion in four studies where the role of caregivers was a part of the intervention (Kendall *et al.*, 2007; Taylor *et al.*, 2009; Van Den Berg *et al.*, 2016; Vloothuis *et al.*, 2019). In five studies, the presence of caregivers was optional (Baskett *et al.*, 1999; Mansfield *et al.*, 2016; Preston, Catherine M Dean, *et al.*, 2017; Ezeugwu and Manns, 2018; DePaul *et al.*, 2020) and the rest of the studies did not indicate any role of caregivers or family members. Table 1 shows participant's characteristics in each study.

3.4.3 Quality of evidence

The highlights of the methodological quality critique of studies can be seen in Table 1. Six studies (Huijbregts, McEwen and Taylor, 2009; Taylor *et al.*, 2009; White *et al.*, 2013; Kanai *et al.*, 2017; Dean *et al.*, 2018; DePaul *et al.*, 2020) were not powered enough to detect changes in the outcomes due to the small sample size. In addition to sampling, five studies (Huijbregts, McEwen and Taylor, 2009; Broetz and Birbaumer, 2013; Richardson *et al.*, 2015; Mansfield *et al.*, 2016; Scrivener *et al.*, 2021) had a high risk of bias across different categories including selection, performance, and detection bias. Three of the RCTs (Baskett *et al.*, 1999; Haworth, Young and Thornton, 2009; Malagoni *et al.*, 2016) had a high risk of performance bias because

the blinding of assessors and participants was impossible due to the nature of the applied intervention. In two studies (Kanai *et al.*, 2017; Ezeugwu and Manns, 2018), there was a high risk of detection bias because the assessors and/ or participants were not blinded. Also, there was a high risk of selection bias in three studies (Broetz and Birbaumer, 2013; Richardson *et al.*, 2015; Mansfield *et al.*, 2016) because of their recruitment methodology which had targeted specific participants. There were only six studies (RCTs) that had an overall low to moderate risk of bias (Olney *et al.*, 2006; Chumbler *et al.*, 2012; Treger *et al.*, 2014; Van Den Berg *et al.*, 2016; Dean *et al.*, 2018; Vloothuis *et al.*, 2019) and one non-randomised controlled trial that had a moderate risk of bias (Paul *et al.*, 2016). The risk of detection and performance bias was unclear in certain studies (Kendall *et al.*, 2007; Richardson *et al.*, 2015) as they did not provide any information about the blinding. In some studies, it was not possible to make a judgment on the risk of bias because of a lack of adequate information (Mansfield *et al.*, 2016; Paul *et al.*, 2016).

In the mixed methods studies (White *et al.*, 2013; Portz *et al.*, 2018) reviewed, there was a high risk of selection bias as the complete outcome data for some participants were missing or not collected for follow-up. Withdrawal rates were not stated and the confounders were not accounted for (Huijbregts, McEwen and Taylor, 2009; Portz *et al.*, 2018). There was a potential for measurement bias as the therapists who executed the study were also the assessors (White *et al.*, 2013). Also, the divergences and inconsistencies between quantitative and qualitative results were not adequately addressed. Using the Grading of Recommendations, Assessment, Development and Evaluation (GRADEpro) software (GRADEpro, 2015), the certainty of evidence within the included studies was rated narratively for the main outcomes. Considering the methodological weaknesses and limitations of the majority of the studies to pro- vide a robust judgment on the effectiveness of the SM interventions, the body of evidence has been

graded ‘moderate, low, or very low’ on the GRADE system for the main outcomes (Supplementary Appendix 10).

Table 3.1 Summary table of the reviewed studies.

Study/ Country/ Design	**Participants**	**Interventions**	**Theoretical frameworks / SM strategies**	**Outcomes**	**Results**	**Methodological Quality**
(Baskett *et al.*, 1999) New Zealand RCT	N= 100 (mean age 71.7 *(IG)* and 67.8 *(CG)* in yrs). • Stroke survivors after discharge. • Subacute stage.	*IG*: • OT and PT visit once a week and exercises prescribed. • Encouraged to exercise several times a day. • Therapists guided the self-directed therapy. *CG:* Outpatient or day hospital therapy *Duration:* 18 months. *Format:* One-to-one. *Delivered by:* PT/OT at home for the intervention group.	**TF:** Unclear. **SM strategies:** Goal setting/ action planning/self-monitoring.	Gait speed, Limb function, Activities of daily living, Time with therapists, Mood of subjects and caregivers, Anticipated outcomes at entry, Perceived outcome at exit.	No statistical differences between the control and experimental groups in any outcome measures.	- High risk of bias (CRoB). - No blinding. - Used surrogate quality of life measures in screening for mood disorders.
(Broetz and Birbaumer, 2013) Germany	54-year-old male who suffered cerebral bleeding with left hemiparesis 25 years ago (chronic stage).	Over the 18-month period the programme included: • Daily intensive exercises x 1 week. • One-hour sessions/ week. Goal-setting. • Self-control cues for exercises Supervision and feedback after successful trials. • Intensive training week repeated at 6 months and 12 months.	**TF:** Behavioural physiotherapy incorporating motor learning. **SM strategies:** Goal setting, Motivation, Supervision, Feedback and Reward.	Walking capacity, Goal attainment, and Change of symptoms.	Rhythmic walking improved from 74 steps/ minute to 112 steps/minute, Walking speed increased from 8.65 seconds to 6.48 seconds, and Running for 80 M.	- High risk of bias (CASP). - Case report of only one participant, high possibility of selection, performance, and detection bias.

Case report		*Duration:* 18 months. *Format:* One-to-one. *Delivered by:* Physiotherapist.				
(Chumbler *et al.*, 2012) USA A prospective, single-blinded RCT	N= 48 (mean age 67.1-67.7 yrs). • Participants with ischemic or haemorrhagic stroke. • Subacute stage. • Discharged to the community. • Not cognitively impaired. • Able to follow a 3-step command. • Discharge motor Functional Independence Measure (FIM) score (18-88).	*IG:* **STeleR** intervention: • 3 home visits, • 5 telephone calls, • In-home messaging device for instructions on functionally based exercises and adaptive strategies. *CG:* usual care *Duration:* 3 months *Format:* One-to-one. *Delivered by:* Therapist via home visit or telephone calls	**TF:** The Verbrugge and Jette's model for the disablement process. **SM strategies:** Goal setting Action planning Self-monitoring.	Telephone Version of Functional Independence Measure Function scales of the Late-Life Function and Disability Instrument (LLFDI).	The outcomes improved at 6 months for the STeleR group and declined for the usual care group 4 of the 5 (LLFDI) component subscales (P0.05),	- Low risk of bias (CRoB). - Sample had majority males and wasn't inclusive for stroke population.
(Dean *et al.*, 2018) UK	N= 45 (mean age 70 (*IG*) and 71 (*CG*) in yrs). • Stroke survivors with mobility issues. • Discharged from rehabilitation services at least 1 month before.	*IG:* **ReTrain** which included: • A one to one to 1 session followed by ten, twice-weekly group classes, • Cardiovascular and strength work, • Self-management strategies, • Functional activities,	**TF:** Action for Rehabilitation following Neurological Injury (ARNI). **SM strategies:** Education Goal setting Action planning	**Primary outcomes:** Rivermead Mobility Index, Timed Up and Go, Modified Patient-Specific Functional Scale, 7-day objective physical activity levels using wrist-worn accelerometer, and Physical activity diary. **Secondary outcomes:**	The trial was not powered to detect differences in any outcomes between trial arms or over time.	- Low risk of bias (MMAT). - It failed to identify a clear primary outcome for a definitive RCT. - Small sample that did not have a wide age range or ethnic diversity. - This was a pilot study, not designed to demonstrate generalisability.

Mixed methods study	• Subacute and chronic stages. • Possessing sufficient physical, cognitive, and communication ability.	• Goal setting, and • Bespoke home-based training programme. *CG:* Exercise after stroke advice booklet plus usual care. *Duration:* 3 months *Format:* Group and one-to-one. *Delivered by:* Personal trainers on the UK Register of Exercise Professionals.	Problem-solving Self-monitoring Group and social support.	Stroke Self-Efficacy Questionnaire, Fatigue Assessment Scale, EuroQol- 5 Dimension (EQ-5D-5L).		
(DePaul *et al.*, 2019) Canada Mixed methods study	N= 10 (mean age 62.3; SD 11.7 years). • Inpatient stroke rehabilitation • Acute and subacute stages. • Functional Ambulation Classification scores (2-4). • Functional Independent Measure ≥ 40.	**IMPACT:** Starts in the hospital and continues after discharge. Usual therapy Physiotherapy -8 sessions x 2weeks *Duration:* 14 days. *Format:* One-to-one. *Delivered by* a trained PT.	**TF:** Social cognition theory and Self-determination theory. **SM strategies:** Education and professional support Goal setting Decision making Action planning Self-monitoring and Feedback.	6 Minutes Walking Test, 5-meter Walk Test, Functional Independence Measure (total and motor), Berg Balance Test, Functional Ambulation Category, Chedoke-McMaster Stroke Assessment (CMSA leg and foot). Therapists' and patients' perceptions were qualitatively collected.	Gait speed improved by an average of 0.32 m/s (SD 0.27 m/s) on 5-m walk test. 6MWT improved on an average of 85.0 m (SD 64.0) over the 2-week intervention period. All patients indicated that the programme helped them increase their activity and indicated they would continue to practice walking-related activities beyond the coaching period.	- High risk of bias (MMAT). - Small and inconclusive sample. - Single therapist and single setting. - Single-group study design. - Not powered to detect outcomes changes. - Amount of training wasn't accurately reported across all participants.
(Ezeugwu and Manns, 2018)	N= 34 (mean age = 64.6 yrs). • Within 2 weeks of discharge from	**STand Up Frequently From Stroke (STUFFS)** Sedentary time was interrupted with upright activities (standing and	**TF:** Social cognitive theory.	Chedoke-McMaster Stroke Assessment (CMSA) for leg and foot, 5-meter walk test, Timed Up and Go,	Sedentary time decreased by 54.213.7 minutes/day (P<.01) at post intervention and 26.814.0 minutes/day (P <0.07) at follow-up,	- Some concerns about risk of bias (CASP). - The sample was limited to specific stroke population.

Canada Single group, longitudinal intervention study	inpatient facilities. • Subacute stage. • Able to stand up from a chair. • Walk at least 5 meters with or without gait aids. • Able to understand 2-step commands.	walking) at home and in the community. A motivational wrist-worn activity monitor was used throughout the intervention. *Duration:* 8-weeks *Format:* One-to-one. *Delivered by* PT at home.	**SM strategies:** Action planning Self-monitoring.	Sedentary behaviour and physical activity (time sedentary, standing, and stepping, the number of steps, sit-to-stand transitions) were measured using the activPAL, The Montreal Cognitive Assessment (MoCA), Stroke Impact Scale, and Self-Efficacy for Exercise Scale Outcomes were assessed with 1-week baseline, 8-week intervention, and 8-week follow-up.	Significant improvements in walking speed, (P<.05). The number of steps and time spent stepping were not statistically different across both time periods.	- No control group. - The duration of the intervention was too short to achieve change in behaviour.
(Haworth, Young and Thornton, 2009) UK An exploratory, single blind RCT	N= 44 (mean age 40.9 (*IG*) and 42.3 (*CG*) in yrs). • Patients with neurological conditions including stroke. • Within 4 weeks of discharge from in-patient care. • Subacute stage. • Able to carry out exercise independently. • Sit and transfer independently.	*IG:* **Exercise and education programme**, twice weekly over four weeks. Education involved lectures about the benefits of exercises and self-management mobility, strength and balance exercises *CG:* Standard follow-up care including medical review clinics and outpatient therapy. *Duration:* 4 weeks. *Format:* Group. *Delivered by:* by research therapist at specialist neurosciences centre.	**TF:** Self-efficacy. **SM strategies:** Education Group intervention.	**Primary outcomes:** Exercise Efficacy Scale and Human Activity Profile. **Secondary outcomes:** 10-metre timed walk Short Form 36 Health Survey, Hospital Anxiety and Depression Scale, UWIST Mood Adjective Checklist, Motricity Index, Frenchay Arm Test, Rivermead Mobility Index, and a visual analogue scale. Data were collected at baseline and at 6, 12 and 24 weeks.	At 6 weeks, significant improvements in exercise efficacy in the treatment group (P = 0.001). Moderate improvements in activity levels were noted for both study groups with no between-group differences. No significant improvements in SF 36 'physical health' Follow-up at 12 and 24 weeks suggested that the improvements noted in exercise self-efficacy, activity levels and quality of life were maintained and were independent of the exercise programme.	- Some concerns about risk of bias (CRoB). - Small sample size. - The intervention needed to be extended to accurately measure HAP. - Weaknesses within the chosen measures.

(Huijbregts, McEwen and Taylor, 2009) Canada Mixed methods study	N= 18 (mean age 61.8 (*IG*) and 65.6 (*CG*) in yrs). • Medical diagnosis of stroke. • Completed active rehabilitation. • Chronic stage. • Living in the community.	*IG:* Telehealth MOST intervention was implemented using videoconferencing. MOST self-management programme included: Discussion and exercise. Goal-setting and problem-solving, Exercise, and community-reintegration skills. *CG:* Waiting list control group. *Duration:* 18 sessions over 9 weeks. *Format:* Group therapy. *Delivered by:* Trained health professional facilitators.	**TF:** Unclear. **SM strategies:** Education Problem solving Goal setting Social support.	Berg Balance Scale (BBS), The Reintegration to Normal Living Index, The Stroke-Adapted Sickness Impact Profile, Chedoke-McMaster Stroke Assessment Activity Inventory, Goal Attainment Scaling, and The Geriatric Depression Scale.	There was a significant difference in BBS scores between the T-MOST group and the WLC group (mean difference -4.27, 95%CI: -6.66 to -1.87).	- High risk of bias (MMAT). - Small sample size - No randomisation - High risk of selection bias due to recruitment strategy. - Baseline differences between groups were not clear.
(Kanai *et al.*, 2017) Japan Pre–post interventional study	N= 22 (mean age 62.5 yrs). • Acute ischemic stroke. • Able to walk without assistance or gait aid • Within seven days of admission.	*IG:* 40–120 min of a supervised rehabilitation program 5–6 times a week until discharge. Instruction on the self-monitoring approach and discussed physical activity (PA) targets, Exercises included body stretches, weight resistance exercises, aerobic exercise. Accelerometer worn 24 h/day until discharge *Duration:* 11 days. *Format:* One-to-one. *Delivered by:* PT at hospital	**TF:** Self-efficacy. **SM strategies:** Education Goal setting Action planning Self-monitoring.	The daily number of steps was taken as an index of Physical Activity and Self-efficacy for physical activity (SEPA) scale.	PA during the intervention was higher than that at the baseline measurement (5709.4 ± 2236.1 vs. 2813.9 ± 1511.9 steps/day, $p < 0.001$). Self-efficacy for PA during the intervention was also higher than that at the baseline measurement (76.4 ± 18.8 vs. 58.9 ± 29.0 points, $p < 0.001$).	- High risk of bias (CASP). - Very small sample size. - No control group. - Was not statistically powered to detect changes in the outcomes. - Used only the number of steps/days as the measure of PA. - Did not assess psychological factors or pre-morbidity exercise habits. - Did not conduct functional tests at discharge.
(Kendall *et al.*, 2007)	N= 100 (mean age 65.96 yrs).	IG: SM education programme targeting mobility and exercise.	**TF:** The Chronic Disease Self-	Stroke Specific Quality of Life scale (SSQOL) and the Self-efficacy Scale.	The study identified a significant impact of the intervention on the quality	- Some concerns about risk of bias (CRoB).

Australia RCT	• First stroke. • Subacute stage. • No dementia or psychiatric illness. • Sufficient English language. • Expectation of discharge to their homes.	*Duration:* 7 weeks. *Format:* Group *Delivered by* professionals in community settings.	Management Course was used to operationalise the concept of psychosocial skill expansion. **SM strategies:** Education Goal setting Action planning Group interaction and Support.		of family roles, self-care, work productivity, and functioning in daily activities within SSQOL (p=0.05). The control and intervention groups differed significantly in self-efficacy levels across all times, F (1, 93) = 9.45, p=0.003, including pre-intervention.	- Minimal data was available about the clinical status of the participants. - People with language difficulties were excluded.
(Malagoni *et al.*, 2016) Italy Feasibility and pilot RCT	N= 12 (mean age 66.5 ±11.9 yrs). • People with chronic stroke. • Ability to ambulate independently at least for 10 meters on level ground. • FAC >3. • Ability to perform TUG.	*IG:* Structured home-based exercise programme with 2 10-minute sessions/day (6 days/week) of intermittent walking. *CG: Standard supervised group therapy programme*. *Duration:* 10 weeks. *Format:* Group and individualised sessions at home. *Delivered by:* Physiotherapists.	**TF:** Unclear. **SM strategies:** Self-monitoring and feedback.	Functional outcome measures included 6-Minutes Walking Test, Timed Up and Go, Stair Climb tests, and Physical activity domain of the SF-36 questionnaire.	6-minute walk test and physical activity domain of the SF-36 significantly increased in both groups (p=0.03). Timed Up and Go improved in both groups, significantly for the home-based exercise group (p=0.03) while stair climb remained stable for both groups.	- High risk of bias (CRoB). - Small sample size - No blinding

(Mansfield *et al.*, 2016) Canada Quasi-experimental feasibility-controlled trail	N= 26 (mean age 62.1 (*IG*) and 67.1 (*CG*) in yrs). • Any type of stroke. • Subacute stage.	*IG:* **PROPEL, included** group exercise and self-management. Supervised and individualised aerobic training 3 times a week, An inpatient module and an outpatient module. *CG:* received in- and outpatient rehabilitation *Duration:* 6 weeks. *Format:* Group. *Delivered:* by a PT and a healthcare student in an outpatient rehabilitation setting.	**TF:** Transtheoretical model + social cognitive theory and self-efficacy. **SM strategies:** Goal setting Action planning Problem solving Self-monitoring	Physical activity level was assessed using an accelerometer, heart rate monitor, and the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD), the Short Self-Efficacy for Exercise (SSEE) scale, the Short Outcome Expectation for Exercise (SOEE) scale, and the Barriers to Being Active Quiz (BBAQ).	PROPEL participants had a higher participation in physical activity than COMP participants (Hedge's $g \geq 0.5$), reported higher SSOE scores (Hedge's g: 0.50) and fewer significant barriers to physical activity in the BBAQ than COMP participants (Hedge's g: −1.18).	- Serious risk of (ROBINS-I). - Extremely low recruitment rate. - Groups were not comparable at baseline. - Patients with communication difficulties were excluded. - Only 34% of daily heart rate data were available.
(Olney *et al.*, 2006) Canada RCT	N= 72 (mean age 63.5 (*IG*) and 65.8 (*CG*) in yrs). • Chronic stroke survivors. • Able to walk a total of 15 minutes with rests (with or without assistive devices except a 4-point walker). • Able to tolerate activity for 45	*IG*: One-week supervised instruction program followed by a 9-week unsupervised home program The unsupervised group had exercises prescribed to them and written instructions to monitor and progress. *CG:* 10-week supervised strengthening and conditioning program (supervised) *Duration:* 10 weeks *Format:* group format for the supervised sessions and 1 to 1 for the unsupervised sessions.	**TF:** Unclear. **SM strategies:** Education and Self-monitoring.	**Primary Outcome:** Walking speed (6MWT). **Secondary Outcomes:** Human Activity Profile (HAP) adjusted activity score, Medical Outcome Study 36-Item Short-Form survey (SF-36), Physiological Cost Index, and lower extremity muscle strength.	The 6MWT speed increased significantly in both groups and remained significantly improved at one year. The HAP showed an increasing trend only in the supervised group and was significant at one year. The SF-36 Physical component summary score increased significantly in the supervised group and remained improved at one year; the unsupervised group showed significant improvement at one year.	- Low risk of bias (CRoB). - It was not possible to blind participants and testers. - The generalisability of the findings might be limited due to restricted eligibility criteria of participation.

	minutes with rests. • No severe coronary artery disease.	*Delivered by:* therapist at rehabilitation centre for the supervised group and at home for the unsupervised group.				
(Paul *et al.*, 2016) UK Quasi-experimental pilot study	N=23 (mean age 55.3 (*IG*) and 56.3 (*CG*) in yrs). • Single unilateral stroke. • Discharged from rehabilitation. • Chronic stage. • Able to walk independently with or without using an aid or orthosis. • Able to comprehend instruction.	*IG:* **STARFISH** program included a mobile phone app-based intervention, with evidence-based behaviour change techniques The intervention started with 1 week of baseline step count using phone accelerometer, followed by use of the STARFISH application over a 6-week period. *CG:* Usual care. *Duration:* 6 weeks. *Format:* Group. *Delivered:* through a mobile app.	**TF:** Behaviour Change Techniques (BCTs). **SM strategies:** Feedback, Self-monitoring and Social support	Physical activity (steps/day), Ten-Meter Walk Test, Sedentary time, Fatigue Severity Scale, Instrumental Activity of Daily Living Scale, Stroke Specific Quality of Life Scale, and Psychological General Well-Being Index.	The average daily step count increased by 39.3% in the intervention group and reduced by 20.2% in the control group (p = 0.005 for group–time interaction). Similar patterns of data and group–time interaction were seen for walking time (p = 0.002) and fatigue (p = 0.003).	- Moderate risk of bias (ROBINS-I). - Sample was not inclusive for stroke population. - Duration of the intervention was short. - Assessor was not blinded. - No randomisation. - The sample was heterogeneous in PA. - Mobile phone accelerometer needs validation.
(Portz *et al.*, 2018) USA	N= 13 (mean age 73.23 yrs). • Individuals with chronic stroke (> 6 months). • Had a fall or current fof. • Completion of post-stroke rehabilitation.	*IG:* **MYOT** a yoga-infused self-management intervention. One hour of group self-management education followed by one hour of yoga (2 times per week). *Duration:* 8 weeks. *Format:* Group. *Delivered by an* OT and a research student	**TF:** Self-efficacy and Problem solving. **SM strategies:** Education Goal setting Action planning/ Problem solving	**Quantitative Outcomes:** Endurance (6-MWT), Strength (30-Second Chair Stand test), and Gait Speed (10-Meter Walk test). **Qualitative outcomes:** Participant perceptions of changes in physical fitness and PA were collected	Physical fitness outcome measures including endurance and lower and upper body strength significantly (p < .02) improved. Based on qualitative results, participants expressed positive changes in endurance, strength, gait speed, flexibility, and balance.	- Some concerns about risk of bias (MMAT). - The long-term effect of the programme was not measured. - It wasn't clear why some patients did not notice any change.

Mixed-methods study	• Able to stand, at risk for falls (≤ 46 on the Berg Balance Scale). • Able to understand English. • Score of ≥ 4 out of 6 on the short Mini Mental Status Exam.		Self-monitoring Group discussion and activities.		They also reported improvements in walking ability and duration and expressed a desire to continue yoga and increase levels of exercise.	
(Preston, Catherine M. Dean, *et al.*, 2017) Australia Single-group, pre-post intervention study	N= 20 (mean age 68 yrs). • Discharged home from an acute stroke unit. • Subacute stage. • Able to walk 10 m across flat ground without any aids at a speed of ≥0.8 m/s. • Scored ≥ 24 on the Mini Mental State Examination. • Resided within 30 km of the hospital. • No moderate to severe receptive aphasia.	Five 60-minute home-based sessions Carer or family member involved. The sessions included: education, goal setting, barrier identification, self-monitoring, and feedback. *Duration:* 3 months. *Format:* One-to-one. *Delivered by:* Physiotherapist.	**TF:** Behaviour Change Techniques (BCTs). **SM strategies:** Education Goal setting Action planning Problem solving Self-monitoring and feedback.	**Primary Outcomes:** Duration of moderate physical activity in min/day and counts of physical activity in steps/day. **Secondary Outcomes:** Self-efficacy, walking ability, participation, and quality of life.	At 3 months, participants completed 27 min/day (95% CI 4–49) more moderate physical activity than at baseline and 16 min/day (95% CI −10 to 42) at 6 months. Participants perceived the self-management program to be useful and there were few adverse events (muscle soreness, falls, and hospitalisation).	- Some concerns about risk of bias (CASP). - No randomisation. - No control group. - There were challenges around using Sense wear armband to collect PA data.

(Richardson *et al.*, 2015) Canada Case report	N= 15 (mean age 65.5 yrs). • Chronic stroke survivors. • First ischemic stroke. • Able to walk at least 2.44 mts. • Able to transfer to a chair. • Some active movement in the UE during recovery. • Cognitive function score of 26 points on the Montreal Cognitive Assessment (MoCA). • No receptive aphasia. • Can communicate in English.	**START:** Self-Management and Task-Oriented Approach to Rehabilitation Training. *Duration:* 10 sessions *Format:* One-to-one. *Delivered by* physiotherapist at home.	**TF:** Self-efficacy. **SM strategies:** Goal setting Action planning Problem solving Self-monitoring.	TUG, Barthel Index, Stroke Impact Scale, Patient Activation Measure, modified version of Patient Satisfaction Questionnaire-18.	Significant changes were observed in the TUG (p <0.01), the Barthel Index (p < 0.01, and the Stroke Impact Scale (p <0.001).	- High risk of bias (CASP). - Very small sample size and not inclusive. - High possibility of bias as there was no randomisation or control group.
(Scrivener *et al.*, 2021) Australia	N= 14 (mean age 57 ±14.2 yrs). • Adults with stroke. • Discharged from rehabilitation. • Chronic stage.	**TASK** programme. A video-guided exercise programme. The programme comprised of two phases: in phase one, four weeks of the program was supported by weekly supervised sessions at the rehabilitation centre.	**TF:** Self-efficacy. **SM strategies:** Education/self-monitoring.	Physical performance, physical activity, and exercise self-efficacy were measured at baseline and 4 and 8 weeks.	Walking speed improved over the duration of the program (mean difference -0.12 m/s, 95% CI -0.22 to -0.02, p= 0:02). Self-efficacy and physical activity did not change over the duration of the program.	- High risk of bias (CASP). - The sample size for this study was small and diverse in characteristics. - High possibility of bias as there was no randomisation or control group.

Pre-post single group study	• Could walk at >0.4 m/s with/without an aid.	In phase two, four weeks of the program was completed at home without direct supervision. *Format:* One-to-one. *Delivered by* physiotherapist at home.				
(Sullivan *et al.*, 2014) US pre-post-test follow up design	N= 11 (mean age 60.4 yrs). • Community-dwelling stroke survivors. • 21 years old or older. • Ambulators. • Stroke onset 6 months or more before participation (chronic stage).	A pedometer monitored, community-based intervention was used for 6 weeks. A brief verbal educational module was provided to each participant addressing the benefits of exercise after stroke, pedometer use, and completion of daily exercise diaries. *Duration:* 6 weeks. *Format:* One-to-one. *Delivered by:* therapist at home through telephone coaching sessions.	**TF:** Self-efficacy. **SM strategies:** Education Goal setting and decision making Self-monitoring.	**Primary Outcomes:** Walking speed (10-mWT) and endurance (6MWT). **Secondary Outcomes:** the Activities-Specific Balance Confidence Scale, Stroke Impact Scale–16 (SIS-16), and a pedometer satisfaction survey.	There were low effect sizes for changes in SIS-16 (0.312) and 6MWT (0.293). Increasing steps correlated with increased perception of physical function.	- Some concerns about risk of bias (CASP). - Small sample size. - The heterogeneity of participants may have affected results. - Possibility of a ceiling effect for the steps/day. - Pedometer was inaccurate with participants who walk slower than 0.5 m/s. - Short duration of intervention.
(Taylor *et al.*, 2009) Canada	N= 12 (mean age72.7 yrs). • Stroke survivors between 3- and 18-months post-stroke • Subacute and chronic stages.	**Moving On after STroke (MOST):** MOST involves sessions with 1 hour of discussion followed by 1 hour of exercise (cardiovascular, range of motion and strength components). Participants learn about stroke-related issues, but more importantly, learn problem-solving and goal-setting skills	**TF:** Unclear. **SM strategies:** Education Goal setting Problem solving Groups with support.	Walking endurance (6MWT), Short-Term Goals (Goal Attainment Scaling), Berg Balance Scale, Activity-Specific Balance Confidence Scale, Geriatric Depression Scale and Reintegration to normal living.	Pre–post improvements were seen in goal setting, mood, balance, balance confidence, and walking endurance. Participants reported that the program provided people with stroke as well as caregivers with greater awareness of stroke, increased social support, and improved ability to cope.	- Some concerns about risk of bias (CASP). - No control group. - No randomisation. - Insufficient numbers to compare the health outcomes of the telehealth participants to those in the group receiving face-to-face care.

Pre-Post intervention feasibility study		Two sessions/week. *Duration:* 9 weeks. *Format:* Group with patients and carers. *Delivered by:* Clinicians via videoconference.				
(Treger *et al.*, 2014) Israel RCT (single blinded)	N= 56 (mean age 56.6 (*IG*) and 62.2 (*CG*) in yrs). • Subacute stage. • Ability to walk independently (with or without walking aids). • FIM score ≥60 at mid-hospitalisation evaluation.	*IG:* Received detailed instructions for 14 exercises and was instructed to walk for at least 30 minutes daily. Follow up phone calls. *CG:* Usual care. *Duration:* 3 months. *Format:* One-to-one. *Delivered by:* a physiotherapist.	**TF:** Unclear. **SM strategies:** Education Self-monitoring/ Review follow up.	The 10-metre walk test (10MWT), 6-minute walk test (6MWT), and Timed Up & Go (TUG) were performed twice; once at the end of the inpatient rehabilitation period and three months later.	A significant improvement was shown in the intervention group in 10MWT (p=0.008), 6MWT (p<0.001) and TUG (p=0.009).	- Moderate risk of bias (CRoB). - Participants were not blinded. - Participants received instructions from therapist without involvement in goal-setting or planning.
(Van Den Berg *et al.*, 2016) Australia RCT	N=63 (mean age 64.5 (*IG*) and 70.1 (*CG*) in yrs). • Stroke survivors within subacute stage. • With mobility problems (FAC score<5). • Caregiver to participate in the programme.	*IG:* **CARE4STROKE:** Caregiver-mediated exercises with e-health support Telerehabilitation services. Participants had 30 minutes, 5x a week Exercises executed by a caregiver plus usual care. *CG:* Usual care. *Duration:* 8 weeks. *Format:* One-to-one. *Delivered by:* Physiotherapist and caregiver at rehabilitation centre or nursing home and	**TF:** Unclear **SM strategies:** Self-monitoring Caregivers' support.	**Primary outcome**: The SIS-mobility domain. **Secondary outcomes**: Length of stay, Motor impairment, Strength, Walking ability, Balance, Extended activities of daily living, Psychosocial functioning, Self-efficacy, QoL, and fatigue. Additionally, caregiver's self-reported fatigue, symptoms of	Intention-to-treat analysis showed no between-group difference in SIS- mobility; Per-protocol analysis, examining those who were discharged home with telerehabilitation showed a trend toward improved mobility (p=0.06), significantly improved extended ADLs scores at week 8 (−3.6, p=0.01) and week 12 (3.0, p=0.03).	- Low risk of bias (CRoB). - Small sample size. - The 2 groups were not comparable at baseline. - Study did not provide definitive measures of effectiveness. - Participants were not blinded. - 11 patients dropped out (high attrition). - Study was not designed or powered to detect adverse events.

(proof of concept)	• Had sufficient cognition to take part and no depression (HADS score <11).	continued at home if patient discharged before finish.		anxiety, self-efficacy, and strain were assessed.		
(Vloothuis *et al.*, 2019) Netherlands RCT (proof of concept)	N= 66 (mean age 59.26 (*IG*) and 60.53 (*CG*) in yrs). • 34 inpatients with stroke. • Subacute stage. • Lived independently before the stroke. • Discharged home. • Able to follow instructions (MMSE > 18 points). • FAC Score < 5. • Had a caregiver to assist.	*IG:* **CARE4STROKE:** Caregiver-mediated exercises with e-health support Telerehabilitation services. Participants had 30 minutes, 5x a week Exercises executed by a caregiver plus usual care. *CG:* Usual care. *Duration:* 8 weeks. Format: One-to-one. *Delivered by:* therapist and caregiver at rehabilitation centre or nursing home and continued at home.	**TF:** Assumptions that more training is better (Motor control theory). **SM strategies:** Goal setting Caregivers' support.	**Primary outcomes:** SIS-mobility domain. **Secondary outcomes:** Motor impairment, Strength, Walking ability, Balance, Mobility and Extended ADL of patients, Caregiver strain of caregivers, and Mood, Self-efficacy, Fatigue and QoL of both patients and caregivers. Outcomes were assessed at baseline, 8 and 12 weeks after randomisation.	No significant between-group differences were found regarding SIS-mobility after 8 and 12 weeks.	- Low risk of bias (CRoB). - Variability in the decision for discharge. - Patients were not included at fixed times after stroke. - Study may be under powered.
(White *et al.*, 2013)	N= 22 (mean age 65.76 yrs).	**MASTERSTROKE**	**TF:** Unclear.	Timed Up and Go (TUG), Six Minute Walk Test,		- Some concerns about risk of bias (MMAT).

Australia Mixed methods study	• Community dwelling stroke survivors. • Chronic stage. • Not accessing other rehabilitation services at the time of enrolment.	A secondary prevention stroke group program with two 2-h sessions weekly (1 hour for education and 1 hour for exercise). The exercise component incorporated fitness, strength, mobility and balance and education focused on secondary stroke prevention whilst also providing chronic condition self-management support. *Duration:* 9 weeks. *Format:* Group. *Delivered by:* PT and multi-professional community-based team.	**SM strategies:** Education Group support.	Participants' perceptions were qualitatively collected.	TUG (mean change=3.89, p=0.00), and quality of life scores (mean = 0.25, p = 0.01). Qualitative responses results confirmed increases in knowledge about stroke and exercise tolerance, successfulness of a group program and lifestyle modification post-stroke.	- Small sample size. - Was not statistically powered, nor controlled. - The assessors were also the therapists who implemented the programme. - Qualitative interviews were limited to one per person that could limit the ability to capture changes over time and sustainability of modifications.

N: Sample size; SM: Self-management; TF: Theoretical Framework; CRoB: Cochrane's Risk of Bias Tool; ROBINS-I: The Risk Of Bias In Non-Randomised Studies of Interventions; MMAT: The Mixed Methods Appraisal Tool;CASP: The Critical Appraisal Skills Programme; RCT: Randomised Controlled Trial; OT: Occupational Therapist; PT: Physiotherapist; FAC: Functional Ambulation Category; PA: Physical Activity.

3.4.4 Themes

The themes arising from the integrative narrative synthesis are presented below.

3.4.4.1 *Conceptualisation of self-management in stroke rehabilitation*

The concept of SM was variably interpreted by the stakeholders (patients, professionals, researchers, and policy makers) within the qualitative components of the studies and authors of some studies included in this review. Qualitative studies indicate that survivors perceived SM as an approach that can help to increase their capabilities to manage their therapy at home or community, motivates them to undertake more training for mobility as implied in *"I was doing three times a week, and I need to make it four or five times"*, and hence promotes their independence and socialisation (Baskett *et al.*, 1999; Langhorne, Bernhardt and Kwakkel, 2011; Veerbeek *et al.*, 2011; Dean *et al.*, 2018; Portz *et al.*, 2018; DePaul *et al.*, 2020).

Policy makers and healthcare provider considered SM as sharing of responsibilities for rehabilitation services with patients and their caregivers (Baskett *et al.*, 1999). From therapists' perspective, the implementation of this concept in real practice has altered their role in ser- vice delivery and allowed for the transition of some responsibilities to patients.

Authors of some studies have narrowed their conceptual understanding of SM interventions to specific elements of its conceptual components such as a behaviour change of patients (Broetz and Birbaumer, 2013; Paul *et al.*, 2016; Ezeugwu and Manns, 2018), self-efficacy (Kanai *et al.*, 2017), patient education (Haworth, Young and Thornton, 2009), or self-directed therapy (Baskett *et al.*, 1999). In the studies that applied SM strategies at the time of discharge from the hospital (Baskett *et al.*, 1999; Olney *et al.*, 2006; Chumbler *et al.*, 2012; Dean *et al.*, 2018), SM was perceived mainly as a strategy to support the delivery of care at home or in the community and to support early supported discharge. During the chronic stage, SM strategies were suggested to increase the ability to manage the ongoing sequelae of stroke

and risk factors for recurrent stroke (Taylor *et al.*, 2009; White *et al.*, 2013; Richardson *et al.*, 2015).

3.4.4.2 ***Theoretical frameworks for self-management interventions***

Using theories is very crucial for the development of complex interventions such as SM (O'Cathain *et al.*, 2019). They can help understand how an intervention can be designed, implemented, and evaluated. The development of the interventions in this review was based on a variety of theoretical frameworks and process guidelines. All theories discussed within SM literature are described below. The social cognitive theory and theory of self-efficacy (SE) were commonly used to develop SM interventions, to mediate individuals' behaviour of self-management, and to measure the effect of SM interventions on stroke survivors. SE in particular was used as a framework for the interventions in three studies (Haworth, Young and Thornton, 2009; Kanai *et al.*, 2017; Portz *et al.*, 2018). Sullivan *et al*.'s (2014) intervention was based on the effect of self- monitoring (a part of SE) to increase participants' level of physical activity. One study used the knowledge-to-action cycle to develop and evaluate an SM and task-oriented intervention called START; however, the SM part of the intervention was developed based on self-efficacy (Richardson *et al.*, 2015).

The social cognitive theory was the foundation for the STUFFS intervention (Ezeugwu and Manns, 2018) and the PROPEL along with the Trans-Theoretical model (Mansfield *et al.*, 2016) or self-determination theory (DePaul *et al.*, 2020). The SteleR intervention was guided by Verbrugge and Jette's model for the disablement process (Chumbler *et al.*, 2012). Kendall *et al*. (2007) used the chronic disease self-management course to provide support for stroke survivors based on the concept of psychosocial skill expansion. Two studies used behaviour change techniques (BCTs) to increase the level of physical activity of participants (Paul *et al.*, 2016; Preston, Catherine M Dean, *et al.*, 2017). Self-determination theory components were also used by Broetz and Birbaumer (2013) in addition to the principles of behavioural

physiotherapy to increase patient autonomy in daily training for walking. Multiple studies were not clear about the theoretical frameworks on which their interventions were developed (Baskett *et al.*, 1999; Olney *et al.*, 2006; Huijbregts, McEwen and Taylor, 2009; Taylor *et al.*, 2009; White *et al.*, 2013; Treger *et al.*, 2014; Malagoni *et al.*, 2016). Overall in studies that showed significant outcomes related to mobility the predominant theories used were identified as self-efficacy in three studies (Sullivan *et al.*, 2014; Richardson *et al.*, 2015; Preston, Catherine M Dean, *et al.*, 2017), social cognitive theory in one study (Paul *et al.*, 2016), behaviour change techniques in three studies (Chumbler *et al.*, 2012; Mansfield *et al.*, 2016), and self-determination theory in two studies (Taylor *et al.*, 2009; Dean *et al.*, 2018).

3.4.4.3 ***Self-management intervention strategies for mobility training***

Mobility rehabilitation was directly targeted by SM intervention in eleven studies (Taylor *et al.*, 2009; Chumbler *et al.*, 2012; Broetz and Birbaumer, 2013; Sullivan *et al.*, 2014; Treger *et al.*, 2014; Malagoni *et al.*, 2016; Paul *et al.*, 2016; Van Den Berg *et al.*, 2016; Dean *et al.*, 2018; Vloothuis *et al.*, 2019; DePaul *et al.*, 2020), while other studies included mobility indirectly as a part of physical activity training (Baskett *et al.*, 1999; Olney *et al.*, 2006; Haworth, Young and Thornton, 2009; Huijbregts, McEwen and Taylor, 2009; Richardson *et al.*, 2015; Mansfield *et al.*, 2016; Kanai *et al.*, 2017; Preston, Catherine M Dean, *et al.*, 2017; Portz *et al.*, 2018; Scrivener *et al.*, 2021), sedentary behaviour change (Ezeugwu and Manns, 2018), stroke prevention (White *et al.*, 2013), or within SM education about mobility (Kendall *et al.*, 2007).

The number and content of SM strategies varied across studies. The most common strategies included providing information, patient education, goal setting and decision making, problem- solving and action planning, identifying barriers, self-monitoring and feedback, and social support (Table 1). SM was accompanied by various types of therapy modalities including, usual care of physical and/or occupational therapy in most of the studies, yoga (Portz *et al.*, 2018), behavioural physiotherapy (Broetz and Birbaumer, 2013), and aerobic exercises

(Mansfield *et al.*, 2016; Kanai *et al.*, 2017). Incorporation of SM within exercise programmes enabled insights into potential options for participants as indicated by *"It opened my eyes to what can be done"* in the qualitative interviews (White *et al.*, 2013; Dean *et al.*, 2018). The duration of the intervention varied from a minimum of one week (Kanai *et al.*, 2017) to a maximum of 3 months (Baskett *et al.*, 1999; Chumbler *et al.*, 2012; Preston, Catherine M Dean, *et al.*, 2017; Dean *et al.*, 2018). The longest duration was a case study that lasted for 18 months (Broetz and Birbaumer, 2013).

The content, intensity, and duration of therapies within SM training followed various clinical guidelines and were tailored based on the individual capacity of participants. Therapies consisted of fitness, mobility, strength, endurance, balance, range of motion, and stretching exercises. Most of the interventions had one or two sessions per week. The average number of sessions per week was 2.5 sessions and the average duration of each session was 54 min. The details of exercises dosage were not clearly reported in some studies (Baskett *et al.*, 1999; Haworth, Young and Thornton, 2009; Richardson *et al.*, 2015). Some participants in the qualitative reports indicated that uncertainty of dosage was evident in their participation in SM programmes and that the trainers were not specific about the exercise dosage at home, implied in *"I could never pin him down to how long that should be for though"* (Dean *et al.*, 2018).

The SM interventions were delivered to the participants in a group format in eight studies (Kendall *et al.*, 2007; Haworth, Young and Thornton, 2009; Huijbregts, McEwen and Taylor, 2009; Taylor *et al.*, 2009; White *et al.*, 2013; Mansfield *et al.*, 2016; Paul *et al.*, 2016; Portz *et al.*, 2018) and in a one-to-one format in thirteen studies (Baskett *et al.*, 1999; Chumbler *et al.*, 2012; Broetz and Birbaumer, 2013; Treger *et al.*, 2014; Sullivan *et al.*, 2014; Richardson *et al.*, 2015; Van Den Berg *et al.*, 2016; Kanai *et al.*, 2017; Preston, Catherine M Dean, *et al.*, 2017; Ezeugwu and Manns, 2018; Vloothuis *et al.*, 2019; DePaul *et al.*, 2020; Scrivener *et al.*, 2021). In three studies (Olney *et al.*, 2006; Malagoni *et al.*, 2016; Dean *et al.*, 2018) the SM

interventions were delivered in groups and in one-to-one format at some points during the intervention. Participants perceived that group sessions were more beneficial for them to share their experiences as it *"was good to talk to them[peers] and find out how they've man- aged"* and to increase socialisation (White *et al.*, 2013). They believed that these sessions allowed them to compare themselves with other participants and appreciate their own circumstances and personal progress.

The majority of interventions were delivered to the participants in their homes (Baskett *et al.*, 1999; Olney *et al.*, 2006; Chumbler *et al.*, 2012; Broetz and Birbaumer, 2013; Treger *et al.*, 2014; Sullivan *et al.*, 2014; Richardson *et al.*, 2015; Malagoni *et al.*, 2016; Paul *et al.*, 2016; Preston, Catherine M Dean, *et al.*, 2017; Ezeugwu and Manns, 2018) or in community settings (Kendall *et al.*, 2007; Haworth, Young and Thornton, 2009; Taylor *et al.*, 2009; White *et al.*, 2013; Mansfield *et al.*, 2016; Dean *et al.*, 2018; Portz *et al.*, 2018). One intervention was delivered to the hospitalised patients to promote their physical activity including mobility (Kanai *et al.*, 2017). Three interventions started in the hospital and continued at home after patient discharge (Van Den Berg *et al.*, 2016; Vloothuis *et al.*, 2019; DePaul *et al.*, 2020). SM has been used with several forms of technology for easier delivery of instruction, feedback, communication, and follow-up with therapists. Examples of applied technology include telerehabilitation/ telehealth, e-health, mobile apps, and phone calls. Telerehabilitation was used as a part of intervention delivery in six studies (Huijbregts, McEwen and Taylor, 2009; Taylor *et al.*, 2009; Chumbler *et al.*, 2012; Sullivan *et al.*, 2014; Van Den Berg *et al.*, 2016; Vloothuis *et al.*, 2019). Phone calls were used for data collection (Kendall *et al.*, 2007; Chumbler *et al.*, 2012; Sullivan *et al.*, 2014) and as a part of an intervention to provide support or coaching sessions in (Sullivan *et al.*, 2014; Ezeugwu and Manns, 2018). E-health was integrated into SM to support the home rehabilitation programme (Van Den Berg *et al.*, 2016; Vloothuis *et al.*, 2019). The STARFISH intervention was delivered through a mobile app which

was also used to track and record physical activity out- comes (Paul *et al.*, 2016). The TASK programme was a video-guided exercise programme (Scrivener *et al.*, 2021) with two phases, 4 weeks with and 4 weeks without supervision.

3.4.4.4 ***Effects of SM on functional mobility and walking***

Overall, SM seems to have a positive impact on functional mobility and walking outcomes. The Time Up and Go (TUG) was improved significantly in five studies (White *et al.*, 2013; Treger *et al.*, 2014; Richardson *et al.*, 2015; Malagoni *et al.*, 2016; Ezeugwu and Manns, 2018). The mean changes in the TUG result across these studies were 3.29 s (p 0.00), 3.8 s ($p < 0.01$), 5.7 s (p 0.03), 13.26 s (p 0.01), and 2.21 s (p 0.00). The TUG improved in 81% of the participants in (White *et al.*, 2013) and subjectively a patient participant indicated *"One of them there, his walking from the first day to the last day improved 100%"*. In (Huijbregts, McEwen and Taylor, 2009) there was a significant difference in the Berg Balance Scores between the intervention group and the control group of the study (mean difference 4.27, 95%CI: 6.66 to 1.87).

Walking speed had significantly improved in five studies. Using the 10-meter walking speed and the 5-meter walk test, the mean change in walking speed in (Broetz and Birbaumer, 2013; Preston, Catherine M Dean, *et al.*, 2017; Ezeugwu and Manns, 2018; DePaul *et al.*, 2020; Scrivener *et al.*, 2021) studies ranged between 0.11 and 0.32 m/s (p 0.02). In (Treger *et al.*, 2014) there was a significant improvement in the intervention group as to the time parameter of the 10MWT (p 0.008), but no significant improvement was found in the number of steps taken. In another study (Olney *et al.*, 2006), the 6-min walking speed significantly increased in both groups post-intervention (0.09 ± 0.02 m/s in the unsupervised group, 0.06 ± 0.02 m/min in the supervised group) and remained significantly improved by 1 year. The improvement in walking speed was accompanied by a significant reduction in the sedentary time in a different study (Ezeugwu and Manns, 2018).

Walking distance significantly increased in six studies. The mean changes in the 6MWT were 20 ± 6 m (p 0.02), 15.36 m (p 0.02), 47.73 m ($p < 0.001$) and 85 ± 64 m post-intervention (Taylor *et al.*, 2009; Treger *et al.*, 2014; Portz *et al.*, 2018; DePaul *et al.*, 2020). In (Preston, Catherine M Dean, *et al.*, 2017) the 6MWT increased by 43 m (95% CI 10–76) at three months and by 61 m (95% CI 27–96) at six months post- intervention. In (Malagoni *et al.*, 2016) the 6MWT was significantly increased (p 0.03) in both groups of the study. One study showed trends toward improvement in the 6MWT in five out of eleven participants post-intervention (mean change 47.56 m) (Sullivan *et al.*, 2014). However, the authors reported a trend towards improved overall in all participants (25.73 ± 87.75 m). The improvement in the walking distance was associated with a significant improvement in the lower body strength (2.51 chair stands, p 0.01) (Portz *et al.*, 2018). The number of steps per day increased significantly in the two studies. The number increased by an average of 2895.5 steps/day ($p < 0.001$) in one study (Kanai *et al.*, 2017) and by 39.3% (4158–5791 steps/day) in the other one (Paul *et al.*, 2016). The walking time was also increased on an average of 20 min/day in this study.

3.4.4.4.1 Global measures of mobility

Participants had improved their ability to perform life tasks including daily activities at home and management of social tasks that involve mobility (Chumbler *et al.*, 2012). This was evident by the significant improvements in the basic lower extremity score within the function sub-scale of the LLFDI (increased from 59.0 to 64.9) and in four of the six LLFDI disability subscales. Participants who had received the intervention at home demonstrated a trend toward improved mobility at the end of intervention (the SIS mobility domain improved by 82.3 (95% CI (74.3–90.3) and the difference between control and intervention scores change was 9.8 (95% CI 20.1–0.4; p 0.06) in a study (Van Den Berg *et al.*, 2016). Participants completed 27 min/day (95% CI 4–49) at 3 months more moderate physical activity than at baseline (Preston, Catherine M Dean, *et al.*, 2017).

These findings were confirmed by participants perspectives regarding the positive changes in their mobility and walking ability after participation in SM programmes as a patient-reported *"I think I can walk easier and go farther now"* (Dean *et al.*, 2018; Portz *et al.*, 2018). The positive change was perceived by a gradual improvement in their physical fitness for mobility (improvement in speed, balance, and strength) and in their walking ability and endurance. The benefits due to incorporation of SM into exercise programmes were recognised by some participants who showed their persistence and desirability to continue exercising after study completion indicated by a patient as *"I had a lot of positive physical changes that gave me confidence to keep coming here"* (White *et al.*, 2013; Portz *et al.*, 2018; DePaul *et al.*, 2020).

3.4.4.4.2 Grade of evidence

The quality of evidence had a very low grade for the change in walking speed, endurance, balance, and physical activity (steps/ day), a low grade for (SIS-mobility domain), and a moderate grade for (Rivermead Mobility Index) (see Supplementary Appendix 10 for details).

3.4.4.5 ***Effect of SM on secondary outcomes***

Multiple studies (Haworth, Young and Thornton, 2009; Kanai *et al.*, 2017; Preston, Catherine M Dean, *et al.*, 2017; Ezeugwu and Manns, 2018) showed a significant improvement in participants' self-efficacy, exercise efficacy, and self-efficacy for physical activity (Table 1) except in two studies study (Preston, Catherine M Dean, *et al.*, 2017; Scrivener *et al.*, 2021) where the improvement was not statistically significant. In qualitative studies, participants perceived that the SM programme was a useful strategy for increasing physical activity and for improving confidence and skills related to participating in regular physical activity (Preston, Catherine M Dean, *et al.*, 2017). Positive change was also suggested by participants to express their improvement in confidence, motivation, self-efficacy, feeling of self-management and

self-control that enhanced their recovery, level of independence and to resume their life after stroke (Huijbregts, McEwen and Taylor, 2009; White *et al.*, 2013). The motivation was considered by participants as a facilitator that helped them to achieve positive changes. They also appreciated the presence of motivating peers and the encouragement provided by professionals and other stroke survivors (White *et al.*, 2013).

Quality of life measures was significantly improved in five studies. The SIS and SSQoL scores of different domains were improved ($p < 0.05$) in (Kendall *et al.*, 2007; Richardson *et al.*, 2015; Van Den Berg *et al.*, 2016; Ezeugwu and Manns, 2018). Also, there were some trends toward improvement in the SIS (mean change 1.45 ± 4.66) in (Sullivan *et al.*, 2014). The improvement of the physical dimension score of the SIS was associated with increasing in the Barthel Index (mean difference 10 and 95% CI 16.98, 3.02) in (Richardson *et al.*, 2015). The SAQoL significantly improved (mean 0.25, p 0.01) and the improvement remained for three months post-intervention (White *et al.*, 2013). The result of the EuroQual-5D showed some trends toward improvement (15 out of 100 points (95% CI 4–26) greater than at baseline) (Preston, Catherine M Dean, *et al.*, 2017). Although the findings of the reviewed studies showed changes in the self-efficacy and quality of life to different extents, the quality of evidence had a very low grade due to methodological issues (see Supplementary Appendix C for details).

Other physical secondary outcomes included participation, extended ADLs, fatigue, pain, and impairment. The included studies showed a significant improvement in the Chedoke-McMaster Stroke Assessment score ($p < 0.01$) for the leg impairment (Ezeugwu and Manns, 2018), Nottingham Extended ADLs (p 0.01) (Van Den Berg *et al.*, 2016), the pain of the knee and back (Broetz and Birbaumer, 2013), and fatigue (p 0.003) in the intervention group (Paul *et al.*, 2016). In the PROPEL trial, the intervention group had higher participation in physical activity measured by PASIPD (Hedge's g 0.5), had fewer barriers to physical activity, and

showed higher outcome expectations of their exercise than the comparison group (effects sizes 0.5 for SSOE) (Mansfield *et al.*, 2016). The SF 36 physical component was significantly improved ($p < 0.01$) in the supervised group who also had trends towards the improvement of HAP results (Olney *et al.*, 2006). One study showed a moderate improvement in activity level in both groups of the study with no between-group differences (Haworth, Young and Thornton, 2009). Also, the SF36 physical and general health domains showed trends towards increased positive change following the intervention, but these did not reach significant levels. Physical activity levels did not change in one study (Scrivener *et al.*, 2021).

The psychological outcomes reported were mood, depression and anxiety, self-esteem, psychological general well-being index, patient confidence and satisfaction. The reviewed studies showed significant improvements in patient's anxiety and caregiver's depression (p 0.023 and p 0.003) in (Vloothuis *et al.*, 2019), mood (p 0.04) in (Taylor *et al.*, 2009), and cognition ($p < 0.01$) in (Ezeugwu and Manns, 2018). In (Treger *et al.*, 2014) the score for the self-esteem within the DUKE Health Profile was significantly higher in the intervention group than that in the controls. Implementing of SM intervention for inpatients led to a significantly shorter stay at the hospital for the intervention group (p 0.04) and fewer read- missions over 12 months of their discharge ($p < 0.05$) (Van Den Berg *et al.*, 2016). Qualitative findings indicate that SM interventions such as video conferencing reduce isolation (Huijbregts, McEwen and Taylor, 2009).

Stroke knowledge was significantly increased in one study with 95% of participants improving their awareness about stroke and exercise tolerance (p 0.00) (White *et al.*, 2013). Qualitative findings (Dean *et al.*, 2018; Portz *et al.*, 2018) showed that increasing knowledge was considered by participants as an important component of SM interventions, explained by one participant as *"that was absolutely important, because it made sense of why you are doing"* (Dean *et al.*, 2018). However, it was not measured appropriately in most of the studies. Also,

goal setting which is deemed to be central for SM programmes was not commonly assessed. Only in (Taylor *et al.*, 2009), 66% of participants achieved their long- term goals and they met about 68% of their short-term weekly goals. The qualitative findings of one study indicated that most of the participants had not achieved all of their goals (White *et al.*, 2013).

3.5 Discussion

This study is one of the first that looked at the role of SM interventions to improve mobility as a specific outcome of stroke rehabilitation. Regardless of limitations in some studies, mainly due to methodological weaknesses, the overall findings of the reviewed literature indicate that SM interventions such as patient education, goal setting, action planning, self-monitoring, and professionals/carers support can help to improve functional mobility and walking. Additionally, other physical activity outcomes, self- efficacy, and quality of life of survivors with mild to moderate impairments post-stroke also showed improvement. The qualitative studies reviewed, highlighted the survivors' perceptions that indicated the importance of involving survivors in their care programmes and facilitating their independence using self-management. Across all studies, SM interventions were found to be feasible, acceptable, and appreciated by participants and their caregivers. SM interventions were not associated with any serious adverse event and can be applied safely in different contexts. Only three studies reported adverse events such as episodes of muscle soreness, fatigue, trips, or non-injurious falls (Paul *et al.*, 2016; Preston, Catherine M Dean, *et al.*, 2017; Dean *et al.*, 2018).

Our findings confirm the short-term efficacy of self-management interventions for mobility rehabilitation post-stroke which is consistent with other reviews on the effectiveness of SM programmes for improving functional ability, self-efficacy, participation, and quality of life post-stroke (Parke *et al.*, 2015; Pearce *et al.*, 2015; Warner *et al.*, 2015). Sustaining of the positive effect of SM interventions for the long term is important for stroke rehabilitation; yet most of the studies did not assess the long-term effect of the interventions.

Our results support the findings of other reviews (Pearce *et al.*, 2015; Warner *et al.*, 2015) that incorporating more of SM strategies in an intervention can lead to better outcomes and that strategies with behaviour change targets have more impact than other strategies. In some studies, it was not easy to identify all strategies that were used as some of them might have been used implicitly as a part of programme delivery. For instance, the process of action planning might include identifying of contextual barriers and motivation of participants without being reported as an explicit part of the intervention. Moreover, the use of some SM strategies such as caregiver support, group therapy, home visit, or tele-visit was described as optional in some studies and the effect of using such strategies was not measured. To draw a clear conclusion about their efficacy, researchers are encouraged to describe all strategies that were incorporated in the SM interventions.

There was no specific therapy training that was considered to be most effective in working with SM. The variability in practice might affect the effectiveness of SM programmes in different contexts. For example, the CARE4STROKE integrated the same SM programme to two different practice guidelines (in Australia and in the Netherlands) and had a different level of improvement in the outcome measures. Hence SM strategies need to be supplementary, flexible and tailored to the patient's context. Some inconsistent results were found regarding the perception of change following the intervention. Participants demonstrated that comorbidities, stroke sequelae and previous level of exercise might make a difference and work as a facilitator or barrier to the improvement in their physical activity post-stroke. All participants in the reviewed studies had mild to moderate impairments and people with severe impairments (physical, cognitive, or aphasia) were excluded. This confirms that this population might have less opportunities within community programmes as reported by the NICE guideline (2016).

This review found some technologies such as telerehabilitation, smartphones, videoconferencing, and online resources as useful tools that help to implement the SM programmes for survivors who live away from the areas of services or cannot physically attend their sessions. They also have been used to promote participants' independence in carrying out their training with minimal supervision of a therapist. This can provide proof of using these technologies for the delivery of care during the current situation of COVID-19 lockdown and related social distancing measures.

SM might not be suitable for every stroke survivor. A prior examination of the patient's readiness and intention to follow the SM programme should be considered. This review found only a few studies that considered this readiness prior to participants' enrolment in SM interventions. The Stages of Change tool within the Transtheoretical Model and Patient Activation Measure (PAM) to assess participants' readiness to change have been recommended by the reviewed studies (Richardson *et al.*, 2015; Mansfield *et al.*, 2016). Qualitative findings of this review indicate that motivated people can do better with SM programmes which reflects the critical role that patient's motivation can play in the successfulness of the implementation of SM interventions. Failure to address these confounding factors per- haps results in withdrawals that were reported in some studies.

Self-management was conceptualised variously by different stakeholders and in different cultures. It seems likely that the concept is ambiguous, or could have different meanings to different parties, or change over time depending on the purpose. This was evident in the participants perspectives about their experience with the SM programmes and in the rhetoric of researchers and authors of the reviewed studies. The conceptualisation of SM might change individual's attitude towards SM. For instance, some patients might think SM is to prevent them from attending rehabilitation facilities and to let them encounter the challenges

in their life after stroke alone and may feel abandoned by the services. Hence, there might be a need for explaining what SM means to the eligible participants.

There were some methodological issues reported in the reviewed study. Blinding was not possible in most studies due to the nature of self-management interventions. The number of men included within studies was notably higher than women in some studies. This does not reflect the incidence of stroke in women. Also, forming a group for interventional groups in the community with planned group sizes might have taken a long time, with possible wait times for some affecting participants' time of entry into the study. The use of cluster RCT has been suggested for future studies that will examine the effectiveness of these interventions to minimise the risk of contamination among participants and to ensure the proper formation of study groups. Our findings also suggest the use of qualitative methods in addition to the quantitative within the effectiveness studies as that can provide valuable insights on how participants perceived the implementation of SM interventions and if there are contextual issues that can affect the effectiveness of these interventions beyond the therapy protocols. Further, the effects or influence of self-management which is a complex intervention should also be interpreted against the background of several confounding factors that are common to rehabilitation research such as stage of recovery, the intensity of therapy, co-morbidities in this population and physical activity and motivational levels prior to their stroke.

The overall certainty in the evidence for the outcomes was rated using GRADE which can include RCTs and other study designs and if a study design and or quality is weaker than an RCT, the quality of evidence can be downgraded. Also, if a non- RCT meets certain criteria they can still be upgraded. We acknowledge that GRADE is not specific to observational studies (Mueller *et al.*, 2018) and that methods currently have not been identified for a gold standard quality assessment across study designs and limitations do exist.

3.6 Implications for rehabilitation research and practice

Self-management interventions can improve mobility-related outcomes, which are considered a priority goal for many stroke survivors. Participants in the reviewed studies valued their participation in self-management integrated care programmes and linked that to the perceived improvement in their rehabilitation outcomes. The outcomes that benefited to a slight extent using self-management were functional mobility, walking ability (speed, distance, and endurance), and a number of steps per day.

The review identifies the following strategies as vital to developing a complex self-management intervention for practice but that needs to be tested using research. The SM strategies highlighted by the reviewed studies for mobility training include patient education, goal setting, self-monitoring, and professionals/carers support. These were incorporated for the development of a self-management intervention that focused on mobility training in the community for stroke survivors (SIMS) in the complex intervention and tested for feasibility in study 3. These interventional components are described below:

1. Patient education has been considered as a fundamental step in increasing patient's awareness about their conditions and preparing them to take the role of self-management. Hence patient education resources need to be developed for practice and research based on patients' needs.
2. The involvement of patients in goal setting and action planning for their rehabilitation with a periodical follow up and encouragement by therapists was identified by the review as a key strategy.
3. Patient's self-monitoring using paper tools was found as a promising strategy that encourages self-motivation leading to patients to maintain/increase therapy.

4. Social support provided by carers, peers, or professionals can help psychosocial aspect of life challenges post stroke. The description of the SIMS is provided in more details in the feasibility study (chapter 5).

3.7 Conclusion

The findings of this chapter show that self-management interventions seem to be an effective approach that helps stroke survivors to improve their mobility training outcomes. However, participants level of ability, their specific goals, and stage of recovery should be considered when planning for any self-management programme to engage motivation and self-efficacy vital for SM. Many of the identified studies were feasibility studies. They were restricted in terms of the use of intensive resources that limited applicability of the intervention to the current NHS system. Also, most of these studies used only a generic outcome such as self-efficacy, quality of life or physical activity and were not clearly built on theory relevant to self-management or with the involvement of community clinicians and patients. Further research should build such interventions and examine the effectiveness of self-management intervention in the long term and report the specific components to improve transferability.

The next chapter (Chapter 4) discusses the need and implications for the role self-management that had been used by stroke survivors during the challenging period of the COVID-19 pandemic during which stroke care services were limited. It also explains the impact of the pandemic on the entire health care system, management strategies used by different stakeholders to cope with the situation, needs and priorities of stroke rehabilitation and suggestions to enhance future practice.

CHAPTER 4

EXPLORING THE EXPERIENCES OF PEOPLE WHO HAD A STROKE AND THERAPISTS WHO MANAGED PEOPLE WITH STROKE DURING THE COVID-19 PANDEMIC: AN EXPLORATORY QUALITATIVE STUDY

This chapter presents the full content of a published paper (Sahely *et al*., 2023), reporting verbatim text of the published paper and additional changes for the purposes of this thesis writing.

Publication and presentations

1. **Sahely, A.,** Kai Ning Hew, S., Ka Chan, Y., Soundy, A., & Rosewilliam, S. (2023). Exploring the experiences of people who had a stroke and therapists who managed people with stroke during the COVID-19 pandemic: An exploratory qualitative study. Plos one, 18(2), e0282325. **(appendix 3)**
2. **Sahely, A.,** Kai Ning Hew, S., Ka Chan, Y., Soundy, A., & Rosewilliam, S. (2022). Exploring the experiences of people who had a stroke and therapists who managed people with stroke during the COVID-19 pandemic: An exploratory qualitative study. World Stroke Congress 2022, Singapore (oral presentation).
3. **Sahely, A.,** Kai Ning Hew, S., Ka Chan, Y., Soundy, A., & Rosewilliam, S. (2022). Exploring the experiences of people who had a stroke and therapists who managed people with stroke during the COVID-19 pandemic: An exploratory qualitative study. UK Stroke Forum 2022, Liverpool, UK (poster).

4.1 Abstract

The COVID-19 pandemic had been hugely affecting access to the health care system and quality of services for all patients including for those who had a stroke during the pandemic. It was important to explore the experiences and issues that patients and providers faced during the pandemic to identify deficits in the system. Further, there was a need to identify possible strategies that were used to tailor stroke care for the benefit of those who faced challenges during the pandemic and for future patients in case of a severe wave. The aim of this chapter was to explore experiences, needs and rehabilitation priorities of patients who had their stroke and the experiences of therapists managing stroke patients during the COVID-19 pandemic.

An exploratory qualitative study was conducted including Twenty-two participants from acute, sub-acute and community stroke facilities. Twelve therapists (all female, mean age 38.5 years) and ten patients (9 female, mean age 51.1 years) who were involved in stroke rehabilitation during the pandemic were interviewed. Methods included individual semi-structured interviews. Interviews were recorded and transcribed before being analysed using a reflexive thematic analysis approach.

Four main themes demonstrate the modifications in the care system as a result of COVID19, impact on the stroke patients at different stage, needs and priorities of stroke rehabilitation, and management strategies that have been used in stroke rehabilitation. Remote rehabilitation and self-management strategies were recommended to deliver care for stroke patients. However, therapists seemed unsatisfied with the quality of care delivered and patients suggested face to face delivery of care with proper personal protection equipment to better address their physical and mental health needs.

The findings of this study explored the impact of the pandemic on stroke care from the perspective of the patients and therapists and provides suggestions for improved delivery of care in similar situations. The findings also demonstrated limited community care services

delivered during that period for stroke survivors, which raised the need for SM strategies to improve recovery. Future research is warranted to examine the long-term effects on people who had inadequate post-stroke rehabilitation during covid pandemic and urgent measures taken to reduce the impact the pandemic has had on the physical and mental issues for these patients.

4.2 Introduction

When the pandemic started early in 2020, the admission rate of stroke cases in the UK (100, 000/year before pandemic) fell markedly (Bersano and Pantoni, 2020; D'Anna *et al.*, 2021; Douiri *et al.*, 2021; Stroke Association, 2018). For example, in one London hospital there was one third reduction in the number of admissions; however, those admitted had significantly higher pre-stroke disability and greater severity of stroke at admission (D'Anna *et al.*, 2021). The rate of hospitalisation for TIA between March 23rd and 30th June 2020, was significantly lower (24.44%) along with reduced rates of thrombolysis [27 (11.49%) vs. 46 (16.25%, p = 0.030)] compared to the same period in 2019. Fear of COVID-19 infections, lockdown isolation, advice from doctors and media could have reduced the prompt admissions and the more severe patients being admitted (Aguiar de Sousa, Sandset and Elkind, 2020). It is possible that these patients who had a stroke during the pandemic suffered due to delayed access and reduced opportunities for rehabilitation.

There has been an increasing effort to understand the impact of the pandemic on the healthcare system for people with stroke; most research investigated the disruption in access and delivery of acute services including paramedical services, admission rates, hyperacute and acute-care, and the strain on the staff and caregivers in various settings (Douiri *et al.*, 2021; Lee *et al.*, 2021; Rees *et al.*, 2021; Sutter-Leve *et al.*, 2021; Busetto *et al.*, 2022). Only few qualitative studies have focused on the experiences of therapists during the pandemic from a rehabilitation lens, yet none has included patients' perspectives (Ditwiler, Swisher and Hardwick, 2021; Palacios-Ceña, Fernández-de-Las-Peñas, Florencio, de-la-Llave-Rincón, *et al.*, 2021; Palacios-Ceña, Fernández-de-Las-Peñas, Florencio, Palacios-Ceña, *et al.*, 2021; Palacios-Ceña, Fernández-de-Las-Peñas, Palacios-Ceña, *et al.*, 2021). Findings from these studies done in Spain and the United States, highlighted the psychological impact of the pandemic on therapists as front-line workers (Palacios-Ceña, Fernández-de-Las-Peñas,

Florencio, de-la-Llave-Rincón, *et al.*, 2021), their professional and ethical challenges when they were re-deployed into COVID-19 units (Ditwiler, Swisher and Hardwick, 2021), and their overall experience with providing care to the COVID-19 patients (Connell *et al.*, 2015; Palacios-Ceña, Fernández-de-Las-Peñas, Florencio, Palacios-Ceña, *et al.*, 2021; Palacios-Ceña, Fernández-de-Las-Peñas, Palacios-Ceña, *et al.*, 2021).

In the UK and other developed countries, recommendations for best practices of stroke care during the pandemic, including rehabilitation, have been developed based on evidence (mainly quantitative data) published during the pandemic and lack the understanding of lived experiences of people which might help better evaluation and addressing of the practice issues (Meyer *et al.*, 2020; Smith *et al.*, 2020; Pandian *et al.*, 2022). The impact of the delayed presentation of people with stroke, resource redirection, and reduced post stroke rehabilitation services on patients' recovery at different stages are still not clear in the current literature. There are also concerns that there will be severe long-term effects on the people who have had their strokes during the pandemic, worsened by the expected increase of having a stroke as one of the post-COVID -19 complications (Avula *et al.*, 2020; Gunasekaran *et al.*, 2020).

As the health services have been resuming their normal services, the backlog of healthcare in England continues to mount, which may take years to clear (British Medical Association, 2021). There is a key need to understand what patients missed during the pandemic and to identify priorities that ensure services can be tailored in any future disruptions. There is a need to be proactive and identify what patients' rehabilitation needs are in preparation for the huge deluge for rehabilitation (De Biase *et al.*, 2020). The aim of this study was to gain insight into experiences of people with stroke, therapists' experiences, management strategies, patients' needs and rehabilitation priorities after their first stroke during the pandemic.

4.3 Methods

Ethical approval for this study was granted by the Science, Technology, Engineering and Mathematics (STEM) ethics committee at the University of Birmingham (reference: ERN_21–0775). The interviews were collected between September 2021and January 2022. We followed the Consolidated criteria for Reporting Qualitative Research (COREQ) for methodological guidance (Tong, Sainsbury and Craig, 2007). A completed COREQ checklist is attached in appendix 18.

4.3.1 Design

The study used an exploratory qualitative design. Qualitative designs are more suitable to investigate individuals' experiences, beliefs, and opinions (Harding and Gantley, 1998). The authors of this study take a critical realist perspective that much of reality happens without an awareness of it. This suggests that an external reality exists, but one must access it through an individual's personal world (Archer, 2016). It aims to produce a deep and thick account of the processes that underpin the effects of pandemic on experiences of people with stroke, their lives and recovery (Archer, 2016).

4.3.2 Participants

Potential participants were recruited from the community via the websites Stroke Association, Different Strokes, and social media to make contact with stroke patients from diverse geographical and ethnic backgrounds. In addition, therapists were recruited through online professional forums such as the Chartered Society of Physiotherapy (CSP) and the Association of Chartered Physiotherapists Interested in Neurology (ACPIN). To identify a wider range of perspectives, a purposive sampling approach was used to recruit people involved in stroke rehabilitation (patients and therapists) since March 2020 (Bowling, 2014). Therapists were

recruited from various stroke clinical settings including hyper-acute, acute, sub-acute and community services to gain a wider insight into their experiences with stroke rehabilitation. At the time of the study many of them were redeployed in other areas due to Covid pressures. However, patient participants were mainly in sub-acute or chronic stage of recovery and they had been discharged into the community; access to patients in the acute setting was not possible because of the Covid restrictions. Eligible participants who contacted the research team to take part in the study were provided with a copy of the study information sheet (appendices 13,14) and asked to sign a written consent (appendices 15,16) electronically before the interviews. Snowball sampling was also employed as participants were asked to pass on the study information to people who they might know who fit the eligibility criteria.

Inclusion criteria for stroke patients were (i) Experienced a stroke (of any type) since March 2020; (ii) age ≥18 years old; (iii) cognitively unimpaired (screened with the Mini Mental State Examination (MMSE) (Folstein, Folstein and McHugh, 1975) and able to communicate clearly to express their views and provide informed consent; (iv) had access to remote meeting technology such as zoom or phone with speaker technology. The study excluded patients who had a TIA and have less need for services, people with severe cognitive or speech problems or cannot meet remotely for the interview. For therapists, the inclusion criteria included physiotherapists and occupational therapists who treated people with stroke during the pandemic and can meet remotely for their interviews.

4.3.3 Data collection

Data collection was done using individual semi-structured interviews using two separate topic guides for therapists and the people who had a stroke during the pandemic. The topic guides explored experiences, opinions, feelings and needs of participants with who had a stroke during the COVID-19 pandemic (attached in the appendices 11 and 12). The interview guides were

developed by experienced qualitative researchers based on the research objectives. The demographic data that included type of stroke, age, gender, time since stroke, and questionnaires for functional ability using Barthel Index (Mahoney, 1965), stroke specific quality of life measure (Williams *et al.*, 1999), mini-mental status evaluation (Folstein, Folstein and McHugh, 1975), and geriatric depression scale (Pracheth, Mayur and Chowti, 2013) were collected verbally with the patient participants. For therapists, data on age, gender, years of clinical experience, band, level of education, and practice setting were collected.

The data collection process was piloted in a sample of one patient and a therapist, carried out over zoom and recorded for transcription. The researcher made field notes following each interview to record emotions and any relevant situations. Interviews lasted on average 1 hour, ranging between 35 minutes and 1 hour 25 minutes. The primary researcher AS with previous experience in conducting qualitative research collected 80% of data and the other 20% were collected by two assistant researchers under the supervision of AS (YC and SH). The researchers had no prior knowledge of or contact with any participants in the study.

Data saturation guided the sample size for this study (Turner and Hersen, 1994; Mason, 2010). Recruitment stopped with simultaneous data analysis when researchers thought no new themes were emerging and which occurred after we completed 10 interviews with therapists and 8 patient interviews. However, two additional interviews were collected from each group to ensure data saturation was reached.

4.3.4 Data analysis

Data from interviews were transcribed using a transcription service. Then data was anonymised by removing any identifiable information and was analysed following the reflexive thematic analysis approach (Braun and Clarke, 2019). Coding and categorisation of data were done by the main researcher (AS) in addition to two research students (YC and SH) each of who

analysed (40%) of data from stroke survivors or therapists independently using iterative analytical methods (Graneheim and Lundman, 2004). The developed codes were shared and discussed between the analysts and then checked by two other senior researchers (SR and AAS) with expertise in qualitative research to improve rigour of data analysis and to solve any disagreement between the analysts. To eliminate researcher's interpretation bias and to increase the integrity of the study's findings, triangulation of codes from different data set (therapists vs. stroke survivors) and between the three researchers was applied (Öhman, 2005; Berger, 2015). The intention of research team was to use the themes derived from data related to the research objectives to build theory and inform future work.

4.4 Results

4.4.1 Description of participants

This study included 12 therapists and 10 stroke survivors with a wide range of stroke severity, in different stages of recovery, and from clinical setting and levels of expertise. There were two patient participants who were excluded because of the time after stroke (more than 6 months) and a therapist who had left the stroke team before the pandemic. Tables 1 and 2 summarise the demographic information of the participants.

Table 4.1 Characteristics of participating therapists.

Age	Mean (range) = 38.5 years (24-59)
Gender	All female
PT/OT	4/8
Years of clinical experience	Mean (range) = 14.6 years (3-37)
Level of education	2 College Diploma/5 BSc/5 MSc

Band	B5 (1 participant), B6 (4 participants), B7 (6 participants) and B8a (1 participant)
Clinical setting	1 hyper-acute, 2 acute, 4 acute and sub-acute, 5 Community

Table 4.2 Characteristics of the participant stroke survivors.

Gender (Male/Female)	1/9
Age	Mean (range) = 51.1 years (34-79)
Time since stroke (months)	Mean (range) = 7.6 months (3-19)
Type of stroke (Ischemic/Haemorrhagic)	8/2
Marital status (single/has partner)	4/6
The Barthel Index*	Mean (range) = 91 (70-100)
Stroke Specific Quality of Life**	Mean (range) = 125.9 (82-186)
Mini Mental Scale Examination***	Mean (range) = 26.6 (23-30)
Geriatric Depression Scale ******	Mean (range) = 5.8 (12-0)

*Scores <62.90 indicate moderate disability and scores <21.30 indicate severe disability (36)
** Higher scores indicate better functioning [28]; no indicative score ranges for low, moderate, high were available.
***A score of 23 or less can be a cut-off point indicating the presence of cognitive impairment [26].
**** A score of > 5 points is suggestive of depression [29].

4.4.2 Themes

The main themes derived from the data demonstrate the impact of modifications in stroke services due to the pandemic on the stroke care system, identify peoples' needs and priorities for stroke rehabilitation at different stages, and provide an insight into the management strategies that were used by different stakeholders in stroke rehabilitation. Fig 1. presents the themes and subthemes that were developed from participants' responses.

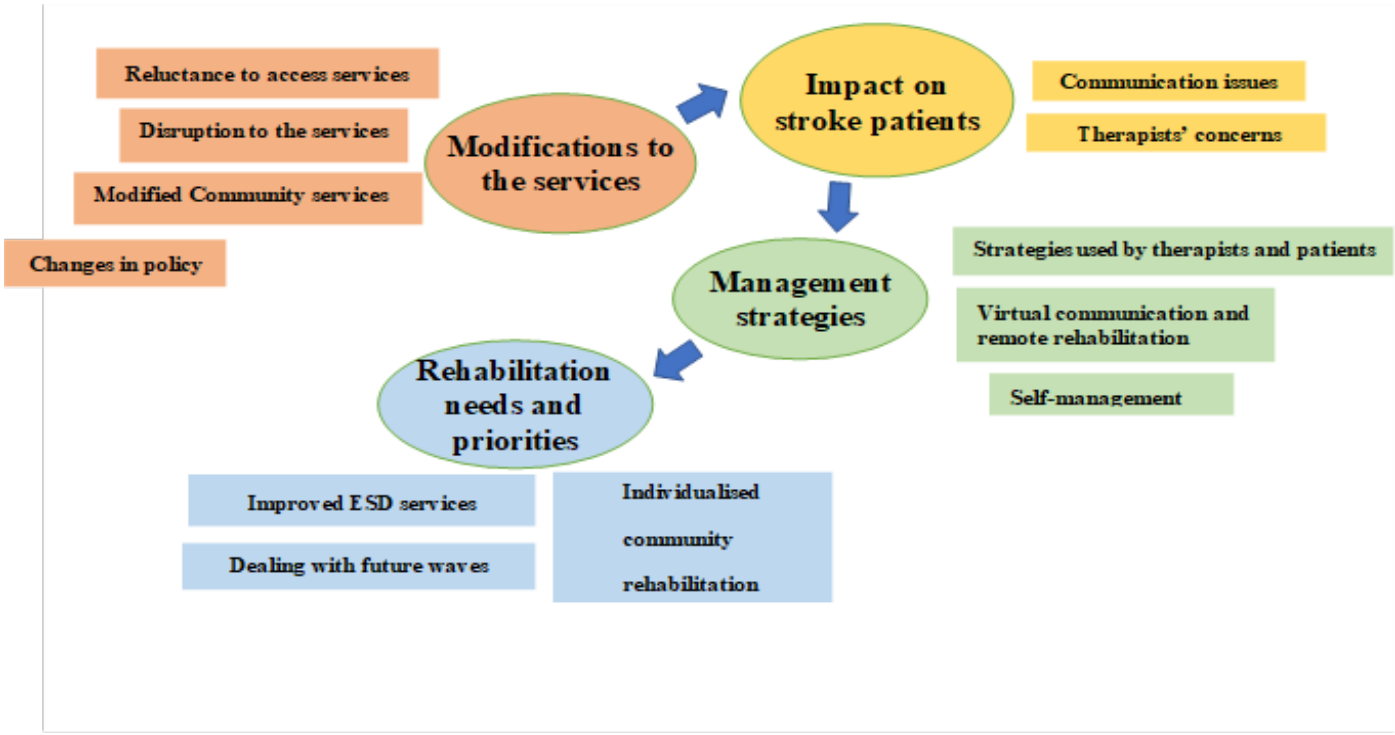


Figure 4.1 Themes and subthemes derived from study's data

4.4.2.1 ***Theme 1: Modifications to the services***

Stroke services, including access and delivery of care in the acute and community settings were disrupted. Changes to policy and staffing issues contributed to the disruption further which will be discussed in this theme.

a. Reluctance to access services.

At the beginning of the pandemic, patients were reluctant to come into hospitals and they suggested that media reports made people to be terrified.

> *''the last thing I wanted to do, I've not had COVID all the way through, and I was like we're in March, I haven't had it and if I if I'm going to hospital I'm probably going to get it in hospital" (Stroke Survivor 1)*

In some cases, it was reported that patients did not like to go to hospital unless they felt they had something serious because of their fear of infection. Moreover, a therapist said some cases had not come into hospital immediately for a first stroke.

''Nobody was presenting themselves to A&E. And then now in retrospect, people have come through the system and had their second stroke, so the first one maybe was a bit more mild and they just cracked on with it." (Therapist 1)

Further, some patients mentioned they had misinterpreted stroke presentation to be vaccine related symptoms and as a result, missed the FAST pathway to manage their initial stroke.

''I had some symptoms. . .but I've put it down to my vaccine because I'd have a vaccine earlier that week." (Stroke survivor 1) ''I believe the reason why I had the stroke is because of the Oxford vaccine." (Stroke survivor 2)

After discharge, some patients had concerns about home visits because of their fear of infection. Hence it was not surprising when therapists reported a reduction in the admissions to stroke unit along with reduced referrals to community services.

b. Disruption to the services.

Patients reported that due to lack of direct access to the GPs, which was limited to phone calls or through the NHS app during lockdown, patients with minor symptoms went unnoticed. Patients reported there were delays in their transfer to the hospital and admission to the hyper acute units.

''So, I went with them [ambulance] for like, seven, eight hours. And finally, while at the end, they did a brain scan." (Stroke survivor 3)

Participants indicated that they were unsatisfied with the NHS care due to the issues such as staff shortage, and delay in the diagnostic services such as CT scan. They believe that these challenges had existed prior to the pandemic but, had become worse during the pandemic.

"I don't think that had to do with the pandemic, it's just the NHS" (Stroke survivor 3)

The stroke wards were converted to COVID units which affected the availability of beds for stroke patients and in some cases people were moved to other locations several times. This issue also caused a lack of the therapy equipment and the space required for therapy.

"No, no. I had nothing in the [acute hospital]. Nothing." (Stroke survivor 2) "So, on our unit we had one of our bays was turned into a unit for COVID patients, so we had a mix of patients, either with or without COVID." (Therapist 2)

c. ***Modified community services***.

Some therapists reported that they were under pressure to discharge stroke patients earlier, since COVID patients were a priority for hospital beds. Therapists realised that some patients and their families were not prepared for discharge with no time for preparation or transition with limited handover. Also, there was no access to the gym and other rehab facilities and all therapy groups had to stop. Also, care homes were not accepting patients from the community stroke team.

"Relatives saying you can't send them home" (Therapist 1) "When people were doing home visits as well, and people couldn't go home to do a home visit to see if there was any equipment required, so again that was like some of the discharges weren't as safe as they should be."(Therapist 5)

Concurrently, there was a reduction in community services for patients after discharge from hospital.

''So, they didn't come. I was discharged in December and the first time they came was in April this year." (Stroke Survivor 5)

Patients also reported lack of therapists' commitment to home visits and delay in delivering essential equipment and services. Patients reported their feeling of being left alone after moving into the community and there was a lack of clear rehabilitation plans.

"No one rang me, they came and assessed me one day, and then they told me, we're sorry we won't be able to send physio. . . Well, I cried when they left, how can I wait 12 weeks for physio. So, I started then thinking, I might as well be dead. I may as well not recover because I can't just sit here and be like this." (Stroke Survivor 7) "I feel like at the time of

discharge, I was just left to it." (Stroke Survivor 2). "But you would have sent me home alone, which I think would have been a massive struggle for me, I could see." (Stroke Survivor 3)

Contrary to the above in some cases, Early Supported Discharge services did not stop (face to face visits) for newly discharged patients. However, therapists were concerned about the limited hours for stroke rehabilitation and that patients were given little if reached in the community (only an exercise sheet on request) in some cases. During the lookdowns, patients became very deconditioned as they were not allowed to go into shops to do mobility and shopping practice and lacked social interaction with people which increased risk of mental and emotional problems.

''We saw a lot of people coming into hospital, having become very deconditioned over the lockdown period because people stopped going out" (Therapist 4) ''They could have been sat in the care home for 4–5 months without any input, ... So, they were put at a disadvantage, and it's quite a lot of them patients, that when we eventually got to them, that they've been that deconditioned it's deemed that you know this is their new baseline, they don't actually have any rehab potential." (Therapist 2) ''patients were very isolated, very bored, very depressed, very scared. Physically they went down as well, downhill" (Therapist 6)

d. *Changes in policy.*

Therapists reported that as a part of safety assurance for people in the care facilities, risk assessments were introduced for therapists and patients. Therapists were classified into (clean & dirty/hot & cold) and therapists with high risk of COVID cannot see patients. Triage systems such as the traffic light (Red, Amber, Green) rating system were used to prioritise patients for receiving care. The triage and initial assessments were done mostly by phone for patients immediately after they were discharged.

"We kind of put a system in place, which was "red, amber, green" . . .. . . So, if they were green, we could go straight in once they were discharged from hospital. Amber the vulnerable, and red would be even if they are showing signs of COVID. . .. . . it works really well, because it helped us identify what patients definitely needed with the face-to-face intervention." (Therapist 4)

Checking against COVID-19 symptoms, wearing of the Personal Protective Equipment (PPE), and avoiding the mix of COVID-19 infected patients with non-infected patients were some of the new policies implemented in therapists' daily routine. In some contexts, there were some additional measures that were added based on personal judgments such as wearing fresh uniforms and washing shoes daily. Therapists were frustrated by these measures especially since proper PPE was not provided at some trusts and COVID-19 test were overwhelming as they took a long time to implement at the beginning of the pandemic.

e. *Staffing issues.*

Staff deployment was happening on different levels. For instance, stroke therapists and nurses were deployed to work on COVID-19 wards. There was also a deployment of staff from other teams to make sure that there's enough staff on the stroke ward.

"And they repatriated quite a lot of staff from the community, they pulled them into the acute setting. . .. . .there weren't enough staff sitting in the community." (Therapist 2)

This has been considered by some participants as taking a new role without proper training and raised a concern of uncertainty about what is coming.

"*We just became a generic therapist. we weren't physios or OTs or speech therapist. So, when the nurses were really short because half of them had COVID, you ended up doing your therapy quite functionally. So, you'd be helping to feed them at lunchtime or walking them to the toilet, or helping them wash, things that as a physio I wouldn't usually do." (Therapist 7)*

4.4.2.2 ***Theme 2: Impact on stroke patients***

Patients felt quite confused, because everything just happened so quickly. Some of them reported their frustration over poor care and losing the chance for better recovery as a result of the disruption to the services. Because of the staffing issue (i.e., staff shortage and deployment), some patients thought they had an awful experience under the care of unqualified nurses during the pandemic and received inadequate rehabilitation in the hospital.

> *"I don't think they could take care of me, though, there wasn't enough staff (Stroke survivor 6) ''I do feel sorry for the nursing staff because so we're under an awful pressure, awful lot of pressure, and I know I'm complaining, I'm not complaining but giving it to you as it is, and I don't like to put the NHS apart, they do a sterling job, but my experience, because of the pandemic, I think this horrendous. And I never ever want to go through it again." (Stroke survivor 2)*

Therapists and patient participants had similar concerns that patients' needs for rehabilitation were not met and that they were susceptible to physical and mental health complications. Therapists suggested that complications due to lack of therapy during acute stages will increase pressure on health care services due to future complications. Stroke patients who got COVID had to stay longer in hospital. Yet, the infected patients had delayed rehabilitation.

> *"And then I caught COVID in the hospital. I was also doubly infected. I think it delayed my beginning of physio and everything." (Stroke Survivor 3)*

a. Communication issues.

Inpatients experienced difficulty in communication with staff, because of the PPE and social distancing measures. This led to a lack of facial recognition and made it hard to build a healthy therapeutic relationship with inpatients. Inpatients were socially isolated as they had no communication with staff or other patients on the ward. Also, interpreters were not allowed to come to help non-English speakers.

"I think those patients for who perhaps English isn't their first language it was really tricky, because initially it was difficult to get formal interpreters to come to the ward." (Therapist 8)

Patients expressed devastation due to lack of family support and therapists reported losing the support of family in caring for inpatients. There was a feeling of loneliness and lack of family/friends support as no visitors were allowed.

"If the hospital could have let my daughter come in, or my granddaughter, or my friends, they could have done a lot for me while they were visiting. But as it was, everything I wanted, every time I wanted to go to the toilet, I had to call the nurse." (Stroke Survivor 4). "I didn't see any family for three and a half months; it was a long time." (Stroke Survivor 3). "This was one of their big issues at that time, not having a proper communication with their families and friends, and kind of feeling isolated at that time." (Therapist 5)

In some cases, the lack of mental and emotional support during the inpatient period had led patients to ask for early discharge from hospital.

"The sister on my ward. . .hasn't got time to talk, I never had a conversation with her ever. . . There was nothing said about your mental health, we were just left." (Stroke Survivor 4)

Additionally, the lack of access to the internet, TV or any other entertainments made it worse while staying in the hospital.

b. Therapists' concerns.

Some therapist participants expressed sadness over losing some of their colleagues in the pandemic and that had made them more scared of the situation. Therapists expressed their frustration with the management as they thought they should have had more training

opportunities for staff and teams in dealing with similar situations. They indicated that it was an even more challenging time for newly qualified therapists.

> *"Some are in their third year of placement. . .. . .the amount of hands on contact they've had with a patient is very minimal. So that's going to have a huge implication on how quickly we going to get out to patients, and also it's going to take us a lot more time trying to train up the band fives confidence." (Therapist 3)*

With regard to patients, therapists reported their feeling of letting patients down as no quality services were provided along the rehab journey even in the acute settings. While some therapists were keen to provide help for their patients, they had concerns about safety and infection control, which limited their support to patients.

> *"It is a difficult balance" (Therapist 1) "You couldn't progress them over the phone onto a walking stick, you just literally couldn't do that, you'd have to do that face to face with them." (Therapist 6)*

4.4.2.3 ***Theme 3: Management strategies***

This theme summaries the strategies that have been used by service providers or stroke survivors and their carers to manage the rehabilitation process and deal with challenges. Some strategies were implemented based on organisational and clinical practice guidelines such as early supported discharge and remote rehabilitation and others were initiated by patients such as self-management, goal setting and seeking social support.

a. Strategies used by therapists and patients.

In the inpatient settings, some participants managed to virtually communicate with relatives and friends. In some hospitals, this was facilitated by care teams to enable communication of inpatients with their families. In the community, patients had to manage their own rehabilitation at home as no services were provided.

"I was already independent before they [community physiotherapists] came in! What I did, I exercised myself, and I was determined to get downstairs. By the time physios came 12 weeks later, I was already doing the stairs and getting down to the bottom." (Stroke Survivor 8)

Some participants said they felt the need for private care while waiting for community services. However, private care was costly and participants were unsatisfied with their care quality. Both groups of participants liked how YouTube videos, online games, online stroke groups, social media helped their rehabilitation, especially when patients had financial challenges to pay for private services.

"*There are games which the patient can do, so that can almost be linked to a therapist device, so they could see how well they are getting on and how much rehab they're doing with their hand each day, you can set targets. . .. . . it tracks their progress and how much rehab they have done on it.". (Therapist 9)*

Some therapists also suggested photographing of the exercise programmes given in the hospital was useful for easier home implementation. Also, lending iPads to patients was a strategy used by some teams to enable patients to access rehabilitation remotely.

b. Virtual communication and remote rehabilitation.

Therapists indicated that the biggest modification for community teams was replacing face-to-face rehabilitation in the community with virtual communication. Virtual communication emerged as a new strategy to reduce direct contact with patients; this included virtual patients' assessments, remote delivery of therapy and follow up. Remote rehabilitation was implemented as the only option for the delivery of rehabilitation therapy for patients post discharge. Some therapists were not happy with the new policies regarding virtual rehabilitation at the beginning because of the lack of technology in the department to deliver services, difficulty in communication with some stroke survivors, and virtual assessments were not always accurate.

It was also challenging for some patients who did not have a device or any access to the internet, not familiar with technology, without carer support and were worried about their safety at home. Some trusts took some time to figure out a platform for virtual delivery of services, which raised staff frustration.

> *"There people who have refused onward referral, because they don't want people in their home, and they haven't got access to technology, or they are not in a position to use that." (Therapist 8)*

However, remote rehabilitation was appreciated by both groups as it was the only way of providing rehabilitation therapy. Therapists also alluded to video-communication as more effective than Tele-care as it allows them to see patients. They also suggested that younger stroke survivors were happy with online support, accepted and benefitted more from the remote therapy. Some therapists viewed virtual communication positively and thought it was more efficient (giving them time to contact more patients per day without physical travelling). They felt phone assessments were quicker and enabled collection of more detailed information.

c. Self-management (SM) strategies.

Although some therapists believe that SM should always be delivered as an important part of rehabilitation even before COVID, most therapists indicated their increasing effort to empower patients and their families for self-management during the pandemic. Patients themselves demonstrated self-motivation to carry out SM without any support from the NHS. There were times where SM was the only option to improve independence after discharge. Further, patients suggested that goal setting was vital for their rehabilitation as it pushed the boundaries for the individuals.

> *"They [the process of goal setting] are vital, absolutely vital, because I know what I'm working on, I've got direction." (Stroke Survivor 8)*

Some Early supported discharge (ESD) teams encouraged referrers to prepare patients for self-management and home exercises before they were referred to them. ESD therapists had also facilitated patients' discharge by providing education, involving patients in goal setting, and planning for training for the various stages of recovery. The constraint induced movement therapy, stretch classes and GRASP were mentioned as good examples of SM programmes.

> *"There was a big move towards giving more education whilst they are in inpatient, so that they were more informed about things like signs, symptoms, FAST, and perhaps more focus in terms of medication, again who to liaise with. . .. . . trying to empower someone, whether they were able to more self-manage." (Therapist 10)*

Another therapist explained that as

> *"we tell patients: We come. We guide. You do.' Instead of we come and do with you" (Therapist 11)*

Providing information packages and compiling apps and online resources from the Stroke Association or Different Strokes were other ways of supporting patients' information needs. Some patients found YouTube and online resources were helpful for teaching SM. Therapists and patient participants agreed that family motivation and encouragement could improve recovery at home.

> *"It was my family, my daughter. She did everything she could, she encouraged me to be motivated, at the time my mental health was down." (Stroke Survivor 2)*

Contrary to the support for SM, some therapists thought that patients' engagement in self-management was very variable ('self-management is not suitable for everyone'). Therapists suggested that the success of self-management strategies can be affected by fatigue, safety, motivation, self-efficacy and lack of preparation for SM. Also, patients explained difficulty of engaging in SM in the early days post discharge and for people with low functional capacity. They also suggested that an individual's SM plan should be regularly checked by professionals.

''I think there needs to be more regular check-ins from, perhaps GP or NHS personnel for stroke survivors. Especially from a learning curve. . .. . .. So, if you're going down the self-management route, then somebody has to govern and make sure that person's okay to do that independent work." (Stroke survivor 10)

4.4.2.4 ***Theme 4: Rehabilitation needs and priorities***

a. Improved ESD services.

Therapists believe people who had stroke during the pandemic experienced longer and slower rehabilitation. Therefore, they suggested that the main priority was maintaining the ESD and the community services on discharge.

''being able to see people on going in their own home, would be the better thing for these patients". (Therapist 2) ''I think, probably, maintaining the ESD and the community services on discharge, and how that happens, is probably the most important thing" (Therapist 4)

They indicated it was important to make a seamless service across the pathway starting with normal inpatient care with proper PPE. To improve inpatient care, therapists suggested better communication and emotional support, family visitations and participation in therapy sessions. Having sufficient staff and training especially for the ESD teams, more funding for social support services, preparing patients for discharge, psychological support and providing better resources for remote rehabilitation with family engagement can help to address rehabilitation needs and manage the waiting list for the community services.

''During the pandemic we managed, and now we're not managing. We can't get staff, and just so many more referrals, so I think that's the main priority that needs sorting out. People need the rehab straightaway, they need the physio straightaway." (Therapist 8)

b. ***Individualised community rehabilitation.***

Patients suggested engagement in individualised rehabilitation plans post discharge from acute care. Mobility was considered by participants as the main goal of physical rehabilitation to improve independence.

> *"My first goal was to stand up. . .. And I just said, I want to stand up, because I need stand up so that I can be transferred onto one of the pieces of equipment so I can move to the toilet and so." (Stroke survivor 6)*

Access to the gym and other equipment and joining therapy groups seemed to be a priority for patients if it was suitable for them.

> *"I hope there would be more OT [Occupation Therapy], I hope there will be more physio. I really like to be in a gym, I'd like to be able to use equipment to do things." (Stroke survivor 5)*

Patients indicated support for their mental health needs in different stages of their recovery. Participants said more conversations and information was needed for mental health in addition to support from the GPs.

> *"I think they should talk to you more, tell you about what's happening, what the prospects are, what you can do to help your mental health, give you more encouragement". (Stroke survivor 6)*

c. Dealing with future waves.

Some therapists described the current practice as a 'new normal' in which services are meant to go back to pre-COVID19 practice with new measures that can help to improve health and safety in future waves. The 'new normal' also gives the option for virtual communication and remote rehabilitation if needed and this was agreed by patients.

> *''I do have a patient currently now who still doesn't really want us to visit. She's much happier for us to converse through WhatsApp calls rather than a face-to-face, and we respect that". (Therapist 12)*

Participants discussed some plans on how things can be better done in the future. For instance, some therapists suggested strategic planning of how to manage their caseload in case of service disruption instead of redeploying staff or a complete stopping of services.

> *''I think there have to be lessons learned about trying to continue with community services and not redeploying staff" (Therapist 8)*

They indicated that the assessment in the beginning and the triaging are important to prioritise care of most needed individuals. Face to face rehab was suggested (by therapists and patients) in future waves with proper PPE even for patients in isolation.

> *"There is no reason for us not to continue normal care for patients". (Therapist 9)*

Therapists suggested remote rehabilitation can be implemented even for individuals who need to be isolated under some circumstances However, safety assurance and additional technology were required for practical delivery. Also, patient education and family involvement could help deliver rehabilitation in the community in addition to the Apps and online groups.

> *"It was in small group, people experiencing something like me, so we understand each other so we encourage each other." (Stroke Survivor 3)*

Patients and therapists agreed that relatives should be allowed to visit inpatients. In this case, infection control could be ensured by applying on site testing for COVID that can be more practical. Priorities for care identified by participants are summarised in appendix 17.

4.5 Discussion

This study is one of the first to describe the impact of the COVID-19 pandemic on stroke rehabilitation from the stakeholders' perspective in England. The findings of this study describe how the pandemic affected the stroke care system in various settings, modifications in patients' and therapists' practice, strategies that were used to manage the disruption in the services and outline the needs and priorities for future rehabilitation practice. The data was collected from patients and therapists' interviews with various demographic characteristics thus improving

validity and creditability of findings. Including participants from different geographical areas showed that there was variability in the organisational response to the pandemic in various settings. These differences in responses in various settings might have been influenced by the rapid spread of the pandemic locally, the daily updates leading to panic and ambiguous guidance from the local decision makers.

Interestingly, some patient participants mentioned that they thought their stroke happened because of their earlier COVID-19 infection which was also evident in other medical research findings (Avula *et al.*, 2020; Gunasekaran *et al.*, 2020). Moreover, participants indicated that the A&E staff and they were confused between stroke and COVID-19 as a cause of their clinical symptoms. Stroke symptoms like musculoskeletal pain and fatigue, headache, blood pressure, and vision problems were commonly found in patients with Covid. This issue might highlight the need for better differential diagnosis techniques when making a new diagnosis for people with a stroke in this pandemic era.

Participants in our study indicated that restrictions on communication and family visits in the acute settings had negatively affected their recovery. Similarly, participants in another study involving clinicians working in the intensive care units across the UK, showed their dissatisfaction with their way of interacting with patients' families during the pandemic and they expected patients, and families, to be negatively impacted due to this (Boulton *et al.*, 2022). In some cases, this issue was successfully solved by allowing inpatients to use technology to communicate with staff and see their families/friends remotely. It was even suggested to improve infrastructure for all inpatients facilities with proper technology to allow patients remote social communication that also reduce the need for physical visits as a part of the new normal services.

The findings of this study demonstrate the lack of quality of care along the continuum of stroke care in terms of rehabilitation. Patients expressed their frustration with the impact the

pandemic had made on the services and suggested face to face delivery of the rehabilitation services with proper precautions. Though most of the recommendations for best practices during the pandemic, suggest remote communication with patients as an ideal approach (Lyden, 2020; Smith *et al.*, 2020) patients still wanted face to face delivery and communication. There is a need to prepare and educate patients on the uptake and benefits of remote rehabilitation.

Despite the findings of some studies that delivery of stroke acute care has been maintained or even improved during the lockdown in the UK and other high-income countries (Douiri *et al.*, 2021; Pandian *et al.*, 2022), our findings show a level of incongruence between system effectiveness from an organisational perspective versus patient satisfaction about services. Also, the previous studies did not discuss community services which have faced more challenges and did not meet standards in some cases. This inadequacy to meet patient needs was reflected in the fact some of the narratives were emotional and patients requested for rest during the interviews. They alluded this emotional upset was due to the lack of psychological support especially during the pandemic and hoped to get that as a priority of care when services are restored.

Despite the relaxing of the COVID-19 measures and coming back to normal service delivery, the most striking issue in current practice for community services is how to manage the long waiting list of patients especially with the current early discharge policy. Our findings support the results of another study that early supported discharge plans for stroke patients were inappropriate, such as being unsafe and uncoordinated (Lucas, Gordon and Heyes, 2021). Patients were found to be discharged with delays in installing home equipment and further community rehabilitation. Moreover, families were inadequately prepared to care for stroke patients at home as a result of restrictions on visitations and communication with family during hospitalisation which was also identified as a big challenge for the caregivers of stroke patients

in another study in the United States (Sutter-Leve *et al.*, 2021). Caregivers in that study thought that frequent attendance of therapy sessions and direct communication with staff could improve their readiness for the discharge of their family members from inpatient rehabilitation. As that was impossible during the pandemic, they suggested alternative measures such as scheduled phone calls from all members of the care team and frequent video conference or footage from therapy sessions to keep the caregiver involved in the plan of care (Sutter-Leve *et al.*, 2021).

The healthcare needs of caregivers emerged strongly from participants' comments. Some carers and family members tended to display emotional vulnerability for the caring roles due to lack of social or psychological support. In a national stroke survey, 78% of the informal carers had alarmingly presented with severe mental health impacts during the pandemic (Stroke Association, 2022); psychosocial support needs to be extended to not only the stroke survivors but also their carers of people who had a stroke during the pandemic. In our study, community psychologist consultations received by a participant's family member was suggested as helpful; professional counselling might be one of the resolutions for caregivers to lessen their emotional burden and could in return benefit stroke patients' recovery (Perrin *et al.*, 2009).

The use of remote rehabilitation, online groups, and SM approaches have been found very effective for some patients in previous literature (Laver *et al.*, 2013; Warner *et al.*, 2015). During the pandemic, dependence on these approaches as the key strategy for improving recovery urges further uptake and adoption of SM during the period when the services are still catching up. However, SM was not the best option for everyone and the capacity of an individual for self-management involving remote rehabilitation should be evaluated (Clark *et al.*, 2018). Also, our findings confirm some challenges for the delivery of remote rehabilitation identified by previous research such as users' poor IT skills and resources, miscommunication between individuals, and safety issues (Di Lorito *et al.*, 2021). The remote delivery of SM is found to work best in cases of motivated survivors, having a supporting caregiver and when

therapists have a healthy relationship with their patients. These factors should be considered when planning for individual care and when planning patients' groups for therapy.

There were some limitations to this study. Some participants were unsatisfied with meeting online for the interviews, especially stroke survivors who weren't familiar with the use of technology. Consequently, the researcher had to do multiple meetings to carry out assessments and interviews in separate sessions. Most of our participants were female in both groups (only one male survivor), which might not represent the perspectives of male stroke survivors in the UK (males' prevalence (51%) > females) (NICE, 2022). However, it was not feasible for this study to purposefully recruit more participants based on their gender. This study included participants from Birmingham and London areas. Hence, to develop a national recommendation for best practices there might be a need for national research that can evaluate the system more widely. Also, the study only included patients from sub-acute and chronic stages; due to this limitation, we might not be entirely sure of the challenges faced by patients in the acute settings. However, as previously explained, access to acute patients was very restricted during the Covid pandemic. The findings of this study demonstrate the situation of the stroke services during the pandemic, when the interviews were collected, and future research can evaluate the long-term impact of the pandemic on service delivery after the relaxation of the control measures and when services return to normal or the new normal practice. A key question remains as what the residual long-term impact of the pandemic is on the health care system and patients who have had stroke during this pandemic situation.

4.6 Clinical messages

- Despite patients recommending face to face delivery with precautions, when offered self-management interventions, their ability to engage in self-management seemed to be activated since professional support was limited during the lockdown.

- Patients' competence to engage in self-management and remote rehabilitation should be assessed prior to delivering self-management due to challenges related to access and ability to use technology.
- According to patients, the use of technology was highly recommended as the only hope for participating in rehabilitation during the pandemic.
- Future clinical practice should consider the digital divide and improve opportunities for Information Technology education.

4.7 Conclusion

The findings of this chapter demonstrated the impact of the pandemic on stroke care and provided suggestions for optimal delivery of care in future situations. Future research is warranted to examine the efficacy of new strategies such as reducing the time for acute care and enhancing remote delivery of rehabilitation for people with mild to moderate impairments post stroke. This chapter also highlighted the valued support for self-management as an autonomous role some of the stroke survivors had to take during that time. They had to rely on their carers, and their individual ability for self-management as the only way of coping with their conditions while lacking formal support for care after stroke. Lessons from lived experience of participants can guide proper use of self-management strategies for survivors based on their individual needs and priorities of rehabilitation. The following findings from this study were considered in the design and delivery of the intervention study:

- Therapist participants suggested that the remote delivery of the intervention could be possible during the lockdown due to social distancing measures. However, some patient participants recommended missing out on receiving face to face therapy. Therefore, the delivery of interventions incorporated the views of both groups of participants, with precautions, the two options were provided to the participants in the feasibility study of SIMS.

- The digital divide was mentioned as a challenge for remote delivery of therapy by participants in this study. In the future studies, the research team was prepared to offer help with setting devices and training of participants if they needed help with online meetings.
- Therapists also suggested the inclusion of patients with cognitive, vision or hearing problems if they have a carer to support their safety at home. The decision making regarding the appropriateness of a patient for participation in programme was delegated to the therapists referring them to the study.
- The importance of online group sessions, providing information and pictures of the exercises to help delivery of the self-management intervention was reiterated by participants in this study. Hence the exercise booklet was designed with pictures and simple instructions based on their recommendations for the intervention.

Next chapter (Chapter 5) examines the feasibility of implementing and future testing of a self-management intervention targeting mobility rehabilitation in the community for stroke survivors.

CHAPTER 5

FEASIBILITY OF A SELF-MANAGEMENT INTERVENTION TO IMPROVE MOBILITY IN THE COMMUNITY AFTER STROKE (SIMS): A MIXED-METHODS PILOT STUDY

This chapter is still under review in preparation for publication in two separate manuscripts. One with the PhD student as a first author and in the other one as a co-author where some of his thesis data were shared with a team member who carried out blinded independent assessments for this study. Reports of the study have been presented in multiple occasions including the School of Sport, Exercise and Rehabilitation Research Day in January 2023, NHS staff part of the research team and the 9th Annual European Stroke Organisation Conference, May 2023.

Publication

Sahely, A., Soundy, A., & Rosewilliam, S. (2023). Feasibility of a Self-Management Intervention to Improve Mobility in the Community after Stroke: A Mixed-Methods Pilot Study. **(Under Review)**

Poster Presentation

Sahely, A., Soundy, A., & Rosewilliam, S. (2023). Feasibility of a Self-Management Intervention to Improve Mobility in the Community after Stroke: A Mixed-Methods Pilot Study. European Stroke Organisation Conference 2023, Munich, Germany (poster).

5.1 Abstract

Background: Self-management interventions have the potential to help stroke survivors to manage their rehabilitation after discharge from acute care. There is a need to develop an effective self-management intervention that can help mobility after stroke.

Objective: To evaluate the feasibility of implementing a self-management intervention to improve mobility in the community for stroke survivors.

Methods: A two-phase sequential mixed methods design was used (a pilot randomised controlled trial and focus groups). Participants were adult stroke survivors within six months post discharge from hospital with functional and cognitive capacity for self-management. The intervention included education sessions, goal setting and action planning, group sessions, self-monitoring and follow up. The control group received only education sessions and goal setting. Both groups enrolled for 3 months in the study in addition to usual care. The feasibility outcomes included recruitment rate, validity of eligibility criteria, retention rate, randomisation and blinding, participants' adherence to the intervention and follow up, appropriateness of outcome measures, and the fidelity and acceptability of the intervention. The assessments were collected at baseline, three months and six months and included outcome measures for functional mobility and walking, self-efficacy, goal attainment, cognitive ability, and general health. A descriptive analysis was done for quantitative data and content analysis for the qualitative data. Findings of quantitative and qualitative data were integrated to present the final results of the study.

Results: Twenty-four participants were recruited and randomised into the study groups (12 each). It was feasible to recruit participants from hospital and community, but the rate was low due to effects of the COVID-19 pandemic. Randomisation and blinding were successful. Eighty-three percent of participants were retained at 3 months assessment and 79.2% at 6

months assessment. Adherence to the intervention components (group sessions, recording dairy and pedometers, and follow up calls) varied mainly due to post stroke fatigue, COVID-19 and the impact of mood changes. It was feasible to deliver the intervention online with no serious events related to their participation. Focus groups discussed participants' motivations for joining the programme, their perspectives on the intervention (fidelity and acceptability) and methodology, perceived improvements in walking outcomes, facilitators and challenges for self-management, and suggestions for improvement.

Conclusion: The self-management intervention seems feasible for implementation for stroke survivors in the community. Participants in intervention group appreciated the support provided and showed the desirability to continue following the protocol after finishing their participation. The study was not powered enough to draw a conclusion about the efficacy of the program and a future full-scale study is warranted.

5.2 Introduction

Every year, stroke affects more than 100 000 individuals in the UK (Stroke Association, 2018). Following a stroke, about half of the people who survive need help with their daily activities as a result of various impairments that affect their physical, cognitive, emotional, and social well-being (Feigin *et al.*, 2008; Heart and Stroke Foundation, 2017). A major physical disability following stroke involves limitations in an individual's lower limb activities such as balance and mobility (Heart and Stroke Foundation, 2017; West and Bernhardt, 2012). Mobility has been found to be a key problem for two-thirds of people after stroke and can lead to depression and isolation (Lawrence *et al.*, 2001; Pinter and Brainin, 2012). Rehabilitation is deemed to be essential for the recovery process after stroke as it helps to improve the impaired functions resulting in a better quality of life for stroke survivors (Veerbeek *et al.*, 2014).

Improvements in functional outcomes can be facilitated by increased intensity of therapy especially during the first 3-6 months after stroke as the neurological and functional recovery are optimal in this period (Lohse, Lang and Boyd, 2014; Livingston-Thomas *et al.*, 2016). However, evaluation of current practice in the UK shows that the intensity of therapy delivered for stroke rehabilitation in the stroke units is less than optimal (11.24 (SD = 7) minutes vs. 45 minutes) and 45% of stroke survivors might not receive adequate therapy after leaving hospital (Stroke Association, 2016a; Clarke *et al.*, 2018; Tyson, Woodward-Nutt and Plant, 2018). The situation had worsened due to the impact of COVID-19 on health services (D'Anna *et al.*, 2021). During the pandemic, stroke survivors were rushed for early discharge from acute care with limited support in the community, due to services that had stopped completely during lockdowns. Survivors had to rely on their carers, and their individual ability for self-management as the only way of coping with their conditions while lacking formal support (Sahely *et al.*, 2023a).

Prior to the pandemic, it has been evident that the delivery of a higher intensity therapy and support for survivors with mild to moderate impairments post-stroke can be provided through Self-management interventions (Sahely et al., 2022; Warner et al., 2015). Self-management (SM) has been recommended as an approach that empowers the role of patients in facilitating their recovery in addition to the usual care provided by professionals (Rudd *et al.*, 2016). SM interventions use strategies such as patient education, involvement in goal setting and action planning, peer support, and self-monitoring to enhance individual's independence in managing their therapy plans (de Silva, 2011). In the last decade, various SM interventions have increasingly shown a positive effect on survivors' self-efficacy, emotional and functional recovery, and social participation (de Silva, 2011; DePaul et al., 2019; McKenna et al., 2015; Parke et al., 2015; Sahely et al., 2022; Warner et al., 2015). However, most of these studies used only a generic outcome such as self-efficacy, quality of life or physical

activity and applied SM interventions that involved extensive involvement of the therapists over a large number of therapy sessions and follow up; such use of resources is unrealistic in practice. There still is a need for development of effective interventions that apply self-management principles for rehabilitation of specific outcomes such as mobility.

Overall, SM interventions for improving the mobility of stroke survivors in the community are uncommon (Lennon, McKenna and Jones, 2013). Recently, there have been some studies that used SM, some of which incorporated interventions to improve mobility outcomes after stroke. Examples of these interventions include the Independent Mobility-related Physical Activity (IMPACT) Program (DePaul *et al.*, 2020), the Rehabilitation Training (ReTrain) intervention (Dean *et al.*, 2018), the Extended Rehabilitation Service (EXTRAS) for **s**troke patients (Shaw *et al.*, 2015), and the Bridges self-management programme (McKenna *et al.*, 2015). The results of the previous studies confirmed that SM interventions delivered for individuals or in groups in the community can be effective for people after stroke. However, most of the interventions used in these studies were criticised for their high resource requirements and ambiguity regarding the theoretical underpinnings, factors that make them challenging to implement in the NHS system. Therefore, development of a comprehensive SM mobility intervention that can be realistically embedded within the current practice of stroke rehabilitation has been suggested (Sahely *et al.*, 2022). To the best of the authors knowledge no further studies have addressed this gap following the publication of the review. Work was undertaken to address the gap in the current practice by developing a self-management intervention that focused on mobility training in the community (SIMS). The SIMS was developed based on evidence from a systematic review of the literature about self-management for mobility rehabilitation following stroke (Sahely et al., 2022) and in consultation with senior stroke survivors and NHS clinicians as an effort for knowledge translation into practice. The description of the SIMS is provided in the intervention section.

5.2.1 Aim and objectives

To examine the feasibility of a newly developed self-management intervention for functional mobility for stroke survivors in the community (SIMS).

The specific objectives were:

1) To evaluate the feasibility of implementing the new intervention in stroke rehabilitation services in the local community using a mixed-methods study design.
2) To explore participants' perspectives about the acceptability, practicality, and fidelity of the new intervention.
3) To scope out methodological feasibility for a future randomised control trial.

5.3 Methodology

5.3.1 Design

A two-phase sequential explanatory mixed methods design was undertaken including a feasibility randomised controlled trial (two arms, assessor blinded) followed by focus groups. The first phase included quantitative methods examining the feasibility of the intervention using standard outcome measures while the intervention was carried out to the participants. This then followed by qualitative focus groups with participants to get deeper understanding of their lived experience within the study and to suggest direction for future research. The mixed methods approach was used to elaborate, complement and triangulate findings from each method (Bryman, 2006). The study was conducted between December 2021 and March 2023. The CONSORT 2010 statement: extension to randomised pilot and feasibility trials (Eldridge *et al.*, 2016) was used to guide the conduct and reporting of this study.

5.3.2 Participants and sampling

Participants were purposefully selected using a criterion-based sampling as they needed to have a certain level of mobility and cognitive ability to participate in this study. Participants were eligible if they; (a) were adults (18 years to 99 years), (b) diagnosed with a first stroke, (c) within six months post-discharge from the hospital, (d) with Functional Ambulation Category (FAC) ≥ 2 (at least able to walk with a maximum of one person assistance, with or without a gait aid (Mehrholz *et al.*, 2007), (e) had cognitive capacity to communicate and consent to participate in the study (screened using MoCA), (f) could speak or had a family member who spoke English, and (g) had access to a suitable electronic device to meet on Zoom if they had to join the study online.

Patients were excluded if they were medically unstable or had other major co-morbidities that might be a risk for community walking, severe cognitive impairments, severe aphasia, severe spasticity or severe arthritis.

5.3.3 Setting

Participants were recruited from different teams (i.e., early discharge, and community service teams) a rehabilitation hospital in Birmingham, UK and online through Stroke Association and Different Stroke websites. We recruited participants from multiple teams since this has the advantage of ensuring the study protocol and intervention can be widely implemented and tested on participants with diverse levels of clinical trial experience and resources (Arnold *et al.*, 2009). All the study activities took place in participant' homes, online via Zoom, or in the school of Sport, Exercise and Rehabilitation Sciences at the University of Birmingham. Data collection (intervention and assessments) took place between December 2021 and March 2023.

5.3.4 Sample size

As no formal sample size calculations are required for feasibility studies and the objectives of trials focused on feasibility can often be met with relatively few numbers of participants, we aimed to recruit 90 participants (45 per group) (Browne, 1995; Thabane *et al.*, 2010).

5.3.5 Randomisation, approach and consent procedure

Stroke survivors were approached by their therapists at the sub-acute rehabilitation hospitals and through referrals made by Early Supported Discharge (ESD) team or the community therapists. Eligible Participants, who showed interest in taking part in the study to their therapists, were provided with a consent to contact form (appendix 25) for further contact by the research team. The researchers contacted the eligible participants to check their readiness in joining the study after providing them with information sheet (appendix 24), data management plan (appendix 26) and obtaining consent for their participation (appendix 23). After providing a written consent, the participants were assessed at baseline and then randomly allocated to treatment or control groups by an administrator using computer-generated randomisation chart.

5.3.6 Intervention

The intervention group received the SIMS in addition to any usual care provided to the participants by the NHS. All components of the SIMS were delivered for the intervention group in their homes when they were visited by the research team or through online zoom meetings over a period of 12-weeks. Self-monitoring was done by participants using a pedometer and a recording diary to record their daily training and number of steps. Details of the SIMS protocol are provided below and reported in the appendix 31 using the TIDieR (Template for Intervention Description and Replication) Checklist.

Week 1: (Group and Individual)

• Education about impact of stroke, improving gait, self-management and safety (appendix 28).

• Self-management strategies including individualised goal setting for mobility goals and action-planning (appendix 29) using exercises from a booklet based on their baseline assessment. The exercise booklet (appendix 19) was developed based on evidence and had a selection of appropriate exercises for strengthening, balance and endurance improvement.

• Patient were taught home exercises using the same exercise booklets and self-monitoring of mobility training was done using a recording diary (appendix 30). A safety tips documents with resources for guidance was provided prior to the start of exercise plan (appendix 27).

Week 2, 4, 6, 8 &10: (Group)

Participants had an online meeting every two weeks for group exercise sessions and peer support was provided by an experienced stroke patient in one of the weeks. The researcher conducted one group session per week for 10-12 people where participants are taught exercises for strengthening, balance, and mobility from the exercise booklets.

To improve safety in zoom classes, a qualified researcher and a registered therapist were both present to deliver the classes.

Patient-experts will provide peer-support during the group sessions. The patient-experts are stroke-survivors who were paid from the PPI costs.

Week 3, 5, 7, 9 &11: (Individual)

A follow up call was made by the research therapist for reviewing goals, updating exercise plan and patient's progress in the programme every fortnight.

Week 12: (Group)

At week 12, a reiteration of safety, review of mobility-training and positive reinforcement were discussed with each participant for long term sustainability.

5.3.7 Control

The participants of this group received an education session about walking safely at the beginning of the study (week1) using a power point presentation. Due to the COVID pandemic the education sessions were delivered through zoom unless patient requested a physical presentation at their homes. They set goals at the start of the study along with the researcher. The control group also received the routinely provided care by the community services for stroke survivors after their discharge from the stroke unit. The usual care in this context is guided by local practice in the NHS and is expected to follow the national clinical guidelines for stroke care.

5.3.8 Outcomes

Participants demographics and stroke related information such as age, gender, height and weight, stroke type, time since onset, affected side of the body, use of mobility aid, presence of carer and GP addresses were collected at the baseline.

Feasibility outcomes included: recruitment rate (proportion of eligible participants who enrolled in the study) and validity of eligibility criteria (number of participants eligible/not eligible for each criterion), feasibility of randomisation and blinding and ability to reduce contamination, retention rates (proportion of enrolled participants who completed the study), fidelity and acceptability of the intervention (lived experiences and perspectives of participants from focus groups), participants' adherence to the intervention and follow up (the number of days the participants did their exercises and recording diary) and feasibility of the selected outcome measures. Participants from both groups were asked to describe what they had received from the NHS as usual care for their rehabilitation at baseline and at the end of their participation.

Focus groups used an interview guide that included questions to explore acceptability, practicality, sustainability, effectiveness, and ways to improve intervention from participants' perspectives (appendix 21).

Progression criteria

The feasibility of conducting this study was determined by some pre-defined criteria following the RAG (Red, Amber, Green) rating system described by Avery *et al.,* 2017. This includes an acceptable rates of recruitment, retention and participants adherence to the SIMS intervention.

Recruitment rate: participant response

- Red: if < 25% of eligible patients were recruited.
- Amber: if 25 - 50% of eligible patients were recruited. If recruitment rate is low, then it is possible to approach patients referred to the early supported discharge team within the trust and apply an online recruitment.
- Green if > 50% of eligible patients were recruited.

Retention rates (at 3 and 6 months):

- Red: Follow-up rate < 50%
- Amber: Follow-up rate 50 -70%. In case of high attrition we will explore reasons and modify barriers
- Green: Follow-up rate > 70%

Adherence to the intervention:

- Red: if < 30% patients.
- Amber: if 30-50% patients. As a plan, adherence will be encouraged through periodical telephone reminders and group meeting.
- Green: if > 50% patients.

Assessments included outcomes related to the constructs of self-management such as self-efficacy and goal-achievement in addition to mobility related physical and psychosocial outcomes. Self-efficacy was measured by using the stroke self-efficacy questionnaire (Jones, Partridge and Reid, 2008). The Goal Attainment Scale (GAS) was used to measure participants ability to achieve their goals (Hurn, Kneebone and Cropley, 2006). The Patient Specific

Functional Scale was used to assess participants' ability to perform specific daily activities related to mobility (Stratford, Kennedy and Wainwright, 2014). Level of adherence and performing of other self-management related elements were examined using the Patient Specific Functional Scale, the recording diaries of physical activities, and action planning documents.

To determine the impact of SIMS on participants' mobility; the Functional Gait Assessment (FGA), Timed Up and Go, 10-meter Walking Test, Six Minutes Walking Test, number of steps walked per day using pedometer were used. These outcome measures have been tested for reliability and validity to detect changes in stroke population (Lam *et al.*, 2010; Lin *et al.*, 2010). To examine the cognitive and psychological well-being, the Montreal Cognitive Assessment (MoCA) and General Health Questionnaire (GHQ-12) were used (Hardy *et al.*, 1999; Cumming *et al.*, 2013). A table demonstrating the rationale and psychometric properties of the used outcome measures is provided in appendix 32.

The selected outcomes were measured at study baseline and three months later (at the end of the intervention) followed by a follow-up assessment at six months from the start of the study. The participants self-selected themselves to participate in focus groups after study completion.

5.3.9 Ethics and registration

Ethics approval for this study was initially obtained in June 2020 from the Health Research Authority (HRA) at the NHS (IRAS project ID: 269079). However, due to the situation of the COVID-19 pandemic, the research team applied for an amendment to the approved protocol to allow for online delivery of the intervention and to recruit participants directly from the community and a final approval was received in June 2021 (appendix 22). The study was registered prospectively on the ISRCTN registry (ISRCTN15728885) in September 2021.

5.3.10 Data analysis

A descriptive statistical analysis was used to describe the demographic data, results of the feasibility and clinical outcomes (Pagano and Gauvreau, 2000; Lancaster, Dodd and Williamson, 2004). The frequency counts such as means, standard deviations or ranges of values were used to summarise the analysed data. The aim of the data analysis for the efficacy outcome measures was to evaluate the feasibility of using these outcome measures, keeping in mind that feasibility trials are underpowered to detect clinically significant treatment effects (Arnold *et al.*, 2009). Microsoft Excel Version 2016 was used to carry out the descriptive analysis of quantitative data.

For the qualitative data from focus group interviews, a qualitative content analysis approach was used to present the identified themes from participants' discussion about the SM intervention (Harding and Gantley, 1998; Graneheim and Lundman, 2004). The data from focus groups were coded by the first author (AS) and themes then built in an iterative process. The other two authors (SR and AS) have independently reviewed the codes and themes and discussed their perspectives in a meeting with first author.

The findings from focus groups were integrated with results of the quantitative outcomes in the results section by matching themes with the relevant quantitative data. The integration of qualitative and quantitative data has been suggested in mixed methods studies to provide a comprehensive presentation of findings from both approaches addressing the same objectives rather than presenting them separately (Guetterman, Fetters and Creswell, 2015).

5.4 Results

The results of feasibility outcomes; recruitment and validity of eligibility criteria, randomisation and blinding, retention, fidelity and acceptability of the intervention, and feasibility of selected outcomes are presented with relevant themes/sub-themes derived from the qualitative data in this section. There were six themes derived from focus groups including

1) motivations for joining the programme, 2) participants' evaluation of the programme, 3) perceived benefits, 4) facilitators of self-management, 5) challenges for participation in self-management, and 6) suggestions for improvement. Participants' quotes are provided anonymously to support the results of qualitative findings as needed. The integration of quantitative and qualitative data relevant to each feasibility objective is summarised in table 1.

Table 5.1 Integration of findings in relation to feasibility objectives

Feasibility objectives	**Quantitative data**	**Themes and sub-themes**
I) Recruitment rate and validity of eligibility criteria	- Participant enrolment - Validity of eligibility criteria (participant exclusion) - Participants characteristics	Theme1) Motivations for joining the programme with the subthemes • the hope for improvement and independence, • helping themselves and others by taking part in research, • not receiving enough care from the NHS and • self-management is a part of journey post-stroke
II) Randomisation and blinding	- Number of participants randomised - Ability to blind assessors and reduce contamination	Theme 2) Participants' evaluation of the programme with the subtheme • perspectives on the randomised design
III) Retention rates	- Number of enrolled participants who completed the study - Adverse events	Theme 2) Participants' evaluation of the programme with subtheme • factors influencing continuation in the programme
IV) Fidelity and acceptability of the intervention	- Delivery of the components of the intervention i.e. education sessions, goal setting and action planning, online group meetings, and follow ups - Reporting of usual care and how the	Theme 2) Participants' evaluation of the programme with sub themes • Effective protocol elements • Adjunct to usual NHS care Theme 3) Perceived benefits with sub themes - achievement of goals, - motivation to work harder, - improvements in walking, - mental health and - socialisation)

	intervention fits with usual care	Theme 4) Facilitators for self-management intervention related with sub themes • education, • peer support, • technology Theme 5) Challenges for self-management with sub themes • stroke and other health related challenges Theme 3) Perceived benefits with sub themes • Adjunct • Flexibility of programme
V) Participants' adherence to the intervention and follow up	- Number of participants who - completed recording dairy, - used pedometer, - Attendance at sessions - Response to the follow up calls	Theme 4) Facilitators for self-management with sub themes • Time for adjustment, • previous knowledge and experience, • social support Theme 5) Challenges for self-management with sub themes • personal factors • technical factors and • environmental factors influencing adherence
VI) Feasibility of collecting outcome measures	- Completion of assessments at 3 assessment points.	Theme 2) Participants' evaluation of the programme with sub theme • perspectives on outcome measures

5.4.1 Feasibility of recruitment and validity of eligibility criteria

5.4.1.1 ***Participant enrolment:***

Screening and recruitment were carried out between November 2021 and August 2022. A total of 451 patients were screened by four care teams at the hospital setting. Thirty-eight patients of the 451 screened were eligible. Of these 38 eligible patients, 17 did not join the study when they were approached (2 admitted to the hospital, 2 went back to work, 3 were found ineligible, 2 had private physiotherapists, 8 refused or thought they were not ready to participate when they were approached). Of the 3 ineligible persons, one person deteriorated and had a poor FAC (< 2), the second person had a cardiopulmonary disease, and the third person had a very poor vision (needing guidance for walking). Twenty-one patients referred by NHS therapists participated in the study. In addition, there was one participant who was referred to us by a previous participant and two participants who joined the study through the Different Strokes website. There were 6 patients from Different Strokes who were excluded after they were found ineligible because they were more than 6 months post discharge from hospital. Applying the RAG system, the recruitment was rated as ‘’Green’’ as more than 50% of eligible participants who were recruited and referred to the research team from the NHS were enrolled in the study. However, the recruitment rate was very low at the study site at screening level which was influenced by COVIID-19 and discussed further in the discussion section.

Therefore, the total number of participants enrolled in the study was twenty-four. The flow of participants in the study is summarised with reasons for not meeting the eligibility criteria in figure 1 based on the CONSORT guidelines.

5.4.1.2 ***Participant exclusion:***

At the screening stage, numbers of patients excluded for each criterion are described. The highest number of exclusions was because of not meeting eligibility for mobility which needed

to be at moderate levels to carry out self-management (83 patients had poor mobility and 72 patients had very good mobility scores). Numbers of patients excluded for other reasons were: not a first stroke (45), co-morbidities (42), communication issues/aphasia (41), cognitive impairments (39), medically unstable (15), > 6 months after discharge (11) and other reasons (42) including language, social issues, leaving UK, moved to another care team, back to work, hearing and vision problems. In addition, there were 29 patients who were eligible, but were not interested in the study or refused physiotherapy.

Eligible participants who joined the study revealed certain reasons that motivated them for participating in the study These motivations are presented with quotes from focus groups below.

5.4.1.3 ***Motivations for joining the programme from theme 1***

Participants' key motivations for joining the study included a hope for improvement and independence in life post-stroke, and a desire to help themselves and others by taking part in research that can improve their status.

> *"I think I'm always happy to help if I can, doing on research - anything - to improve things" (P2, IG).*
>
> *"hopefully, we can pass information over that's benefitted us and hopefully benefits other people." (P5, IG).*
>
> *"one of the problems I've had for a while because of the strokes, has been the balance, and because you were doing a research-type programme on balance. I considered that you would be looking at things slightly different from the normal people, which may mean that you find something that they haven't, that helps me" (P6, IG).*

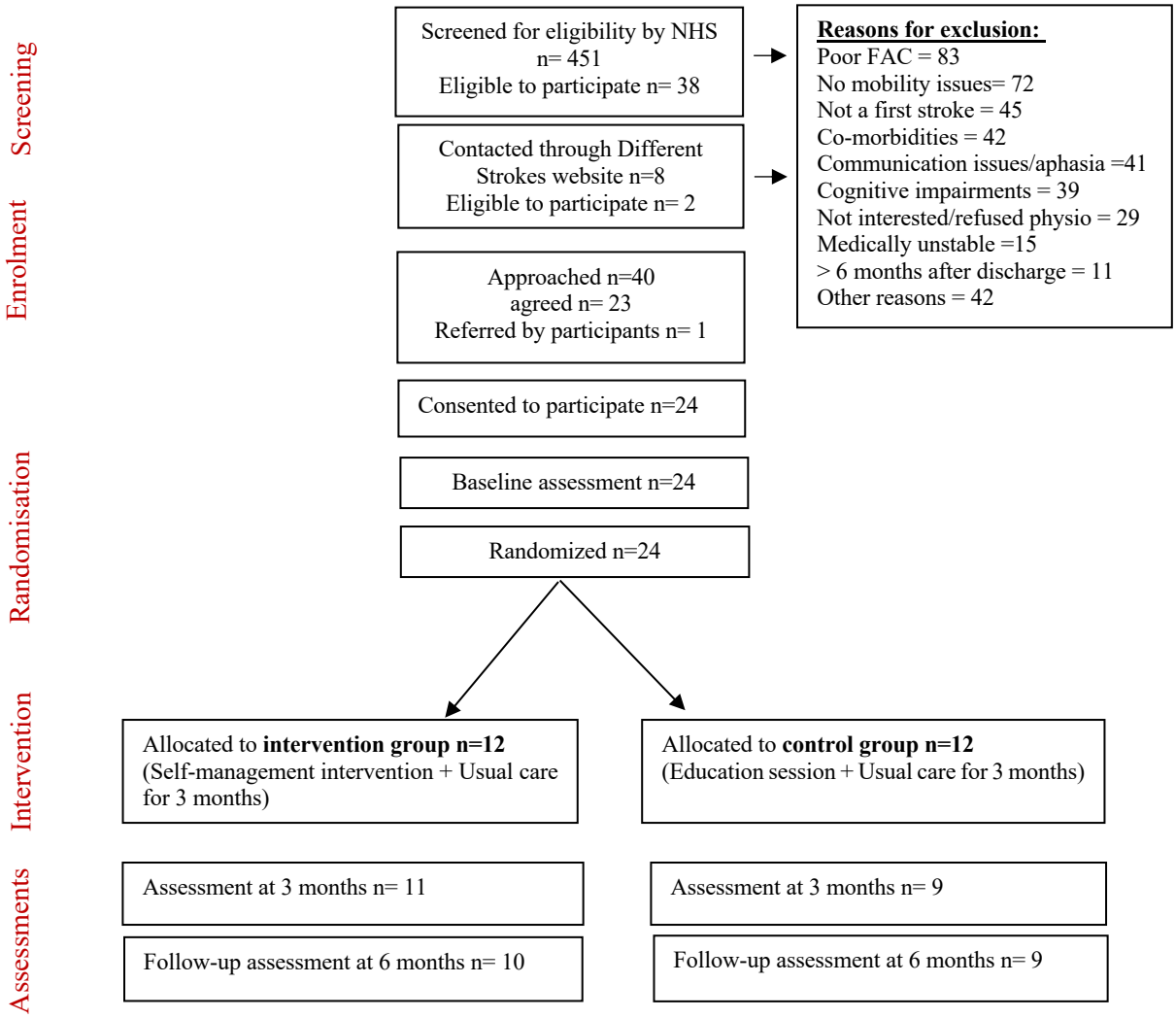
They were not receiving enough care from the NHS and that lead to their belief that the ability to self-manage their condition is a part of journey post-stroke.

"I wasn't really getting very much therapy from hospital, so anything that could help me recover was a good shout." (P4, IG).

"It fitted in quite well, and the only thing I found was if we were trying to get through to the NHS, you wouldn't be able to get through them that quick." (P9, CG).

"Yes, because it just is part of your journey and you improve." (P1, IG).

Figure 5.1 Flow of participants in the study.



5.4.1.4 ***Participants characteristics***

The sample represented a wide range of characteristics of stroke population in the post-acute stage. Participants aged between 36 and 87 years (mean = 67 years). The number of male participants was higher than females (14 vs. 10 participants). Nineteen participants had an

ischemic stroke and 5 had a haemorrhagic stroke. The left side of the body was affected in 14 participants and the right side in 10 participants. Participants were within 6 months of discharge from hospital (mean time = 4.3 months) except one person who started the programme 7 months after discharge. There were 16 participants who lived with a carer/family member. The mean scores of outcome measures for both groups at baseline are presented with demographic data in table 2.

Table 5.2 Participants' demographics and baseline data

	Total **N = 24** Mean (range)	**Intervention group** **(n=12)** Mean (range)	**Control group** **(n=12)** Mean (range)
Mean age (range)*	67 years (36-87)	63 years (36-86)	71 years (45-87)
Gender (F/M)	10/14	6/6	4/8
Height (cm)*	166.35 (147.32-185.42)	166.87 (147.32-184.15)	165.84 (152-185.42)
Weight (kg)*	72.20 (45-101.6)	76.59 (45-101.6)	67.81 (46-98.42)
Time since stroke (months)*	4.3 (2-7)	4 (2-7)	4.5 (3-7)
Stroke type (Ischemic/Haemorrhagic)	19/5	9/3	10/2
Have a carer	16	9	7
Affected side of the body	14 Left and 10 Right	7 Left and 5 Right	7 Left and 5 Right
Stroke self-efficacy questionnaire*	86.16 (61-121)	85.83 (111-61)	86.5 (121-61)
Functional gait assessment*	17.58 (7-29)	18 (12-29)	17.16 (7-26)
10 Meter walking test (m/sec)*	Comfortable walking = 0.51 (0.06-1.44)	Comfortable walking = 0.53 (1.44-0.11)	Comfortable walking = 0.493 (1.12-0.06)
	Fast walking = 0.60 (0.09-1.28)	Fast walking = 0.607 (1.02-0.11)	Fast walking = 0.59 (1.28-0.09)
Timed up and go (sec)*	26.28 (5.97-97.44)	23.15 (58.34-10.92)	29.42 (97.44-5.97)
6 minutes walking test (m)*	141.1 (26-300)	151.87 (40-260)	130.29 (26-300)
Patient specific functional scale*	3.75 (0.5-7)	3.74 (0.6-7)	3.76 (0.5-6.66)
Montreal Cognitive Assessment*	22.7 (11-30)	22.41 (11-30)	22.91 (18-26)
General Health Quesionnaire-12*	18.04 (33-6)	16.25 (6-29)	19.83 (9-33)

**Values are provided with means and range*

5.4.2 Feasibility of randomisation and blinding

After baseline assessment, all the 24 participants who consented to participate were successfully randomised to one of the two study groups (12 participants each). At post intervention assessment, participants were asked if they knew any other participant in the study and only 2 participants (8.33%) said yes. However, they were both in the same group and were friends before joining the study.

Blinding of the assessors was considered successful as no participant revealed their allocation during assessments and the first assessor was not able to identify any group assignment of participants. Each of the second and third assessors correctly identified 16.66 % of assignments when they were asked after the study.

Participants perspectives on randomised design from theme 2

Some participants in the focus groups were generally satisfied with the structure of the study which involved a control group receiving minimal help.

> *"I thought the structure was good." (P1, IG).*

Two participants from intervention group expressed that they would have had concerns about not receiving the intervention, if they had been assigned to the control group. They suggested comparing two effective treatments instead of no treatment in one group.

> *"if you've got two groups surely they should have the same." (P5, IG).*
>
> *"Can I say I don't believe or don't like placebo effects, ……. So, you're not really sure whether you're being treated properly or whether you're just being left to let it happen as it happens." (P6, IG).*
>
> *"I think you can have two groups who have different treatments, but they are treatments, and you work out which one is the better one, but not there's one who's not having any treatment at all" (P5, IG).*

5.4.3 Retention

Of the 24 participants enrolled at baseline, 20 (11 from intervention group and 9 from control group) were retained at three months assessment, and 19 at follow up (10 from intervention group and 9 from control group). Following baseline assessment, 1 participant from the intervention group withdrew as he moved to another country and another participant from the control group died before the 3 months' assessment. Two participants from control group were not available for post intervention and follow up assessments due to social issues and a fracture of leg (unrelated to participation). At follow up assessment, another participant in the intervention group was lost due to admission to the hospital for unrelated condition (chest infection). The retention rate was rated as ''Green'' (>70%) of participants at each point of assessment.

5.4.3.1 ***Adverse events***

There were some reported events that were related to participation each of which are commonly experienced to different levels by stroke survivors. These events included muscle pain, fatigue and depression because of not achieving some goals. Other events (not-related to participation) included a death of one participant the control group after baseline assessment, 2 fractures (1 neck and 1 leg), 5 COVID-19 infections, 1 pneumonia and 1 chest infection.

5.4.3.2 ***Factors influencing continuation within programme from theme 2***

Participants attributed their motivation to continue in the study to certain elements of the study. For instance, some participants attributed the continuation in the study to the increased understanding of their condition and the programme that was provided throughout the education sessions.

"I have a better understanding. So, you don't actually give up because you've got a purpose and a goal to aim at, and that's because of the support that you've been given from this understanding" (P6, IG).

Also, participants liked the level of independence the programme gave them in carrying out their daily training with support of therapist provided if needed.

"I quite liked the fact that you weren't in my face all the while. Even though I knew you were there, that you weren't hassling, you weren't going how's it going? You set the target. Yes, and you just left us to it." (P10, CG).

Another element that motivated them to continue was the goal-setting introduced to them through the education session provided at the beginning of the programme.

"It was really easy because it's mostly like target setting, when he was talking about it[education], in your head you could - in my head, I could see what I could possibly do or not do" (P10, CG).

5.4.4 Fidelity and acceptability of the intervention

5.4.4.1 ***Delivery of the intervention components:***

Fidelity in this context is described as the extent to which the intervention is delivered as planned in the protocol (Breitenstein *et al.*, 2010). This section provides an evaluation of the ability to deliver the components of the intervention (education sessions, goal setting and action planning, group sessions, and follow ups) and qualitative data around, factors that affected the fidelity of intervention (facilitators and challenges for self-management). Acceptability is illustrated by factors relevant to perceived benefits that lead to acceptance of the protocol, presented from focus groups responses.

Over the period of the study (15 months), we were able to deliver 20 education sessions. Most of the sessions were delivered individually for participants in both groups except for 4

participants who had their education sessions with another participant. Most of sessions were delivered online via Zoom meetings except for 2 participants from control group who asked for physical delivery of the sessions at their homes. Each session took 25-53 minutes.

Goal setting and action planning were delivered during a home visit for each participant except for 2 participants who joined the study online from distant geographical area. Each session took around 60-90 minutes. All participants were all provided with hard copies of the exercise booklet, safety tips brochures, recording diaries and pedometers in person for everyone except for those who lived far away in which case these documents were sent by email or post. They also successfully received training on how to use these materials.

For the online group meetings, we were able to deliver 28 sessions out of 30 scheduled during 15 months of intervention delivery (session/2weeks). Each session took 57-83 minutes. Two sessions were cancelled because of bank holidays. All the sessions were carried out online although the participants were given the option for physical attendance of sessions. To follow up with participants regarding the goals and exercises plans, 5 calls were scheduled for each participant in the intervention group during their participation (total = 60 calls). We were able to successfully make 49 calls (13-27 minutes each).

5.4.4.2 ***Participants' evaluation of the programme from theme 2***

Participants in the focus groups considered the protocol to be structured and components of the self-management as helpful for patients with complex situations.

> *''I think it was very good, in a way, you have a set programme to go by and trying to work as closely as you can" (P2, IG).*
>
> *"It has helped me quite a bit really, because I'd had more problems and I found you very helpful." (P8, CG).*

Particularly, participants found the information provided in the education sessions simple to understand.

‘‘it was easy to understand, yes.” (P8, CG). ‘‘the information was obviously good and …… I get on with them and it's very good the way I think your programme is run.” (P5, IG). ‘‘it was really easy ……. when he was talking - in my head, I could see what I could possibly do or not do. So yes, it was very good.” (P10, CG).

Some participants positively commented on the methods of communication used by the research team considering participants’ individual preferences.

“It's good communication, emails, Zoom and text message and actually call” (P1, IG).

They were positive about the exercises provided within the booklet and the recording diary and desired to continue using them after the programme finished, further indicating acceptability of the study elements.

“I managed to get through them all, which I was very pleased with because it's that extra push again, isn't it, to try and motivate yourself into doing a bit more.” (P3, IG).

“Also, something that I found very, very useful was filling in the diary. Having that each day to complete, I found that really useful as well as the Zoom sessions.” (P3, IG).

“So until it becomes the norm I'll continue, and I want to do a lot of things.” (P7, IG).

“I think in fairness, you were very, very considerate, because there's a lot of the times that I couldn't make and you went out of your way to try and compensate for me, and I appreciated that quite a lot.” (P6, IG).

5.4.4.3 ***Perceived benefits from theme 3***

5.4.4.3.1 A good push for more training

Participants indicated that they were encouraged by the components of the intervention to increase their training. They considered this ‘a *good push for more training '.*

The education session and goal setting were seen to work together to support the planning of therapy.

> *"Well, the main thing about that was the understanding of what you were offering and what was wrong with me, because if I have an understanding of what's wrong and what you're offering, I can coordinate the two and it makes more sense then." (P6, IG).*

The programme gave them a plan for the day and enabled self-monitoring which encouraged them to do more training.

> *"I think the design of the study is, well, very well organised and it's right in what you've got to do everyday" (P1, IG).*
>
> *"It's given me another a couple of batteries in and I'm setting myself goals again, whereas before I was just going down and down and down" (P7, IG).*
>
> *"I did find that it gave me that extra motivation to exceed my previous scores - which is good - and then week by week I can see, track my improvement. Yes…" (P4, IG).*
>
> *"It encouraged you to do a bit more" (P9, CG).*
>
> *"Every morning it introduced me to a pattern where I knew I'd got to do something, and at night recording it. So that, even though it's not a lot, it helped me out." (P10, CG).*

They indicated that they gained more confidence to do their exercises and desired to follow the same protocol after finishing the programme.

> *"Sometimes I think you can give up on exercises, and if somebody comes back and helps you to get back onto it you've got that encouragement, because it's hard." (P5, IG).*

They also expressed their fear of losing this motivation after finishing their participation.

> *"since we've taken that off, we haven't got that little motivation now" (P9, CG).*

5.4.4.3.2 Goals were reached

Participants showed their happiness due to achieving goals. Some patients explained that they were encouraged by goal setting to achieve better outcomes such as independence and desired to continue setting goals in their future.

> *"Yes, I definitely am. Once I've reached those goals, I want these goals until I get back to as normal as you can." (P1, IG). "I fortunately have managed to… As I had my assessment the other day, I was able to… I have, yes, achieved pretty well the goals that I wanted to" (P3, IG). "over the time period of the programme, you have an independence to go even to the toilet or just walk around with this. I think I wouldn't have done it, but in the end with this programme we are achieving, and we are moving forward." (P4, IG). "Oh yes, I did reach those. I think I've told you, I go dancing." (P8, CG).*

A participant indicated that prioritizing of goals at the beginning of the programme might be a challenge and therapist's support can help in overcoming this challenge.

> *"At that time, you didn't know what your first priority was." (P9, CG).*

The scores of goal attainment scale for the intervention group participants showed that 2 out of 11 participants achieved their mobility related goals much better than expected (> 60) 3 month (end of intervention), 3 achieved their goals better than expected (50-59), 5 less well than expected (40-49) and 1 much less than expected (< 40). For control group, there were 2 participants who achieved their goals much better than expected (> 60) at 3 months, 2 better than expected (50-59), and 5 less well than expected (40-49).

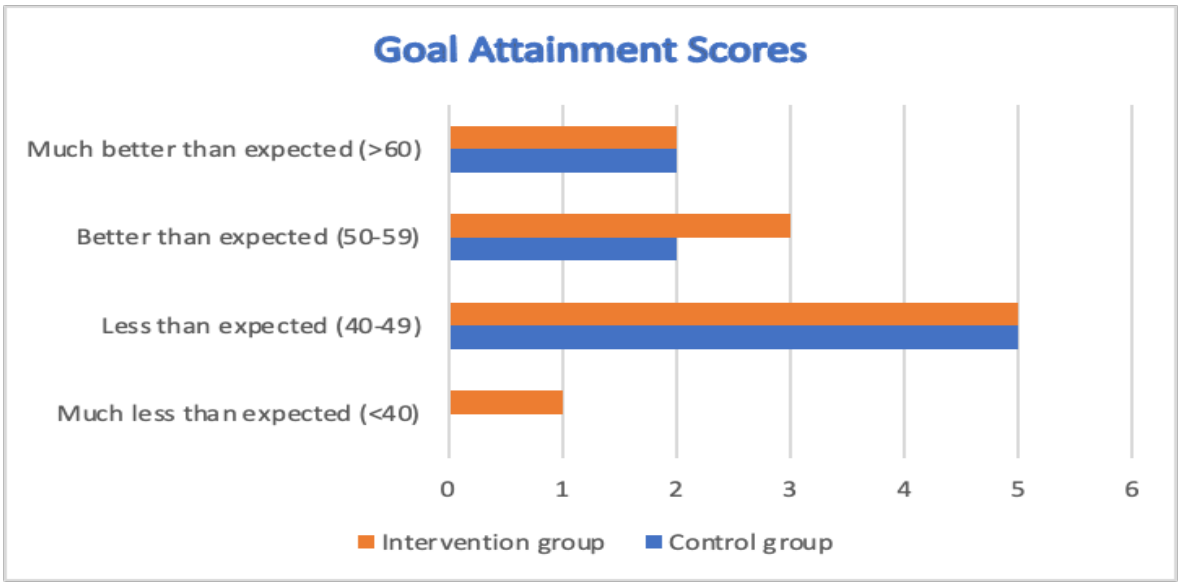


Figure 5.2 GAS scores for both groups

5.4.4.3.3 Walking improvement

Improvement in walking variables were seen in the result of assessments. Table 2 show the difference in the walking outcome measures (walking speed, distance, endurance) at the second and third assessments. Steps per day have been increased in the intervention group from 1674.14 steps to 3293.42 steps on average within 12 weeks. In the control group, the average of steps per day has increased from 1790.55 to 3002.77 steps. Figure 3 shows steps per day over time for both groups. Number of participants using assistive devices has been reduced in both groups from 5 to 3 in the intervention group and from 7 to 3 in the control group post intervention. This improvement was sustained till the time of follow up assessment (6 months) in the two groups.

Table 5.3 Mean scores and standard deviations of functional outcome measures at baseline, 3 month and 6 months.

	Baseline		***3 months***		***6 months***		
Outcome measures Mean (SD)	**Intervention**	**Control**	**Intervention**	**Control**	**Intervention**	**Control**	***Effect size (Hedges' g)***
Stroke self-efficacy questionnaire	85.83 (17.97)	86.5 (19.43)	98.2 (17.22)	97.44 (18.11)	93.9 (21.57)	99.88 (17.81)	0.043

Functional gait assessment	18 (5.70)	17.16 (6.05)	20.4 (5.01)	19.33 (6.22)	20.50 (5.70)	19.44 (7.17)	0.19
10 Meter walking test (comfortable)	0.53 (0.34)	0.49 (0.31)	0.54 (0.27)	0.54 (0.28)	0.53 (0.28)	0.60 (0.23)	0.00
10 Meter walking test (fast)	0.60 (0.29)	0.59 (0.33)	0.71 (0.38)	0.66 (0.38)	0.70 (0.40)	0.72 (0.30)	0.13
Timed up and go	23.15 (12.97)	29.42 (25.66)	20.24 (12.75)	16.73 (9.09)	17.94 (10.18)	16.54 (8.06)	0.31
6 minutes walking test	151.87 (67.66)	130.29 (87.03)	153.4 (70.40)	171.27 (68.49)	168.7 (67.45)	179 (75.01)	0.25
Patient specific functional scale	3.74 (2.23)	3.76 (1.8)	5.16 (2.77)	6.99 (1.80)	5.43 (2.39)	7.14 (1.83)	0.76
Montreal Cognitive Assessment	22.41 (5.51)	22.91 (2.67)	21.8 (5.31)	22.77 (3.59)	22.5 (4.79)	22.88 (3.62)	0.20
General Health Quesionnaire-12	16.25 (6.31)	19.83 (7.32)	13.3 (6.40)	13.55 (6.48)	14.10 (6.80)	14.87 (9.46)	0.03
Goal attainment scale	-	-	50.43 (11.25)	51.81 (12.85)	-	-	0.11
Use of assistive device	5	7	3	3	3	3	-

Participants reported perceived improvements in their walking in the focus groups from their lived experience.

"I've seen the difference, the strength in my leg; it's been brilliant, to be fair" (P1, IG).

Particularly, participants mentioned walking more steps without a stick, increased confidence in walking, improved walking beyond NHS care, and that they have Improved because of the programme.

"I found that very good. I pass my goals kind of thing. I've done 10,000 steps and I feel

I could do that easy now daily, but I'm now without my stick now, which is brilliant." (P1, IG).

"I found all of it very useful because I started off just about being able to move with a frame and to walk, and now I can walk in the house just using a stick - which is brilliant really - within just a few months." (P3, IG).

"Following on from the physiotherapy that I had via the hospital meant that I was able to walk better." (P3, IG).

"It does give you a little bit more confidence. I've started to walk again around the road." (P5, IG).

An improvement in socialisation and participation was also attributed to the programme in the focus groups.

"It's only because of the programme, I think, we're doing this: it's only because of the programme, you pushing us." (P2, IG). "So yes, and I'm going out now, walking, and I'm socialising more. So yes, I think I have reached the goals that I wanted to." (P8, CG).

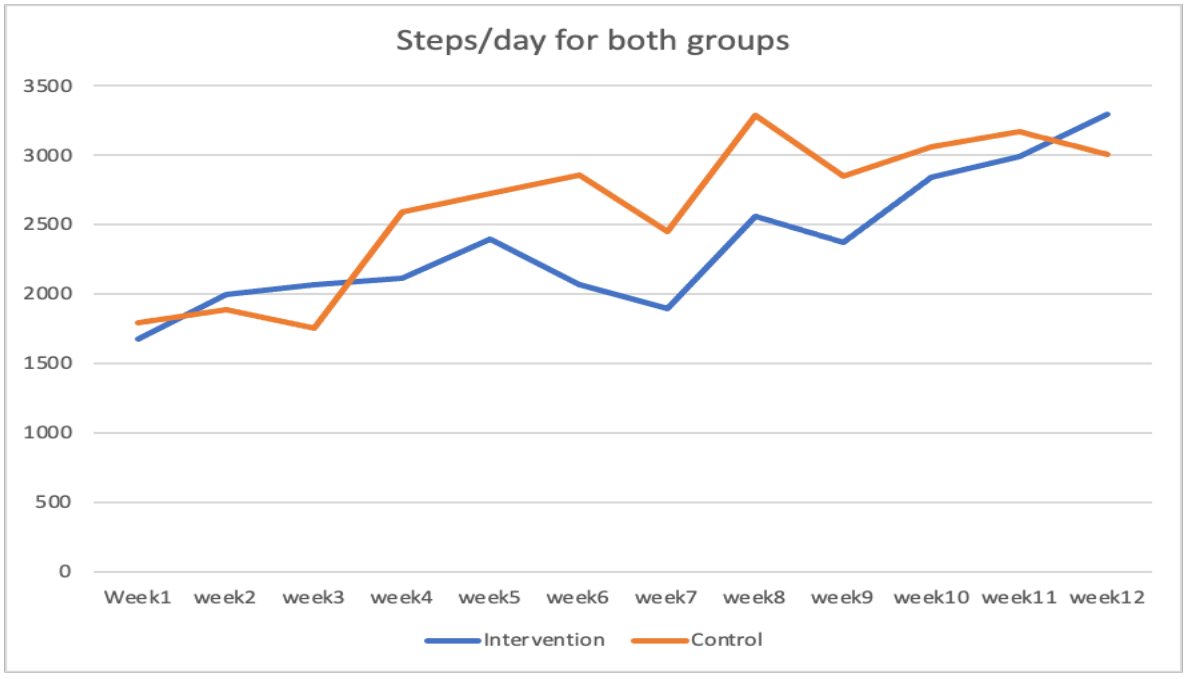


Figure 5.3 steps/day for intervention and control groups

5.4.4.3.4 Benefits of group sessions

Participants appreciated their participation in the group sessions as they had a chance to meet other people with stroke and share their stories.

> *"It was good seeing others, even if they were struggling." (P1, IG). "There's a lot of nice people on there and you could feel the warmth as such and, yes, it was I find everything I've done has been helpful" (P5, IG).*

A participant had shared his study experience with another person who had Parkinsonism and reported that they benefited from the shared knowledge.

> *"I've told people about it and I've actually shown them some of the programmes so they could try them out. Some of them ……found some of the sit-down ones very, very useful." (P6, IG). "He was a very advanced Parkinson's disease man……. and I was able to show him some of the exercises and some of the things that helped him become… Or feel more normal." (P6, IG).*

Participants indicated that they were inspired by talks of senior patients delivered during group sessions.

> *"It was really helpful, yes. It was really inspiring as well. More of that, please [laughs]!" (P4, IG).*

5.4.4.3.5 Good for mental health

> *"it was good for the mental health as well, like you didn't feel you're on your own kind of thing then. That's what I thought was very good." (P1, IG)*

5.4.4.4 ***Facilitators for participation in self-management from theme 4***

Participants identified some factors such as education, peer support and technology that help their participation in this intervention.

They appreciated the value of education sessions provided at the beginning of the programme in helping their understanding of how to manage issues appropriately. This enabled continuation in the programme.

> *"Having somebody, a third eye watching you and saying, 'Look, it's not quite right. Can we do it this way' - which is a part of the programme. We can learn from each other." (P2, IG). "Since I have a better understanding, so you don't actually give up because you've got a purpose and a goal to aim at, and that's because of the support that you've been given from this understanding." (P6, IG). "I'll just keep carrying on and doing the exercises, because I think exercise is really important to get your limbs going and to get focused on things." (P8, CG).*

Some participants thought the expert peer support provided within the programme has enhanced their ability for self-management.

> *"I thought she was really, really good. You felt encouraged by her and I really do think that those sorts of people, they give you confidence." (P5, IG).*

Participants mentioned some devices that can help self-management of rehabilitation post stroke such as pedometer or physical activity tracker to challenge ability of walking more steps or increasing training intensity.

> *"Let's say I had three, 4,000 whatever steps, the next day I wanted to get more, and I think that was a challenge in itself. I haven't got that now, but on my phone I can do the steps and the walking." (P5, IG). "I do feel like I have gained more strength in doing the little exercises, while I was wearing that, because I'd set myself a target." (P9, CG).*

5.4.4.5 ***Challenges for self-management from theme 5***

Participants identified challenges to their participation in the programme some of which were related stroke and other because of other health conditions such as COVID-19 and having other co-morbidities.

Challenges such as speed of recovery, poor level of walking at the beginning, and other stroke related problems (i.e. pain, fatigue, weakness, mood) were commonly reported by the participants as challenges that affected their participation in the intervention.

> *"It was a challenge. Some of the exercises I still can't do because, I don't know, the brain to the muscle, that bit." (P1, IG). "I do at the moment still suffer quite badly with fatigue, which I've found a difficult part of the stroke. I've heard about strokes over the years but I didn't realise quite what - how the fatigue can affect you" (P3, IG). "Well, the big one for me was the walking because in the beginning it wasn't very good" (P6, IG).*

Participants who got COVID during or prior to the study demonstrated a huge impact on their recovery and ability for self-management.

> *"I was doing six, 7,000 steps a day and I thought, I'm going to crack this not a problem. Then all of a sudden COVID and I wasn't walking as good……. you do lose your confidence." (P5, IG). "I had COVID, I couldn't do as much walking as I wanted to do, but I focused on doing what I could." (P8, CG).*

A participant with a chronic hearing problem had difficulties with balance and only low-level exercises provided to him to ensure safety.

> *"When I was 19, they botched an operation in my ear and took all my ear out, and I lost balance completely and it took me three years to learn to walk. I did overcome all that, but since the stroke, I think the balance mechanism in the ear that was damaged has got worse." (P6, IG).*

5.4.4.6 ***Reporting of usual care and fitting in with usual care:***

This section shows the feasibility of reporting usual care and how the programme fits with what had been received by participants as a usual care from community services. Reporting of usual care received by participants was obtained from 23 participants (Appendix 20 shows details of

usual care received by each participant). 16 of the participants received NHS therapy in the community immediately (1-2 weeks) after they discharged from hospital and 7 participants received therapy after 4-7 weeks of discharge. Only 3 participants had their NHS therapy concurrently delivered during the study programme.

Most of participants (69.5%) received usual care for 6-8 weeks in the community. Other participants received total of 8-16 weeks of usual care. There were 3 participants who had a private therapy as a part of their usual care.

Usual care plans included physical and occupational therapy with various of exercise intensity and number of home visits. Home exercises included: standing, walking, leg strengthening, balance, endurance, stairs climbing and descending and upper limb exercises. In addition, some participants reported sensory re-education, teaching the use of assistive devices, and strategies for community reintegration such as walking to local shop or park and back. Most of participants (78%) had received the usual care programmes in their homes. Other participants had their care at home in addition to therapy at rehabilitation centres for some of the sessions where they need some equipment such as treadmill.

5.4.4.6.1 Perceived benefits from theme 3

The qualitative data showed that the study intervention was considered adjunct to the usual care. In a focus group, participants indicated that the intervention provided an additional help to what received from the NHS**.** Moreover, the flexibility of being able to fit the study intervention around other NHS care enabled them to manage their schedules alongside NHS appointments.

> *"I thought it was excellent additional help" (P10, CG).*
>
> *"it was good because I could let you know what I was doing because I knew the week before my appointments and things like that. So I was always okay and the private physio was always on a Saturday. NHS was usually a Monday, Tuesday or Wednesday*

and if you were a Wednesday I'd be in touch with them, 'Can I have that Tuesday' or something. So it's been flexible" (P1, IG).

"It actually fits in quite well. I'm just pleased that I'm doing it really, because it gives you so much support." (P8, CG).

Other participants who finished the NHS therapy before joining the study considered the programme as a continuation of what was received from the NHS.

"I had three different physiotherapists visit me, which was very good. So, therefore the programme has followed on from that so it's been just a continuation for me - which has been brilliant really, thank you, yes." (P3, IG).

5.4.5 Participants' adherence to the intervention and follow up

5.4.5.1 ***Adherence to the recording diary and use of pedometer***

Recording diary was fully completed by 10 of the participants from both groups (70% from control group), 2 provided uncompleted diaries (10-60% missing days), 4 provided only the number of steps/days through email. There were 2 participants who completed but said they lost them before handing them to the researchers and other 5 participants did not return their recording diaries.

Nine participants used the pedometers provided by the research team, 1 participant started with pedometer and then used a Fitbit device. 8 participants had chosen other devices such as Fitbit, I watch, and mobile phones and 5 participants did not use any devices. The participants' adherence to the intervention was rated as ''Amber'' as there were some issues with recording diaries, using pedometer and performing daily exercise.

5.4.5.1.1 Facilitators for participation in self-management from theme 4

Adherence to the protocol was attributed by participants to several factors including time, knowledge and experience.

Having free time was mentioned by participants as a factor that increased their ability for self-management post-stroke.

> *"Well, I have quite a lot of time on my own, actually, so fitting things in like that is not a problem" (P6, IG).*

Previous knowledge and engagement in exercises before stroke was believed to help individual's engagement and adherence for self-management.

> *"I was quite sporty when I was younger, so the warming up and cooling down I already knew" (P4, IG).*
>
> *"I found them quite easy for the simple reason that before the stroke I was going to the gym for 12 years before that." (P5, IG).*

Self-motivation for improvement and independence was considered as a key for successfully engaging in self-management.

> *"You've got to be positive. You've got to get the mind right, the mindset; that's where it all starts…… because I'm motivated, it was good for me." (P1, IG).*

Social support that included family/carer support was very important to encourage participants' adherence to the programme and to ensure safety at home or in the community. Examples of family/carers support included partners' encouragement for participating in exercises sessions. In some instances, role models within the families inspired participants to engage in self-management.

> *"My family, really; they like to know how I'm doing all the time so they help me with… They've helped watch me with the programme" (P3, IG). "I think my wife has to take an awful lot of credit. … She's on the ball all the time and I'm so grateful." (P5, IG). "He's been behind me, making sure that I don't fall, things like that." (P8, CG).*

"So somebody coming and helping you and watching you does make a big difference." (P6, IG). "my mother-in-law, she's 88, and she said, 'I don't worry about those little pedometers,' and she walks around her block, which is a good walk, and she does that virtually every day, and she's 88, with a stick. She went, 'If I can do it, you can do it,' and it was an encouraging thing." (P7, IG).

Contrarily, family support might negatively affect self-management if they do everything for participant.

"I'm lucky because I've got a strong family base and they do most of the things for me, but I don't want them to do that for me; *I want to do it myself because I'm independent." (P2, IG).*

5.4.5.1.2 Challenges for self-management from theme 5

Reported challenges for the use the recording diary and pedometer included personal, technical and environmental factors such as forgetting, being busy with work, not familiar with the device, bad weather, or lost devices or documents.

"I'm going to get better at it. I think because just generally I get so many emails and stuff, I wake up in the mornings and I'm like, 'Right, I've got to sort out work' and then I get distracted so I have to try and… I have to physically make the time to make sure that I put it in the diary." (P4, IG).

"I think the only barrier was when it was raining, you didn't want to…" (P9, CG).

2 pedometers were lost and replaced during the intervention period, 1 damaged and one lost at the end of intervention.

5.4.5.2 ***Attendance of the group sessions and follow up***

Overall, participants in the intervention group attended 58% of the scheduled group sessions (5 sessions for each participant over 12 weeks).

5.4.5.2.1 Challenges for self-management from theme 5

Similar to adherence, participants reported personal, technical and environmental factors that affected attendance and follow up. Some reasons that were reported in the focus groups for missing sessions were low mood, forgetting, technical issues with equipment and travelling. Some of them said they needed someone to set up the Zoom meeting for them and they had missed sessions if they did not get help.

> *"I enjoyed that too (group sessions)- but just the same: I am useless with Zoom. If my husband hadn't arrived back from the GP, I still wouldn't be with you [laughs]! I am not able to use Zoom at all so he's better at it than me, I'm sure." (P3, IG).*

Another issue was that participants felt that it was hard to follow the instructor and the demonstration during the assessment or exercise sessions.

> *"I think it was harder for me doing everything online just because you couldn't fully assess how I was walking." (P4, IG).*
>
> *"I thought the group sessions were quite good except sometimes you couldn't see what the person is doing." (P5, IG).*

A 90% of the scheduled phone calls for the intervention group were successfully carried out. Participants said they were motivated for better improvement as they were encouraged in the follow up calls to do more training.

> *"It gives you more motivation to move, so otherwise if we're not getting this sort of thing we won't be doing anything" (P2, IG).*

5.4.6 Feasibility of collecting outcome measures

Table 2 shows mean scores and standard deviations of all functional outcome measures. Overall, it was feasible to collect and retain an acceptable rate of the necessary data for all measures across the timeline of assessments. At baseline, outcome measures were collected for

a 100% of participants. At 3 months and 6 months, 83.33 % and 79.16% of outcome measures were collected respectively. Figure 4 shows the collection of each outcome measure across the three points of assessment.

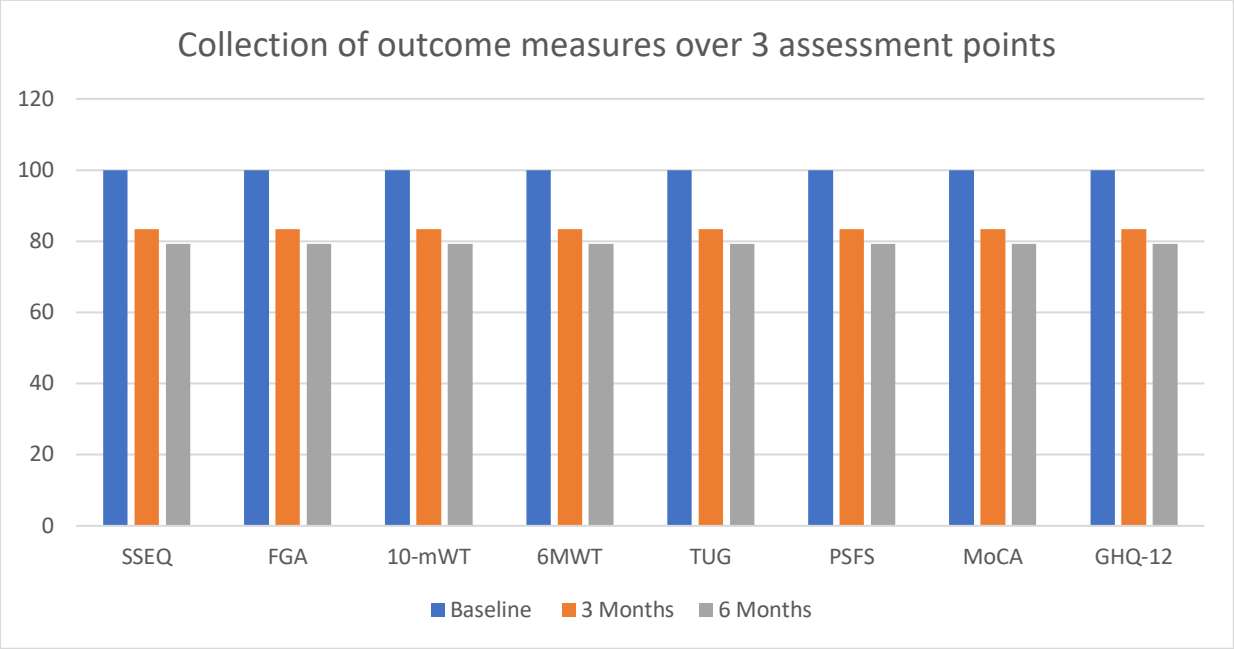


Figure 5.4 Collection of outcome measures at baseline, 3 months and 6 months

5.4.6.1 ***Participants' perspectives on selected outcome measures from theme 2***

In the focus groups, participants described their perspectives on the outcome measures used. Patients suggested that assessments were very sensible and used outcomes that are relevant to their rehabilitation needs.

> *"I thought the pedometer for instance, was a relevant thing because it was giving a measurement, where in some cases you wouldn't have bothered." (P5, IG).*
>
> *"I thought they were very, very, good actually and quite sensible, and of course you had got the comparison of the beginning and the end. So I quite agreed with that." (P6, IG).*

All assessments were completed in one session except for 2 participants who had to complete their baseline assessments over two visits because of fatigue.

5.4.7 Suggestions for improvement

Participants in the focus groups mentioned ideas to improve the programme in future. These suggestions included physical attendance at group meetings, addition of more group sessions and follow up calls, providing of feedback regarding the results of assessments, training for brain activities and virtual communication technology, having a physician as a part of the research team, and adapting the programme to patients with other conditions.

Overall, most of participants suggested no changes were needed to the current protocol.

> *"I just think everything that's been on the courses have been helpful." (P5, IG).*
>
> *"I think there's nothing really that you could change." (P9, CG).*

Although the study has offered physical attendance of group sessions, all participants agreed to attend them virtually. In the focus groups, some participants suggested that meetings were better when physical and more sessions (every week) can be added to the current protocol.

> *"I would've liked every - once a week, me personally, because I felt a togetherness and you're meeting with other people." (P1, IG). "if occasionally all the people involved got together physically, so that they could meet and talk and show one another how they're progressing." (P7, IG).*

More communication (follow up) and providing of feedback on assessments' results were suggested.

> *"Very good really, in a way. It's helped, but what I'd like is feedback from you. So, after the test, how did we do? I think the link is missing. You take information away but we don't know how we've done." (P2, IG). "I think the only thing that I think would help is more communication in one form or another." (P6, IG).*

To improve other aspects of recovery, the addition of brain activities and having a physician within the team for medical advice were suggested.

"at the same time there is something more can be done around actually on the brain side of it, ... I think doing the puzzles or something like that, I think this way they can improve, yes. Just doing the puzzles also, it was activating your mind. If your mind is active then your body. That's what I believe in anyway." (P2, IG).

"A way I think it could be improved is maybe having a medical person advising you… I don't know, could we do an improvement on this?" (P2, IG).

To improve virtual communication, a participant recommended more reminders of how to use Zoom during the course of the intervention.

"Probably when you go around, probably show them what to do because a few of them were struggling, weren't they, to get on the Zoom at first?" (P1, IG)

A participant suggested the adaptation of the intervention protocol for patients with other conditions.

5.5 Discussion

This study examined the feasibility of delivering a self-management intervention to improve mobility in the community for stroke survivors after leaving hospital. The findings of the study indicate the feasibility of recruitment, retention, randomisation and blinding, implementing and collecting outcome measures for the self-management intervention targeting mobility training for the stroke survivors in the local community. Participants' perspectives show that the intervention was acceptable, applicable and they had perceived benefits in mobility outcomes. The findings also confirm the appropriateness of the study design, structure and feasibility of using randomised control trial for a future full-scale study.

It was feasible to recruit participants from multiple teams within NHS sub-acute care facilities and community services however at a lower rate due to disruptions due the pandemic sequelae. Also, as the study provided an option for online recruitment and virtual delivery of intervention, it was feasible to recruit and successfully deliver the intervention for 2

participants from other cities within England. The study provided qualitative evidence about the effectiveness of the SM intervention for the improvement of mobility and walking parameters after stroke. Although the study was not powered to detect significant changes in performance outcomes, improvement in walking was a common theme perceived by participants in the focus groups. Other perceived improvements were reported in participants' independence, mental health, socialisation and participation. Our findings confirm the findings of previous studies about the utility of self-management for mobility rehabilitation post stroke albeit through qualitative and descriptive data (Sahely et al., 2022; Warner et al., 2015). The perceived improvement in the walking (speed, endurance, balance), self-efficacy and participation were also reported in previous studies. However, sustaining of these improvements on long-term scale need further assessment along with well-powered efficacy studies.

The recruitment plan included strategies that can help obtain the proposed sample size (90 participants) that was estimated based on a moderate sample size required for a feasibility study (Billingham, Whitehead and Julious, 2013). However, the target recruitment rate was not reached due to reasons such as impact of the pandemic on health services, fear of participants getting infected and hence reducing admissions of moderately affected patients, lack of technology to join the study virtually and other severity of issues related to stroke (Geed *et al.*, 2021; Sahely *et al.*, 2023b). Most important reason for rejection was that a large proportion (34%) of screened patients were excluded because of mobility being too poor or too good. The participants in early stages might have been deemed ineligible due to reduced rehabilitation potential against the background of the early discharge policy (due to COVID) that was in effect at the time of screening. Similar issue of low recruitment because of clinical judgment was previously reported in a study examining the feasibility of self-management in stroke rehabilitation (McKenna *et al.*, 2015). Authors of that study claimed that some of patients who

were potentially eligible for the programme had been excluded based on care team perception of potential poor recovery or unwillingness to participation in the programme. Moreover, it has been suggested that due to the high workload of stroke rehabilitation clinicians, a therapist's role in recruitment for clinical trials can be challenged (Ferreira *et al.*, 2019). For more effective recruitment, research bodies should apply effective strategies providing time and resources. Recommendations for better recruitment include employing of research assistants, combination of multiple strategies of recruitment (i.e. involving other clinicians in the recruitment, flyers, newspapers, online advertisement), piloting and evaluation of the process to solve problems and deal with challenges (Ferreira *et al.*, 2019; Reuter *et al.*, 2021).

Other reasons for exclusion represented various health problems a stroke survivor with mild impairment might have. Current literature suggested that not all patients with mild disability after stroke have a rapid and complete recovery as it had been commonly believed (Preston, Catherine M Dean, *et al.*, 2017). Mild disability post stroke has shown detrimental influence on people's participation in daily activities, psychosocial status and quality of life (Rochette *et al.*, 2007; Tellier, Rochette and Lefebvre, 2011; Altieri *et al.*, 2012; Hildebrand, Brewer and Wolf, 2012). This notion was also confirmed by participants in our study who considered the consequences of stroke such as fatigue, memory and mental status as challenges for engaging in self-management. From another aspect, the qualitative data suggested that engagement in self-management after stroke might require time for adjustment for some participants. This adjustment period is possibly required due to the stress and confusion that stroke survivors and their families might experience at the time of discharge from acute care. This warrants a better support for smooth transition to community where they can then start self-management (Satink *et al.*, 2018; Kalavina *et al.*, 2019). Researchers should consider this stressful transition in addition to other functional and psychosocial factors when communicating with participants and allow for adjustment period as a part of plan if needed.

This study excluded patients with severe impairments or co-morbidities that affected their safety and functional ability. Safety assurance is very important for the delivery of any SM type intervention especially when there is minimal supervision of formal therapists. Stroke is related to various health issues related to safety and some of them might not be commonly assessed in the early stages. For instance, stroke impact on vision and hearing are not often reported or assessed after stroke (Koohi, 2014; Sand *et al.*, 2016). Also, cognitive impairments could affect 30-50% of stroke survivors to various extent. It might be worthy to consider including these people in self-management programmes with some consideration of social and environment support in future studies (Mellon *et al.*, 2015). We had some concerns about participations of some patients (eligible from mobility wise) who referred to the study but had some other issues with cognition, vision or hearing problems. In this study although the MoCA was considered as a standardised measure of cognitive status of participants, a decision to include people with some level of cognitive problem was negotiated with their therapists. Participants with a relatively low cognitive capacity (MoCA<18) were included if they had a familiy member who can help with communication and adherence to the daily protocol. As there is no cut-off assessment for inclusion of some participants with hearing or vision impairments loss, cases were individually assessed and discussed with clinical therapists. Patients with mild to moderate impairments were included if they had a carer/family member and only those people with severe impairments that affect their safety were excluded.

Finding of this study confirms the finding of other studies about the role of family and carers in supporting self-management (Warner *et al.*, 2015; Lawler, Shields and Taylor, 2019). This role has been considered as essential to manage challenges at home and for reintegration in the community after discharge from hospital as it can increase the likelihood of improvement in functional and participation outcomes. For participants who joined our study remotely, it was easier and more convenient for individuals who had a carer/family member to help

carrying out the online assessments and meetings. Although the support of relative/carers has been mainly considered as a facilitator for SM and reintegration in the community, in some cases too much support might limit patient's skills for SM. This idea was mentioned by some participants in the study and discussed earlier in the literature (Satink *et al.*, 2015). A clear description of a carer role in the SM process might be suggested to facilitate patient's independence and ensure the ideal level of social support for the successful uptake of SM interventions.

Findings of the study show a high level of acceptance and appreciation of the participants for the support they had received during the course of the intervention. Even the participants in the control group who only received an education session at the beginning of their enrolment expressed their appreciation of information provided and the provision of pedometer to track their daily steps and setting goals for rehabilitation. Previous studies show different level of patient's satisfaction with community services in the current practice. Issues such as long waiting for services, staff shortage and inadequate amount of delivered therapy were shown to affect the quality of rehabilitation post stroke (Lucas, Gordon and Heyes, 2021; Sahely *et al.*, 2022). Lack of continuity in care can increase the pressure on survivors and their families to adjust to life after discharge from hospital care and might require them to consider other options for care including private therapy. In this study, 3 participants indicated they hired private physiotherapists before joining the programme as they were waiting for community services or thought they needed more therapy than what they had received. However, it might not be feasible for every individual to have access to private care highlighting a gap in health inequality. Self-management interventions like the proposed are intended to fulfil survivors' need for continuity in care in the community with minimal resources and pressure on the NHS.

In this study, the remote delivery of intervention was suggested to suit the social distancing policy because of the pandemic, additionally the study provided the option of face-to-face delivery of the intervention. Most participants agreed to participate in the remote sessions for delivery of the education and group meetings via Zoom. In the focus groups, some participants mentioned some challenges they had experienced during their participation around remote sessions. This included poor IT skills and resources (devices and internet), less effective communication, and safety concerns. These issues have been acknowledged in rehabilitation literature and recommendations include having a facilitator (not necessarily to be a professional) who can help with service delivery, providing smart devices, or arranging for physical meetings to meet patients' preferences (Clark *et al.*, 2018; Sahely *et al.*, 2023b).

The recording diary was used in this study as an outcome measure for the recording of daily training and number of steps per day. Data collected from recording diaries and compliance of participants for their use indicated a concern about the compliance of participants in completing the recording diary. In focus groups, several reasons were mentioned for low compliance such as missing documents or forgetting or skipping the recording due to memory issues, and low mood or other stroke related physical consequences. Data collected from the recording diaries can be collected objectively using advanced devices such as pedometers or accelerometers, however, the use of recording diary was meant to emphasise the role of self-monitoring and autonomy a participant requires to achieve a previously selected goal. Similar issues with participant's compliance with recording diary have been discussed in the literature suggesting the use of electronic diaries with 'compliance-enhancing' options (Stone *et al.*, 2003). Further, phone reminders or email reminders can be used to improve compliance.

Education sessions were mainly delivered individually for each participant in the two groups. Just 2 sessions were delivered for a group of two participants. From our experience, it

was not clear if the delivery of sessions in groups has more advantage than individual delivery. However, a recent study about the education for stroke survivors indicated that participants preferred the delivery of stroke education in groups (Finch *et al.*, 2022). The same study has also suggested the need to adapt content of education session for each individual based on their needs.

5.6 Strengths and limitations

This study included stroke survivors with a wide range of clinical and demographic characteristics to examine the feasibility of the SM intervention making it applicable for a wider group of people. Lessons from previous self-management studies were considered during the development and delivery of this intervention including patient involvement in therapy planning, individualisation of plans, patient's safety, reduction of formal supervision of therapists. As the study took place during COVID-19 pandemic, the protocol of the original study was amended to tailor to the new policy in service delivery and applying some safety measures. This included the addition of remote rehabilitation, and strategies for online communication. The exercise booklet provided ability to tailor exercises within the intervention since it had three level of exercises considering that participants' ability for recovery can vary post-stroke.

The study used a mixed methods design to examine the feasibility of the intervention accounting for subjective and objective outcomes which is recommended in the examination of rehabilitation interventions (Guetterman, Fetters and Creswell, 2015). Using mixed methods approach helped to account for individual factors such as functional capacity, and psychosocial factors affecting patient's participation in the study (Lohse, Lang and Boyd, 2014; Livingston-Thomas *et al.*, 2016). Moreover, in the process of goal setting and action planning for daily training, these factors were considered by the research therapist for each participant.

There were some limitations in this study. Firstly, the recruitment rate of the participants was affected by the impact of pandemic on health care system. As we did not screen patients and only relied on teams of care, we cannot be sure of specific reasons for exclusion at screening level. It might be suggested for the definitive trial that recruitment of participants must be from a wider range of stroke care facilities to increase the possibility of having a large sample. Also, future research must investigate the residual impact of the pandemic on current policy and practice in accounting and referring of eligible patients to self-management programmes or research. Also, as the study only did focus groups with patient participants to collect patient perspectives and to discuss issues of low recruitment from NHS sites, it might be useful to include therapists who screened patients for the study in focus groups to have a better understanding of the recruitment issues they faced. Secondly, because of the nature of the intervention, it was not possible to blind the participants, however, to minimise bias, all three assessors were blinded, and effort was made to avoid communication between participants from both groups during the intervention. Although blinding has been suggested in clinical research, there has been a debate about the value of measuring the successfulness of blinding. This debate was based on the findings of some pharmaceutical studies where the interpretation of the success of blinding could problematic or misleading (Webster *et al.*, 2021). We sought the measuring of blinding success as an important element for the feasibility of implementing the self-management intervention in the community considering the influential impact of personal bias on study outcomes. To ensure double blinding in future studies, a cluster RCT design might be used to assign participants to a study group based on their care settings. Thirdly, there were some issues that affected participants' adherence to the intervention. In this study, some participants were allowed to use their own smart phones/watches that they were familiar with to track their activities. However, the accuracy of data collected by different devices might be considered in future studies focusing on physical

activity level in particular (Fuller et al., 2020). Lastly, as the study was not powered enough to detect differences in outcome between study's arms or over time, the patterns of means were not interpreted. A future study that is adequately powered is warranted to examine any improvements in the outcome measures.

5.7 Implications for rehabilitation:

- The self-management intervention is feasible for implementation to facilitate mobility related therapy for stroke survivors in the community.
- Patients were able to engage in goal setting, action planning and self-monitoring of their daily training with support of the research therapist.
- Group sessions are valuable to stroke survivors and can lead to perceived improvements in psychosocial outcomes.
- Survivor's physical, cognitive, psychological and environmental appropriateness should be assessed at the initial planning for self-management.

5.8 Conclusion

The self-management intervention seems feasible for implementation for stroke survivors in the community in one geographical area. Participants in the intervention group appreciated the support provided and desired to continue following the exercise protocol after finishing their participation. The study was not powered enough to draw a conclusion about the efficacy of the program and a future full-scale study is warranted.

CHAPTER 6

DISCUSSION AND CONCLUSION

6.0 Chapter overview

This chapter provides an overall discussion of the research work included in this thesis. It provides a summary of the main findings, positions the added contribution from this work within stroke rehabilitation literature and gives a direction for future research. It also discusses the strengths and limitations related to the thesis work and the challenges faced at multiple phases. The main findings are discussed with critical comparison to the available research evidence identifying similarities and discrepancies. The chapter is concluded by providing summary statements for the thesis based on the findings and implications for future practice and research.

6.1 Summary of the main findings

6.1.1 SM interventions for mobility training within stroke rehabilitation literature

Findings from the systematic review found self-management strategies such as patient education, providing information, goal setting, problem-solving, action planning, self-monitoring, and social support were commonly integrated with rehabilitation therapy to improve mobility post-stroke. SM interventions in the reviewed studies were integrated with formal therapy to increase patients' independence in coping with life after stroke; however, were not considered as a substitute therapy. The review confirms that SM interventions that utilise behaviour change strategies or integrate multiple SM strategies can be more effective in achieving better outcomes (Parke *et al.*, 2015; Warner *et al.*, 2015).

In the systematic review, SM interventions demonstrated an increase in physical activity levels, such as in functional mobility and walking ability. However, the quality of evidence was rated on the GRADE system as a 'very low' for the changes in walking speed, endurance, balance, physical activity (steps/day). The changes in functional mobility had a 'low' grade on the Stroke Impact Scale-mobility domain and a 'moderate' grade on the Rivermead Mobility Index. The participants in qualitative studies considered the self-management interventions as a valuable addition to their therapy and perceived the improvement in their mobility following them.

The review revealed that components of SM within various interventions were varying in content and intensity of therapy. This variation could make standardised application in practice or research challenging. However, SM for mobility training requires effective action plans of therapy in addition to any behaviour enhancement that includes integrating knowledge and skills into sessions in order to achieve optimal outcomes. This requires SM to be tailored and individualistic rather than a standardised protocol delivery. The diversity in stroke

survivors' characteristics adds an additional element of complexity which supports the notion that SM cannot be strictly standardised. Hence, it is recommended that individualisation in lieu of standardisation and a thorough assessment of the appropriateness of stroke survivors and their needs for SM is considered at the start of SM interventions as a key for successful implementation.

6.1.2 Conceptualisation of SM

Our findings show that stakeholders of stroke rehabilitation (patients vs. therapists) might hold a different conceptualisation of SM. The systematic review revealed multiple perspectives about SM as contextually dependant. Therapists mainly conceptualise SM as sharing of responsibilities for care with patients and patients view it as a strategy that can improve their ability to manage their therapy in their homes or communities, that encourages them to increase mobility training, and so facilitate their independence. The view that SM is a part of patients' stroke journey despite any level of support that services offered was a prominent view in the literature. This was reiterated by patients in study 2, especially during the lack of services during the pandemic. During this period participants believed that they had to rely on themselves to manage their conditions when the community services were stopped or hugely disrupted. The participants in the feasibility study who were discharged from hospital with no family or carer in the community expressed the role of SM as a part of their journey whether initiated by health services or otherwise.

6.1.3 Need and use of Self-management during COVID-19 pandemic

Patient and therapist experiences with stroke rehabilitation during the pandemic were demonstrated within four themes; modifications were made within the healthcare system because of COVID- 19, that impacted on the stroke patients at different stages, leading to their

unmet needs. The most striking impact was on the care continuum, seen in the lack of support after discharge from acute care which were also rushed discharges. Minimal care was delivered by community services for stroke patients with long waiting periods that has lasted ever since. Therapists expressed their unsatisfaction with the level of help provided to their patients and the shift in their roles following policy changes in the system. However, patients' and professionals' prioritised stroke rehabilitation, hence set up novel management strategies during the pandemic. Many participants in this covid study indicated that they relied on their own motivation and help of family or private carers to help their recovery post stroke. Therapists' strategies focused on the provision of information and teaching patients self-management strategies using online resources, remote rehabilitation, virtual communication, prioritisation of patients based on needs, and early provision of equipment.

6.1.4 Experience of SM in stroke rehabilitation during the pandemic

In the qualitative study, 'SM as only hope' emerged as a common subtheme from patients' and therapists' lived experiences with rehabilitation during the COVID-19 pandemic. During the pandemic, the delivery of SM interventions was supported by remote rehabilitation approaches, ensuring peoples' safety and provided professional support when possible from clinicians. However, therapists indicated that survivors with severe impairments could not be helped by SM interventions. Despite the growth of remote rehabilitation, patient participants suggested physical delivery of therapy with proper personal protection equipment to better address patients' physical and mental health needs.

6.1.5 Feasibility of implementing SM intervention in local context

The feasibility study indicated that it was feasible to recruit 24 participants from the NHS sites as well as community facilities, randomise them into two groups of the study (intervention vs.

control), implement the intervention, and retain 83.33% of participants for assessments at 3 months and 79.16% at 6 months follow up. Although the study was not powered enough to draw a conclusion about the efficacy of the intervention, participants' perspectives about the intervention and the perceived benefits on their recovery were promising. Results of this study warrants a future full-scale RCT study.

The focus groups highlighted factors related to stroke survivors that can facilitate or challenge their SM behaviour. Facilitators included self-motivation, patient's knowledge, time for adjustment, social support (family/carer/peer), previous physical activity level, technology and assistive devices. Challenges included health related problems, prioritising and developing of realistic and relevant goals for rehabilitation, technical problems, remote rehabilitation, and environmental issues such as weather or safety of training at home or in the community. These factors should be considered while planning the protocol for the future trial to improve effectiveness of uptake and outcomes.

6.2 Contribution to the literature

Previous research had found discrepancies in the conceptualisation of SM within stroke patients and clinicians (Norris and Kilbride, 2014; Sadler *et al.*, 2017). Certain extreme perspectives of patients such as patients taking care of themselves and losing rights to receiving supervised care since they believed therapists were shifting a part of their responsibility to patients, were revealed from the literature. This raises concerns about patients' understanding of SM and a need to improve education about SM to fill the knowledge practice gap. Most participants in study 2 and 3 seemed to be familiar with the term 'self-management' and had experienced SM to different extents. Therefore, it is important to work on patient's knowledge and awareness about SM and this education must be targeted in contexts where patients suitable for SM programmes might have misconceptions.

6.2.1 Optimal period for SM

Rehabilitation after stroke is time sensitive as the neuroplastic potential is believed to reach the peak during the first six months post stroke (Lohse, Lang and Boyd, 2014; Livingston-Thomas *et al.*, 2016). However, patients spend most of their time during hospitalisation alone and inactive outside formal therapy sessions (West and Bernhardt, 2012; Janssen *et al.*, 2014; Saunders DH and English, 2021). If self-management can be supplementary to therapy at all stages of rehabilitation rather than leaving it till the community phase, that can help in increasing the volume and intensity of training even in the acute phase. Further, SM initiated in the early stages of recovery and rehabilitation helps to prepare patients for transition to the community.

Previous studies demonstrate that it might be challenging for survivors to engage in SM in the early stages after stroke due to stroke-related cognitive impairments and fatigue (Satink *et al.*, 2015). Also, qualitative research indicates that the biomedical approach to treatment and organisational policies (i.e. early discharge) in the acute care settings, were considered by physiotherapist as barriers to supporting SM at this stage (Sadler *et al.*, 2017). Participants in this study demonstrated that providing SM support for inpatients within a stroke unit was challenging. Additionally, the goal setting literature suggests that survivors may not have capacity to set goals and engage in self-management programs in the earliest stage of recovery process (Laver *et al.*, 2010).

One way of addressing this limitation may be the inclusion of family members in the planning for self-management programmes or by screening participants based on their appropriateness for joining the programme at this stage. It is evident that collaborative goal setting between family members, health professionals and patients have been shown to be of value to all parties (Conneeley, 2004; Satink *et al.*, 2015; Sadler *et al.*, 2017). However, extra support from family/carers might limit patient's skills for SM as discussed by participants in

the feasibility study (chapter 5) (Satink *et al.*, 2018). In this study, a participant expressed his resentment of having everything done for him without having a chance to overcome some of challenges to do daily activities independently. Satink et al's (2018) focus groups with stroke survivors indicated that some spouses of the survivors tried to take over the responsibilities from them to keep a peaceful relationship believing that stroke survivors cannot do their previous roles in life. Lack of spouses' knowledge and support for SM was commonly reported by participants in this study urging the need for the engagement of spouses in the planning and delivery of rehabilitation process (Satink *et al.*, 2018). Defining the role of spouses/carers in the planning for SM for each patient could reduce the negative effects of overwhelming carer support in the initiation and adherence to SM strategies.

6.2.2 SM recommendations for rehabilitation practice

This study provides a review of the effect of SM on outcomes related to mobility post stroke such as functional mobility (SIS-mobility domain and Rivermead Mobility Index), walking speed, endurance, balance, and physical activity (steps/ day). These outcomes can be incorporated within routine practice to support evaluation of SM. The findings of this work suggest including different level of complexity and progression within the exercise booklet for improvement of mobility. SM has helped survivors manage their conditions at home during the pandemic while lacking community services support (chapter 4). Survivors demonstrated their independence by finding sources through the NHS, stroke organisations, social media and online groups. Hence clinicians can encourage this independence in finding knowledge sources at every contact they make.

In addition, the findings of the feasibility study (chapter 5) provide evidence for the feasibility of integrating SM interventions within the local context of stroke rehabilitation in the community and providing remote rehabilitation. Therefore, the findings at different

stages/contexts within this work are helpful to define the structure and content of SM within therapy plans in line with the national clinical guidelines for stroke care (NICE, 2012; Rudd *et al.*, 2016).

This study emphasises what has been established in the literature that SM might not be suitable for every survivor (Clark *et al.*, 2018; Wray, Clarke and Forster, 2018). Overall, our findings correspond to factors affecting the appropriateness of a survivor for SM, which include 1) survivor's capacity for SM, 2) level of support and 3) self-management environment (Boger, Demain and Latter, 2015). The capacity for SM includes physical, cognitive and psychological status. Based on this, stroke survivors with severe impairments could benefit less from SM. The support level reflects the amount of support a survivor can receive from their caregivers, peers or health care professionals. SM environment refers to factors that can affect patient's ability to engage in SM beyond the individual, family, and health services such as political influences, societal influences for instance how impairment is perceived by others (Boger, Demain and Latter, 2015). These three factors could act as facilitators or challenges to a patient's engagement in SM. The most striking factors affecting capacity for SM in our studies included comorbidities, stroke related physical challenges (i.e. weakness, pain, fatigue), patient's knowledge, previous level of exercise, self-motivation, self-efficacy, using assistive devices and having enough time for adjustment post stroke. Support level included family and caregivers support, peers support, and the amount of care received by community health services. Factors related to the SM environment were the least reported as we did not have a particular focus on exploring political or organisational factors. However, participants raised issues for reintegration in the community such as lack of social support services, consideration of safety for training outside their homes and attitude of other people towards stroke survivors in the community.

In the literature, apart from functional capacity, the role of the survivor's psychological status is considered very important for the success of the implementation of any SM programme in addition to other factors such as resources, social support, the role of health care professionals, and patient's cognitive capacity. It has been evident that patients with positive psychological status can take a greater active role in their rehabilitation and can have better outcomes (Coulter and Ellins, 2006; Sadler *et al.*, 2017). In an attempt to describe the characteristics of stroke survivor who can be a 'good self-manager' from a policy makers' perspectives, a qualitative study demonstrated that this a survivor who is *"remoralised; thus taking responsibility for their health; is knowledgeable and uses this to manage risks; and, is 'active' in using information to make informed decisions regarding health and social wellbeing." (Ellis et al., 2017, P1).* Our findings support the definition of a good self-manager previously suggested that the patients' level of physical activity before stroke and their knowledge about SM can influence ability for SM (Kramer, Hung and Brodtmann, 2019).

The systematic review in chapter 3 and previous reviews' findings confirm the efficacy of SM intervention for mobility rehabilitation on a short-term scale (Parke *et al.*, 2015; Pearce *et al.*, 2015; Warner *et al.*, 2015; Sahely *et al.*, 2022). The majority (60-70%) of these studies used pre-post intervention assessment or a short period of follow up (≤ 3 month). However, we assessed the sustainability of SM effect on a long-term follow up period (6 months) with a good retention rate (> 75%) in both arms of the feasibility study. Our study confirms the feasibility of follow up assessment in this population. Participants can be encouraged to continue SM programmes through self-monitoring strategies and training in goal-setting.

Remote rehabilitation has been regarded in the literature as an effective approach in the delivery of therapy (Warner *et al.*, 2015; Laver KE and Sherrington, 2020). Our findings confirm the feasibility and applicability of remote rehabilitation; however, not all participants were satisfied with this approach. During the pandemic, participants (therapists and patients)

had to adopt remote rehabilitation and virtual communication as a new policy in rehabilitation services. Our findings corroborated some previously identified contextual challenges that can affect delivery of remote therapy including poor IT skills and resources, miscommunication between individuals, and safety problems (Clark *et al.*, 2018). We found that participants who were motivated, younger, with a healthy relationship with therapists and having supportive caregivers were relatively more satisfied with using technology for remote communication and therefore could benefit more from remote rehabilitation. Survivors' appropriateness and preference should be considered when planning for therapy plans and it might be suggested to provide a face-to-face option for individuals who have difficulties in remote communication.

Previously available literature has only evaluated the impact of the pandemic on the services, policy changes, and management of the resources most of which were based on the observational studies or assessment of the official reports or health records, but no study within UK has discussed the impact of the pandemic from end users' perspectives (therapists and patients). The management strategies at multiple levels within the system (national, organisational, individual) can help improve decision making on the most appropriate strategies to employ in similar situations. Current literature shows that a residual impact of the pandemic is still ongoing with a large backlog that can hopefully be managed in the next couple of years (British Medical Association, 2021). This study summarises survivors needs and priorities of rehabilitation which can be considered by policy makers in dealing with the deluge of patients who missed out on rehabilitation during pandemic.

6.3 Contribution to methodology and theory

This study has utilized a mixed methods design and is an illustration of how both quantitative and qualitative approaches can be utilized to supplement and improve each other's findings (Tariq and Woodman, 2013). This thesis can contribute to the methodology covering the use of mixed methods in rehabilitation research by providing a successful example of how the

quantitative and qualitative approaches can be used sequentially to provide a wider conclusion about the researched problem. Focus groups were conducted after the feasibility examination of the SIMS. It was necessary to complement the quantitative data gathered to understand participants perspectives on the applicability and acceptability of the intervention and the methods used in the research process. The findings of the systematic review were also another example of integrating data from both approaches (quantitative and qualitative) to provide a better synthesis of evidence about the use of SM interventions for mobility after stroke. Our study emphasises the importance of using clear methods for the integration process which has been considered as the most challenging step (Guetterman, Fetters and Creswell, 2015).

The study's findings have contributed to the theoretical understanding of SM in stroke rehabilitation by establishing in chapter 3 that various SM strategies can be utilized by stroke survivors and by theorizing in chapters 4 and 5 that SM can play a crucial part in stroke recovery. Our findings add to that theoretical articulation that the ability for SM can lead to a better self-efficacy and physical activity outcomes if implemented appropriately. SM in previous research has been mainly understood through the constructs of the theory of self-efficacy which was also reinforced by our findings (Bandura, 1977). Our findings suggest that any effort for behaviour change to improve patient's SM ability can be done by enabling patient's self-efficacy. Also, it was clear that self-efficacy, SM and physical activity are associated with each other in a triangular relationship. For instance, our findings reinforce the well-established association in the literature that self-efficacy can increase the ability for SM and level of physical activity. Also, having a better physical activity level can increase self-efficacy with some other factors (such as psychosocial factors) which lead to a better capacity for SM. The successfulness of any SM intervention as discussed earlier require a preparation of an active survivor (with knowledge and skills) to take the role in managing their conditions.

6.4 The quality of research in the thesis in drawing conclusions

To ensure quality of research conducted throughout this thesis, various risk of bias tools and reporting guidelines have been used to help drawing meaningful conclusions. In the systematic review (chapter 3), as it was integrating data from quantitative, qualitative or mixed methods studies, different tools suitable for each design were used. In particular, the Cochrane's Risk of Bias Tool (RoB2) was used to critically appraise the randomised controlled trials, the Risk of Bias In Non-Randomised Studies of Interventions (ROBINS-I) was used to evaluate the non-controlled trials. The Mixed Methods Appraisal Tool (MMAT) was used for the quality assessment of the mixed-methods studies. The Critical Appraisal Skills Programme (CASP) was used for the critical appraisal of studies with other designs. Two reviewers carried out the data search, screening, data extraction and independently assessed the quality of the included studies and a third reviewer solved the discrepancy between their results.

The protocol of the review was registered on the International Prospective Register of Systematic Reviews (PROSPERO) and conducted according to PRISMA guidelines (Moher et al., 2015). In addition, the numbers and reasons for excluding studies were reported at different stages of the review. The eligibility criteria for studies were identified using the PICOS (Participants, Intervention, Comparison, Outcome, Study design) acronym to determine specific components of the target evidence. The Grading of Recommendations, Assessment, Development and Evaluations (GRADE) framework was used to rate the overall strength of evidence around outcomes, based on the quality of the reviewed quantitative studies (GRADEpro, 2015). The GRADE can include RCTs and other study designs and if a study design and or quality is weaker than an RCT, the quality of evidence can be downgraded. Also, if a non- RCT meets certain criteria they can still be upgraded. We acknowledge that GRADE is not specific to observational studies and that methods currently have not been identified for

a gold standard quality assessment across study designs and limitations do exist (Mueller *et al.*, 2018).

In the qualitative study (chapter 4), the Consolidated criteria for Reporting Qualitative Research (COREQ) for was used for methodological guidance. In this study, the effort was made to eliminate bias at different steps. The processes of data collection and analysis were done collaboratively involving three researchers. The researchers had no prior knowledge of or contact with any participants in the study. To eliminate researcher's interpretation bias and to increase the integrity of the study's findings, triangulation of codes from different data set (therapists vs. stroke survivors) and between the three researchers was applied.

In chapter 5 (feasibility study), the CONSORT 2010 statement: extension to randomised pilot and feasibility trials (Eldridge *et al.*, 2016) was used to guide the conduct and reporting of this study. In this study, 3 assessors who were blinded collected assessments at different occasions to reduce possibility of detection bias. Also, every effort has been made to minimise contamination between participants to eliminate intervention bias. The data from focus groups were coded by the first author (AS) and themes then built in an iterative process. Supervising authors (SR and AS) independently reviewed the codes and themes and discussed their perspectives in a meeting with first author to increase the rigor and creditability of the findings (Johnson, Adkins and Chauvin, 2020).

In this thesis, effort has been made to ensure that bias is limited, and that findings are clearly presented. Researcher's reflexivity has been declared in the methodology chapter with emphasis on being an insider or outsider throughout different stages of the research process.

6.5 Strengths of the study

This research has focused on the examination of the role of self-management interventions in the rehabilitation of functional mobility post stroke. Previous studies have addressed the efficacy of SM to improve other rehabilitation outcomes to a great extent including physical

activity in general, but not for mobility which is key for independence. The presented work employed different research methods to address the objectives set for each stage of the study. The intention was to cover the research problem from multiple aspects, which is optimal in rehabilitation research since rehabilitation often uses complex interventions. An acknowledgment and appreciation of the advantages and challenges in using mixed-methods has been considered by the main researcher (the PhD student) in addition to a close review and feedback that were periodically provided by the academic supervisors (2 senior researchers with experience in mixed-methods) to ensure quality standards and academic integrity. Moreover, studies within this thesis were carried out in line with the new Medical Research Council guidelines (2021) which suggest the design of any complex intervention should be tested for acceptability among its target population (Skivington *et al.*, 2021). This was also facilitated by the involvement of stakeholders (senior patients and clinicians) at different stages during this thesis work. Also, the thesis was presented in an alternative thesis format, which allowed for external experts in the field to review individual sections, provide helpful feedback, increase the work's credibility, and provide the opportunity to publish significant contributions to evidence as soon as possible.

The involvement of different stakeholders was very helpful for the development and evaluation of the research process linking the theoretical planning into real practice considering contextual factors. From another aspect, the feasibility and applicability of the SIMS has been checked by survivors from different stroke subgroups such as chronic (senior patients involved in the PPI) and sub-acute stage (participants in the feasibility study) which can increase the applicability of the intervention to wider groups of patients. Generalisability was sought in the systematic review of the literature applying a wide range of inclusion criteria at searching stage to provide a detailed synthesis of the evidence around SM for mobility post stroke. The eligibility criteria for the qualitative study in chapter 4 was wide and considered the

involvement of any stroke survivor who had their strokes (any age, stroke type, stage of recovery, location in England) during the pandemic and therapists (any setting, degree, band, clinical experience) with experience of stroke rehabilitation during the pandemic. The aim was to provide a thorough description of the situation and including perspectives of individuals with different demographics within the wider UK population of stroke survivors, thus improving transferability of the qualitative findings. Also, the themes developed in this study were based on triangulation of data from patients as service users and therapists as providers.

In the feasibility study, the piloting of study design for a future full-scale study was one of the objectives. It has been recommended for the feasibility to use the same design of future study that can be used to examine the efficacy of an intervention (Arnold *et al.*, 2009; Thabane *et al.*, 2010). Therefore, a feasibility randomised control trail (RCT) was conducted within the feasibility examination of the new SM intervention. This provided a guidance for future research about the practical considerations that should be taken in data collection, analysis and presentation with the use of a randomised design. Safety is first, as the intervention included mobility training at home or in the community, safety of participants was considered in every step in this thesis work. the main causes of fall are functional, related to balance and other post-stroke physical impairments or comorbidities in older adults (Xu *et al.*, 2018). However, the examination of survivor's physical appropriateness for home exercise programme has been suggested before planning of any SM intervention to ensure their safety.

6.6 Limitations of the study

Effort was made to ensure quality of research process at every step in this thesis; however, limitations do exist and most of them were acknowledged to the audience throughout the chapters.

Clinical heterogeneity has been regarded as a common problem in stroke rehabilitation research at multiple levels (Parke et al., 2015; Warner et al., 2015). Stage of recovery, functional

impairments, levels of physical and psychosocial challenges, intensity of therapy, multiple outcome measures are examples of factors that influence the homogeneity in stroke care literature. This issue made it difficult to perform a meta-analysis in the review that could combine results of the reviewed studies to ensure sufficient power to examine whether SM interventions effectively improve mobility outcomes. Although wide inclusion criteria were used to expand the possibility of identifying relevant studies for systematic review as highlighted in Chapter two, inclusion of only English studies might limit the results of data search. Also, some authors did not respond to confirm the cohort of their study when they were contacted by the researcher. From another perspective, most of the studies included in the review had small sample sizes, which limited their power to detect a statistically significant difference between the intervention and the control groups. Despite these limitations, it is unlikely that any additional studies would change the overall conclusions of the review given the number of studies that were included in the review, and which was considered relatively high (24 studies), comparing to relevant reviews (Korpershoek, van der Bijl and Hafsteinsdóttir, 2011; Boger, Demain and Latter, 2013; Lennon, McKenna and Jones, 2013; Warner *et al.*, 2015).

The findings of the feasibility study indicate that it was feasible to implement and assess the SM intervention in the community with promising results of retention, fidelity, acceptability, and validity of methods. However, the study had a relatively small sample size. As no formal sample size calculations are required for feasibility studies (Thabane *et al.*, 2010) and the objectives of a feasibility trial can often be met with relatively few numbers of participants, the study was supposed to include a sample of 45 participants for each group of the study with a total of 90 persons with stroke. This estimation was based on what has been confirmed in the similar studies that sample size estimates should not be derived based on the estimated effect of interventions on a clinically important outcome, instead, sample size

estimates should be based upon the specific objectives and outcomes of the pilot trial (Arnold *et al.*, 2009). For instance, the sample size estimation for this study was based on statistics of patients discharged over a year in 2019 (before COVID-19) and allowing for some level of attrition and withdrawal from the study. Moreover, it has been recommended for feasibility studies to have at least 30 data sets to be able to estimate any variations in the outcome variables of the study (Browne, 1995). However, having the impact of COVID-19 during the study period and given the time and resources granted for the PhD level, and having just one NHS site for recruitment did not allow for the estimated numbers to be recruited.

Although we did add more options to the recruitment plan to include participants from community in addition to the NHS site, the recruitment rate was relatively low (<10%) reflecting the impact of the COVID-19 on the services and reduced research interest from participants, NHS staff and research managers during the pandemic. Around 10 % of eligible patients have refused to participate, which emphasises one of the findings in chapter 4 that survivors might have been afraid of getting infected when visited at home. The large proportion of screened patients (34%) were not eligible because of reasons related to their mobility (either too poor or too good). A further investigation of recruitment issues such as settings and teams involved in screening, eligibility criteria, recruitment strategies and decision making on eligibility of patients with other comorbidities can help estimation of sampling for future research (Ferreira *et al.*, 2019; Gillies K and Aceves-Martins, 2021).

There was some possibility of bias in the feasibility study (chapter 5). Because of the nature of the intervention in the feasibility study, it was difficult to blind patient participants in the pilot RCT which might cause performance bias. A cluster RCT has been suggested for future studies using similar interventions. A possibility of situational bias was detected in the response of some participants who had their follow up assessments collected remotely. For instance, a participant was not comfortable when answering some questions about mental

health while having some kids/family members around them in the house. In qualitative study (chapter 4), there might be a possibility of recall bias as some of the participants answered questions about their experience with care provided earlier when they had their stroke several months ago. However, a triangulation of patients' responses with therapists' perspectives and constant comparisons with other participants' perspectives were done to check the validity of data.

In the individual interviews and focus groups in study 2 and 3 some participants were unsatisfied with meeting online for the interviews. This was notable for stroke survivors who were not familiar with the use of technology. Also, participants included in these two studies were from Birmingham and London areas. Hence, to develop a national recommendation for best practices there might be a need for national research that can evaluate the system more widely.

In study 2, most of our participants were females in both groups (only one male survivor), which might not represent the perspectives of male stroke survivors in the UK. However, it was not feasible for this study to purposefully recruit more participants based on their gender. Also, the study only included patients from sub-acute and chronic stages; due to this limitation, we might not be entirely sure of the challenges faced by patients in the acute settings. However, as previously explained, access to acute patients was very restricted during the Covid pandemic.

Funding, timing, organisational issues, ethics, behavioural and cultural differences of participants were evident in this research work. The researcher, supported by his supervisory team have gone through them with resilience and expression of skills for problem solving and overcoming challenges.

6.7 Implications for rehabilitation

Mobility, which is considered a priority goal of rehabilitation for many stroke survivors can be improved using self-management interventions through helping patients to manage their long-term conditions. Particularly, we found SM elements such as patient education, involvement in goal setting and action planning for therapy, self-monitoring, group sessions, and follow up with positive encouragement can help stroke survivors with their mobility training in the community. Though not powered, the mobility outcomes that showed improvement in descriptive analysis were; functional mobility, walking ability (speed, distance, and endurance), and a number of steps per day. Therapists can use the findings of this study to better interpret and tailor clinical recommendations for each survivor based on their needs and priorities of rehabilitation. Since it is clear that SM might not be suitable to every survivor and the extent to which an individual can get involved in SM needs to be assessed at the beginning of therapy planning.

Our findings show that some of eligible patients for SM might be reluctant to participate in SM programmes because of conceptual misunderstanding of SM concept identified by previous research (Sadler *et al.*, 2017). For these patients, patient education is an essential step to increase their awareness and knowledge in preparation for SM prior to discharge. In previous literature, the addition of patient education to usual care was found to make a difference in rehabilitation outcomes (Kendall *et al.*, 2007). Our findings show patient perceived benefits and appreciation of education sessions provided to participants in the control group where no active therapy (i.e. exercises) were prescribed. An addition of patient education at the time of discharge seems to be of benefit and can be delivered within a standardised protocol. Education can be augmented with other elements of SM such as goal setting, action planning, self-monitoring, and social support.

Our findings show that participants liked the level of push a SM intervention can provide in terms of follow up and regular group meetings, which they considered as a key for keeping them on board for daily training and trying to achieve goals. Creating peer groups prior to discharge of patients can create environments that support exchange of vicarious experiences for these patients which keeps them motivated in their goals. Participants appreciated the amount of support provided by research therapist although it was not on daily basis which some previous studies did, and which was time and resource intensive. They related the communication with health professionals to the perceived improvement in their rehabilitation outcomes. Hence, continuity in communication with healthcare teams through channels that are more accessible post-covid are recommended to provide support post-discharge. Our findings also suggest the use of technology in rehabilitation process to facilitate the role of SM. Patients' competence to engage in remote rehabilitation using technology should be assessed prior to delivering self-management technology. Future clinical practice should consider the digital divide and improve opportunities for Information Technology education.

From another aspect, home visit is very important to assess patients in the environment in which they will carry out their training involving SM (Mayo, 2016). Although our intervention had to provide an option for remote delivery, which was feasible and worked better for some participants; however, some participants indicated more satisfaction to be assessed and visited for goal setting and action planning in person. Moreover, even during the pandemic measure of lockdown and social distancing, participants (patients and therapists) in the qualitative study have suggested face to face delivery of therapy in the community with proper personal protection equipment. This might reflect the importance of physical meeting with therapists for communication (i.e. facial and body expression), receiving clear instructions and building a healthy therapist/patient relationship.

Lastly, a consideration should be taken for SM to be integrated to formal therapy plans not as a separate intervention (Boger, Demain and Latter, 2015; Rudd *et al.*, 2016; Sahely *et al.*, 2022). It has been evident that individual capacity for SM is not sufficient for functional improvement without being augmented by effective training plans. There has been an increasing body of literature providing most effective exercises and physiotherapy modalities. They should work together with using SM to increase the survivors' physical activity level and improve other psychosocial outcomes.

6.8 Direction for future research

As stroke prevalence and rate of survivorship are expected to increase in the UK and worldwide, survivors are more likely to take a bigger role in their rehabilitation process due to the political movement of promoting individualistic responsibility rather than organisational responsibility of care (Graffigna and Barello, 2018). Future research might explore people's readiness to take on the responsibility if SM within care plans becomes mandatory. This awareness of readiness might help in shaping more feasible and applicable policies for SM within current practice.

Most of the current studies that have examined the feasibility and fidelity of SM interventions for stroke population, provide insufficient evidence to draw a formative conclusion about their effectiveness for improving performance outcomes. Future research could use robust methods to examine the effectiveness of SM for stroke rehabilitation in multiple contexts. Including of qualitative methods in addition to quantitative methods is recommended in the evaluation of any complex intervention, ones such as SM integrated interventions. In addition, adherence of participants to the protocol of intervention was varying due to multiple factors identified in the focus groups; however, future research might discuss these issues in more details using individual interviews where better understanding of contextual factors can be obtained. In our focus groups, some participants might have been

reluctant to share some of their personal challenges in a group. Identifying factors affecting individuals' adherence to SM interventions can help future studies to address barriers and increase adherence and uptake of participants to the SM intervention. Also, behaviour change interventions can be applied to involve more of eligible patients for SM to take part as they might be influenced by other social or psychological factors. This can include social groups to meet with senior survivors who had experience with SM, problem solving, psychological support and counselling, involvement of family member/carer and using knowledge brokers (Willems *et al.*, 2016; Mudge *et al.*, 2017; Ahmed *et al.*, 2021).

The SIMS used in chapter 6 seemed to be feasible and acceptable by survivors in the local context of stroke rehabilitation in England; future studies can test the feasibility of this intervention in multiple (national/international) context to examine the feasibility of delivering the intervention for wider population of stroke. As this study had relied to a certain extent on a qualified therapist for delivery, it might be worthy to test the feasibility and efficacy of the intervention in lower income countries in which poor quality or no services might be provided for stroke survivors in the community. This will help identifying global practical and cultural variability in stroke rehabilitation and for establishing greater feasibility for the intervention by accounting for contextual variables.

Our results are consistent with other reviews regarding the short-term efficacy of SM programmes for enhancing functional ability, self-efficacy, participation, and quality of life following stroke (Parke *et al.*, 2015; Pearce *et al.*, 2015; Warner *et al.*, 2015). However, the long-term maintenance of the beneficial effects of SM which is crucial in rehabilitation of chronic conditions such as stroke is not commonly assessed. It is recommended that future research can examine the long-term efficacy of SM for the management of chronic impact of stroke.

Although many of the restrictions on service delivery because of the pandemic have been released, current literature shows some relevant issues of the pandemic that are still in effect. This include early discharge of patients from acute settings and long waiting for community services (British Medical Association, 2021; Pandian *et al.*, 2022). Future research can evaluate the long-term impact of the pandemic on service delivery after the relaxation of the control measures and when services return to normal or to the new normal practice.

Considering the limitations in the feasibility study, the following recommendations can help guiding future research in the area:

- A future study that is adequately powered is warranted to examine the effectiveness of the SIMS intervention.
- Regarding the sampling and recruitment, it is suggested for the definitive trial that recruitment of participants must be from a wider range of stroke care facilities to increase the possibility of having a large sample.
- Regarding the inclusion and exclusion criteria mentioned in chapter 5 (the feasibility study), researchers might use a clear description of who should be included in case of vision, hearing or cognitive impairments and whether they have a carer or not.
- Regarding the inclusion criteria for mobility, the score of 2-5 on FAC should remain as a criterion for inclusion of stroke survivors due to safety challenges for training in the community and poor recovery prospective after stroke.
- For more effective recruitment plans, future research should consider the residual impact of the pandemic on current policy and practice in accounting and referring of eligible patients to self-management programmes or research.

- Also, as the study only did focus groups with patient participants to collect patient perspectives and to discuss issues of low recruitment from NHS sites, it might be useful to include therapists who screened patients for the study in focus groups to have a better understanding of the recruitment issues they faced.
- To ensure double blinding in future studies, a cluster RCT design might be used to assign participants to a study group based on their care settings.
- The accuracy of data collected by different devices might be considered in future studies focusing on physical activity level in particular (Fuller et al., 2020).

6.9 Conclusion

This thesis has focused on self-management interventions for the rehabilitation of mobility in the community post stroke. It has reviewed literature around self-management and identified the types and details of commonly used intervention for stroke rehabilitation. Concurrently, the impact of the pandemic on different aspects of stroke care was explored. In addition, the role of self-management and other management strategies in addressing survivors' needs during lack of formal care in the community was discussed. It has also established evidence around the feasibility of integration and implementation of Self-management intervention in local context. Future research is needed to examine the efficacy of self-management interventions to improve functional mobility outcomes and sustainability of any improvement on long term scale. It is crucial to consider the appropriateness of survivors for self-management prior to their involvement in their therapy planning and for plans to be supplementary, flexible and tailored to the patient's context.

LIST OF REFERENCES

Adamson, J., Beswick, A. and Ebrahim, S. (2004) 'Is stroke the most common cause of disability?', *Journal of stroke and cerebrovascular diseases*, 13(4), pp. 171–177.

Aggarwal, G., Lippi, G. and Michael Henry, B. (2020) 'Cerebrovascular disease is associated with an increased disease severity in patients with coronavirus disease 2019 (COVID-19): a pooled analysis of published literature', *International Journal of Stroke*, 15(4), pp. 385–389.

Aguiar de Sousa, D., Sandset, E.C. and Elkind, M.S. V (2020) 'The curious case of the missing strokes during the COVID-19 pandemic'. Am Heart Assoc.

Ahmed, S. *et al.* (2021) 'Behaviour change techniques in personalised care planning for older people: a systematic review', *British Journal of General Practice*, 71(703), pp. e121–e127.

Altieri, M. *et al.* (2012) 'Depression after minor stroke: prevalence and predictors', *European Journal of Neurology*, 19(3), pp. 517–521.

Alzahrani, M., Dean, C. and Ada, L. (2011) 'Relationship between walking performance and types of community-based activities in people with stroke: an observational study', *Brazilian Journal of Physical Therapy*, 15(1), pp. 45–51.

Amir-Behghadami, M. and Janati, A. (2020) 'Population, Intervention, Comparison, Outcomes and Study (PICOS) design as a framework to formulate eligibility criteria in systematic reviews', *Emergency Medicine Journal* [Preprint].

Andersen, K.K., Andersen, Z.J. and Olsen, T.S. (2010) 'Age- and gender-specific prevalence of cardiovascular risk factors in 40 102 patients with first-ever ischemic stroke: A Nationwide Danish Study', *Stroke*, 41(12), pp. 2768–2774. Available at: https://doi.org/10.1161/STROKEAHA.110.595785.

Archer, M.S. (2016) 'Reconstructing sociology: The critical realist approach', *Journal of Critical Realism*, 15(4), pp. 425–431.

Arnold, D.M. *et al.* (2009) 'The design and interpretation of pilot trials in clinical research in critical

care', *Critical Care Medicine*, 37(Supplement), pp. S69–S74. Available at: https://doi.org/10.1097/CCM.0b013e3181920e33.

Aromataris, E. and Pearson, A. (2014) 'The systematic review: an overview', *AJN The American Journal of Nursing*, 114(3), pp. 53–58.

Association, S. (2016) 'A new era for stroke: Our campaign for a new national stroke strategy'.

Association, S. (2018) 'State of the nation Stroke statistics - Februrary 2018', (February). Available at: https://www.stroke.org.uk/system/files/sotn_2018.pdf.

Avery, Kerry NL, et al. "Informing efficient randomised controlled trials: exploration of challenges in developing progression criteria for internal pilot studies." *BMJ open* 7.2 (2017): e013537.

Avula, A. *et al.* (2020) 'COVID-19 presenting as stroke', *Brain, behavior, and immunity*, 87, pp. 115–119.

Azzara, C. (2010) 'Qualitatively Speaking: The focus group vs. in-depth interview debate', *Quirk's Media*, 24(6), p. 16.

Baetens, T. *et al.* (2013) 'Gait analysis with cognitive-motor dual tasks to distinguish fallers from nonfallers among rehabilitating stroke patients', *Archives of Physical Medicine and Rehabilitation*, 94(4), pp. 680–686. Available at: https://doi.org/10.1016/j.apmr.2012.11.023.

Balami, J.S., Chen, R.L. and Buchan, A.M. (2013) 'Stroke syndromes and clinical management', *QJM: An International Journal of Medicine*, 106(7), pp. 607–615.

Bandura, A. (1977) 'Self-efficacy: toward a unifying theory of behavioral change.', *Psychological review*, 84(2), p. 191.

Bandura, A. (1989) 'Human agency in social cognitive theory.', *American psychologist*, 44(9), p. 1175.

Bandura, A. (1994) 'Self efficacy, encylopedia of human, ın ramachaudran'. New York: Academic Press.

Barr, V. *et al.* (2003) 'The expanded chronic care model', *Hosp Q*, 7(1), pp. 73–82.

Baskett, J.J. *et al.* (1999) 'Shared responsibility for ongoing rehabilitation: a new approach to home-based therapy after stroke', *Clinical Rehabilitation*, 13(1), pp. 23–33.

Bastian, H., Glasziou, P. and Chalmers, I. (2010) 'Seventy-five trials and eleven systematic reviews a day: how will we ever keep up?', *PLoS medicine*, 7(9), p. e1000326.

Bayley, M.T. *et al.* (2012) 'Barriers to implementation of stroke rehabilitation evidence: Findings from a multi-site pilot project', *Disability and Rehabilitation*, 34(19), pp. 1633–1638. Available at: https://doi.org/10.3109/09638288.2012.656790.

Beck, C.T. (1999) 'Facilitating the work of a meta-analyst', *Research in nursing & health*, 22(6), pp. 523–530.

Van Den Berg, M. *et al.* (2016) 'Early supported discharge by caregiver-mediated exercises and e-health support after stroke: a proof-of-concept trial', *Stroke*, 47(7), pp. 1885–1892.

Berger, R. (2015) 'Now I see it, now I don't: researcher's position and reflexivity in qualitative research', *Qualitative Research*, 15(2), pp. 219–234. Available at: https://doi.org/10.1177/1468794112468475.

Bersano, A. *et al.* (2020) 'Stroke care during the COVID-19 pandemic: experience from three large European countries', *European journal of neurology*, 27(9), pp. 1794–1800.

Bersano, A. and Pantoni, L. (2020) 'Impact of the SARS-CoV-2 pandemic on stroke care: a warning message'.

Best, C. *et al.* (2012) 'A survey of community exercise programmes for stroke survivors in Scotland', *Health & social care in the community*, 20(4), pp. 400–411.

De Biase, S. *et al.* (2020) 'The COVID-19 rehabilitation pandemic', *Age and ageing*, 49(5), pp. 696–700.

Billingham, S.A.M., Whitehead, A.L. and Julious, S.A. (2013) 'An audit of sample sizes for pilot and feasibility trials being undertaken in the United Kingdom registered in the United Kingdom Clinical Research Network database', *BMC medical research methodology*, 13, pp.

1–6.

Bodenheimer, T. and Grumbach, K. (2007) ‘Self-management support for people with chronic illness’, *Improving primary care: strategies and tools for a better practice*, pp. 79–98.

Boger, E.J., Demain, S. and Latter, S. (2013) ‘Self-management: a systematic review of outcome measures adopted in self-management interventions for stroke’, *Disability and Rehabilitation*, 35(17), pp. 1415–1428. Available at: https://doi.org/10.3109/09638288.2012.737080.

Boger, E.J., Demain, S.H. and Latter, S.M. (2015) ‘Stroke self-management: A focus group study to identify the factors influencing self-management following stroke’, *International journal of nursing studies*, 52(1), pp. 175–187.

Boulton, A.J. *et al.* (2022) ‘Intensive care unit visiting and family communication during the COVID-19 pandemic: A UK survey’, *Journal of the Intensive Care Society*, 23(3), pp. 293–296.

Bovend’Eerdt, T.J.H., Botell, R.E. and Wade, D.T. (2009) ‘Writing SMART rehabilitation goals and achieving goal attainment scaling: a practical guide’, *Clinical rehabilitation*, 23(4), pp. 352–361.

Bowling, A. (2014) *Research methods in health: investigating health and health services*. McGraw-hill education (UK).

Braun, V. and Clarke, V. (2019) ‘Reflecting on reflexive thematic analysis’, *Qualitative research in sport, exercise and health*, 11(4), pp. 589–597.

Braun, V. and Clarke, V. (2021) ‘Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches’, *Counselling and Psychotherapy Research*, 21(1), pp. 37–47.

Braun, V.C.V. (2006) ‘Using thematic analysis in psychology’, *Qualitative Research in Psychology*, pp. 1–41.

Bray, B.D. *et al.* (2013) 'Associations between the organisation of stroke services, process of care, and mortality in England: prospective cohort study', *Bmj*, 346, p. f2827.

Bray, B.D. *et al.* (2016) 'Weekly variation in health-care quality by day and time of admission: a nationwide, registry-based, prospective cohort study of acute stroke care', *The Lancet*, 388(10040), pp. 170–177. Available at: https://doi.org/10.1016/S0140-6736(16)30443-3.

Breitenstein, S.M. *et al.* (2010) 'Implementation fidelity in community-based interventions', *Research in nursing & health*, 33(2), pp. 164–173.

British Medical Association (2021) 'Rest, recover, restore: Getting UK health services back on track'.

Broetz, D. and Birbaumer, N. (2013) 'Behavioral physiotherapy in post stroke rehabilitation', *NeuroRehabilitation*, 33(3), pp. 377–384.

Browne, R.H. (1995) 'On the use of a pilot sample for sample size determination', *Statistics in medicine*, 14(17), pp. 1933–1940.

Bruce, R., Kusumi, F. and Hosmer, D. (1973) 'Maximal oxygen intake and nomographic assessment of functional aerobic impairment in cardiovascular disease', *American heart journal*, 85(4), pp. 546–562.

Bryman, A. (2006) 'Integrating quantitative and qualitative research: how is it done?', *Qualitative research*, 6(1), pp. 97–113.

Bryman, A. (2007) 'Barriers to integrating quantitative and qualitative research', *Journal of mixed methods research*, 1(1), pp. 8–22.

Bryman, A. (2015) *Social research methods*.

Busetto, L. *et al.* (2022) '"But it's a nice compromise" – Qualitative multi-centre study of barriers and facilitators to acute telestroke cooperation in a regional stroke network', *European Journal of Neurology*, 29(1), pp. 208–216. Available at: https://doi.org/10.1111/ene.15130.

Campbell, K.A. *et al.* (2021) 'Reflexive thematic analysis for applied qualitative health research',

The Qualitative Report, 26(6), pp. 2011–2028.

Carey, M.A. and Smith, M.W. (1994) 'Capturing the group effect in focus groups: A special concern in analysis', *Qualitative health research*, 4(1), pp. 123–127.

CASP, N.H.S. (2003) 'Critical Appraisal Skills Programme (CASP): appraisal tools', *Public Health Resource Unit, NHS* [Preprint].

Chalmers, I., Hedges, L. V and Cooper, H. (2002) 'A brief history of research synthesis', *Evaluation & the health professions*, 25(1), pp. 12–37.

Chandratheva, A. *et al.* (2009) 'Population-based study of risk and predictors of stroke in the first few hours after a TIA', *Neurology*, 72(22), pp. 1941–1947. Available at: https://doi.org/10.1212/WNL.0b013e3181a826ad.

Chumbler, N.R. *et al.* (2012) 'Effects of telerehabilitation on physical function and disability for stroke patients: a randomized, controlled trial', *Stroke*, 43(8), pp. 2168–2174.

Chun, H.-Y.Y. *et al.* (2018) 'Anxiety after stroke: the importance of subtyping', *Stroke*, 49(3), pp. 556–564.

Clark, E. *et al.* (2018) 'One size does not fit all–stroke survivor's views on group self-management interventions', *Disability and rehabilitation*, 40(5), pp. 569–576.

Clarke, D.J. *et al.* (2018) 'Why do stroke survivors not receive recommended amounts of active therapy? Findings from the ReAcT study, a mixed-methods case-study evaluation in eight stroke units', *Clinical rehabilitation*, 32(8), pp. 1119–1132.

Conn, V.S. and Rantz, M.J. (2003) 'Research methods: Managing primary study quality in meta-analyses', *Research in Nursing & Health*, 26(4), pp. 322–333.

Conneeley, A.L. (2004) 'Interdisciplinary collaborative goal planning in a post-acute neurological setting: A qualitative study', *British Journal of Occupational Therapy*, 67(6), pp. 248–255.

Connell, L.A. *et al.* (2015) 'Development of a behaviour change intervention to increase upper limb exercise in stroke rehabilitation', *Implementation Science*, 10(1), pp. 1–9. Available at:

https://doi.org/10.1186/s13012-015-0223-3.

Connelly, L.M. (2016) 'Trustworthiness in qualitative research', *Medsurg nursing*, 25(6), p. 435.

Corbin, J.M. and Strauss, A. (1988) *Unending work and care: Managing chronic illness at home.* Jossey-Bass.

Couillard, P., Poppe, A.Y. and Coutts, S.B. (2009) 'Predicting recurrent stroke after minor stroke and transient ischemic attack', *Expert review of cardiovascular therapy*, 7(10), pp. 1273–1281.

Coulter, A. and Ellins, J. (2006) *Patient-focused interventions: a review of the evidence*. Health Foundation London.

Creswell, J.W. (2011) 'Controversies in mixed methods research', *The Sage handbook of qualitative research*, 4(1), pp. 269–284.

Creswell, J.W. and Clark, V.L.P. (2017) *Designing and conducting mixed methods research*. Sage publications.

Creswell, J.W. and Creswell, J.D. (2017) *Research design: Qualitative, quantitative, and mixed methods approaches*. Sage publications.

Crotty, M. (1998) *The foundations of social research: Meaning and perspective in the research process*. Sage.

Cumming, T.B. *et al.* (2013) 'Montreal cognitive assessment and mini-mental state examination are both valid cognitive tools in stroke', *Acta Neurologica Scandinavica*, 128(2), pp. 122–129. Available at: https://doi.org/10.1111/ane.12084.

D'Anna, L. *et al.* (2021) 'Impact of national lockdown on the hyperacute stroke care and rapid transient ischaemic attack outpatient service in a comprehensive tertiary stroke centre during the COVID-19 pandemic', *Frontiers in neurology*, 12, p. 37.

Damush, T.M. *et al.* (2007) 'Barriers and facilitators to exercise among stroke survivors', *Rehabilitation nursing*, 32(6), pp. 253–262.

Dean, S.G. *et al.* (2016) 'Community-based Rehabilitation Training after stroke: protocol of a pilot

randomised controlled trial (ReTrain)', *BMJ open*, 6(10), p. e012375.

Dean, S.G. *et al.* (2018) 'Community-based rehabilitation training after stroke: results of a pilot randomised controlled trial (ReTrain) investigating acceptability and feasibility', *BMJ open*, 8(2), p. e018409.

Denzin, N.K. and Lincoln, Y.S. (2011) *The Sage handbook of qualitative research*. sage.

DePaul, V.G. *et al.* (2019) 'Promoting Independent Mobility-related Physical ACTivity (IMPACT) in an inpatient stroke rehabilitation unit: a proof-of-concept evaluation of self-management intervention', *Disability and Rehabilitation*, pp. 1–10.

DePaul, V.G. *et al.* (2020) 'Promoting Independent Mobility-related Physical ACTivity (IMPACT) in an inpatient stroke rehabilitation unit: a proof-of-concept evaluation of self-management intervention', *DISABILITY AND REHABILITATION*, 42(22), pp. 3172–3181. Available at: https://doi.org/10.1080/09638288.2019.1587012.

DePaul, V.G., Moreland, J.D. and Dehueck, A.L. (2013) 'Physiotherapy needs assessment of people with stroke following discharge from hospital, stratified by acute functional independence measure score', *Physiotherapy Canada*, 65(3), pp. 204–214.

Dhamoon, M.S. *et al.* (2009) 'Long-term functional recovery after first ischemic stroke: the Northern Manhattan Study', *Stroke*, 40(8), pp. 2805–2811.

Dilshad, R.M. and Latif, M.I. (2013) 'Focus group interview as a tool for qualitative research: An analysis.', *Pakistan Journal of Social Sciences (PJSS)*, 33(1).

Dimyan, M.A. and Cohen, L.G. (2011) 'Neuroplasticity in the context of motor rehabilitation after stroke', *Nature Reviews Neurology*, 7(2), p. 76.

Ditwiler, R.E., Swisher, L.L. and Hardwick, D.D. (2021) 'Professional and ethical issues in united states acute care physical therapists treating patients with COVID-19: stress, walls, and uncertainty', *Physical Therapy*, 101(8), p. pzab122.

Douiri, A. *et al.* (2021) 'Stroke care in the United Kingdom during the COVID-19 pandemic',

Stroke, 52(6), pp. 2125–2133.

Duncan, E.A.S. and Nicol, M.M. (2004) 'Subtle realism and occupational therapy: An alternative approach to knowledge generation and evaluation', *British Journal of Occupational Therapy*, 67(10), pp. 453–456.

Duncan, F. *et al.* (2012) 'Fatigue after stroke: a systematic review of associations with impaired physical fitness', *International Journal of Stroke*, 7(2), pp. 157–162.

Eldridge, S.M. *et al.* (2016) 'CONSORT 2010 statement: extension to randomised pilot and feasibility trials', *bmj*, 355.

Ellis, J. *et al.* (2017) 'Conceptualisation of the 'good'self-manager: A qualitative investigation of stakeholder views on the self-management of long-term health conditions', *Social Science & Medicine*, 176, pp. 25–33.

England, N. (2019) *Stroke Care in the West Midlands : Clinical Stroke Care in the West Midlands : Early Review Visits for 7 Day Services Supported Discharge & Rehabilitation*.

England, N.H.S. (2014) 'Five year forward view (NHS England, London)', *National Institute for Health and Care Excellence (2014) Public Health Guidance (PH53) Weight Management: Lifestyle Services for Overweight or Obese Adults. www. nice. org. uk/guidance/ph53 (Last accessed: 6 December 2018.)* [Preprint].

English, C. *et al.* (2016) 'Sitting and activity time in people with stroke', *Physical therapy*, 96(2), pp. 193–201.

Ercikan, K. and Roth, W.-M. (2006) 'What good is polarizing research into qualitative and quantitative?', *Educational researcher*, 35(5), pp. 14–23.

Evans, D. and Pearson, A. (2001) 'Systematic reviews: gatekeepers of nursing knowledge', *Journal of clinical nursing*, 10(5), pp. 593–599.

Excellence., N.I. for H. and C. (2022) *What is the prevalence of stroke and TIA in the UK?*

Ezeugwu, V.E. and Manns, P.J. (2018) 'The feasibility and longitudinal effects of a home-based

sedentary behavior change intervention after stroke', *Archives of Physical Medicine and Rehabilitation*, 99(12), pp. 2540–2547.

Fearon, P., Langhorne, P. and Trialists, E.S.D. (2012) 'Services for reducing duration of hospital care for acute stroke patients', *Cochrane Database of Systematic Reviews* [Preprint], (9).

Feigin, V.L. *et al.* (2008) 'Long-term neuropsychological and functional outcomes in stroke survivors: current evidence and perspectives for new research', *International Journal of Stroke*, 3(1), pp. 33–40.

Feigin, V.L. *et al.* (2022) 'World Stroke Organization (WSO): global stroke fact sheet 2022', *International Journal of Stroke*, 17(1), pp. 18–29.

Ferguson, N.M. *et al.* (2020) 'Impact of non-pharmaceutical interventions (NPIs) to reduce COVID-19 mortality and healthcare demand'.

Ferreira, I.S. *et al.* (2019) 'Recruitment challenges in stroke neurorecovery clinical trials', *Contemporary clinical trials communications*, 15, p. 100404.

Field, M.J. *et al.* (2013) 'Physical Activity after Stroke: A Systematic Review and Meta-Analysis', *ISRN Stroke*, 2013, pp. 1–13. Available at: https://doi.org/10.1155/2013/464176.

Finch, E. *et al.* (2022) 'What do stroke survivors want in stroke education and information provision in Australia?', *Health & Social Care in the Community* [Preprint].

Fleming, M.K. *et al.* (2020) 'Sleep Disruption After Brain Injury Is Associated With Worse Motor Outcomes and Slower Functional Recovery', *NEUROREHABILITATION AND NEURAL REPAIR*, 34(7), pp. 661–671. Available at: https://doi.org/10.1177/1545968320929669.

Folstein, M.F., Folstein, S.E. and McHugh, P.R. (1975) '"Mini-mental state": a practical method for grading the cognitive state of patients for the clinician', *Journal of psychiatric research*, 12(3), pp. 189–198.

Forhan, M. and Gill, S. V (2013) 'Obesity, functional mobility and quality of life', *Best Practice & Research Clinical Endocrinology & Metabolism*, 27(2), pp. 129–137.

Friedman, L.M. *et al.* (2015) *Fundamentals of clinical trials*. Springer.

Fulk, G., Duncan, P. and Klingman, K.J. (2020) 'Sleep problems worsen health-related quality of life and participation during the first 12 months of stroke rehabilitation', *CLINICAL REHABILITATION*, 34(11), pp. 1400–1408. Available at: https://doi.org/10.1177/0269215520935940.

Galvin, R. (2002) 'Disturbing notions of chronic illness and individual responsibility: Towards a genealogy of morals', *Health*, 6(2), pp. 107–137. Available at: https://doi.org/10.1177/136345930200600201.

Garrard, J. (2020) 'Health sciences literature review made easy'.

Geed, S. *et al.* (2021) 'Why are stroke rehabilitation trial recruitment rates in single digits?', *Frontiers in Neurology*, 12, p. 674237.

Gillies K, K.A.K.C.T.S.H.J.B.V.C.C.T.H.A.M.L.C.P.J.R.G.M.P. and Aceves-Martins, M. (2021) 'Strategies to improve retention in randomised trials', *Cochrane Database of Systematic Reviews* [Preprint], (3). Available at: https://doi.org/10.1002/14651858.MR000032.pub3.

GRADEpro, G.D.T. (2015) 'GRADEpro guideline development tool [software]', *McMaster University* [Preprint].

Graffigna, G. and Barello, S. (2018) 'Spotlight on the Patient Health Engagement model (PHE model): a psychosocial theory to understand people's meaningful engagement in their own health care', *Patient preference and adherence*, pp. 1261–1271.

Graneheim, U.H. and Lundman, B. (2004) 'Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness', *Nurse education today*, 24(2), pp. 105–112.

Guest, G. *et al.* (2017) 'Comparing focus groups and individual interviews: findings from a randomized study', *International Journal of Social Research Methodology*, 20(6), pp. 693–708.

Guetterman, T.C., Fetters, M.D. and Creswell, J.W. (2015) 'Integrating quantitative and qualitative results in health science mixed methods research through joint displays', *The Annals of Family Medicine*, 13(6), pp. 554–561.

Gunasekaran, K. *et al.* (2020) 'Stroke in a young COVID-19 patient', *QJM: An International Journal of Medicine* [Preprint].

Halkier, B. (2010) 'Focus groups as social enactments: integrating interaction and content in the analysis of focus group data', *Qualitative research*, 10(1), pp. 71–89.

Hammersley, M. (2018) *What's wrong with ethnography?: Methodological explorations*. Routledge.

Hankey, G.J. *et al.* (2002) 'Long-term disability after first-ever stroke and related prognostic factors in the Perth Community Stroke Study, 1989–1990', *Stroke*, 33(4), pp. 1034–1040.

Harding, G. and Gantley, M. (1998) 'Qualitative methods: beyond the cookbook.', *Family Practice*, 15(1), pp. 76–79.

Hardy, G.E. *et al.* (1999) 'Validation of the General Health Questionnaire-12: Using a sample of employees from England's health care services.', *Psychological Assessment*, 11(2), p. 159.

Harrington, R. *et al.* (2010) 'A community-based exercise and education scheme for stroke survivors: a randomized controlled trial and economic evaluation', *Clinical Rehabilitation*, 24(1), pp. 3–15.

Hatem, S.M. *et al.* (2016) 'Rehabilitation of motor function after stroke: a multiple systematic review focused on techniques to stimulate upper extremity recovery', *Frontiers in human neuroscience*, 10, p. 442.

Haworth, J., Young, C. and Thornton, E. (2009) 'The effects of an'exercise and education'programme on exercise self-efficacy and levels of independent activity in adults with acquired neurological pathologies: an exploratory, randomized study', *Clinical rehabilitation*, 23(4), pp. 371–383.

Health, D. of (2005) 'Self Care–A Real Choice. Self Care Support–A Practical Option', *Gateway*

reference, 4401.

Health Foundation (2016) 'Person-centred care made simple What everyone should know about person-centred care', (January), p. 45.

Health, M. of (2016) 'Self-management support for people with long-term conditions'. Author Wellington, New Zealand.

Heart and Stroke Foundation (2017) *Different Strokes: Stroke recovery across the ages*.

Heart Health (2014) *Heart attack and stroke: Men vs. women*, *Harvard Health Publishing*.

Hebert, D. *et al.* (2016) 'Canadian stroke best practice recommendations: Stroke rehabilitation practice guidelines, update 2015', *International Journal of Stroke*, 11(4), pp. 459–484. Available at: https://doi.org/10.1177/1747493016643553.

Hildebrand, M., Brewer, M. and Wolf, T. (2012) 'The impact of mild stroke on participation in physical fitness activities', *Stroke research and treatment*, 2012.

Hinder, S. and Greenhalgh, T. (2012) '" This does my head in". Ethnographic study of self-management by people with diabetes', *BMC Health Services Research*, 12(1), p. 83.

Hinkle, J.L. *et al.* (2017) 'Poststroke fatigue: emerging evidence and approaches to management: a scientific statement for healthcare professionals from the American Heart Association', *Stroke*, 48(7), pp. e159–e170.

Holloway, M. *et al.* (2022) 'How have acute stroke care staffing levels changed between 2019 and 2021? Data from the Sentinel Stroke National Audit Programme (SSNAP).', in. UK Stroke Forum.

Holloway, I. and Galvin, K. (2016) *Qualitative research in nursing and healthcare*.

Hong, Q.N. *et al.* (2018) 'Mixed methods appraisal tool (MMAT), version 2018', *Registration of copyright*, 1148552.

Huang, C. *et al.* (2020) 'Clinical features of patients infected with 2019 novel coronavirus in Wuhan, China', *The lancet*, 395(10223), pp. 497–506.

Huijbregts, M.P.J., McEwen, S. and Taylor, D. (2009) 'Exploring the feasibility and efficacy of a telehealth stroke self-management programme: a pilot study', *Physiotherapy Canada*, 61(4), pp. 210–220.

Hurn, J., Kneebone, I. and Cropley, M. (2006) 'Goal setting as an outcome measure: a systematic review', *Clinical rehabilitation*, 20(9), pp. 756–772.

Inciardi, R.M. *et al.* (2020) 'Cardiac involvement in a patient with coronavirus disease 2019 (COVID-19)', *JAMA cardiology*, 5(7), pp. 819–824.

Ivey, F.M. *et al.* (2005) 'Cardiovascular health and fitness after stroke', *Topics in stroke rehabilitation*, 12(1), pp. 1–16.

Janssen, H. *et al.* (2014) 'An enriched environment increases activity in stroke patients undergoing rehabilitation in a mixed rehabilitation unit: a pilot non-randomized controlled trial', *Disability and Rehabilitation*, 36(3), pp. 255–262. Available at: https://doi.org/10.3109/09638288.2013.788218.

Johnson, J.L., Adkins, D. and Chauvin, S. (2020) 'A review of the quality indicators of rigor in qualitative research', *American journal of pharmaceutical education*, 84(1).

Johnson, R.B., Onwuegbuzie, A.J. and Turner, L.A. (2007) 'Toward a definition of mixed methods research', *Journal of mixed methods research*, 1(2), pp. 112–133.

Jones, F., Partridge, C. and Reid, F. (2008) 'The Stroke Self-Efficacy Questionnaire: measuring individual confidence in functional performance after stroke', *Journal of clinical nursing*, 17(7b), pp. 244–252.

Jordan, Z. *et al.* (2015) 'Now that we're here, where are we? The JBI approach to evidence-based healthcare 20 years on', *JBI Evidence Implementation*, 13(3), pp. 117–120.

Kalavina, R. *et al.* (2019) 'The challenges and experiences of stroke patients an their spouses in Blantyre, Malawi', *MALAWI MEDICAL JOURNAL*, 31(2), pp. 112–117. Available at: https://doi.org/10.4314/mmj.v31i2.2.

Kalra, L. *et al.* (2004) 'Training carers of stroke patients: randomised controlled trial', *Bmj*, 328(7448), p. 1099.

Kanai, M. *et al.* (2017) 'Promoting physical activity in hospitalized patients with mild ischemic stroke: a pilot study', *Topics in stroke rehabilitation*, 24(4), pp. 256–261.

Kendall, E. *et al.* (2007) 'Recovery following stroke: the role of self-management education', *Social science & medicine*, 64(3), pp. 735–746.

Kitzinger, J. (2005) 'Focus group research: using group dynamics', *Qualitative research in health care*, 56, p. 70.

Koohi, N. (2014) 'Hearing loss in stroke', *Auditory event-related potentials to words: Implications for audiologists* [Preprint].

Korpershoek, C., van der Bijl, J. and Hafsteinsdóttir, T.B. (2011) 'Self-efficacy and its influence on recovery of patients with stroke: a systematic review', *Journal of Advanced Nursing*, 67(9), pp. 1876–1894.

Kramer, S.F., Hung, S.H. and Brodtmann, A. (2019) 'The impact of physical activity before and after stroke on stroke risk and recovery: a narrative review', *Current neurology and neuroscience reports*, 19, pp. 1–9.

Kroll, T. and Morris, J. (2009) 'Challenges and opportunities in using mixed method designs in rehabilitation research', *Archives of Physical Medicine and Rehabilitation*, 90(11), pp. S11–S16.

Kroll, T., Neri, M.T. and Miller, K. (2005) 'Using mixed methods in disability and rehabilitation research', *Rehabilitation nursing*, 30(3), pp. 106–113.

Lam, H.S.P. *et al.* (2010) 'The validity and reliability of a 6-metre timed walk for the functional assessment of patients with stroke', *Physiotherapy theory and practice*, 26(4), pp. 251–255.

Lancaster, G.A., Dodd, S. and Williamson, P.R. (2004) 'Design and analysis of pilot studies:recommendations for good practice', *Journal of Evaluation in Clinical Practice*, pp.

307–312. Available at: https://doi.org/10.1111/j..2002.384.doc.x.

Langhorne, P., Bernhardt, J. and Kwakkel, G. (2011) 'Stroke care 2', *Stroke rehabilitation. Lancet*, 377(9778), pp. 1693–1702.

Langhorne, P., Coupar, F. and Pollock, A. (2009) 'Motor recovery after stroke: a systematic review', *The Lancet Neurology*, 8(8), pp. 741–754. Available at: https://doi.org/10.1016/S1474-4422(09)70150-4.

Laver, K. *et al.* (2010) 'Patient readiness and ability to set recovery goals during the first 6 months after stroke', *Journal of allied health*, 39(4), pp. 149E-154E.

Laver, K.E. *et al.* (2013) 'Telerehabilitation services for stroke', *Cochrane Database of Systematic Reviews* [Preprint], (12).

Laver KE, A.Z.C.M.L.N.A.G.S. and Sherrington, C. (2020) 'Telerehabilitation services for stroke', *Cochrane Database of Systematic Reviews* [Preprint], (1). Available at: https://doi.org/10.1002/14651858.CD010255.pub3.

Lawler, K., Shields, N. and Taylor, N.F. (2019) 'Training family to assist with physiotherapy for older people transitioning from hospital to the community: a pilot randomized controlled trial', *CLINICAL REHABILITATION*, 33(10), pp. 1625–1635. Available at: https://doi.org/10.1177/0269215519853874.

Lawrence, E.S. *et al.* (2001) 'Estimates of the prevalence of acute stroke impairments and disability in a multiethnic population', *Stroke*, 32(6), pp. 1279–1284.

LeBrasseur, N.K. *et al.* (2006) 'Muscle impairments and behavioral factors mediate functional limitations and disability following stroke', *Physical therapy*, 86(10), pp. 1342–1350.

Lee, J.J. *et al.* (2021) 'Qualitative Study of Chinese Stroke Caregivers' Caregiving Experience during the COVID-19 Pandemic', *Stroke*, (April), pp. 1407–1414. Available at: https://doi.org/10.1161/STROKEAHA.120.032250.

Lennon, S., McKenna, S. and Jones, F. (2013) 'Self-management programmes for people post stroke:

a systematic review', *Clinical Rehabilitation*, 27(10), pp. 867–878.

Lenzen, S.A. *et al.* (2017) 'Disentangling self-management goal setting and action planning: A scoping review', *PloS one*, 12(11).

Leon, A.C., Davis, L.L. and Kraemer, H.C. (2011) 'The role and interpretation of pilot studies in clinical research', *Journal of psychiatric research*, 45(5), pp. 626–629.

Liberati, A. *et al.* (2009) 'The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration', *Annals of internal medicine*, 151(4), p. W-65.

Lichtman, M. (2012) *Qualitative research in education: A user's guide*. Sage publications.

Lieber, E. (2009) 'Mixing qualitative and quantitative methods: Insights into design and analysis issues.', *Journal of Ethnographic & Qualitative Research*, 3(4).

Lin, J.-H. *et al.* (2010) 'Psychometric comparisons of 3 functional ambulation measures for patients with stroke', *Stroke*, 41(9), pp. 2021–2025.

Livingston-Thomas, J. *et al.* (2016) 'Exercise and Environmental Enrichment as Enablers of Task-Specific Neuroplasticity and Stroke Recovery', *Neurotherapeutics*, 13(2), pp. 395–402. Available at: https://doi.org/10.1007/s13311-016-0423-9.

Lohse, K.R., Lang, C.E. and Boyd, L.A. (2014) 'Is more better? Using metadata to explore dose–response relationships in stroke rehabilitation', *Stroke*, 45(7), pp. 2053–2058.

Lorig, K.R. *et al.* (1999) 'Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial', *Medical care*, pp. 5–14.

Di Lorito, C. *et al.* (2021) 'Tele-rehabilitation for people with dementia during the COVID-19 pandemic: a case-study from England', *International Journal of Environmental Research and Public Health*, 18(4), p. 1717.

Lucas, L., Gordon, S. and Heyes, R. (2021) 'Impact of COVID-19 on the stroke rehabilitation

pathway: Multidisciplinary team reflections on a patient and carer journey from acute to community stroke services', *BMJ Case Reports*, 14(11). Available at: https://doi.org/10.1136/bcr-2021-245544.

Luker, J. *et al.* (2015) 'Stroke Survivors' Experiences of Physical Rehabilitation: A Systematic Review of Qualitative Studies', *Archives of Physical Medicine and Rehabilitation*, 96(9), pp. 1698-1708e10. Available at: https://doi.org/10.1016/j.apmr.2015.03.017.

Lyden, P. (2020) 'Temporary emergency guidance to US stroke centers during the COVID-19 pandemic on behalf of the AHA/ASA Stroke Council Leadership', *Stroke*, 10(10.1161).

Mahoney, F.I. (1965) 'Functional evaluation: the Barthel index', *Maryland state medical journal*, 14(2), pp. 61–65.

Malagoni, A.M. *et al.* (2016) 'Effects of a" test in-train out" walking program versus supervised standard rehabilitation in chronic stroke patients: a feasibility and pilot randomized study.', *European journal of physical and rehabilitation medicine*, 52(3), pp. 279–287.

Mansfield, A. *et al.* (2016) 'Promoting optimal physical exercise for life: an exercise and self-management program to encourage participation in physical activity after discharge from stroke rehabilitation—a feasibility study', *Stroke research and treatment*, 2016.

Marshall, I.J. *et al.* (2015) 'The effects of socioeconomic status on stroke risk and outcomes', *The Lancet Neurology*, 14(12), pp. 1206–1218. Available at: https://doi.org/10.1016/S1474-4422(15)00200-8.

Mason, M. (2010) 'Sample size and saturation in PhD studies using qualitative interviews', in *Forum qualitative Sozialforschung/Forum: qualitative social research*.

Matthews, C.E. *et al.* (2008) 'Amount of time spent in sedentary behaviors in the United States, 2003–2004', *American journal of epidemiology*, 167(7), pp. 875–881.

Mayo, N.E. (2016) 'Stroke rehabilitation at home: lessons learned and ways forward', *Stroke*, 47(6), pp. 1685–1691.

McKenna, S. *et al.* (2015) 'Bridges self-management program for people with stroke in the community: a feasibility randomized controlled trial', *International Journal of Stroke*, 10(5), pp. 697–704.

Mehrholz, J. *et al.* (2007) 'Predictive Validity and Responsiveness of the Functional Ambulation Category in Hemiparetic Patients After Stroke', *Archives of Physical Medicine and Rehabilitation*, 88(10), pp. 1314–1319. Available at: https://doi.org/10.1016/j.apmr.2007.06.764.

Mehta, S. *et al.* (2012) 'Effectiveness of psychological interventions in chronic stage of stroke: a systematic review', *Topics in stroke rehabilitation*, 19(6), pp. 536–544.

Mellon, L. *et al.* (2015) 'Cognitive impairment six months after ischaemic stroke: a profile from the ASPIRE-S study', *BMC neurology*, 15(1), pp. 1–9.

Meyer, D. *et al.* (2020) 'A stroke care model at an academic, comprehensive stroke center during the 2020 COVID-19 pandemic', *Journal of Stroke and Cerebrovascular Diseases*, 29(8), p. 104927.

Meza, H.T. *et al.* (2020) 'Impact of COVID-19 outbreak on ischemic stroke admissions and in-hospital mortality in North-West Spain', *International Journal of Stroke*, 15(7), pp. 755–762.

Michael, K.M., Allen, J.K. and Macko, R.F. (2005) 'Reduced ambulatory activity after stroke: the role of balance, gait, and cardiovascular fitness', *Archives of physical medicine and rehabilitation*, 86(8), pp. 1552–1556.

Miles, M.B. and Huberman, A.M. (1994) *Qualitative data analysis: An expanded sourcebook*. sage.

Moher, D. *et al.* (2009) 'Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement', *PLoS medicine*, 6(7), p. e1000097.

Morgan, D.L. (2007) 'Paradigms lost and pragmatism regained: Methodological implications of combining qualitative and quantitative methods', *Journal of mixed methods research*, 1(1), pp. 48–76.

Morris, J. *et al.* (2012) 'The importance of psychological and social factors in influencing the uptake and maintenance of physical activity after stroke: a structured review of the empirical literature', *Stroke research and treatment*, 2012.

Mudge, S. *et al.* (2017) 'What influences the implementation of the New Zealand stroke guidelines for physiotherapists and occupational therapists?', *Disability and Rehabilitation*, 39(5), pp. 511–518.

Mueller, M. *et al.* (2018) 'Methods to systematically review and meta-analyse observational studies: a systematic scoping review of recommendations', *BMC medical research methodology*, 18, pp. 1–18.

Munce, S.E.P. *et al.* (2017) 'Perspectives of health care professionals on the facilitators and barriers to the implementation of a stroke rehabilitation guidelines cluster randomized controlled trial', *BMC Health Services Research*, 17(1), p. 440. Available at: https://doi.org/10.1186/s12913-017-2389-7.

Munn, Z., Peters, M.D.J., *et al.* (2018) 'Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach', *BMC medical research methodology*, 18, pp. 1–7.

Munn, Z., Stern, C., *et al.* (2018) 'What kind of systematic review should I conduct? A proposed typology and guidance for systematic reviewers in the medical and health sciences', *BMC medical research methodology*, 18(1), pp. 1–9.

Munn, Z., Tufanaru, C. and Aromataris, E. (2014) 'JBI's systematic reviews: data extraction and synthesis', *AJN The American Journal of Nursing*, 114(7), pp. 49–54.

Nannoni, S. *et al.* (2020) 'Stroke in COVID-19: A systematic review and meta-analysis', *International Journal of Stroke*, 16(2), pp. 137–149. Available at: https://doi.org/10.1177/1747493020972922.

Nicca, D. *et al.* (2012) 'Symptom management in HIV/AIDS: a mixed methods approach to describe

collaboration and concordance between persons living with HIV and their close support persons', *Journal of mixed methods research*, 6(3), pp. 217–235.

NICE (2010) 'Stroke in adults', *Quality Standard* [Preprint].

Nijland, R.H.M. *et al.* (2010) 'Presence of finger extension and shoulder abduction within 72 hours after stroke predicts functional recovery: Early prediction of functional outcome after stroke: The EPOS cohort study', *Stroke*, 41(4), pp. 745–750. Available at: https://doi.org/10.1161/STROKEAHA.109.572065.

Norris, M. and Kilbride, C. (2014) 'From dictatorship to a reluctant democracy: stroke therapists talking about self-management', *Disability and rehabilitation*, 36(1), pp. 32–38.

O'Cathain, A. *et al.* (2019) 'Guidance on how to develop complex interventions to improve health and healthcare', *BMJ open*, 9(8), p. e029954.

O'Connor, H. and Gibson, N. (2003) 'A step-by-step guide to qualitative data analysis', *Pimatisiwin: A Journal of Indigenous and Aboriginal Community Health*, 1(1), pp. 63–90.

O'Donnell, M.J. *et al.* (2010) 'Risk factors for ischaemic and intracerebral haemorrhagic stroke in 22 countries (the INTERSTROKE study): A case-control study', *The Lancet*, 376(9735), pp. 112–123. Available at: https://doi.org/10.1016/S0140-6736(10)60834-3.

O'Mathúna, D.P. (2000) 'Evidence-based practice and reviews of therapeutic touch', *Journal of Nursing Scholarship*, 32(3), pp. 279–285.

Öhman, A. (2005) 'Qualitative methodology for rehabilitation research', *Journal of Rehabilitation Medicine*, 37(5), pp. 273–280. Available at: https://doi.org/10.1080/16501970510040056.

Olney, S.J. *et al.* (2006) 'A randomized controlled trial of supervised versus unsupervised exercise programs for ambulatory stroke survivors', *Stroke*, 37(2), pp. 476–481.

Pagano, M. and Gauvreau, K. (2000) *Principles of Biostatistics*.

Palacios-Ceña, D., Fernández-de-Las-Peñas, C., Florencio, L.L., de-la-Llave-Rincón, A.I., *et al.* (2021) 'Emotional experience and feelings during first COVID-19 outbreak perceived by

physical therapists: a qualitative study in Madrid, Spain', *International journal of environmental research and public health*, 18(1), p. 127.

Palacios-Ceña, D., Fernández-de-Las-Peñas, C., Florencio, L.L., Palacios-Ceña, M., *et al.* (2021) 'Future challenges for physical therapy during and after the COVID-19 pandemic: a qualitative study on the experience of physical therapists in Spain', *International Journal of Environmental Research and Public Health*, 18(16), p. 8368.

Palacios-Ceña, D., Fernández-de-Las-Peñas, C., Palacios-Ceña, M., *et al.* (2021) 'Working on the frontlines of the COVID-19 pandemic: A qualitative study of physical therapists' experience in Spain', *Physical therapy*, 101(4), p. pzab025.

Pandian, J.D. *et al.* (2022) 'Maintaining stroke care during the COVID-19 pandemic in lower-and middle-income countries: World Stroke Organization Position Statement endorsed by American Stroke Association and American Heart Association', *International Journal of Stroke*, 17(1), pp. 9–17.

Parke, H.L. *et al.* (2015) 'Self-management support interventions for stroke survivors: a systematic meta-review', *PLoS One*, 10(7), p. e0131448.

Party, I.S.W. (2012) *National clinical guideline for stroke*. Citeseer.

Patel, A. *et al.* (2017) 'Executive summary part 2: societal costs of stroke in the next 20 years and potential returns from increased spending on research', *Stroke Association, October* [Preprint].

Paul, L. *et al.* (2016) 'Increasing physical activity in stroke survivors using STARFISH, an interactive mobile phone application: a pilot study', *Topics in stroke rehabilitation*, 23(3), pp. 170–177.

Pearce, G. *et al.* (2015) 'Experiences of self-management support following a stroke: a meta-review of qualitative systematic reviews', *PloS one*, 10(12), p. e0141803.

Pearson, A. (2004) 'Balancing the evidence: incorporating the synthesis of qualitative data into

systematic reviews', *JBI reports*, 2(2), pp. 45–64.

Pearson, A. *et al.* (2005) 'The JBI model of evidence-based healthcare', *International Journal of Evidence-Based Healthcare*, 3(8), pp. 207–215.

Pearson, A. *et al.* (2015) 'A mixed-methods approach to systematic reviews', *JBI Evidence Implementation*, 13(3), pp. 121–131.

Perrin, P.B. *et al.* (2009) 'Identifying at-risk, ethnically diverse stroke caregivers for counseling: a longitudinal study of mental health.', *Rehabilitation Psychology*, 54(2), p. 138.

Physicians, R.C. of (2017) 'Rising to the Challenge: The Fourth SSNAP Annual Report', in. Royal College of Physicians London.

Pinter, M.M. and Brainin, M. (2012) 'Rehabilitation after stroke in older people', *Maturitas*, 71(2), pp. 104–108.

Pope, C., Mays, N. and Popay, J. (2007) *Synthesising qualitative and quantitative health evidence: A guide to methods: A guide to methods*. McGraw-Hill Education (UK).

Portz, J.D. *et al.* (2018) 'Self-management and yoga for older adults with chronic stroke: A mixed-methods study of physical fitness and physical activity', *Clinical Gerontologist*, 41(4), pp. 374–381.

Powell, R.A. and Single, H.M. (1996) 'Focus groups', *International journal for quality in health care*, 8(5), pp. 499–504.

Pracheth, R., Mayur, S.S. and Chowti, J. V (2013) 'Geriatric depression scale: A tool to assess depression in elderly', *Int J Med Sci Public Health*, 2(1), pp. 31–35.

Pranata, R. *et al.* (2020) 'Impact of cerebrovascular and cardiovascular diseases on mortality and severity of COVID-19–systematic review, meta-analysis, and meta-regression', *Journal of stroke and cerebrovascular diseases*, 29(8), p. 104949.

Preston, E., Dean, Catherine M, *et al.* (2017) 'Promoting physical activity after stroke via self-management: a feasibility study', *Topics in sTroke rehabiliTaTion*, 24(5), pp. 353–360.

Preston, E., Dean, Catherine M., *et al.* (2017) 'Promoting physical activity after stroke via self-management: A feasibility study', *Topics in Stroke Rehabilitation*, 24(5), pp. 353–360. Available at: https://doi.org/10.1080/10749357.2017.1304876.

Rand, D. *et al.* (2009) 'How active are people with stroke? Use of accelerometers to assess physical activity', *Stroke*, 40(1), pp. 163–168.

Raven, M.C. *et al.* (2011) 'An intervention to improve care and reduce costs for high-risk patients with frequent hospital admissions: a pilot study', *BMC health services research*, 11(1), pp. 1–10.

Rees, N. *et al.* (2021) 'Paramedic experiences of providing care in wales (UK) during the 2020 COVID-19 pandemic (PECC-19): A qualitative study using evolved grounded theory', *BMJ Open*, 11(6), pp. 1–14. Available at: https://doi.org/10.1136/bmjopen-2021-048677.

Rehman, A., Berry, J. and Siddiqui, M.A. (2014) 'Post stroke rehabilitation based on SMART goals: a case study', *J Exp Integr Med*, 4(1), p. 71.

Reuter, K. *et al.* (2021) 'General practice and digital methods to recruit stroke survivors to a clinical mobility study: comparative analysis', *Journal of Medical Internet Research*, 23(10), p. e28923.

Richardson, J. *et al.* (2015) 'Development and evaluation of Self-management and Task-oriented Approach to Rehabilitation Training (START) in the home: Case report', *Physical Therapy*, 95(6), pp. 934–943.

Rimmer, J.H., Wang, E. and Smith, D. (2008) 'Barriers associated with exercise and community access for individuals with stroke.', *Journal of rehabilitation research & development*, 45(2).

Rochette, A. *et al.* (2007) 'Changes in participation after a mild stroke: quantitative and qualitative perspectives', *Topics in stroke rehabilitation*, 14(3), pp. 59–68.

Roman, M.W. (2008) 'Lessons learned from a school for stroke recovery', *Topics in stroke rehabilitation*, 15(1), pp. 59–71.

Roth, E.J. (1993) ‘Heart disease in patients with stroke: incidence, impact, and implications for rehabilitation part 1: classification and prevalence’, *Archives of physical medicine and rehabilitation*, 74(7), pp. 752–760.

Rothwell, P.M. *et al.* (2004) ‘Change in stroke incidence, mortality, case-fatality, severity, and risk factors in Oxfordshire, UK from 1981 to 2004 (Oxford Vascular Study)’, *The Lancet*, 363(9425), pp. 1925–1933.

Rudd, T. *et al.* (2016) ‘National clinical guideline for stroke Prepared by the Intercollegia the Stroke Working Party. 2016’.

Sadler, E. *et al.* (2017) ‘Exploring stroke survivors’ and physiotherapists’ views of self-management after stroke: a qualitative study in the UK’, *BMJ open*, 7(3), p. e011631.

Sahely, A. *et al.* (2022) ‘Self-management interventions to improve mobility after stroke: an integrative review’, *Disability and rehabilitation*, pp. 1–18.

Sahely, A. *et al.* (2023a) ‘Exploring the experiences of people who had a stroke and therapists who managed people with stroke during the COVID-19 pandemic: An exploratory qualitative study’, *PLOS ONE*, 18(2), p. e0282325.

Sahely, A. *et al.* (2023b) ‘Exploring the experiences of people who had a stroke and therapists who managed people with stroke during the COVID-19 pandemic: An exploratory qualitative study’, *Plos one*, 18(2), p. e0282325.

Sand, K.M. *et al.* (2016) ‘Vision problems in ischaemic stroke patients: effects on life quality and disability’, *European journal of neurology*, 23, pp. 1–7.

Satink, T. *et al.* (2015) ‘Self-management: challenges for allied healthcare professionals in stroke rehabilitation–a focus group study’, *Disability and rehabilitation*, 37(19), pp. 1745–1752.

Satink, T. *et al.* (2018) ‘The perspectives of spouses of stroke survivors on self-management – a focus group study Ton’, *Disability and Rehabilitation*, 40(2), pp. 176–184. Available at: https://doi.org/10.1080/09638288.2016.1247920.

Saunders DH, M.G.E.F.C.K.P. van W.F.V.O.B.K. and English, C. (2021) 'Interventions for reducing sedentary behaviour in people with stroke', *Cochrane Database of Systematic Reviews* [Preprint], (6). Available at: https://doi.org/10.1002/14651858.CD012996.pub2.

Schünemann, H. *et al.* (2013) 'GRADE handbook for grading quality of evidence and strength of recommendations. Updated October 2013. The GRADE Working Group, 2013', *Available from guidelinedevelopment. org/handbook* [Preprint].

Scrivener, K. *et al.* (2021) 'Feasibility of a Self-Managed, Video-Guided Exercise Program for Community-Dwelling People with Stroke', *STROKE RESEARCH AND TREATMENT*, 2021. Available at: https://doi.org/10.1155/2021/5598100.

Shaw, L. *et al.* (2015) 'A trial to evaluate an extended rehabilitation service for stroke patients (EXTRAS)', in *SRR Summer meeting 2015*. Newcastle University.

de Silva, D. (2011) *Helping people help themselves: A review of the evidence considering whether it is worthwhile to support self-management*. Health Foundation.

Simpson, D. *et al.* (2018) 'Increasing intensity of practice after stroke using apps, internet and sensors to connect patients and therapists remotely: A feasibility study', in *INTERNATIONAL JOURNAL OF STROKE*. SAGE PUBLICATIONS LTD 1 OLIVERS YARD, 55 CITY ROAD, LONDON EC1Y 1SP, ENGLAND, p. 3.

Skivington, K. *et al.* (2021) 'A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance', *BMJ*, p. n2061. Available at: https://doi.org/10.1136/bmj.n2061.

Smith, E.E. *et al.* (2020) 'Canadian stroke best practice guidance during the COVID-19 pandemic', *Canadian Journal of Neurological Sciences*, 47(4), pp. 474–478.

Sprague, M.A., Shultz, J.A. and Branen, L.J. (2006) 'Understanding patient experiences with goal setting for diabetes self-management after diabetes education', *Family & community health*, 29(4), pp. 245–255.

Sterne, J.A.C. *et al.* (2016) 'ROBINS-I: a tool for assessing risk of bias in non-randomised studies of interventions', *bmj*, 355.

Sterne, J.A.C. *et al.* (2019) 'RoB 2: a revised tool for assessing risk of bias in randomised trials', *bmj*, 366.

Stoecklin, S.B. *et al.* (2020) 'First cases of coronavirus disease 2019 (COVID-19) in France: surveillance, investigations and control measures, January 2020', *Eurosurveillance*, 25(6), p. 2000094.

Stone, A.A. *et al.* (2003) 'Patient compliance with paper and electronic diaries', *Controlled clinical trials*, 24(2), pp. 182–199.

Stratford, P.W., Kennedy, D.M. and Wainwright, A. V (2014) 'Assessing the Patient-Specific Functional Scale's ability to detect early recovery following total knee arthroplasty', *Physical therapy*, 94(6), pp. 838–844.

Straus, R.A. (2010) 'When and why to choose focus group vs. one-on-one interviews', *The Research Playbook* [Preprint].

Stroke Association (2016a) 'A new era for stroke? Stroke Association', *British Journal of Neuroscience Nursing*, 12(Sup2), pp. S6–S8.

Stroke Association (2016b) *State of the Nation Stroke statistics*.

Stroke Association (2022) *Stroke Recoveries at Risk*.

Stroke, I. and Party, W. (2012) 'National clinical guideline for stroke Prepared by the Intercollegiate Stroke', (July).

Sullivan, J.E. *et al.* (2014) 'Feasibility and outcomes of a community-based, pedometer-monitored walking program in chronic stroke: a pilot study', *Topics in Stroke Rehabilitation*, 21(2), pp. 101–110.

Sun, J.-H., Tan, L. and Yu, J.-T. (2014) 'Post-stroke cognitive impairment: epidemiology, mechanisms and management', *Annals of translational medicine*, 2(8).

Sun, P. *et al.* (2020) 'Understanding of COVID-19 based on current evidence', *Journal of medical virology*, 92(6), pp. 548–551.

Sutter-Leve, R. *et al.* (2021) 'The caregiver experience after stroke in a covid-19 environment: A qualitative study in inpatient rehabilitation', *Journal of Neurologic Physical Therapy*, 45(1), pp. 14–20. Available at: https://doi.org/10.1097/NPT.0000000000000336.

Tabah, F.T.D. *et al.* (2020) 'Factors influencing stroke patient adherence to physical activity: a systematic review', *JOURNAL OF GERONTOLOGY AND GERIATRICS*, 68(3), pp. 174–179. Available at: https://doi.org/10.36150/2499-6564-389.

Tariq, S. and Woodman, J. (2013) 'Using mixed methods in health research', *JRSM short reports*, 4(6), p. 2042533313479197.

Taylor, D.M. *et al.* (2009) 'Exploring the feasibility of videoconference delivery of a self-management program to rural participants with stroke', *Telemedicine and e-Health*, 15(7), pp. 646–654.

Teasell, R. (2012) 'Challenges in the Implementation of Evidence in Stroke Rehabilitation', *Topics in Stroke Rehabilitation*, 19(2), pp. 93–95. Available at: https://doi.org/10.1310/tsr1902-93.

Teasell, R. *et al.* (2012) 'Time to rethink long-term rehabilitation management of stroke patients', *Topics in stroke rehabilitation*, 19(6), pp. 457–462.

Teddlie, C. and Tashakkori, A. (2010) 'Overview of contemporary issues in mixed methods research', *Sage handbook of mixed methods in social and behavioral research*, 2, pp. 1–44.

Teddlie, C. and Yu, F. (2007) 'Mixed methods sampling: A typology with examples', *Journal of mixed methods research*, 1(1), pp. 77–100.

Van Teijlingen, E. and Hundley, V. (2001) 'The importance of pilot studies', *Social research update*, (35), pp. 1–4.

Van Teijlingen, E.R. *et al.* (2001) 'The importance of conducting and reporting pilot studies: the example of the Scottish Births Survey', *Journal of advanced nursing*, 34(3), pp. 289–295.

Tellier, M., Rochette, A. and Lefebvre, H. (2011) 'Impact of mild stroke on the quality of life of spouses', *International Journal of Rehabilitation Research*, 34(3), pp. 209–214.

Thabane, L. *et al.* (2010) 'A tutorial on pilot studies: the what, why and how', *BMC Medical Research Methodology*, 10(1), p. 1. Available at: https://doi.org/10.1186/1471-2288-10-1.

Tieges, Z. *et al.* (2015) 'Sedentary behavior in the first year after stroke: a longitudinal cohort study with objective measures', *Archives of physical medicine and rehabilitation*, 96(1), pp. 15–23.

Tong, A., Sainsbury, P. and Craig, J. (2007) 'Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups', *International journal for quality in health care*, 19(6), pp. 349–357.

Towfighi, A. *et al.* (2017) 'Poststroke depression: a scientific statement for healthcare professionals from the American Heart Association/American Stroke Association', *Stroke*, 48(2), pp. e30–e43.

Treger, I. *et al.* (2014) 'Influence of home-based exercises on walking ability and function of post-stroke individuals', *International Journal of Therapy and Rehabilitation*, 21(9), pp. 441–446.

Tudor-Locke, C. *et al.* (2011) 'How many steps/day are enough? For older adults and special populations', *International Journal of Behavioral Nutrition and Physical Activity*, 8(1), p. 80.

Tudor-Locke, C., Washington, T.L. and Hart, T.L. (2009) 'Expected values for steps/day in special populations', *Preventive medicine*, 49(1), pp. 3–11.

Turner, S.M. and Hersen, M. (1994) 'The interviewing process', in *Diagnostic interviewing*. Springer, pp. 3–24.

Tyson, S.F., Woodward-Nutt, K. and Plant, S. (2018) 'How are balance and mobility problems after stroke treated in England? An observational study of the content, dose and context of physiotherapy', *Clinical rehabilitation*, 32(8), pp. 1145–1152.

Üstün, T.B. *et al.* (2003) 'The International Classification of Functioning, Disability and Health: A new tool for understanding disability and health', *Disability and Rehabilitation*, 25(11–12),

pp. 565–571. Available at: https://doi.org/10.1080/0963828031000137063.

Vaismoradi, M., Turunen, H. and Bondas, T. (2013) 'Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study', *Nursing & health sciences*, 15(3), pp. 398–405.

Veerbeek, J.M. *et al.* (2011) 'Effects of augmented exercise therapy on outcome of gait and gait-related activities in the first 6 months after stroke: A meta-analysis', *Stroke*, 42(11), pp. 3311–3315. Available at: https://doi.org/10.1161/STROKEAHA.111.623819.

Veerbeek, J.M. *et al.* (2014) 'What is the evidence for physical therapy poststroke? A systematic review and meta-analysis.', *PloS one*, 9(2), p. e87987. Available at: https://doi.org/10.1371/journal.pone.0087987.

Verheyden, G.S.A.F. *et al.* (2013) 'Interventions for preventing falls in people after stroke', *Cochrane database of systematic reviews* [Preprint], (5).

Vloothuis, J.D.M. *et al.* (2019) 'Caregiver-mediated exercises with e-health support for early supported discharge after stroke (CARE4STROKE): A randomized controlled trial', *PloS one*, 14(4), p. e0214241.

Wallace, D.M., Ramos, A.R. and Rundek, T. (2012) 'Sleep disorders and stroke', *International Journal of Stroke*, 7(3), pp. 231–242.

Warner, G. *et al.* (2015) 'A systematic review of the effectiveness of stroke self-management programs for improving function and participation outcomes: self-management programs for stroke survivors', *Disability and Rehabilitation*, 37(23), pp. 2141–2163. Available at: https://doi.org/10.3109/09638288.2014.996674.

Webster, R.K. *et al.* (2021) 'Measuring the success of blinding in placebo-controlled trials: Should we be so quick to dismiss it?', *Journal of Clinical Epidemiology*, 135, pp. 176–181.

West, T. and Bernhardt, J. (2012) 'Physical activity in hospitalised stroke patients', *Stroke Research and Treatment*, 2012(October 2010). Available at: https://doi.org/10.1155/2012/813765.

White, J.H. *et al.* (2013) 'Masterstroke: a pilot group stroke prevention program for community dwelling stroke survivors', *Disability and rehabilitation*, 35(11), pp. 931–938.

Whittemore, R. and Knafl, K. (2005) 'The integrative review: updated methodology', *Journal of advanced nursing*, 52(5), pp. 546–553.

WHO MONICA Project Principal Investigators (1988) 'The world health organization monica project (monitoring trends and determinants in cardiovascular disease): A major international collaboration', *Journal of Clinical Epidemiology*, 41(2), pp. 105–114. Available at: https://doi.org/10.1016/0895-4356(88)90084-4.

WHO, W. (2017) 'The top 10 causes of death', *Fact Sheet No. 310 (Updated May 2014)* [Preprint].

Wilkins, K. and Woodgate, R. (2008) 'Designing a mixed methods study in pediatric oncology nursing research', *Journal of Pediatric Oncology Nursing*, 25(1), pp. 24–33.

Wilkinson, A. and Whitehead, L. (2009) 'Evolution of the concept of self-care and implications for nurses: a literature review', *International Journal of nursing studies*, 46(8), pp. 1143–1147.

Willems, M. *et al.* (2016) 'Encouraging post-stroke patients to be active seems possible: results of an intervention study with knowledge brokers', *Disability and Rehabilitation*, 38(17), pp. 1748–1755.

Williams, L.S. *et al.* (1999) 'Development of a stroke-specific quality of life scale', *Stroke*, 30(7), pp. 1362–1369.

World Health Organization. (2020) *WHO Director-General's opening remarks at the media briefing on COVID-19 - 11 March 2020*. Available at: https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020.

Wray, F., Clarke, D. and Forster, A. (2018) 'Post-stroke self-management interventions: a systematic review of effectiveness and investigation of the inclusion of stroke survivors with aphasia', *Disability and rehabilitation*, 40(11), pp. 1237–1251.

Xu, T. *et al.* (2018) ‘Risk factors for falls in community stroke survivors: a systematic review and meta-analysis’, *Archives of physical medicine and rehabilitation*, 99(3), pp. 563–573.

Zhao, J. *et al.* (2020) ‘Impact of the COVID-19 epidemic on stroke care and potential solutions’, *Stroke*, 51(7), pp. 1996–2001.

Zimmerman, B.J., Bandura, A. and Martinez-Pons, M. (1992) ‘Self-motivation for academic attainment: The role of self-efficacy beliefs and personal goal setting’, *American educational research journal*, 29(3), pp. 663–676.

APENDICES

Appendix 1- Alternative format thesis guidelines

UNIVERSITY OF BIRMINGHAM

Alternative format thesis guidelines

1) Extract from University of Birmingham regulations:

7.4.1 (g) A Registered Student may submit material for assessment which has already been published provided that the following conditions are satisfied.
The material published must:

(i) be appropriately integrated, either in the body of the work or as an appendix to which reference is made; and

(ii) be adequately identified and referenced.

7.4.1 (h) If material submitted is the result of collaborative research or work, the submission must clearly identify the Registered Student's contribution.

Full regs at: http://www.birmingham.ac.uk/Documents/university/legal/regulations-part7.pdf

2) The Alternative Format thesis allows a postgraduate researcher to incorporate sections that are in a format suitable for submission for publication in a peer-reviewed journal. Apart from the inclusion of such materials, the alternative format thesis must conform to the same standards expected for a standard thesis and candidates should follow the guidance found at: https://intranet.birmingham.ac.uk/as/studentservices/graduateschool/rsa/thesissubmission.aspx and specifically 'presenting your thesis'.

3) Materials included in the alternative format thesis may include those which are solely and/or partly authored by the student and may be already published, not yet published but of publishable standard, accepted for publication, or submitted for publication in externally refereed contexts such as journals and conference proceedings. Papers can be included in a modified form as long as the paper is unpublished).

To be able to clearly demonstrate their contribution, the postgraduate researcher would normally be first author on such papers. In all cases the postgraduate researcher must acknowledge co-authors and their contribution to the paper.

4) The thesis should remain an original contribution to the field of research by the student, regardless of the form of the thesis. The student should use the introductory section of their thesis to explain and justify in full the nature and extent of the candidate's own contribution and the contribution of co-authors and other collaborators to the publications presented. A significant proportion of the researched materials should be derived from original research undertaken after the date the student initially registered with this University. Where data from a published paper is included where the postgraduate researcher is solely/majorly responsible for one section but not the rest of the paper, they must clearly state which part(s) of the paper is theirs.

5) The number of papers included in the alternative format thesis may vary according to discipline and is not prescribed, but should reflect the quantity, quality and originality of research and analysis expected of a candidate submitting a standard thesis. Postgraduate researchers should discuss the structure of their thesis with their supervisor in the first instance.

6) The work must constitute a body of publication tending towards a coherent and continuous thesis, rather than a series of disconnected publications. As such, any publications should be adapted and integrated within the structure of the thesis. Any sections of the thesis which are published or in publishable format should be clearly identified.

7) Since the alternative format thesis includes copies or offprints of journal articles, book chapters etc, which already have page numbers, the pages of the publications themselves will not be included in the pagination sequence of the submission. Candidates should insert a sheet of A4 before each publication on which is displayed the publication number, publication title, and the page number of the thesis. For example, if the publications section starts on p75, insert an A4 sheet before the first publication on which is printed the name and number of the publication and p75. The first publication will then follow, with its own pagination.

Before the second publication insert another A4 sheet on which is printed the name and number of the second publication and p76, and so on. This applies equally to the print and electronic thesis. Additional commentary should be included after each published paper where appropriate.

Where “data not shown” is part of the published paper, the data should be included as supplementary data or as an appendix.

Authors will need to heed the terms of their publishing agreement, particularly if they have transferred copyright ownership to their publisher. Whilst it is rare for publishers to prevent the incorporation of published material in a thesis for assessment purposes, authors should be aware that it may be necessary later to redact publisher-owned material from the access version of the electronic thesis.

8) Any work submitted within the alternative format thesis must be substantially different from any work which may have previously been submitted for any degree at this or any other institution.

9) It is essential that the alternative format thesis includes detailed and critical analysis of the work and methods used, since sections formatted for publication / dissemination may not already include this level of detail. The structure of the alternative format thesis should include the following:

i. All required pages detailed in regulation 7.4.2:
http://www.birmingham.ac.uk/Documents/university/legal/regulations-part7.pdf

ii. Review of previous research including sections summarising and synthesising previous research in the field of investigation

iii. Methodology detailing the methods employed during the research and a detailed critical analysis of those methods and the information they provided

iv. Presentation of results and their analysis in a format suitable for presentation in a peer-reviewed journal and/or in conventional thesis chapters as in the standard PhD thesis

v. Summary / conclusion drawing together the various outcomes of the work into a coherent synthesis and indicating directions for future work

vii. References and appendices should be included as in the standard PhD thesis

10) The incorporation of publication-style chapters in the thesis will inevitably lead to some duplication since each publication-style chapter will have self-contained components that will overlap with parts of the other sections of the thesis. The incorporation of published materials may generate a close match alert when the thesis is checked for plagiarism. Similarly, if an unpublished chapter is submitted to a journal after the degree has been awarded, the author should alert the journal editors that the work is included in their thesis, and reference the e-version of the thesis. Occasionally, publishers request that open release of the thesis full text be deferred until after the paper’s publication in the journal. If necessary, authors can request this when they submit their e-thesis to the Library.

11) As with the standard doctoral thesis, examiners should satisfy themselves that the alternative format thesis meets the requirements of the doctoral degree as prescribed in the appropriate regulations and policies. The fact that a thesis contains material that has been published or accepted for publication does not guarantee that the examiner will recommend the award for which the candidate is being examined.

12) The submission of an alternative format thesis is a separate process distinct from the PhD by publication route which is only open to members of staff.
Examples of successful theses submitted in this format can be found in the University's e-Theses Repository:

http://etheses.bham.ac.uk/3786/ http://etheses.bham.ac.uk/4391/ http://etheses.bham.ac.uk/4430/ http://etheses.bham.ac.uk/4676/ http://etheses.bham.ac.uk/4403/

Appendix 2- (Sahely et al., 2022)

DISABILITY AND REHABILITATION
2023, VOL. 45, NO. 1, 9–26
https://doi.org/10.1080/09638288.2022.2028019

Taylor & Francis
Taylor & Francis Group

REVIEW

OPEN ACCESS Check for updates

Self-management interventions to improve mobility after stroke: an integrative review

Ahmad Sahely[a], Daniel Giles[a], Carron Sintler[b], Andrew Soundy[a] and Sheeba Rosewilliam[a]

[a]School of Sports, Exercise and Rehabilitation Sciences, University of Birmingham, Birmingham, UK; [b]University Hospitals Birmingham NHS Foundation Trust, Queen Elizabeth Hospital Birmingham, Birmingham, UK

ABSTRACT

Purpose: To review the evidence around self-management interventions used to improve mobility post-stroke.

Materials and methods: An integrative review was carried out. Eight databases were searched from 1992 to July 2021 using keywords based on the PICOS strategy. Two reviewers independently screened and extracted the relevant data. Quality of studies was assessed and a quantitatively led narrative synthesis of data, supported by qualitative evidence, was then conducted.

Results: Twenty-four studies with 823 participants were reviewed. Self-management strategies such as patient education, providing information, goal setting, problem-solving, action planning, self-monitoring, and social support were integrated with rehabilitation therapy to improve mobility post-stroke. The reviewed studies showed improvements in functional mobility and walking ability, self-efficacy, participation in physical activity, and quality of life to various extents. Participants in qualitative studies considered the self-management interventions as a valuable addition to their therapy and perceived the improvement in their mobility following them.

Conclusion: There is some evidence that self-management interventions help to improve mobility outcomes post-stroke. Heterogeneity of data in the studies made meta-analysis impossible. Most of the identified studies examined the feasibility and fidelity of the interventions and further research is warranted to examine the efficacy of these interventions to improve functional mobility post-stroke.

ARTICLE HISTORY
Received 3 March 2021
Revised 27 December 2021
Accepted 7 January 2022

KEYWORDS
Stroke; rehabilitation; self-management; functional mobility; walking; community care; exercise

➤ IMPLICATIONS FOR REHABILITATION

- Self-management interventions can improve mobility-related outcomes, which are considered a priority goal for many stroke survivors.
- Survivors valued their participation in self-management integrated care programmes and linked that to the perceived improvement in their rehabilitation outcomes.
- Self-management interventions such as patient education, goal-setting, self-monitoring, and professionals/carers support have been found to improve mobility outcomes for stroke survivors.
- The outcomes that benefited to a slight extent using self-management were; functional mobility, walking ability (speed, distance, and endurance), and a number of steps per day.

Introduction

A stroke can impact individuals' lives to varying extents [1]. The motor impairments might restrict the functional mobility of survivors and affect their physical activity and psychosocial status post-stroke [2,3]. Walking, an important form of functional mobility can be a challenge for about 75% of individuals recovering from a stroke [2,4]. Walking is considered a crucial goal for stroke survivors' mobility after stroke [5]. Therefore, therapy plans should include the most effective strategies that help survivors to achieve their functional mobility goals.

Rehabilitation post-stroke aims to improve survivors' functional recovery and to increase their capabilities for community reintegration [6]. During stroke rehabilitation, it has been evident that high intensity of physical activity training can lead to better functional outcomes such as walking [7]. A meta-analysis of the studies of the effectiveness of walking training post-stroke found that intensive walking training improved walking capacity and ability to self-care at different stages of stroke rehabilitation [8]. However, research has identified that rehabilitation services in the UK have not been able to offer intensive walking training for stroke survivors [5,9]. Patients are discharged home with early discharge strategies with a shortened hospital stay. However, there is a lack of adequate support, feeling of being lost or abandoned, or receiving- poor care at home following discharge [5,10].

CONTACT Ahmad Sahely axs1638@student.bham.ac.uk School of Sports, Exercise and Rehabilitation Sciences, University of Birmingham, B15 2TT, Edgbaston, UK

Supplemental data for this article can be accessed here.

This article has been corrected with minor changes. These changes do not impact the academic content of the article.

© 2022 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.
This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (http://creativecommons.org/licenses/by-nc-nd/4.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

Considering the need to improve mobility and independence after discharge and the limited availability of therapy resources following discharge there is a need to consider strategies that can empower patients. Promoting patients' role of self-management can help them to cope better with the consequences and achieve their priority goal of walking.

The main principle of Self-Management (SM) is to empower individuals with knowledge, skills, and confidence that can increase survivors' capabilities for functional rehabilitation and reintegration into the community [11]. Supporting strategies are taught to enable patients to overcome challenges after discharge from hospital care [12,13]. SM was defined by the National Clinical Guideline for Stroke in the UK as the *"actions and confidence of individuals to manage the medical and emotional aspects of their condition in order to maintain or create new life roles"* (5,p.28). SM can support rehabilitation efforts during early supported discharge from acute care and has been positively associated with functional and psychosocial outcomes of rehabilitation during both subacute and chronic stages of stroke recovery [11,14]. Therefore, it has been recommended by clinical guidelines as a considerable part of therapy planning [5]. Based on the above evidence, increasing patients' SM skills might positively influence functional mobility outcomes post-stroke, hence, there is a need to explore the characteristics of the most effective SM strategies relevant to functional mobility.

In the rehabilitation literature, strategies used to enhance self-management behaviours range from providing patients with information or education about their conditions to more complex strategies such as involving a patient in goal setting, decision making, problem-solving, or self-monitoring during their rehabilitation process [15,16]. Theoretically, incorporating multiple strategies in an intervention can be most effective especially when behaviour change needs to be targeted [11,16]. Previously, reviews have evaluated the effectiveness of SM as a holistic approach that explores aspects of rehabilitation such as functional ability, participation, self-efficacy, and quality of life [11,16]; yet there has been no review of SM interventions for improving mobility post-stroke. This review aims to provide an evidence synthesis of the SM-based interventions that can be used by rehabilitation professionals to improve patients' mobility post-stroke.

Objectives

To collect, review, synthesise evidence around self-management interventions to improve mobility and the relevant outcomes that were studied within stroke rehabilitation.

Review question

What are the effects and outcomes of self-management interventions related to the rehabilitation of mobility post-stroke?

Methods

An integrative review of relevant studies was undertaken [17]. A subtle realist perspective was assumed for this review that focuses on the common reality experienced across individuals. This perspective supports the combination of different methodologies to explore participants' perceptions of reality [18,19]. The study protocol was registered on the International Prospective Register of Systematic Reviews (PROSPERO Registration # CRD42019151051).

Search strategy

A systematic search was undertaken on the following electronic databases from January 1992 until July 2021: PubMed, MEDLINE, EMBASE, PsycINFO, AMED, CINAHL, Cochrane Database of Systematic Reviews, and Web of Science. The search terms included: 'stroke', 'rehabilitation', 'self-management', 'walking', and 'functional mobility. These terms were exploded using synonyms from relevant literature and identification of MeSH terms from PubMed (see Supplementary Appendix A for a detailed list). Further, searching was undertaken using electronic search engines including Google Scholar and ScienceDirect. We used limiters to search for the articles that were published in English, related to humans, and when keywords were found within abstracts. References from shortlisted articles and a search of grey literature including publications from conference proceedings were also conducted as a secondary search. If the initial search had returned any PhD theses we searched for articles published from this work. We wrote to authors of theses and conference abstracts to check for any relevant publications.

Eligibility criteria

The following eligibility criteria for studies were identified using the PICOS (Participants, Intervention, Comparison, Outcome, Study design) acronym. The eligibility criteria have been set out below based on the PICOS.

Participants

Studies that included results detailing separate (if mixed samples) and identifiable analysis of stroke survivors with any type or severity of a stroke, who have received any form of self-management support interventions to improve their mobility at any time after stroke. Studies were excluded if they recruited stroke survivors under 18 years of age or used self-management specifically for stroke prevention.

Interventions

The review included studies that used self-management strategies that targeted improved mobility either individually or in clusters. Studies were excluded if they involved psychosocial and/or behavioural interventions in isolation without targeting self-management behaviour. For example, (tele) rehabilitation or cognitive therapy that did not encourage self-management behaviours were excluded.

Comparison groups

Articles were included whether they had a comparator, usual care or no comparator intervention. We did not specify any inclusion criteria for the comparator treatments (all types) provided to the control groups of participants.

Outcomes

Studies were included if they provided qualitative or quantitative data related to functional mobility (individual's physiological ability to move independently and safely to perform ADLs in a different environment [20]) outcomes, in addition to other self-management-related outcomes such as psychological, social, or general well-being measures.

Study designs

There was no restriction on the types of study design for inclusion in this review.

Study selection

The identified results from the databases search were transferred and saved into the RefWorks reference management software (ProQuest LLC, 2020). The duplicates were removed and an initial screening of titles was done by a reviewer (AS). This was followed by a screening of abstracts which was done independently by reviewers (AS, SR and DG). Irrelevant studies were excluded at this stage based on the inclusion criteria. The full-text screening was done by two independent reviewers (AS and DG). Conflicts between the two reviewers were resolved by a third reviewer (SR) at each stage of screening. A PRISMA Flow Diagram was used to summarise the results of the screening.

Quality appraisal

To assess the risk of bias in the selected studies, the Cochrane's Risk of Bias Tool (the updated version) was used to critically appraise the randomised controlled trials [21]. The Risk Of Bias In Non-Randomised Studies of Interventions (ROBINS-I) was used to evaluate the non-controlled trials [22]. The Mixed Methods Appraisal Tool (MMAT) was used for the quality assessment of the mixed-methods studies [23]. The Critical Appraisal Skills Programme (CASP) was used for the critical appraisal of studies with other designs [24]. Studies with poor quality were not excluded from the review as we planned to describe all possible effects of self-management interventions on the stroke population. The Grading of Recommendations, Assessment, Development and Evaluations (GRADE) framework was used to rate the overall strength of evidence around outcomes, based on the quality of the reviewed quantitative studies [25]. Two reviewers (AS and DG) assessed the quality of the included studies independently and a third reviewer solved the discrepancy between their results (SR).

Data extraction

A data extraction template was adopted from the Cochrane Data Extraction and Assessment Template for each study and a summary table of the extracted information from all studies was created. This was done independently by two reviewers (AS and DG) and checked by a third reviewer (SR). The extracted data included information about participants' characteristics, study methods, interventions, outcomes and findings. Specific details about the strategies and protocols of self-management interventions used in the studies were extracted. Ten study authors were contacted for any missing data relevant to the review question.

Data synthesis

The data analysis process is suggested to follow the steps of data reduction, data display, data comparison, conclusion drawing, and verification [17,26]. Step 1 data reduction: Data from articles were reduced to a manageable format by initially classifying them into two main groups, quantitative and qualitative. Step 2 data display: The key elements of the studies were extracted using tabulation techniques (see Table 1 and Supplementary Appendix B). The articles were presented within the data extraction table in alphabetical order. Step 3 data comparison: Identified themes from step 2 were compared using a constant comparison method to identify the similarities and differences in the contents of the included studies. The data was organised under key sections that served as overarching themes. Qualitative findings were independently analysed by AS and SR using thematic analysis [51] (see Supplementary Appendix B). Findings were compared and conflicts were discussed between the reviewers until they reached a consensus. Each theme included subthemes that covered different aspects of participant's perspectives regarding that theme (see Supplementary Appendix B). Conclusions were presented by integrating the thematic analysis with the quantitative data sections supported by the qualitative findings under the themes.

Results

Study characteristics

A total of 1903 studies were found from the databases searched. Secondary searches resulted in 45 articles. After screening, twenty-four studies conducted between January 1999 and July 2021 were included in this review (Figure 1 PRISMA flow diagram). Nine studies were randomised controlled trials [27,29,33,36,37,39,47–49], two quasi-experimental studies [38,40], one single group longitudinal study [32], five pre-post designs [35,42,44–46], and two case reports [28,43]. Five studies used mixed-methods designs to examine the feasibility of different SM interventions [30,31,34,41,50].

Studies were conducted in different countries: Canada (7 studies), Australia (5 studies), UK (3 studies), USA (3 studies), Netherlands (1 study), Japan (1 study), New Zealand (1 study), Israel (1 study), Italy (1 study) and Germany (1 study). Participants were recruited from various settings involving various stages of recovery defined as acute (less than 2 weeks after stroke), subacute (within 6 months from the onset of stroke) and chronic (more than 6 months after onset). Eleven studies were recruited from acute and subacute stages [27,29,31–33,36,38,42,47–49], ten studies from the chronic stage [28,34,37,39–41,43–45,50], one study recruited only from the acute stage (3 ± 1 days from stroke onset) [35], and two studies recruited participants including both subacute and chronic stage of recovery [30,46].

Description of participants

A total of 823 participants (523 men and 300 women) with a mean age of 63.7 years (age range: 40.9-73.2 years) were included in the selected studies. Nineteen studies indicated that participants had to have mild to moderate impairments ((FIM $\geq$ 40) or were able to walk independently or with minimal assistance (FAC $<$ 5)) to be eligible for participation in the selected studies [27–33,35,37,39–45,47–49]. Three studies had recruited survivors with ischemic stroke [35,43,47], six studies had a mix of ischemic and haemorrhagic [29,30,32,37,48,49] and one study had only one participant with haemorrhagic stroke [28]. Other studies did not specify the stroke type of their participants.

The availability of a caregiver was an eligibility criteria for inclusion in four studies where the role of caregivers was a part of the intervention [36,46,48,49]. In five studies, the presence of caregivers was optional [27,31,32,38,42] and the rest of the studies did not indicate any role of caregivers or family members. Table 1 shows participant's characteristics in each study.

Quality of evidence

The highlights of the methodological quality critique of studies can be seen in Table 1. Six studies [30,31,34,35,46,50] were not powered enough to detect changes in the outcomes due to the small sample size. In addition to sampling, five studies [28,34,38,43,44] had a high risk of bias across different categories including selection, performance, and detection bias. Three of the

Table 1. Summary table of the reviewed studies.

Study/ Country/Design	Participants	Interventions	Theoretical frameworks/ SM strategies	Outcomes	Results	Methodological quality
Baskett et al. [27] New ZealandRCT	*N* = 100 (mean age 71.7 *(IG)* and 67.8 *(CG)* in yrs). • Stroke survivors after discharge. • Subacute stage.	*IG*: • OT and PT visit once a week and exercises prescribed. • Encouraged to exercise several times a day. • Therapists guided the self-directed therapy. *CG:* Outpatient or day hospital therapy*Duration:* 18 months. *Format:* One-to-one. *Delivered by:* PT/OT at home for the intervention group.	**TF:** Unclear. **SM strategies:** Goal setting/ action planning/ self-monitoring.	Gait speed, Limb function, Activities of daily living, Time with therapists, Mood of subjects and caregivers, Anticipated outcomes at entry, Perceived outcome at exit.	No statistical differences between the control and experimental groups in any outcome measures.	• High risk of bias (CRoB). • No blinding. • Used surrogate quality of life measures in screening for mood disorders.
Broetz & Birbaumer [28] GermanyCase report	54-year-old male who suffered cerebral bleeding with left hemiparesis 25 years ago (chronic stage).	Over the 18-month period the programme included: • Daily intensive exercises × 1 week. • One-hour sessions/ week. Goal-setting. • Self-control cues for exercises Supervision and feedback after successful trials. • Intensive training week repeated at 6 months and 12 months. *Duration:* 18 months. *Format:* One-to-one. *Delivered by:* Physiotherapist.	**TF:** Behavioural physiotherapy incorporating motor learning. **SM strategies:** Goal setting, Motivation, Supervision, Feedback and Reward.	Walking capacity, Goal attainment, andChange of symptoms.	Rhythmic walking improved from 74 steps/ minute to 112 steps/minute, Walking speed increased from 8.65 s to 6.48 s, and Running for 80 M.	• High risk of bias (CASP). • Case report of only one participant, high possibility of selection, performance, and detection bias.
Chumbler et al. [29] USAA prospective, single-blinded RCT	*N* = 48(mean age 67.1–67.7 yrs). Participants with ischemic or haemorrhagic stroke. • Subacute stage. • Discharged to the community. • Not cognitively impaired. • Able to follow a 3-step command. • Discharge motor Functional Independence Measure (FIM) score (18–88).	*IG:* **STeleR** intervention: • 3 home visits, • 5 telephone calls, • In-home messaging device for instructions on functionally based exercises and adaptive strategies. *CG:* usual care *Duration:* 3 months*Format:* One-to-one. *Delivered by:* Therapist *via* home visit or telephone calls	**TF:** The Verbrugge and Jette's model for the disablement process. **SM strategies:** Goal settingAction planningSelf-monitoring.	Telephone Version of Functional Independence Measure Function scales of the Late-Life Function and Disability Instrument (LLFDI).	The outcomes improved at 6 months for the STeleR group and declined for the usual care group4 of the 5 (LLFDI) component subscales (P0.05),	• Low risk of bias (CRoB). • Sample had majority males and wasn't inclusive for stroke population.
Dean et al. [30] UKMixed methods study	*N* = 45 (mean age 70 (*IG*) and 71 (*CG*) in yrs).	*IG:* **ReTrain** which included: • A one to one to 1 session followed by ten,	**TF:** Action for Rehabilitation following Neurological	**Primary outcomes:** Rivermead Mobility Index, Timed Up and Go, Modified Patient-	The trial was not powered to detect differences in any outcomes between	• Low risk of bias (MMAT). • It failed to identify a clearprimary

(*continued*)

Table 1. Continued.

Study/ Country/Design	Participants	Interventions	Theoretical frameworks/ SM strategies	Outcomes	Results	Methodological quality
	• Stroke survivors with mobility issues. • Discharged from rehabilitation services at least 1 month before. • Subacute and chronic stages. • Possessing sufficient physical, cognitive, and communication ability.	twice-weekly group classes, • Cardiovascular and strength work, • Self-management strategies, • Functional activities, • Goal setting, and • Bespoke home-based training programme. *CG:* Exercise after stroke advice booklet plus usual care. *Duration:* 3 months*Format:* Group and one-to-one. *Delivered by:* Personal trainers on the UK Register of Exercise Professionals.	Injury (ARNI). **SM strategies:** EducationGoal settingAction planningProblem-solvingSelf-monitoringGroup and social support.	Specific Functional Scale, 7-day objective physical activity levels using wrist-worn accelerometer, and Physical activity diary. **Secondary outcomes:** Stroke Self-Efficacy Questionnaire, Fatigue Assessment Scale, EuroQol- 5 Dimension (EQ-5D-5L).	trial arms or over time.	outcome for a definitive RCT. • Small sample that did not have a wide age range or ethnic diversity. • This was a pilot study, not designed to demonstrate generalisability.
DePaul et al. [31] CanadaMixed methods study	$N = 10$ (mean age 62.3; SD 11.7 years). • Inpatient stroke rehabilitation • Acute and subacute stages. • Functional Ambulation Classification scores (2-4). • Functional Independent Measure ≥ 40.	**IMPACT:** Starts in the hospital and continues after discharge. Usual therapyPhysiotherapy −8 sessions × 2 weeks *Duration:* 14 days. *Format:* One-to-one. *Delivered by* a trained PT.	**TF:** Social cognition theory and Self-determination theory. **SM strategies:** Education and professional supportGoal setting Decision makingAaction planningSelf-monitoring and Feedback.	6 min Walking Test, 5-meter Walk Test, Functional Independence Measure (total and motor), Berg Balance Test, Functional Ambulation Category, Chedoke-McMaster Stroke Assessment (CMSA leg and foot). Therapists' and patients' perceptions were qualitatively collected.	Gait speed improved by an average of 0.32 m/s (SD 0.27 m/s) on 5-m walk test. 6MWT improved on an average of 85.0 m (SD 64.0) over the 2-week intervention period. All patients indicated that the programme helped them increase their activity and indicated they would continue to practice walking-related activities beyond the coaching period.	• High risk of bias (MMAT). • Small and inconclusive sample. • Single therapist and single setting. • Single-group study design. • Not powered to detect outcomes changes. • Amount of training wasn't accurately reported across all participants.
Ezeugwu & Manns [32] CanadaSingle group, longitudinal intervention study	$N = 34$ (mean age = 64.6 yrs). • Within 2 weeks of discharge from inpatient facilities. • Subacute stage. • Able to stand up from a chair. • Walk at least 5 meters with or without gait aids. • Able to understand 2-step commands.	**STand Up Frequently From Stroke (STUFFS)** Sedentary time was interrupted with upright activities (standing and walking) at home and in the community. A motivational wrist-worn activity monitor was used throughout the intervention. *Duration:* 8-weeks *Format:* One-to-one. *Delivered by* PT at home.	**TF:** Social cognitive theory. **SM strategies:** Action planningSelf-monitoring.	Chedoke-McMaster Stroke Assessment (CMSA) for leg and foot, 5-meter walk test, Timed Up and Go, Sedentary behaviour and physical activity (time sedentary, standing, and stepping, the number of steps, sit-to-stand transitions) were measured using the activPAL, The Montreal Cognitive Assessment (MoCA), Stroke Impact Scale, and Self-Efficacy for Exercise Scale	Sedentary time decreased by 54.213.7 min/day ($p <$ .01) at post intervention and 26.814.0 min/day ($p < 0.07$) at follow-up, Significant improvements in walking speed, ($p <$ .05). The number of steps and time spent stepping were not statistically different across both time periods.	• Some concerns about risk of bias (CASP). • The sample was limited to specific stroke population. • No control group. • The duration of the intervention was too short to achieve change in behaviour.

(*continued*)

Table 1. Continued.

Study/ Country/Design	Participants	Interventions	Theoretical frameworks/ SM strategies	Outcomes	Results	Methodological quality
				Outcomes were assessed with 1-week baseline, 8-week intervention, and 8-week follow-up.		
Haworth et al. [33] UKAn exploratory, single blind RCT	*N* = 44 (mean age 40.9 (*IG*) and 42.3 (*CG*) in yrs). • Patients with neurological conditions including stroke. • Within 4 weeks of discharge from in-patient care. • Subacute stage. • Able to carry out exercise independently. • Sit and ransfer independently.	*IG:* **Exercise and education programme** twice weekly over four weeks. Education involved lectures about the benefits of exercises and self-management mobility, strength and balance exercises *CG:* Standard follow-up care including medical review clinics and outpatient therapy. *Duration:* 4 weeks. *Format:* Group.*Delivered by:* by research therapist at specialist neurosciences centre.	**TF:** Self-efficacy. **SM strategies:** EducationGroup intervention.	**Primary outcomes:** Exercise Efficacy Scale and Human Activity Profile. **Secondary outcomes:** 10-metre timed walkShort Form 36 Health Survey, Hospital Anxiety and Depression Scale, UWIST Mood Adjective Checklist, Motricity Index, Frenchay Arm Test, Rivermead Mobility Index, and a visual analogue scale. Data were collected at baseline and at 6, 12 and 24 weeks.	At 6 weeks, significant improvements in exercise efficacy in the treatment group ($p = 0.001$). Moderate improvements inactivity levels were noted for both study groups with no between-group differences. No significant improvements in SF 36 'physical health' Follow-up at 12 and 24 weeks suggested that the improvements noted in exercise self-efficacy, activity levels and quality of life were maintained and were independent of the exercise programme.	• Some concerns about risk of bias (CRoB).Small sample size. • The intervention needed to be extended to accurately measure HAP. • Weaknesses within the chosen measures.
Huijbregts et al. [34] CanadaMixed methods study	*N* = 18 (mean age 61.8 (*IG*) and 65.6 (*CG*) in yrs). • Medical diagnosis of stroke. • Completed active rehabilitation. • Chronic stage. • Living in the community.	*IG:* Telehealth MOST intervention was implemented using videoconferencing. MOST self-management programme included: Discussion and exercise. Goal-setting andproblem-solving, Exercise, and community- reintegration skills. *CG:* Waiting list control group. *Duration:* 18 sessions over 9 weeks. *Format:* Group therapy. *Delivered by:* Trained health professional facilitators.	**TF:** Unclear. **SM strategies:** EducationProblem solvingGoal settingSocial support.	Berg Balance Scale (BBS), The Reintegration to Normal Living Index, The Stroke-Adapted Sickness Impact Profile, Chedoke-McMaster Stroke Assessment Activity Inventory, Goal Attainment Scaling, and The Geriatric Depression Scale.	There was a significant difference in BBS scores between the T-MOST group and the WLC group (mean difference −4.27, 95%CI: −6.66 to −1.87).	• High risk of bias (MMAT). • Small sample size • No randomisation • High risk of selection bias due to recruitment strategy. • Baseline differences between groups were not clear.
Kanai et al. [35] JapanPre–post interventional study	*N* = 22 (mean age 62.5 yrs). • Acute ischemic stroke.	*IG:* 40–120 min of a supervised rehabilitation program 5–6 times a week until discharge. Instruction on the self-monitoring	**TF:** Self-efficacy. **SM strategies:** EducationGoal settingAction	The daily number of steps was taken as an index of Physical Activity andSelf-	PA during the intervention was higher than that at the baseline measurement	• High risk of bias (CASP). • Very small sample size. • No control group.

(*continued*)

Table 1. Continued.

Study/ Country/Design	Participants	Interventions	Theoretical frameworks/ SM strategies	Outcomes	Results	Methodological quality
	• Able to walk without assistance or gait aid • Within seven days of admission.	approach and discussed physical activity (PA) targets, Exercises included body stretches, weight resistance exercises, aerobic exercise. Accelerometer worn 24 h/day until discharge *Duration:* 11 days. *Format:* One-to-one. *Delivered by:* PT at hospital	planningSelf-monitoring.	efficacy for physical activity (SEPA) scale.	(5709.4 ± 2236.1 vs. 2813.9 ± 1511.9 steps/day, $p < 0.001$). Self-efficacy for PA during the intervention was also higher than that at the baseline measurement (76.4 ± 18.8 vs. 58.9 ± 29.0 points, $p < 0.001$).	• Was not statistically powered to detect changes in the outcomes. • Used only the number of steps/day as the measure of PA. • Did not assess psychological factors or pre-morbidity exercise habits. • Did not conduct functional tests at discharge.
Kendall et al. [36] AustraliaRCT	*N* = 100 (mean age 65.96 yrs). • First stroke. • Subacute stage. • No dementia or psychiatric illness. • Sufficient English language. • Expectation of discharge to their homes.	IG: SM education programme targetting mobility and exercise. *Duration:* 7 weeks. *Format:* Group *Delivered by* professionals in community settings.	**TF:** The Chronic Disease Self-Management Course was used to operationalise the concept of psychosocial skill expansion. **SM strategies:** EducationGoal settingAction planningGroup interaction and Support.	Stroke Specific Quality of Life scale (SSQOL) and the Self-efficacy Scale.	The study identified a significant impact of the intervention on the quality of family roles, self-care, work productivity, and functioning in daily activities within SSQOL ($p = 0.05$). The control and intervention groups differed significantly in self-efficacy levels across all times, $F(1, 93) = 9.45$, $p = 0.003$, including pre-intervention.	• Some concerns about risk of bias (CRoB). • Minimal data was available about the clinical status of the participants. • People with language difficulties were excluded.
Malagoni et al. [37] Italy Feasibility and pilot RCT	*N* = 12 (mean age 66.5 ± 11.9 yrs). • People with chronic stroke. • Ability to ambulate independently at least for 10 meters on level ground. • FAC > 3. • Ability to perform TUG.	*IG:* Structured home-based exercise programme with 2 10-minute sessions/day (6 days/week) of intermittent walking. *CG: Standard supervised group therapyprogramme*. *Duration:* 10 weeks. *Format:* Group and individualised sessions at home. *Delivered by:* Physiotherapists.	**TF:** Unclear. **SM strategies:** Self-monitoring and feedback.	Functional outcome measures included 6-Minutes Walking Test, Timed Up and Go, Stair Climb tests, and Physical activity domain of the SF-36 questionnaire.	6-minute walk test and physical activity domain of the SF-36 significantly increased in both groups ($p = 0.03$). Timed Up and Go improved in both groups, significantly for the home-based exercise group ($p = 0.03$) while stair climb remained stable for both groups.	• High risk of bias (CRoB). • Small sample size • No blinding
Mansfield et al. [38] CanadaQuasi-experimental feasibility-controlled trail	*N* = 26 (mean age 62.1 (*IG*) and 67.1 (*CG*) in yrs). • Any type of stroke. • Subacute stage.	*IG:* **PROPEL, included** group exercise and self-management. Supervised and individualised aerobic training 3 times a week, An	**TF:** Transtheoretical model + social cognitive theory and self-efficacy. **SM strategies:**	Physical activity level was assessed using an accelerometer, heart rate monitor, and the Physical	PROPEL participants had a higher participation in physical activity than COMP participants (Hedge's	• Serious risk of (ROBINS-I). • Extremely low recruitment rate.

(*continued*)

Table 1. Continued.

Study/ Country/Design	Participants	Interventions	Theoretical frameworks/ SM strategies	Outcomes	Results	Methodological quality
		inpatient module and an outpatient module. *CG:* received in- and outpatient rehabilitation *Duration:* 6 weeks. *Format:* Group. *Delivered:* by a PT and a healthcare student in an outpatient rehabilitation setting.	Goal settingAction planningProblem solvingSelf-monitoring	Activity Scale for Individuals with Physical Disabilities (PASIPD), the Short Self-Efficacy for Exercise (SSEE) scale, the Short Outcome Expectation for Exercise (SOEE) scale, and the Barriers to Being Active Quiz (BBAQ).	$g \geq 0.5$),reported higher SSOE scores (Hedge's *g*: 0.50) and fewer significant barriers to physical activity in the BBAQ than COMP participants (Hedge's *g*: −1.18).	• Groups were not comparable at baseline. • Patients with communication difficulties were excluded. • Only 34% of daily heart rate data were available.
Olney et al. [39] CanadaRCT	*N* = 72 (mean age 63.5 (*IG*) and 65.8 (*CG*) in yrs). • Chronic stroke survivors. • Able to walk a total of 15 min with rests (with or without assistive devices except a 4-point walker). • Able to tolerate activity for 45 min with rests. • No severe coronary artery disease.	*IG*: One week supervised instruction program followed by a 9-week unsupervised home programThe unsupervised group had exercises prescribed to them and written instructions to monitor and progress. *CG:* 10-week supervised strengthening and conditioning program (supervised) *Duration:* 10 weeks*Format:* group format for the supervised sessions and 1 to 1 for the unsupervised sessions. *Delivered by:* therapist at rehabilitation centre for the supervised group and at home for the unsupervised group.	**TF:** Unclear. **SM strategies:** Education and Self-monitoring.	**Primary Outcome:** Walking speed (6MWT). **Secondary Outcomes:** Human Activity Profile (HAP) adjusted activity score, Medical Outcome Study 36-Item Short-Form survey (SF-36), Physiological Cost Index, and lower extremity muscle strength.	The 6MWT speed increased significantly in both groups and remained significantly improved at one year. The HAP showed an increasing trend only in the supervised group and was significant at one year. The SF-36 Physical component summary score increased significantly in the supervised group and remained improved at one year; the unsupervised group showed significant improvement at one year.	• Low risk of bias (CRoB). • It was not possible to blind participants and testers. • The generalisability of the findings might be limited due to restricted eligibility criteria of participation.
Paul et al. [40] UKQuasi-experimental pilot study	*N* = 23 (mean age 55.3 (*IG*) and 56.3 (*CG*) in yrs). • Single unilateral stroke. • Discharged from rehabilitation. • Chronic stage. • Able to walk independently with or without using an aid or orthosis. • Able to comprehend instruction.	*IG:* **STARFISH** program included a mobile phone app-based intervention, with evidence-based behaviour change techniquesThe intervention started with 1 week of baseline step count using phone accelerometer, followed by use of the STARFISH application over a 6-week period. *CG:* Usual care. *Duration:* 6 weeks. *Format:* Group. *Delivered:* through a mobile app.	**TF:** Behaviour Change Techniques (BCTs). **SM strategies:** Feedback, Self-monitoring and Social support	Physical activity (steps/ day), Ten-Meter Walk Test, Sedentary time, Fatigue Severity Scale, Instrumental Activity of Daily Living Scale, Stroke Specific Quality of Life Scale, and Psychological General Well-Being Index.	The average daily step count increased by 39.3% in the intervention group and reduced by 20.2% in the control group ($p = 0.005$ for group–time interaction). Similar patterns of data and group–time interaction were seen for walking time ($p = 0.002$) and fatigue ($p = 0.003$).	• Moderate risk of bias (ROBINS-I). • Sample was not inclusive for stroke population. • Duration of the intervention was short. • Assessor was not blinded. • No randomisation. • The sample was heterogeneous in PA. • Mobile phone accelerometer needs validation.
	N = 13 (mean age 73.23 yrs).	*IG:* **MYOT** a yoga-infused self-management intervention.	**TF:** Self-efficacy and Problem solving.	**Quantitative Outcomes:** Endurance (6-MWT),	Physical fitness outcome measures including	

(*continued*)

Table 1. Continued.

Study/ Country/Design	Participants	Interventions	Theoretical frameworks/ SM strategies	Outcomes	Results	Methodological quality
Portz et al. [41] USAMixed-methods study	• Individuals with chronic stroke (> 6 months). • Had a fall or current fof. • Completion of post-stroke rehabilitation. • Able to stand, at risk for falls (≤ 46 on the Berg Balance Scale). • Able to understand English. • Score of ≥ 4 out of 6 on the short Mini Mental Status Exam.	One hour of group self-management education followed by one hour of yoga (2 times per week). *Duration:* 8 weeks. *Format:* Group. *Delivered by an* OT and a research student	**SM strategies:** EducationGoal settingAction planning/Problem solvingSelf-monitoringGroup discussion and activities.	Strength (30-Second Chair Stand test), and Gait Speed (10-Meter Walk test). **Qualitative outcomes:** Participant perceptions of changes in physical fitness and PA were collected	endurance and lower and upper body strength significantly ($p < .02$) improved. Based on qualitative results, participants expressed positive changes in endurance, strength, gait speed, flexibility, and balance. They also reported improvements in walking ability and duration and expressed a desire to continue yoga and increase levels of exercise.	• Some concerns about risk of bias (MMAT). • The long-term effect of the programme was not measured. • It wasn't clear why some patients did not notice any change.
Preston et al. [42] AustraliaSingle-group, pre-post intervention study	$N = 20$ (mean age 68 yrs). • Discharged home from an acute stroke unit. • Subacute stage. • Able to walk 10 m across flat ground without any aids at a speed of ≥ 0.8 m/s. • Scored ≥ 24 on the Mini Mental State Examination. • Resided within 30 km of the hospital. • No moderate to severe receptive aphasia.	Five 60-minute home-based sessionsCarer or family member involved. The sessions included: education, goal setting, barrier identification, self-monitoring, and feedback. *Duration:* 3 months. *Format:* One-to-one. *Delivered by:* Physiotherapist.	**TF:** Behaviour Change Techniques (BCTs). **SM strategies:** EducationGoal settingAction planningProblem solving Self-monitoring and feedback.	**Primary Outcomes:** Duration of moderate physical activity in min/day and counts of physical activity in steps/day. **Secondary Outcomes:** Self-efficacy, walking ability, participation, and quality of life.	At 3 months, participants completed 27 min/day (95% CI 4–49) more moderate physical activity than at baseline and 16 min/day (95% *CI* − 10–42) at 6 months. Participants perceived the self-management program to be useful and there were few adverse events (muscle soreness, falls, and hospitalisation).	• Some concerns about risk of bias (CASP). • No randomisation. • No control group. • There were challenges around using Sensewear armband to collect PA data.
Richardson et al. [43] CanadaCase report	$N = 15$ (mean age 65.5 yrs). • Chronic stroke survivors. • First ischemic stroke. • Able to walk at least 2.44 mts. • Able to transfer to a chair. • Some active movement in the UE during recovery.	**START:** Self-Management and Task-Oriented Approach to Rehabilitation Training. *Duration:* 10 sessions *Format:* One-to-one. *Delivered by* physiotherapist at home.	**TF:** Self-efficacy. **SM strategies:** Goal settingAction planningProblem solvingSelf-monitoring.	TUG, Barthel Index, Stroke Impact Scale, Patient Activation Measure, modified version of Patient Satisfaction Questionnaire-18.	Significant changes were observed in the TUG ($p < 0.01$), the Barthel Index ($p < 0.01$, and the Stroke Impact Scale ($p < 0.001$).	• High risk of bias (CASP). • Very small sample size and not inclusive. • High possibility of bias as there was no randomisation or control group.

(*continued*)

Table 1. Continued.

Study/ Country/Design	Participants	Interventions	Theoretical frameworks/ SM strategies	Outcomes	Results	Methodological quality
	• Cognitive function score of 26 points on the Montreal Cognitive Assessment (MoCA). • No receptive aphasia. • Can communicate in English.					
Scrivener et al. [44] AustraliaPre-post single group study	$N = 14$ (mean age 57 ± 14.2 yrs). • Adults with stroke. • Discharged from rehabilitation. • Chronic stage. • Could walk at > 0.4 m/s with/ without an aid.	**TASK** programme. A video-guided exercise programme. The programme comprised of two phases: in phase one, four weeks of the program was supported by weekly supervised sessions at the rehabilitation centre. In phase two, four weeks of the program was completed at home without direct supervision. *Format:* One-to-one. *Delivered by* physiotherapist at home.	**TF:** Self-efficacy. **SM strategies:** Education/ self-monitoring.	Physical performance, physical activity, and exercise self-efficacy were measured at baseline and 4 and 8 weeks.	Walking speed improved over the duration of the program (mean difference −0.12 m/s, 95% CI −0.22 to −0.02, $p = 0{:}02$). Self-efficacy and physical activity did not change over the duration of the program.	• High risk of bias (CASP). • The sample size for this study was small and diverse in characteristics. • High possibility of bias as there was no randomisation or control group.
Sullivan et al. [45] USpre-post test follow up design	$N = 11$ (mean age 60.4 yrs). • Community-dwelling stroke survivors. • 21 years old or older. • Ambulators. • Stroke onset 6 months or more before participation (chronic stage).	A pedometer monitored, community-based intervention was used for 6 weeks. A briefverbal educational module was provided to eachparticipant addressing the benefits of exerciseafter stroke, pedometer use, and completion ofdaily exercise diaries. *Duration:* 6 weeks. *Format:* One-to-one. *Delivered by:* therapist at home through telephone coaching sessions.	**TF:** Self-efficacy. **SM strategies:** EducationGoal setting and decision makingSelf-monitoring.	**Primary Outcomes:** Walking speed (10-mWT) and endurance (6MWT). **Secondary Outcomes:** the Activities-Specific Balance Confidence Scale, Stroke Impact Scale–16 (SIS-16), and a pedometer satisfaction survey.	There were low effect sizes for changes in SIS-16 (0.312) and 6MWT (0.293). Increasing steps correlated with increased perception of physical function.	• Some concerns about risk of bias (CASP). • Small sample size. • The heterogeneity of participants may have affected results. • Possibility of a ceiling effect for the steps/day. • Pedometer was inaccurate with participants who walk slower than 0.5 m/s. • Short duration of intervention.
Taylor et al. [46] CanadaPre-Post intervention feasibility study	$N = 12$ (mean age72.7 yrs). • Stroke survivors between 3 and 18 months post-stroke • Subacute and chronic stages.	**Moving On after STroke (MOST):** MOST involves sessions with 1 h of discussion followed by 1 h of exercise (cardiovascular, range of motion and strength components). Participants learn about stroke-related issues, but	**TF:** Unclear. **SM strategies:** EducationGoal settingProblem solvingGroups with support.	Walking endurance (6MWT) Short-Term Goals Goal Attainment Scaling,Berg, Berg Balance Scale, Activity-Specific Balance Confidence Scale), Geriatric	Pre–post improvements were seen in goal setting, mood, balance, balance confidence, and walking endurance. Participants reported that the program provided people with	• Some concerns about risk of bias (CASP). • No control group. • No randomisation. • Insufficient numbers to compare the health outcomes of the

(*continued*)

Table 1. Continued.

Study/ Country/Design	Participants	Interventions	Theoretical frameworks/ SM strategies	Outcomes	Results	Methodological quality
		more importantly, learn problem-solving and goal-setting skillsTwo sessions/ week. *Duration:* 9 weeks. *Format:* Group with patients and carers. *Delivered by:* Clinicians *via* videoconference.		Depression Scale and Reintegration to normal living), .	stroke as well as caregivers with greater awareness of stroke, increased social support, and improved ability to cope.	telehealth participants to those in the group receiving face-to-face care.
Treger et al. [47] IsraelRCT (single blinded)	$N = 56$ (mean age 56.6 (*IG*) and 62.2 (*CG*) in yrs). • Subacute stage . • Ability to walk independently (with or without walking aids). • FIM score ≥ 60 at mid-hospitalisation evaluation.	*IG:* Received detailed instructions for 14 exercises and was instructed to walk for at least 30 min daily. Follow up phone calls. *CG:* Usual care. *Duration:* 3 months. *Format:* One-to-one. *Delivered by:* a physiotherapist.	**TF:** Unclear. **SM strategies:** EducationSelf-monitoring/ Review follow up.	The 10-metre walk test (10MWT), 6-minute walk test (6MWT), and Timed Up & Go (TUG) were performed twice; once at the end of the inpatient rehabilitation period and three months later.	A significant improvement was shown in the intervention group in 10MWT ($p = 0.008$), 6MWT ($p < 0.001$) and TUG ($p = 0.009$).	• Moderate risk of bias (CRoB). • Participants were not blinded. • Participants received instuctions from therapist without involvement in goal-setting or planning.
Van den berg et al. [48] AustraliaRCT (proof of concept)	$N = 63$ (mean age 64.5 (*IG*) and 70.1 (*CG*) in yrs). • Stroke survivors within subacute stage. • With mobility problems (FAC score < 5). • Caregiver to participate in the programme. • Had sufficient cognition to take part and no depression (HADS score < 11).	*IG:* **CARE4STROKE:** Caregiver-mediated exercises with e-health support Telerehabilitation services. Participants had 30 min, 5x a week Exercises executed by a caregiver plus usual care. *CG:* Usual care. *Duration:* 8 weeks. *Format:* One-to-one. *Delivered by:* Physiotherapist and caregiver at rehabilitation centre or nursing home and continued at home if patient discharged before finish.	**TF:** Unclear**SM strategies:** Self-monitoringCaregivers' support.	**Primary outcome**: The SIS-mobility domain. **Secondary outcomes**: Length of stay, Motor impairment, Strength, Walking ability, Balance, Extended activities of daily living, Psychosocial functioning, Self-efficacy, QoL, and fatigue. Additionally, caregiver's self-reported fatigue, symptoms of anxiety, self-efficacy, and strain were assessed.	Intention-to-treat analysis showed no between-group difference in SIS-mobility; Per-protocol analysis, examining those who were discharged home with telerehabilitation showed a trend toward improved mobility ($p = 0.06$), significantly improved extended ADLs scores at week 8 (-3.6, $p = 0.01$) and week 12 (3.0, $p = 0.03$).	• Low risk of bias (CRoB). • Small sample size. • The 2 groups were not comparable at baseline. • Study did not provide definitive measures of effectiveness. • Participants were not blinded.

(*continued*)

Table 1. Continued.

Study/ Country/Design	Participants	Interventions	Theoretical frameworks/ SM strategies	Outcomes	Results	Methodological quality
• 11 patients dropped out (high attrition). • Study was not designed or powered to detect adverse events.						
Vloothuis et al. [49] NetherlandsRCT (proof of concept)	$N = 66$ (mean age 59.26 (*IG*) and 60.53 (*CG*) in yrs). • 34 inpatients with stroke. • Subacute stage. • Lived independently before the stroke. • Discharged home. • Able to follow instructions (MMS$E > 18$ points). • FAC Score < 5. • Had a caregiver to assist.	*IG:* **CARE4STROKE:** Caregiver-mediated exercises with e-health support Telerehabilitation services. Participants had 30 min, 5x a week Exercises executed by a caregiver plus usual care. *CG:* Usual care. *Duration:* 8 weeks. Format: One-to-one. *Delivered by:* therapist and caregiver at rehabilitation centre or nursing home and continued at home.	**TF:** Assumptions that more training is better (Motor control theory). **SM strategies:** Goal settingCaregivers' support.	**Primary outcomes:** SIS-mobility domain . **Secondary outcomes:** Motor impairment, Strength, Walking ability, Balance, Mobility and Extended ADL of patients, Caregiver strain of caregivers, and Mood, Self-efficacy, Fatigue and QoL of both patients and caregivers. Outcomes were assessed at baseline, 8 and 12 weeks after randomisation.	No significant between-group differences were found regarding SIS-mobility after 8 and 12 weeks.	• Low risk of bias (CRoB). • Variability in the decision for discharge. • Patients were not included at fixed times after stroke. • Study may be under powered.
White et al. [50] AustraliaMixed methods study	$N = 22$ (mean age 65.76 yrs). • Community dwelling stroke survivors. • Chronic stage. • Not accessing other rehabilitation services at the time of enrolment.	**MASTERSTROKE** A secondary prevention stroke group program with two 2-h sessions weekly (1 h for education and 1 h for exercise). The exercise component incorporated fitness, strength, mobility and balance and education focused on secondary stroke prevention whilst also providing chronic condition self-management support. *Duration:* 9 weeks. *Format:* Group.*Delivered by:* PT and multi-professional community-based team.	**TF:** Unclear. **SM strategies:** EducationGroup support.	Timed Up and Go (TUG), Six Minute Walk Test, Participants' perceptions were qualitatively collected.	TUG (mean change $= 3.89$, $p = 0.00$), and quality of life scores (mean $= 0.25$, $p = 0.01$). Qualitative responses results confirmed increases in knowledge about stroke and exercise tolerance, successfulness of a group program and lifestyle modification post-stroke.	• Some concerns about risk of bias (MMAT). • Small sample size. • Was not statistically powered, nor controlled. • The assessors were also the therapists who implemented the programme. • Qualitative interviews were limited to one per person that could limit the ability to capture changes over time and sustainability of modifications.

N: Sample size; SM: Self-management; TF: Theoretical Framework; CRoB: Cochrane's Risk of Bias Tool; ROBINS-I: The Risk Of Bias In Non-Randomised Studies of Interventions; MMAT: The Mixed Methods Appraisal Tool; CASP: The Critical Appraisal Skills Programme; RCT: Randomised Controlled Trial; OT: Occupational Therapist; PT: Physiotherapist; FAC: Functional Ambulation Category; PA: Physical Activity.

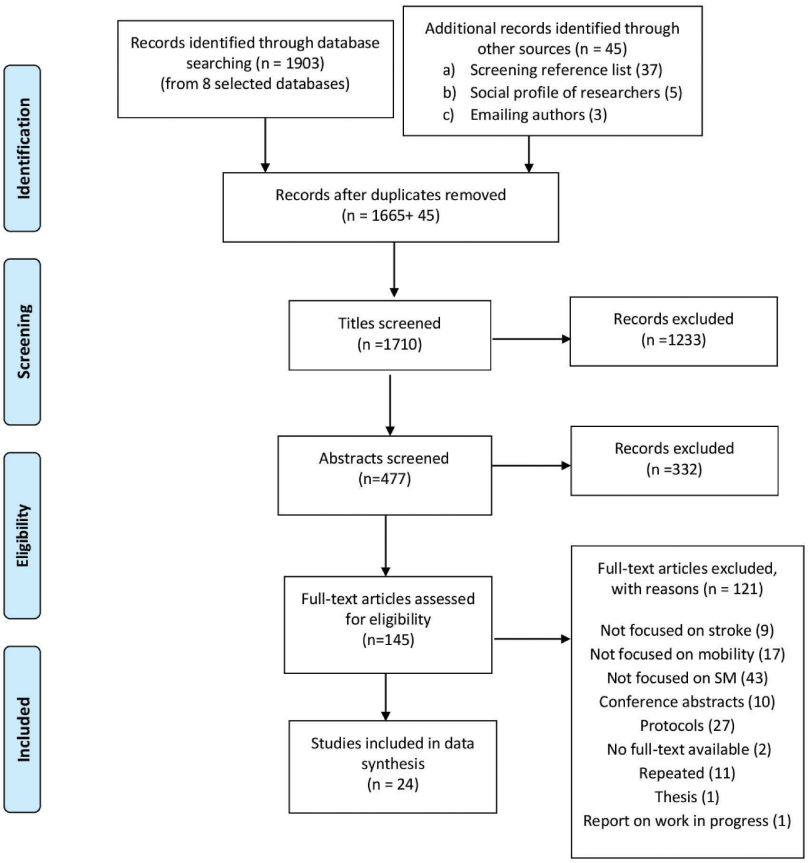


Figure 1. PRISMA flow diagram of study selection [53].

RCTs [27,33,37] had a high risk of performance bias because the blinding of assessors and participants was impossible due to the nature of the applied intervention. In two studies [32,35], there was a high risk of detection bias because the assessors and/or participants were not blinded. Also, there was a high risk of selection bias in three studies [28,38,43] because of their recruitment methodology which had targeted specific participants. There were only six studies (RCTs) that had an overall low to moderate risk of bias [29,30,39,47–49] and one non-randomised controlled trial that had a moderate risk of bias [40]. The risk of detection and performance bias was unclear in certain studies [36,43] as they did not provide any information about the blinding. In some studies, it was not possible to make a judgment on the risk of bias because of a lack of adequate information [38,40].

In the mixed methods studies [28,43] reviewed, there was a high risk of selection bias as the complete outcome data for some participants were missing or not collected for follow-up. Withdrawal rates were not stated and the confounders were not accounted for [34,41]. There was a potential for measurement bias as the therapists who executed the study were also the assessors [50]. Also, the divergences and inconsistencies between quantitative and qualitative results were not adequately addressed. Using the Grading of Recommendations, Assessment, Development and Evaluation (GRADEpro) software [52], the certainty of evidence within the included studies was rated narratively for the main outcomes. Considering the methodological weaknesses and limitations of the majority of the studies to provide a robust judgment on the effectiveness of the SM interventions, the body of evidence has been graded 'moderate, low, or very low' on the GRADE system for the main outcomes (Supplementary Appendix C).

The themes arising from the integrative narrative synthesis are presented below.

1. Conceptualisation of self-management in stroke rehabilitation

The concept of SM was variably interpreted by the stakeholders (patients, professionals, researchers, and policy makers) within the qualitative components of the studies and authors of some studies included in this review. Qualitative studies indicate that survivors perceived SM as an approach that can help to increase their capabilities to manage their therapy at home or community,

motivates them to undertake more training for mobility as implied in *"I was doing three times a week, and I need to make it four or five times"*, and hence promotes their independence and socialisation [6,7,27,30,31,41].

Policy makers and healthcare provider considered SM as sharing of responsibilities for rehabilitation services with patients and their caregivers [27]. From therapists' perspective, the implementation of this concept in real practice has altered their role in service delivery and allowed for the transition of some responsibilities to patients.

Authors of some studies have narrowed their conceptual understanding of SM interventions to specific elements of its conceptual components such as a behaviour change of patients [28,32,40], self-efficacy [35], patient education [33], or self-directed therapy [27]. In the studies that applied SM strategies at the time of discharge from the hospital [27,29,30,39], SM was perceived mainly as a strategy to support the delivery of care at home or in the community and to support early supported discharge. During the chronic stage, SM strategies were suggested to increase the ability to manage the ongoing sequelae of stroke and risk factors for recurrent stroke [43,46,50].

2. Theoretical frameworks for self-management interventions

Using theories is very crucial for the development of complex interventions such as SM [54]. They can help understand how an intervention can be designed, implemented, and evaluated. The development of the interventions in this review was based on a variety of theoretical frameworks and process guidelines. All theories discussed within SM literature are described below. The social cognitive theory and theory of self-efficacy (SE) were commonly used to develop SM interventions, to mediate individuals' behaviour of self-management, and to measure the effect of SM interventions on stroke survivors. SE in particular was used as a framework for the interventions in three studies [33,35,41]. Sullivan et al.'s [45] intervention were based on the effect of self-monitoring (a part of SE) to increase participants' level of physical activity. One study used the knowledge-to-action cycle to develop and evaluate an SM and task-oriented intervention called START; however, the SM part of the intervention was developed based on self-efficacy [43].

The social cognitive theory was the foundation for the STUFFS intervention [32] and the PROPEL along with the Trans-Theoretical model [38] or self-determination theory [31]. The SteleR intervention was guided by Verbrugge and Jette's model for the disablement process [29]. Kendall et al. [36] used the chronic disease self-management course to provide support for stroke survivors based on the concept of psychosocial skill expansion. Two studies used behaviour change techniques (BCTs) to increase the level of physical activity of participants [40,42]. Self-determination theory components were also used by Broetz and Birbaumer [28] in addition to the principles of behavioural physiotherapy to increase patient autonomy in daily training for walking. Multiple studies were not clear about the theoretical frameworks on which their interventions were developed [27,34,37,39,46,47,50]. Overall in studies that showed significant outcomes related to mobility the predominant theories used were identified as self-efficacy in three studies [42,43,45], social cognitive theory in one study [40], behaviour change techniques in three studies [29,38], and self-determination theory in two studies [30,46].

3. Self-management intervention strategies for mobility training

Mobility rehabilitation was directly targeted by SM intervention in eleven studies [28–31,37,40,45–49], while other studies included mobility indirectly as a part of physical activity training [27,33–35,38,39,41–44], sedentary behaviour change [32], stroke prevention [50], or within SM education about mobility [36].

The number and content of SM strategies varied across studies. The most common strategies included providing information, patient education, goal setting and decision making, problem-solving and action planning, identifying barriers, self-monitoring and feedback, and social support (Table 1). SM was accompanied by various types of therapy modalities including, usual care of physical and/or occupational therapy in most of the studies, yoga [41], behavioural physiotherapy [28], and aerobic exercises [35,38]. Incorporation of SM within exercise programmes enabled insights into potential options for participants as indicated by *"It opened my eyes to what can be done"* in the qualitative interviews [30,50]. The duration of the intervention varied from a minimum of one week [35] to a maximum of 3 months [27,29,30,42]. The longest duration was a case study that lasted for 18 months [28].

The content, intensity, and duration of therapies within SM training followed various clinical guidelines and were tailored based on the individual capacity of participants. Therapies consisted of fitness, mobility, strength, endurance, balance, range of motion, and stretching exercises. Most of the interventions had one or two sessions per week. The average number of sessions per week was 2.5 sessions and the average duration of each session was 54 min. The details of exercises dosage were not clearly reported in some studies [27,33,43]. Some participants in the qualitative reports indicated that uncertainty of dosage was evident in their participation in SM programmes and that the trainers were not specific about the exercise dosage at home, implied in *"I could never pin him down to how long that should be for though"* [30].

The SM interventions were delivered to the participants in a group format in eight studies [33,34,36,38,40,41,46,50] and in a one-to-one format in thirteen studies [27–29,31,32,35,42–45,47–49]. In three studies [30,37,39] the SM interventions were delivered in groups and in one-to-one format at some points during the intervention. Participants perceived that group sessions were more beneficial for them to share their experiences as it *"was good to talk to them[peers] and find out how they've managed"* and to increase socialisation [50]. They believed that these sessions allowed them to compare themselves with other participants and appreciate their own circumstances and personal progress.

The majority of interventions were delivered to the participants in their homes [27–29,32,37,39,40,42,43,45,47] or in community settings [30,33,36,38,41,46,50]. One intervention was delivered to the hospitalised patients to promote their physical activity including mobility [35]. Three interventions started in the hospital and continued at home after patient discharge [31,48,49]. SM has been used with several forms of technology for easier delivery of instruction, feedback, communication, and follow-up with therapists. Examples of applied technology include telerehabilitation/telehealth, e-health, mobile apps, and phone calls. Telerehabilitation was used as a part of intervention delivery in six studies [29,34,45,46,48,49]. Phone calls were used for data collection [29,36,45] and as a part of an intervention to provide support or coaching sessions in [32,45]. E-health was integrated into SM to support the home rehabilitation programme [48,49]. The STARFISH intervention [40] was delivered through a mobile app which was also used to track and record physical activity outcomes. The TASK programme was a video-guided exercise programme [44] with two phases, 4 weeks with and 4 weeks without supervision.

4. Effects of SM on functional mobility and walking

Overall, SM seems to have a positive impact on functional mobility and walking outcomes. The Time Up and Go (TUG) was improved significantly in five studies [32,37,43,47,50]. The mean changes in the TUG result across these studies were −3.29 s ($p = 0.00$), −3.8 s ($p < 0.01$), −5.7 s ($p = 0.03$), −13.26 s ($p = 0.01$), and −2.21 s ($p = 0.00$). The TUG improved in 81% of the participants in [50] and subjectively a patient participant indicated *"One of them there, his walking from the first day to the last day improved 100%"*. In [34] there was a significant difference in the Berg Balance Scores between the intervention group and the control group of the study (mean difference −4.27, 95%CI: −6.66 to −1.87).

Walking speed had significantly improved in five studies. Using the 10-meter walking speed and the 5-meter walk test, the mean change in walking speed in [28,31,32,42,44] studies ranged between 0.11 and 0.32 m/s ($p \leq 0.02$). In [47] there was a significant improvement in the intervention group as to the time parameter of the 10MWT ($p = 0.008$), but no significant improvement was found in the number of steps taken. In another study [39], the 6-min walking speed significantly increased in both groups post-intervention (0.09 ± 0.02 m/s in the unsupervised group, 0.06 ± 0.02 m/min in the supervised group) and remained significantly improved by 1 year. The improvement in walking speed was accompanied by a significant reduction in the sedentary time in a different study [32].

Walking distance significantly increased in six studies. The mean changes in the 6MWT were 20 ± 6 m ($p = 0.02$), 15.36 m ($p = 0.02$), 47.73 m ($p < 0.001$) and 85 ± 64 m post-intervention [31,41,46,47]. In [42] the 6MWT increased by 43 m (95% CI 10–76) at three months and by 61 m (95% CI 27–96) at six months post-intervention. In [37] the 6MWT was significantly increased ($p = 0.03$) in both groups of the study. One study showed trends toward improvement in the 6MWT in five out of eleven participants post-intervention (mean change 47.56 m) [45]. However, the authors reported a trend towards improved overall in all participants (−25.73 ± 87.75 m). The improvement in the walking distance was associated with a significant improvement in the lower body strength (2.51 chair stands, $p = 0.01$) [41]. The number of steps per day increased significantly in the two studies. The number increased by an average of 2895.5 steps/day ($p < 0.001$) in one study [35] and by 39.3% (4158–5791 steps/day) in the other one [40]. The walking time was also increased on an average of 20 min/day in this study.

Global measures of mobility

Participants had improved their ability to perform life tasks including daily activities at home and management of social tasks that involve mobility [29]. This was evident by the significant improvements in the basic lower extremity score within the function subscale of the LLFDI (increased from 59.0 to 64.9) and in four of the six LLFDI disability subscales. Participants who had received the intervention at home demonstrated a trend toward improved mobility at the end of intervention (the SIS mobility domain improved by 82.3 (95% CI (74.3–90.3) and the difference between control and intervention scores change was −9.8 (95% CI −20.1–0.4; $p = 0.06$) in a study [48]. Participants completed 27 min/day (95% CI 4–49) at 3 months more moderate physical activity than at baseline [42].

These findings were confirmed by participants perspectives regarding the positive changes in their mobility and walking ability after participation in SM programmes as a patient-reported *"I think I can walk easier and go farther now"* [30,41]. The positive change was perceived by a gradual improvement in their physical fitness for mobility (improvement in speed, balance, and strength) and in their walking ability and endurance. The benefits due to incorporation of SM into exercise programmes were recognised by some participants who showed their persistence and desirability to continue exercising after study completion indicated by a patient as *"I had a lot of positive physical changes that gave me confidence to keep coming here"* [31,41,50].

Grade of evidence

The quality of evidence had a very low grade for the change in walking speed, endurance, balance, and physical activity (steps/day), a low grade for (SIS-mobility domain), and a moderate grade for (Rivermead Mobility Index) (see Supplementary Appendix C for details).

5. Effect of SM on secondary outcomes

Multiple studies [32,33,35,42] showed a significant improvement in participants' self-efficacy, exercise efficacy, and self-efficacy for physical activity (Table 1) except in two studies study [42,44] where the improvement was not statistically significant. In qualitative studies, participants perceived that the SM programme was a useful strategy for increasing physical activity and for improving confidence and skills related to participating in regular physical activity [42]. Positive change was also suggested by participants to express their improvement in confidence, motivation, self-efficacy, feeling of self-management and self-control that enhanced their recovery, level of independence and to resume their life after stroke [34,50]. The motivation was considered by participants as a facilitator that helped them to achieve positive changes. They also appreciated the presence of motivating peers and the encouragement provided by professionals and other stroke survivors [50].

Quality of life measures was significantly improved in five studies. The SIS and SSQoL scores of different domains were improved ($p < 0.05$) in [32,36,43,48]. Also, there were some trends toward improvement in the SIS (mean change = 1.45 ± 4.66) in [45]. The improvement of the physical dimension score of the SIS was associated with increasing in the Barthel Index (mean difference = 10 and 95% CI= −16.98, −3.02) in [43]. The SAQoL significantly improved (mean = 0.25, $p = 0.01$) and the improvement remained for three months post-intervention [50]. The result of the EuroQual-5D showed some trends toward improvement (15 out of 100 points (95% CI 4–26) greater than at baseline) [42]. Although the findings of the reviewed studies showed changes in the self-efficacy and quality of life to different extents, the quality of evidence had a very low grade due to methodological issues (see Supplementary Appendix C for details).

Other physical secondary outcomes included participation, extended ADLs, fatigue, pain, and impairment. The included studies showed a significant improvement in the Chedoke-McMaster Stroke Assessment score ($p < 0.01$) for the leg impairment [32], Nottingham Extended ADLs ($p = 0.01$) [48], the pain of the knee and back [28], and fatigue ($p = 0.003$) in the intervention group [40]. In the PROPEL trial, the intervention group had higher participation in physical activity measured by PASIPD (Hedge's $g \geq 0.5$), had fewer barriers to physical activity, and showed higher outcome expectations of their exercise than the comparison group (effects sizes ≥0.5 for SSOE) [38]. The SF 36 physical component was significantly improved ($p < 0.01$) in the supervised group who also had trends towards the improvement of HAP results [39]. One study showed a moderate improvement in activity level in both groups of the study with no between-group differences [33]. Also, the SF36 physical and general health domains showed trends towards increased positive change following the

intervention, but these did not reach significant levels. Physical activity levels did not change in one study [44].

The psychological outcomes reported were mood, depression and anxiety, self-esteem, psychological general well-being index, patient confidence and satisfaction. The reviewed studies showed significant improvements in patient's anxiety and caregiver's depression ($p = 0.023$ and $p = 0.003$) in [49], mood ($p = 0.04$) in [46], and cognition ($p < 0.01$) in [32]. In [47] the score for the self-esteem within the DUKE Health Profile was significantly higher in the intervention group than that in the controls. Implementing of SM intervention for inpatients led to a significantly shorter stay at the hospital for the intervention group ($p = 0.04$) and fewer readmissions over 12 months of their discharge ($p < 0.05$) [48]. Qualitative findings indicate that SM interventions such as video conferencing reduce isolation [34]

Stroke knowledge was significantly increased in one study with 95% of participants improving their awareness about stroke and exercise tolerance ($p = 0.00$) [50]. Qualitative findings [30,41] showed that increasing knowledge was considered by participants as an important component of SM interventions, explained by one participant as *"that was absolutely important, because it made sense of why you are doing"* [30]. However, it was not measured appropriately in most of the studies. Also, goal setting which is deemed to be central for SM programmes was not commonly assessed. Only in [46], 66% of participants achieved their long-term goals and they met about 68% of their short-term weekly goals. The qualitative findings of one study indicated that most of the participants had not achieved all of their goals [50].

Discussion

This study is one of the first that looked at the role of SM interventions to improve mobility as a specific outcome of stroke rehabilitation. Regardless of limitations in some studies, mainly due to methodological weaknesses, the overall findings of the reviewed literature indicate that SM interventions such as patient education, goal setting, action planning, self-monitoring, and professionals/carers support can help to improve functional mobility and walking. Additionally, other physical activity outcomes, self-efficacy, and quality of life of survivors with mild to moderate impairments post-stroke also showed improvement. The qualitative studies reviewed highlighted the survivors' perceptions that indicated the importance of involving survivors in their care programmes and facilitating their independence using self-management. Across all studies, SM interventions were found to be feasible, acceptable, and appreciated by participants and their caregivers. SM interventions were not associated with any serious adverse event and can be applied safely in different contexts. Only three studies reported adverse events such as episodes of muscle soreness, fatigue, trips, or non-injurious falls [30,40,42].

Our findings confirm the short-term efficacy of self-management interventions for mobility rehabilitation post-stroke which is consistent with other reviews on the effectiveness of SM programmes for improving functional ability, self-efficacy, participation, and quality of life post-stroke [11,14,16]. Sustaining of the positive effect of SM interventions for the long term is important for stroke rehabilitation; yet most of the studies did not assess the long-term effect of the interventions.

Our results support the findings of other reviews [11,16] that incorporating more of SM strategies in an intervention can lead to better outcomes and that strategies with behaviour change targets have more impact than other strategies. In some studies, it was not easy to identify all strategies that were used as some of them might have been used implicitly as a part of programme delivery. For instance, the process of action planning might include identifying of contextual barriers and motivation of participants without being reported as an explicit part of the intervention. Moreover, the use of some SM strategies such as caregiver support, group therapy, home visit, or tele-visit was described as optional in some studies and the effect of using such strategies was not measured. To draw a clear conclusion about their efficacy, researchers are encouraged to describe all strategies that were incorporated in the SM interventions.

There was no specific therapy training that was considered to be most effective in working with SM. The variability in practice might affect the effectiveness of SM programmes in different contexts. For example, the CARE4STROKE integrated the same SM programme to two different practice guidelines (in Australia and in the Netherlands) and had a different level of improvement in the outcome measures. Hence SM strategies need to be supplementary, flexible and tailored to the patient's context. Some inconsistent results were found regarding the perception of change following the intervention. Participants demonstrated that comorbidities, stroke sequelae and previous level of exercise might make a difference and work as a facilitator or barrier to the improvement in their physical activity post-stroke. All participants in the reviewed studies had mild to moderate impairments and people with severe impairments (physical, cognitive, or aphasia) were excluded. This confirms that this population might have less opportunities within community programmes as reported by the NICE guideline (2016) [5].

This review found some technologies such as telerehabilitation, smartphones, videoconferencing, and online resources as useful tools that help to implement the SM programmes for survivors who live away from the areas of services or cannot physically attend their sessions. They also have been used to promote participants' independence in carrying out their training with minimal supervision of a therapist. This can provide proof of using these technologies for the delivery of care during the current situation of COVID-19 lockdown and related social distancing measures.

SM might not be suitable for every stroke survivor. A prior examination of the patient's readiness and intention to follow the SM programme should be considered. This review found only a few studies that considered this readiness prior to participants' enrolment in SM interventions. The Stages of Change tool within the Transtheoretical Model and Patient Activation Measure (PAM) to assess participants' readiness to change have been recommended by the reviewed studies [38,43]. Qualitative findings of this review indicate that motivated people can do better with SM programmes which reflects the critical role that patient's motivation can play in the successfulness of the implementation of SM interventions. Failure to address these confounding factors perhaps results in withdrawals that were reported in some studies.

Self-management was conceptualised variously by different stakeholders and in different cultures. It seems likely that the concept is ambiguous, or could have different meanings to different parties, or change over time depending on the purpose. This was evident in the participants perspectives about their experience with the SM programmes and in the rhetoric of researchers and authors of the reviewed studies. The conceptualisation of SM might change individual's attitude towards SM. For instance, some patients might think SM is to prevent them from attending rehabilitation facilities and to let them encounter the challenges in their life after stroke alone and may feel abandoned by the services. Hence, there might be a need for explaining what SM means to the eligible participants.

There were some methodological issues reported in the reviewed study. Blinding was not possible in most studies due to the nature of self-management interventions. The number of men included within studies was notably higher than women in some studies. This does not reflect the incidence of stroke in women. Also, forming a group for interventional groups in the community with planned group sizes might have taken a long time, with possible wait times for some affecting participants' time of entry into the study. The use of cluster RCT has been suggested for future studies that will examine the effectiveness of these interventions to minimise the risk of contamination among participants and to ensure the proper formation of study groups. Our findings also suggest the use of qualitative methods in addition to the quantitative within the effectiveness studies as that can provide valuable insights on how participants perceived the implementation of SM interventions and if there are contextual issues that can affect the effectiveness of these interventions beyond the therapy protocols. Further, the effects or influence of self-management which is a complex intervention should also be interpreted against the background of several confounding factors that are common to rehabilitation research such as stage of recovery, the intensity of therapy, co-morbidities in this population and physical activity and motivational levels prior to their stroke.

The overall certainty in the evidence for the outcomes was rated using GRADE which can include RCTs and other study designs and if a study design and or quality is weaker than an RCT, the quality of evidence can be downgraded. Also, if a non-RCT meets certain criteria they can still be upgraded. We acknowledge that GRADE is not specific to observational studies [55] and that methods currently have not been identified for a gold standard quality assessment across study designs and limitations do exist.

Conclusion

Self-management interventions seem to be an effective approach that helps stroke survivors to improve their mobility training outcomes. However, participants level of ability, their specific goals, and stage of recovery should be considered when planning for any self-management programme to engage motivation and self-efficacy vital for SM. Many of the identified studies were feasibility studies. Further research should examine the effectiveness of self-management intervention in the long term and report the specific components in order to compare their effectiveness.

Disclosure statement

The authors report no conflict of interests. The authors alone are responsible for the content and writing of this review.

Funding

The authors confirm that they have not received any funding for this work.

ORCID

Andrew Soundy http://orcid.org/0000-0002-5118-5872

References

[1] Association S. State of the nation Stroke statistics – Februrary 2018. 2018. (February). Available from: https://www.stroke.org.uk/system/files/sotn_2018.pdf.
[2] Lawrence ES, Coshall C, Dundas R, et al. Estimates of the prevalence of acute stroke impairments and disability in a multiethnic population. Stroke. 2001;32(6):1279–1284.
[3] Pinter MM, Brainin M. Rehabilitation after stroke in older people. Maturitas. 2012;71(2):104–108.
[4] Luker J, Lynch E, Bernhardsson S, et al. Stroke survivors' experiences of physical rehabilitation: a systematic review of qualitative studies. Arch Phys Med Rehabil. 2015;96(9):1698–1708.
[5] Rudd T, Bowen A, James M, et al. National clinical guideline for stroke: prepared for the intercollegiate stroke working party. 2016.
[6] Langhorne P, Bernhardt J, Kwakkel G. Stroke care 2. Stroke Rehabil Lancet. 2011;377(9778):1693–1702.
[7] Veerbeek JM, Koolstra M, Ket JCF, et al. Effects of augmented exercise therapy on outcome of gait and gait-related activities in the first 6 months after stroke: a meta-analysis. Stroke. 2011;42(11):3311–3315.
[8] Peurala SH, Karttunen AH, Sjögren T, et al. Evidence for the effectiveness of walking training on walking and self-care after stroke: a systematic review and meta-analysis of randomized controlled trials. J Rehabil Med. 2014;46(5):387–399.
[9] Physicians RC of. Rising to the Challenge: The Fourth SSNAP Annual Report. In Royal College of Physicians London; 2017.
[10] Stroke association. Struggling to recover. Spring. 2012;1–45.
[11] Warner G, Packer T, Villeneuve M, et al. A systematic review of the effectiveness of stroke self-management programs for improving function and participation outcomes: self-management programs for stroke survivors. Disabil Rehabil. 2015;37(23):2141–2163.
[12] Barr V, Robinson S, Marin-Link B, et al. The expanded chronic care model. Hosp Q. 2003;7(1):73–82.
[13] Health M of. Self-management support for people with long-term conditions. Author Wellington, New Zealand; 2016.
[14] Pearce G, Pinnock H, Epiphaniou E, et al. Experiences of self-management support following a stroke: a meta-review of qualitative systematic reviews. PLoS One. 2015;10(12):e0141803.
[15] de Silva D. Helping people help themselves: a review of the evidence considering whether it is worthwhile to support self-management. London: Health Foundation; 2011.
[16] Parke HL, Epiphaniou E, Pearce G, et al. Self-management support interventions for stroke survivors: a systematic meta-review. PLoS One. 2015;10(7):e0131448.
[17] Whittemore R, Knafl K. The integrative review: updated methodology. J Adv Nurs. 2005;52(5):546–553.
[18] Duncan EAS, Nicol MM. Subtle realism and occupational therapy: an alternative approach to knowledge generation and evaluation. Br J Occup Ther. 2004;67(10):453–456.
[19] Pope C, Mays N, Popay J. Synthesising qualitative and quantitative health evidence: a guide to methods: a guide to methods. UK: McGraw-Hill Education; 2007.
[20] Forhan M, Gill SV. Obesity, functional mobility and quality of life. Best Pract Res Clin Endocrinol Metab. 2013;27(2):129–137.

[21] Sterne JAC, Savović J, Page MJ, et al. RoB 2: a revised tool for assessing risk of bias in randomised trials. BMJ. 2019; 366:l4898.
[22] Sterne JAC, Hernán MA, Reeves BC, et al. ROBINS-I: a tool for assessing risk of bias in non-randomised studies of interventions. BMJ. 2016;355:i4919.
[23] Hong QN, Pluye P, Fàbregues S, et al. Mixed methods appraisal tool (MMAT), version 2018. Educ Inf. 2018;34(4): 285–291.
[24] CASP NHS. Critical appraisal skills programme (CASP): appraisal tools. UK: Public Health Resource Unit, NHS; 2003.
[25] Schünemann H, Brożek J, Guyatt G, et al. GRADE handbook for grading quality of evidence and strength of recommendations. Updated October 2013. The GRADE Working Group, 2013. Available from Guidel Org/handb.
[26] Miles MB. Huberman Am Qualitative data analysis: an expanded sourcebook. Thousand Oaks (CA): Sage; 1994.
[27] Baskett JJ, Broad JB, Reekie G, Hocking C, et al. Shared responsibility for ongoing rehabilitation: a new approach to home-based therapy after stroke. Clin Rehabil. 1999; 13(1):23–33.
[28] Broetz D, Birbaumer N. Behavioral physiotherapy in post stroke rehabilitation. NeuroRehabilitation. 2013;33(3): 377–384.
[29] Chumbler NR, Quigley P, Li X, et al. Effects of telerehabilitation on physical function and disability for stroke patients: a randomized, controlled trial. Stroke. Stroke. 2012;43(8): 2168–2174.
[30] Dean SG, Poltawski L, Forster A, et al. Community-based rehabilitation training after stroke: results of a pilot randomised controlled trial (ReTrain) investigating acceptability and feasibility. BMJ Open. 2018;8(2):e018409.
[31] DePaul VG, Bosch J, Oczkowski WJ, et al. Promoting independent mobility-related physical ACTivity (IMPACT) in an inpatient stroke rehabilitation unit: a proof-of-concept evaluation of self-management intervention. Disabil Rehabil. 2020;42(22):3172–3181.
[32] Ezeugwu VE, Manns PJ. The feasibility and longitudinal effects of a home-based sedentary behavior change intervention after stroke. Arch Phys Med Rehabil. 2018;99(12):2540–2547.
[33] Haworth J, Young C, Thornton E. The effects of an 'exercise and education' programme on exercise self-efficacy and levels of independent activity in adults with acquired neurological pathologies: an exploratory, randomized study. Clin Rehabil. 2009;23(4):371–383.
[34] Huijbregts MPJ, McEwen S, Taylor D. Exploring the feasibility and efficacy of a telehealth stroke self-management programme: a pilot study. Physiother Can. 2009;61(4): 210–220.
[35] Kanai M, Nozoe M, Izawa KP, et al. Promoting physical activity in hospitalized patients with mild ischemic stroke: a pilot study. Top Stroke Rehabil. 2017;24(4):256–261.
[36] Kendall E, Catalano T, Kuipers P, et al. Recovery following stroke: the role of self-management education. Soc Sci Med. 2007;64(3):735–746.
[37] Malagoni AM, Cavazza S, Ferraresi G, et al. Effects of a" test in-train out" walking program versus supervised standard rehabilitation in chronic stroke patients: a feasibility and pilot randomized study. Eur J Phys Rehabil Med. 2016; 52(3):279–287.
[38] Mansfield A, Knorr S, Poon V, et al. Promoting optimal physical exercise for life: an exercise and self-management program to encourage participation in physical activity after discharge from stroke rehabilitation—a feasibility study. Stroke Res Treat. 2016;2016:9476541.
[39] Olney SJ, Nymark J, Brouwer B, et al. A randomized controlled trial of supervised versus unsupervised exercise programs for ambulatory stroke survivors. Stroke. 2006;37(2): 476–481.
[40] Paul L, Wyke S, Brewster S, et al. Increasing physical activity in stroke survivors using STARFISH, an interactive mobile phone application: a pilot study. Top Stroke Rehabil. 2016; 23(3):170–177.
[41] Portz JD, Waddington E, Atler KE, et al. Self-management and yoga for older adults with chronic stroke: a mixed-methods study of physical fitness and physical activity. Clin Gerontol. 2018;41(4):374–381.
[42] Preston E, Dean CM, Ada L, et al. Promoting physical activity after stroke via self-management: a feasibility study. Top Stroke Rehabil. 2017;24(5):353–360.
[43] Richardson J, DePaul V, Officer A, et al. Development and evaluation of self-management and task-oriented approach to rehabilitation training (START) in the home: case report. Phys Ther. 2015;95(6):934–943.
[44] Scrivener K, Sewastenko J, Bouvier-Farrell A, et al. Feasibility of a self-managed, video-guided exercise program for community-dwelling people with stroke. Stroke Res Treat. 2021;2021:5598100.
[45] Sullivan JE, Espe LE, Kelly AM, et al. Feasibility and outcomes of a community-based, pedometer-monitored walking program in chronic stroke: a pilot study. Top Stroke Rehabil. 2014;21(2):101–110.
[46] Taylor DM, Cameron JI, Walsh L, et al. Exploring the feasibility of videoconference delivery of a self-management program to rural participants with stroke. Telemed J E Health. 2009;15(7):646–654.
[47] Treger I, Landesman C, Tabacaru E, et al. Influence of home-based exercises on walking ability and function of post-stroke individuals. Int J Ther Rehabil. 2014;21(9):441–446.
[48] Van Den Berg M, Crotty M, Liu E, et al. Early supported discharge by caregiver-mediated exercises and e-health support after stroke: a proof-of-concept trial. Stroke. 2016; 47(7):1885–1892.
[49] Vloothuis JDM, Mulder M, Nijland RHM, et al. Caregiver-mediated exercises with e-health support for early supported discharge after stroke (CARE4STROKE): a randomized controlled trial. PLoS One. 2019;14(4):e0214241.
[50] White JH, Bynon BL, Marquez J, et al. 'Masterstroke: a pilot group stroke prevention program for community dwelling stroke survivors'. Disabil Rehabil. 2013;35(11):931–938.
[51] O'Connor H, Gibson N. A step-by-step guide to qualitative data analysis. Pimatisiwin A J Indig Aborig Community Heal. 2003;1(1):63–90.
[52] GRADEpro GDT. GRADEpro guideline development tool [software]. Canada: McMaster University; 2015.
[53] Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med. 2009;6(7):e1000097.
[54] O'Cathain A, Croot L, Duncan E, et al. Guidance on how to develop complex interventions to improve health and healthcare. BMJ Open. 2019;9(8):e029954.
[55] Mueller M, D'Addario M, Egger M, et al. Methods to systematically review and meta-analyse observational studies: a systematic scoping review of recommendations. BMC Med Res Methodol. 2018;18(1):44.

Appendix 3- (Sahely et al., 2023)

PLOS ONE

RESEARCH ARTICLE

Exploring the experiences of people who had a stroke and therapists who managed people with stroke during the COVID-19 pandemic: An exploratory qualitative study

Ahmad Sahely[1,2]*, **Shara Kai Ning Hew**[1], **Yik Ka Chan**[1], **Andrew Soundy**[1], **Sheeba Rosewilliam**[1]

1 School of Sports, Exercise and Rehabilitation Sciences, University of Birmingham, Birmingham, United Kingdom, **2** Faculty of Applied Medical Science, Physiotherapy Department, Jazan University, Jazan, Saudi Arabia

* axs1638@student.bham.ac.uk

Check for updates

OPEN ACCESS

Citation: Sahely A, Kai Ning Hew S, Ka Chan Y, Soundy A, Rosewilliam S (2023) Exploring the experiences of people who had a stroke and therapists who managed people with stroke during the COVID-19 pandemic: An exploratory qualitative study. PLoS ONE 18(2): e0282325. https://doi.org/10.1371/journal.pone.0282325

Editor: Walid Kamal Abdelbasset, Prince Sattam Bin Abdulaziz University, College of Applied Medical Sciences, SAUDI ARABIA

Received: September 30, 2022

Accepted: February 14, 2023

Published: February 28, 2023

Peer Review History: PLOS recognizes the benefits of transparency in the peer review process; therefore, we enable the publication of all of the content of peer review and author responses alongside final, published articles. The editorial history of this article is available here: https://doi.org/10.1371/journal.pone.0282325

Copyright: © 2023 Sahely et al. This is an open access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Abstract

Objective

To explore experiences, needs and rehabilitation priorities of patients who had their stroke and the experiences of therapists managing stroke patients during the COVID-19 pandemic.

Design

Exploratory qualitative study.

Setting

Acute, sub-acute and community stroke facilities.

Subjects

Twenty-two participants. Twelve therapists (all female, mean age 38.5 years) and ten patients (9 female, mean age 51.1 years) who were involved in stroke rehabilitation during the pandemic were interviewed.

Methods

Individual semi-structured interviews were conducted. Interviews were recorded and transcribed before being analysed using a reflexive thematic analysis approach.

Results

Four main themes demonstrate the modifications in the care system as a result of COVID-19, impact on the stroke patients at different stage, needs and priorities of stroke rehabilitation, and management strategies that have been used in stroke rehabilitation. Remote rehabilitation and self-management strategies were recommended to deliver care for stroke

Data Availability Statement: All relevant data are within the manuscript and its Supporting Information files.

Funding: The author(s) received no specific funding for this work.

Competing interests: The authors have declared that no competing interests exist.

patients. However, therapists seemed unsatisfied with the quality of care delivered and patients suggested face to face delivery of care with proper personal protection equipment to better address their physical and mental health needs.

Conclusion

The findings of this study explored the impact of the pandemic on stroke care from the perspective of the patients and therapists and provides suggestions for improved delivery of care in similar situations. Future research is warranted to examine the long-term effects on people who had inadequate post-stroke rehabilitation during covid pandemic and urgent measures taken to reduce the impact the pandemic has had on the physical and mental issues for these patients.

Introduction

Stroke is a major cause of disability worldwide [1]. In the UK, more than 100,000 incidents of stroke had been reported each year prior to the COVID-19 pandemic [2]. Since the start of the pandemic, the admission rate of stroke cases fell markedly [3–5]. For example, in one London hospital there was one third reduction in the number of admissions; however, those admitted had significantly higher pre-stroke disability and greater severity of stroke at admission [5]. The rate of hospitalisation for TIA between March 23rd and 30th June 2020, was significantly lower (24.44%) along with reduced rates of thrombolysis [27 (11.49%) vs. 46 (16.25%, $p = 0.030$)] compared to the same period in 2019. Fear of COVID-19 infections, lockdown isolation, advice from doctors and media could have reduced the prompt admissions and the more severe patients being admitted [6]. It is possible that these patients who had a stroke during the pandemic suffered due to delayed access and reduced opportunities for rehabilitation.

There has been an increasing effort to understand the impact of the pandemic on the healthcare system for people with stroke; most research investigated the disruption in access and delivery of acute services including paramedical services, admission rates, hyperacute and acute-care, and the strain on the staff and caregivers in various settings [3, 7–10]. Only few qualitative studies have focused on the experiences of therapists during the pandemic from a rehabilitation lens, yet none has included patients' perspectives [11–14]. Findings from these studies done in Spain and the United States, highlighted the psychological impact of the pandemic on therapists as front-line workers [11], their professional and ethical challenges when they were re-deployed into COVID-19 units [14], and their overall experience with providing care to the COVID-19 patients [12, 13].

In the UK and other developed countries, recommendations for best practices of stroke care during the pandemic, including rehabilitation, have been developed based on evidence (mainly quantitative data) published during the pandemic and lack the understanding of lived experiences of people which might help better evaluation and addressing of the practice issues [15–17]. The impact of the delayed presentation of people with stroke, resource redirection, and reduced post stroke rehabilitation services on patients' recovery at different stages are still not clear in the current literature. There are also concerns that there will be severe long-term effects on the people who have had their strokes during the pandemic, worsened by the expected increase of having a stroke as one of the post-COVID -19 complications [18, 19].

As the health services have been resuming their normal services, the backlog of healthcare in England continues to mount, which may take years to clear [20]. There is a key need to understand what patients missed during the pandemic and to identify priorities that ensure services can be tailored in any future disruptions. There is a need to be proactive and identify what patients' rehabilitation needs are in preparation for the huge deluge for rehabilitation [21]. The aim of this study was to gain insight into experiences of people with stroke, therapists' experiences, management strategies, patients' needs and rehabilitation priorities after their first stroke during the pandemic.

Methods

Ethical approval for this study was granted by the Science, Technology, Engineering and Mathematics (STEM) ethics committee at the University of Birmingham (reference: ERN_21–0775). The interviews were collected between September 2021and January 2022. We followed the Consolidated criteria for Reporting Qualitative Research (COREQ) for methodological guidance [22]. A completed COREQ checklist is attached as Appendix D in S2 File.

Design

The study used an exploratory qualitative design. Qualitative designs are more suitable to investigate individuals' experiences, beliefs, and opinions [23]. The authors of this study take a critical realist perspective that much of reality happens without an awareness of it. This suggests that an external reality exists, but one must access it through an individual's personal world [24]. It aims to produce a deep and thick account of the processes that underpin the effects of pandemic on experiences of people with stroke, their lives and recovery [24].

Participants

Potential participants were recruited from the community via the websites Stroke Association, Different Strokes, and social media to make contact with stroke patients from diverse geographical and ethnic backgrounds. In addition, therapists were recruited through online professional forums such as the Chartered Society of Physiotherapy (CSP) and the Association of Chartered Physiotherapists Interested in Neurology (ACPIN). To identify a wider range of perspectives, a purposive sampling approach was used to recruit people involved in stroke rehabilitation (patients and therapists) since March 2020 [25]. Therapists were recruited from various stroke clinical settings including hyper-acute, acute, sub-acute and community services to gain a wider insight into their experiences with stroke rehabilitation. At the time of the study many of them were redeployed in other areas due to Covid pressures. However, patient participants were mainly in sub-acute or chronic stage of recovery and they had been discharged into the community; access to patients in the acute setting was not possible because of the Covid restrictions. Eligible participants who contacted the research team to take part in the study were provided with a copy of the study information sheet and asked to sign a written consent electronically before the interviews. Snowball sampling was also employed as participants were asked to pass on the study information to people who they might know who fit the eligibility criteria.

Inclusion criteria for stroke patients were (i) Experienced a stroke (of any type) since March 2020; (ii) age $\geq$18 years old; (iii) cognitively unimpaired (screened with the Mini Mental State Examination (MMSE) [26] and able to communicate clearly to express their views and provide informed consent; (iv) had access to remote meeting technology such as zoom or phone with speaker technology. The study excluded patients who had a TIA and have less need for services, people with severe cognitive or speech problems or cannot meet remotely

for the interview. For therapists, the inclusion criteria included physiotherapists and occupational therapists who treated people with stroke during the pandemic and can meet remotely for their interviews.

Data collection

Data collection was done using individual semi-structured interviews using two separate topic guides for therapists and the people who had a stroke during the pandemic. The topic guides explored experiences, opinions, feelings and needs of participants with who had a stroke during the COVID-19 pandemic (attached as Appendices A and B in S2 File). The interview guides were developed by experienced qualitative researchers based on the research objectives. The demographic data that included type of stroke, age, gender, time since stroke, and questionnaires for functional ability using Barthel Index [27], stroke specific quality of life measure [28], mini-mental status evaluation [26], and geriatric depression scale [29] were collected verbally with the patient participants. For therapists, data on age, gender, years of clinical experience, band, level of education, and practice setting were collected.

The data collection process was piloted in a sample of one patient and a therapist, carried out over zoom and recorded for transcription. The researcher made field notes following each interview to record emotions and any relevant situations. Interviews lasted on average 1 hour, ranging between 35 minutes and 1 hour 25 minutes. The primary researcher AS with previous experience in conducting qualitative research collected 80% of data and the other 20% were collected by two assistant researchers under the supervision of AS (YC and SH). The researchers had no prior knowledge of or contact with any participants in the study.

Data saturation guided the sample size for this study [30, 31]. Recruitment stopped with simultaneous data analysis when researchers thought no new themes were emerging and which occurred after we completed 10 interviews with therapists and 8 patient interviews. However, two additional interviews were collected from each group to ensure data saturation was reached.

Data analysis

Data from interviews were transcribed using a transcription service. Then data was anonymised by removing any identifiable information and was analysed following the reflexive thematic analysis approach [32]. Coding and categorisation of data were done by the main researcher (AS) in addition to two research students (YC and SH) each of who analysed (40%) of data from stroke survivors or therapists independently using iterative analytical methods [33]. The developed codes were shared and discussed between the analysts and then checked by two other senior researchers (SR and AAS) with expertise in qualitative research to improve rigour of data analysis and to solve any disagreement between the analysts. To eliminate researcher's interpretation bias and to increase the integrity of the study's findings, triangulation of codes from different data set (therapists vs. stroke survivors) and between the three researchers was applied [34, 35]. The intention of research team was to use the themes derived from data related to the research objectives to build theory and inform future work.

Results

Description of participants

This study included 12 therapists and 10 stroke survivors with a wide range of stroke severity, in different stages of recovery, and from clinical setting and levels of expertise. There were two patient participants who were excluded because of the time after stroke (more than 6 months)

and a therapist who had left the stroke team before the pandemic. Tables 1 and 2 summarise the demographic information of the participants.

Themes. The main themes derived from the data demonstrate the impact of modifications in stroke services due to the pandemic on the stroke care system, identify peoples' needs and priorities for stroke rehabilitation at different stages, and provide an insight into the management strategies that were used by different stakeholders in stroke rehabilitation. Fig 1 presents the themes and subthemes that were developed from participants' responses.

Theme 1: *Modifications to the services*. Stroke services, including access and delivery of care in the acute and community settings were disrupted. Changes to policy and staffing issues contributed to the disruption further which will be discussed in this theme.

a. Reluctance to access services. At the beginning of the pandemic, patients were reluctant to come into hospitals and they suggested that media reports made people to be terrified.

> "*the last thing I wanted to do, I've not had COVID all the way through, and I was like we're in March, I haven't had it and if I if I'm going to hospital I'm probably going to get it in hospital" (Stroke Survivor 1)*

In some cases, it was reported that patients did not like to go to hospital unless they felt they had something serious because of their fear of infection. Moreover, a therapist said some cases had not come into hospital immediately for a first stroke.

> "*Nobody was presenting themselves to A&E. And then now in retrospect, people have come through the system and had their second stroke, so the first one maybe was a bit more mild and they just cracked on with it." (Therapist 1)*

Further, some patients mentioned they had misinterpreted stroke presentation to be vaccine related symptoms and as a result, missed the FAST pathway to manage their initial stroke.

> *" I had some symptoms. . .but I've put it down to my vaccine because I'd have a vaccine earlier that week." (Stroke survivor 1) "I believe the reason why I had the stroke is because of the Oxford vaccine." (Stroke survivor 2)*

After discharge, some patients had concerns about home visits because of their fear of infection. Hence it was not surprising when therapists reported a reduction in the admissions to stroke unit along with reduced referrals to community services.

b. Disruption to the services. Patients reported that due to lack of direct access to the GPs, which was limited to phone calls or through the NHS app during lockdown, patients with minor symptoms went unnoticed. Patients reported there were delays in their transfer to the hospital and admission to the hyper acute units.

Table 1. Characteristics of participating therapists.

Age	Mean (range) = 38.5 years (24–59)
Gender	All female
PT/OT	4/8
Years of clinical experience	Mean (range) = 14.6 years (3–37)
Level of education	2 College Diploma/5 BSc/5 MSc
Band	B5 (1 participant), B6 (4 participants), B7 (6 participants) and B8a (1 participant)
Clinical setting	1 hyper-acute, 2 acute, 4 acute and sub-acute, 5 Community

https://doi.org/10.1371/journal.pone.0282325.t001

Table 2. Characteristics of the participant stroke survivors.

Gender (Male/Female)	1/9
Age	Mean (range) = 51.1 years (34–79)
Time since stroke (months)	Mean (range) = 7.6 months (3–19)
Type of stroke (Ischemic/Haemorrhagic)	8/2
Marital status (single/has partner)	4/6
The Barthel Index (0–100)*	Mean (range) = 91 (70–100)
Stroke Specific Quality of Life (49–245)**	Mean (range) = 125.9 (82–186)
Mini Mental Scale Examination (0–30)***	Mean (range) = 26.6 (23–30)
Geriatric Depression Scale (0–15)****	Mean (range) = 5.8 (12–0)

* Scores <62.90 indicate moderate disability and scores <21.30 indicate severe disability [36].

** Higher scores indicate better functioning [28]; no indicative score ranges for low, moderate, high were available.

*** A score of 23 or less can be a cut-off point indicating the presence of cognitive impairment [26].

**** A score of > 5 points is suggestive of depression [29].

https://doi.org/10.1371/journal.pone.0282325.t002

" So, I went with them [ambulance] for like, seven, eight hours. And finally, while at the end, they did a brain scan." (Stroke survivor 3)

Participants indicated that they were unsatisfied with the NHS care due to the issues such as staff shortage, and delay in the diagnostic services such as CT scan. They believe that these challenges had existed prior to the pandemic but, had become worse during the pandemic.

"I don't think that had to do with the pandemic, it's just the NHS" (Stroke survivor 3).

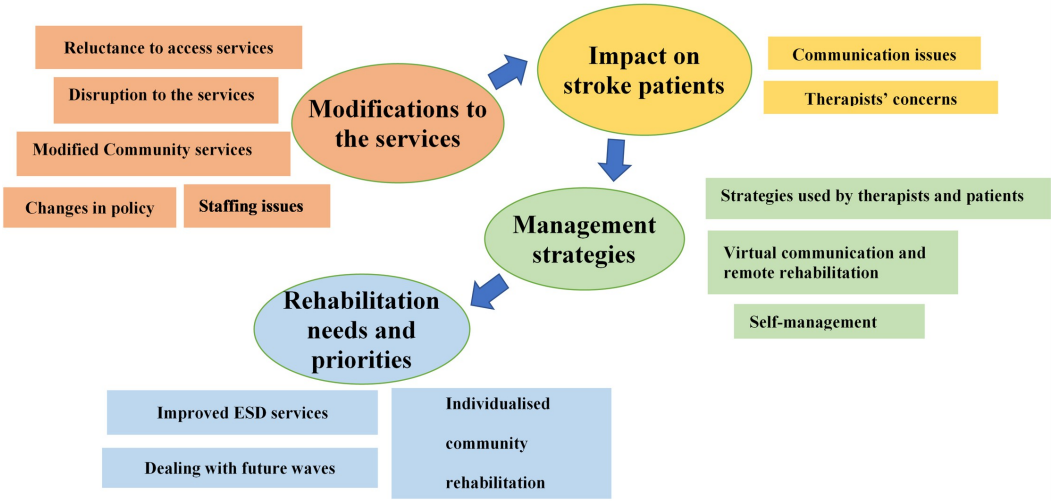


Fig 1. Themes and subthemes derived from study's data.

https://doi.org/10.1371/journal.pone.0282325.g001

The stroke wards were converted to COVID units which affected the availability of beds for stroke patients and in some cases people were moved to other locations several times. This issue also caused a lack of the therapy equipment and the space required for therapy.

"No, no. I had nothing in the [acute hospital]. Nothing." (Stroke survivor 2)

"So, on our unit we had one of our bays was turned into a unit for COVID patients, so we had a mix of patients, either with or without COVID." (Therapist 2)

c. Modified community services. Some therapists reported that they were under pressure to discharge stroke patients earlier, since COVID patients were a priority for hospital beds. Therapists realised that some patients and their families were not prepared for discharge with no time for preparation or transition with limited handover. Also, there was no access to the gym and other rehab facilities and all therapy groups had to stop. Also, care homes were not accepting patients from the community stroke team.

"Relatives saying you can't send them home" (Therapist 1) "When people were doing home visits as well, and people couldn't go home to do a home visit to see if there was any equipment required, so again that was like some of the discharges weren't as safe as they should be."(Therapist 5)

Concurrently, there was a reduction in community services for patients after discharge from hospital.

"So, they didn't come. I was discharged in December and the first time they came was in April this year." (Stroke Survivor 5)

Patients also reported lack of therapists' commitment to home visits and delay in delivering essential equipment and services. Patients reported their feeling of being left alone after moving into the community and there was a lack of clear rehabilitation plans.

"No one rang me, they came and assessed me one day, and then they told me, we're sorry we won't be able to send physio. . . Well, I cried when they left, how can I wait 12 weeks for physio. So, I started then thinking, I might as well be dead. I may as well not recover because I can't just sit here and be like this." (Stroke Survivor 7)

"I feel like at the time of discharge, I was just left to it." (Stroke Survivor 2). "But you would have sent me home alone, which I think would have been a massive struggle for me, I could see." (Stroke Survivor 3)

Contrary to the above in some cases, Early Supported Discharge services did not stop (face to face visits) for newly discharged patients. However, therapists were concerned about the limited hours for stroke rehabilitation and that patients were given little if reached in the community (only an exercise sheet on request) in some cases.

During the lookdowns, patients became very deconditioned as they were not allowed to go into shops to do mobility and shopping practice and lacked social interaction with people which increased risk of mental and emotional problems.

"*We saw a lot of people coming into hospital, having become very deconditioned over the lockdown period because people stopped going out" (Therapist 4) "They could have been sat in the care home for 4–5 months without any input, ... So, they were put at a disadvantage, and it's*

quite a lot of them patients, that when we eventually got to them, that they've been that deconditioned it's deemed that you know this is their new baseline, they don't actually have any rehab potential." (Therapist 2) "patients were very isolated, very bored, very depressed, very scared. Physically they went down as well, downhill" (Therapist 6)

d. Changes in policy. Therapists reported that as a part of safety assurance for people in the care facilities, risk assessments were introduced for therapists and patients. Therapists were classified into (clean & dirty/hot & cold) and therapists with high risk of COVID cannot see patients. Triage systems such as the traffic light (Red, Amber, Green) rating system were used to prioritise patients for receiving care. The triage and initial assessments were done mostly by phone for patients immediately after they were discharged.

"We kind of put a system in place, which was "red, amber, green" . . .. . . So, if they were green, we could go straight in once they were discharged from hospital. Amber the vulnerable, and red would be even if they are showing signs of COVID. . .. . . it works really well, because it helped us identify what patients definitely needed with the face-to-face intervention." (Therapist 4)

Checking against COVID-19 symptoms, wearing of the Personal Protective Equipment (PPE), and avoiding the mix of COVID-19 infected patients with non-infected patients were some of the new policies implemented in therapists' daily routine. In some contexts, there were some additional measures that were added based on personal judgments such as wearing fresh uniforms and washing shoes daily. Therapists were frustrated by these measures especially since proper PPE was not provided at some trusts and COVID-19 test were overwhelming as they took a long time to implement at the beginning of the pandemic.

e. Staffing issues. Staff deployment was happening on different levels. For instance, stroke therapists and nurses were deployed to work on COVID-19 wards. There was also a deployment of staff from other teams to make sure that there's enough staff on the stroke ward.

"And they repatriated quite a lot of staff from the community, they pulled them into the acute setting. . .. . .there weren't enough staff sitting in the community." (Therapist 2)

This has been considered by some participants as taking a new role without proper training and raised a concern of uncertainty about what is coming.

"We just became a generic therapist. we weren't physios or OTs or speech therapist. So, when the nurses were really short because half of them had COVID, you ended up doing your therapy quite functionally. So, you'd be helping to feed them at lunchtime or walking them to the toilet, or helping them wash, things that as a physio I wouldn't usually do." (Therapist 7)

Theme 2: *Impact on stroke patients*. Patients felt quite confused, because everything just happened so quickly. Some of them reported their frustration over poor care and losing the chance for better recovery as a result of the disruption to the services. Because of the staffing issue (i.e., staff shortage and deployment), some patients thought they had an awful experience under the care of unqualified nurses during the pandemic and received inadequate rehabilitation in the hospital.

"I don't think they could take care of me, though, there wasn't enough staff (Stroke survivor 6) "I do feel sorry for the nursing staff because so we're under an awful pressure, awful lot of

pressure, and I know I'm complaining, I'm not complaining but giving it to you as it is, and I don't like to put the NHS apart, they do a sterling job, but my experience, because of the pandemic, I think this horrendous. And I never ever want to go through it again." (Stroke survivor 2)

Therapists and patient participants had similar concerns that patients' needs for rehabilitation were not met and that they were susceptible to physical and mental health complications.

Therapists suggested that complications due to lack of therapy during acute stages will increase pressure on health care services due to future complications.

Stroke patients who got COVID had to stay longer in hospital. Yet, the infected patients had delayed rehabilitation.

"And then I caught COVID in the hospital. I was also doubly infected. I think it delayed my beginning of physio and everything." (Stroke Survivor 3)

a. Communication issues. Inpatients experienced difficulty in communication with staff, because of the PPE and social distancing measures. This led to a lack of facial recognition and made it hard to build a healthy therapeutic relationship with inpatients. Inpatients were socially isolated as they had no communication with staff or other patients on the ward. Also, interpreters were not allowed to come to help non-English speakers.

"I think those patients for who perhaps English isn't their first language it was really tricky, because initially it was difficult to get formal interpreters to come to the ward." (Therapist 8)

Patients expressed devastation due to lack of family support and therapists reported losing the support of family in caring for inpatients. There was a feeling of loneliness and lack of family/friends support as no visitors were allowed.

"If the hospital could have let my daughter come in, or my granddaughter, or my friends, they could have done a lot for me while they were visiting. But as it was, everything I wanted, every time I wanted to go to the toilet, I had to call the nurse." (Stroke Survivor 4). "I didn't see any family for three and a half months; it was a long time." (Stroke Survivor 3). "This was one of their big issues at that time, not having a proper communication with their families and friends, and kind of feeling isolated at that time." (Therapist 5).

In some cases, the lack of mental and emotional support during the inpatient period had led patients to ask for early discharge from hospital.

"The sister on my ward. . .hasn't got time to talk, I never had a conversation with her ever. . . There was nothing said about your mental health, we were just left." (Stroke Survivor 4)

Additionally, the lack of access to the internet, TV or any other entertainments made it worse while staying in the hospital.

b. Therapists' concerns. Some therapist participants expressed sadness over losing some of their colleagues in the pandemic and that had made them more scared of the situation. Therapists expressed their frustration with the management as they thought they should have had more training opportunities for staff and teams in dealing with similar situations. They indicated that it was an even more challenging time for newly qualified therapists.

"Some are in their third year of placement. . .. . .the amount of hands on contact they've had with a patient is very minimal. So that's going to have a huge implication on how quickly we going to get out to patients, and also it's going to take us a lot more time trying to train up the band fives confidence." (Therapist 3)

With regard to patients, therapists reported their feeling of letting patients down as no quality services were provided along the rehab journey even in the acute settings. While some therapists were keen to provide help for their patients, they had concerns about safety and infection control, which limited their support to patients.

"It is a difficult balance" (Therapist 1) "You couldn't progress them over the phone onto a walking stick, you just literally couldn't do that, you'd have to do that face to face with them." (Therapist 6)

Theme 3: *Management strategies*. This theme summaries the strategies that have been used by service providers or stroke survivors and their carers to manage the rehabilitation process and deal with challenges. Some strategies were implemented based on organisational and clinical practice guidelines such as early supported discharge and remote rehabilitation and others were initiated by patients such as self-management, goal setting and seeking social support.

a. Strategies used by therapists and patients. In the inpatient settings, some participants managed to virtually communicate with relatives and friends. In some hospitals, this was facilitated by care teams to enable communication of inpatients with their families.

In the community, patients had to manage their own rehabilitation at home as no services were provided.

"I was already independent before they [community physiotherapists] came in! What I did, I exercised myself, and I was determined to get downstairs. By the time physios came 12 weeks later, I was already doing the stairs and getting down to the bottom." (Stroke Survivor 8)

Some participants said they felt the need for private care while waiting for community services. However, private care was costly and participants were unsatisfied with their care quality. Both groups of participants liked how YouTube videos, online games, online stroke groups, social media helped their rehabilitation, especially when patients had financial challenges to pay for private services.

"There are games which the patient can do, so that can almost be linked to a therapist device, so they could see how well they are getting on and how much rehab they're doing with their hand each day, you can set targets. . .. . . it tracks their progress and how much rehab they have done on it.". (Therapist 9)

Some therapists also suggested photographing of the exercise programmes given in the hospital was useful for easier home implementation. Also, lending iPads to patients was a strategy used by some teams to enable patients to access rehabilitation remotely.

b. Virtual communication and remote rehabilitation. Therapists indicated that the biggest modification for community teams was replacing face-to-face rehabilitation in the community with virtual communication. Virtual communication emerged as a new strategy to reduce direct contact with patients; this included virtual patients' assessments, remote delivery of therapy and follow up. Remote rehabilitation was implemented as the only option for the delivery of rehabilitation therapy for patients post discharge. Some therapists were not happy with the

new policies regarding virtual rehabilitation at the beginning because of the lack of technology in the department to deliver services, difficulty in communication with some stroke survivors, and virtual assessments were not always accurate. It was also challenging for some patients who did not have a device or any access to the internet, not familiar with technology, without carer support and were worried about their safety at home. Some trusts took some time to figure out a platform for virtual delivery of services, which raised staff frustration.

"There people who have refused onward referral, because they don't want people in their home, and they haven't got access to technology, or they are not in a position to use that." (Therapist 8)

However, remote rehabilitation was appreciated by both groups as it was the only way of providing rehabilitation therapy. Therapists also alluded to video-communication as more effective than Tele-care as it allows them to see patients. They also suggested that younger stroke survivors were happy with online support, accepted and benefitted more from the remote therapy. Some therapists viewed virtual communication positively and thought it was more efficient (giving them time to contact more patients per day without physical travelling). They felt phone assessments were quicker and enabled collection of more detailed information.

c. Self-management (SM) strategies. Although some therapists believe that SM should always be delivered as an important part of rehabilitation even before COVID, most therapists indicated their increasing effort to empower patients and their families for self-management during the pandemic. Patients themselves demonstrated self-motivation to carry out SM without any support from the NHS. There were times where SM was the only option to improve independence after discharge. Further, patients suggested that goal setting was vital for their rehabilitation as it pushed the boundaries for the individuals.

"They [the process of goal setting] are vital, absolutely vital, because I know what I'm working on, I've got direction." (Stroke Survivor 8)

Some Early supported discharge (ESD) teams encouraged referrers to prepare patients for self-management and home exercises before they were referred to them. ESD therapists had also facilitated patients' discharge by providing education, involving patients in goal setting, and planning for training for the various stages of recovery. The constraint induced movement therapy, stretch classes and GRASP were mentioned as good examples of SM programmes.

"There was a big move towards giving more education whilst they are in inpatient, so that they were more informed about things like signs, symptoms, FAST, and perhaps more focus in terms of medication, again who to liaise with. . .. . . trying to empower someone, whether they were able to more self-manage." (Therapist 10) Another therapist explained that as *"we tell patients: We come. We guide. You do.' Instead of we come and do with you" (Therapist 11)*

Providing information packages and compiling apps and online resources from the Stroke Association or Different Strokes were other ways of supporting patients' information needs. Some patients found YouTube and online resources were helpful for teaching SM. Therapists and patient participants agreed that family motivation and encouragement could improve recovery at home.

"It was my family, my daughter. She did everything she could, she encouraged me to be motivated, at the time my mental health was down." (Stroke Survivor 2)

Contrary to the support for SM, some therapists thought that patients' engagement in self-management was very variable ('self-management is not suitable for everyone'). Therapists suggested that the success of self-management strategies can be affected by fatigue, safety, motivation, self-efficacy and lack of preparation for SM. Also, patients explained difficulty of engaging in SM in the early days post discharge and for people with low functional capacity. They also suggested that an individual's SM plan should be regularly checked by professionals.

" I think there needs to be more regular check-ins from, perhaps GP or NHS personnel for stroke survivors. Especially from a learning curve. . .. . .. So, if you're going down the self-management route, then somebody has to govern and make sure that person's okay to do that independent work." (Stroke survivor 10)

Theme 4: *Rehabilitation needs and priorities*. ***a. Improved ESD services.*** Therapists believe people who had stroke during the pandemic experienced longer and slower rehabilitation. Therefore, they suggested that the main priority was maintaining the ESD and the community services on discharge.

" being able to see people on going in their own home, would be the better thing for these patients". (Therapist 2) " I think, probably, maintaining the ESD and the community services on discharge, and how that happens, is probably the most important thing" (Therapist 4)

They indicated it was important to make a seamless service across the pathway starting with normal inpatient care with proper PPE. To improve inpatient care, therapists suggested better communication and emotional support, family visitations and participation in therapy sessions. Having sufficient staff and training especially for the ESD teams, more funding for social support services, preparing patients for discharge, psychological support and providing better resources for remote rehabilitation with family engagement can help to address rehabilitation needs and manage the waiting list for the community services.

"During the pandemic we managed, and now we're not managing. We can't get staff, and just so many more referrals, so I think that's the main priority that needs sorting out. People need the rehab straightaway, they need the physio straightaway.". (Therapist 8)

b. Individualised community rehabilitation. Patients suggested engagement in individualised rehabilitation plans post discharge from acute care. Mobility was considered by participants as the main goal of physical rehabilitation to improve independence.

"My first goal was to stand up. . .. And I just said, I want to stand up, because I need stand up so that I can be transferred onto one of the pieces of equipment so I can move to the toilet and so." (Stroke survivor 6)

Access to the gym and other equipment and joining therapy groups seemed to be a priority for patients if it was suitable for them.

"I hope there would be more OT [Occupation Therapy], I hope there will be more physio. I really like to be in a gym, I'd like to be able to use equipment to do things." (Stroke survivor 5)

Patients indicated support for their mental health needs in different stages of their recovery. Participants said more conversations and information was needed for mental health in addition to support from the GPs.

"I think they should talk to you more, tell you about what's happening, what the prospects are, what you can do to help your mental health, give you more encouragement". (Stroke survivor 6)

c. Dealing with future waves. Some therapists described the current practice as a 'new normal' in which services are meant to go back to pre-COVID19 practice with new measures that can help to improve health and safety in future waves. The 'new normal' also gives the option for virtual communication and remote rehabilitation if needed and this was agreed by patients.

" I do have a patient currently now who still doesn't really want us to visit. She's much happier for us to converse through WhatsApp calls rather than a face-to-face, and we respect that". (Therapist 12)

Participants discussed some plans on how things can be better done in the future. For instance, some therapists suggested strategic planning of how to manage their caseload in case of service disruption instead of redeploying staff or a complete stopping of services.

"I think there have to be lessons learned about trying to continue with community services and not redeploying staff" (Therapist 8)

They indicated that the assessment in the beginning and the triaging are important to prioritise care of most needed individuals. Face to face rehab was suggested (by therapists and patients) in future waves with proper PPE even for patients in isolation.

"There is no reason for us not to continue normal care for patients". (Therapist 9)

Therapists suggested remote rehabilitation can be implemented even for individuals who need to be isolated under some circumstances However, safety assurance and additional technology were required for practical delivery. Also, patient education and family involvement could help deliver rehabilitation in the community in addition to the Apps and online groups.

"It was in small group, people experiencing something like me, so we understand each other so we encourage each other." (Stroke Survivor 3)

Patients and therapists agreed that relatives should be allowed to visit inpatients. In this case, infection control could be ensured by applying on site testing for COVID that can be more practical.

Discussion

This study is one of the first to describe the impact of the COVID-19 pandemic on stroke rehabilitation from the stakeholders' perspective in England. The findings of this study describe how the pandemic affected the stroke care system in various settings, modifications in patients' and therapists' practice, strategies that were used to manage the disruption in the services and outline the needs and priorities for future rehabilitation practice. The data was collected from

patients and therapists' interviews with various demographic characteristics thus improving validity and creditability of findings. Including participants from different geographical areas showed that there was variability in the organisational response to the pandemic in various settings. These differences in responses in various settings might have been influenced by the rapid spread of the pandemic locally, the daily updates leading to panic and ambiguous guidance from the local decision makers.

Interestingly, some patient participants mentioned that they thought their stroke happened because of their earlier COVID-19 infection which was also evident in other medical research findings [18, 19]. Moreover, participants indicated that the A&E staff and they were confused between stroke and COVID-19 as a cause of their clinical symptoms. Stroke symptoms like musculoskeletal pain and fatigue, headache, blood pressure, and vision problems were commonly found in patients with Covid. This issue might highlight the need for better differential diagnosis techniques when making a new diagnosis for people with a stroke in this pandemic era.

Participants in our study indicated that restrictions on communication and family visits in the acute settings had negatively affected their recovery. Similarly, participants in another study involving clinicians working in the intensive care units across the UK, showed their dissatisfaction with their way of interacting with patients' families during the pandemic and they expected patients, and families, to be negatively impacted due to this [37]. In some cases, this issue was successfully solved by allowing inpatients to use technology to communicate with staff and see their families/friends remotely. It was even suggested to improve infrastructure for all inpatients facilities with proper technology to allow patients remote social communication that also reduce the need for physical visits as a part of the new normal services.

The findings of this study demonstrate the lack of quality of care along the continuum of stroke care in terms of rehabilitation. Patients expressed their frustration with the impact the pandemic had made on the services and suggested face to face delivery of the rehabilitation services with proper precautions. Though most of the recommendations for best practices during the pandemic, suggest remote communication with patients as an ideal approach [17, 38] patients still wanted face to face delivery and communication. There is a need to prepare and educate patients on the uptake and benefits of remote rehabilitation.

Despite the findings of some studies that delivery of stroke acute care has been maintained or even improved during the lockdown in the UK and other high-income countries [3, 15], our findings show a level of incongruence between system effectiveness from an organisational perspective versus patient satisfaction about services. Also, the previous studies did not discuss community services which have faced more challenges and did not meet standards in some cases. This inadequacy to meet patient needs was reflected in the fact some of the narratives were emotional and patients requested for rest during the interviews. They alluded this emotional upset was due to the lack of psychological support especially during the pandemic and hoped to get that as a priority of care when services are restored.

Despite the relaxing of the COVID-19 measures and coming back to normal service delivery, the most striking issue in current practice for community services is how to manage the long waiting list of patients especially with the current early discharge policy. Our findings support the results of another study that early supported discharge plans for stroke patients were inappropriate, such as being unsafe and uncoordinated [39]. Patients were found to be discharged with delays in installing home equipment and further community rehabilitation. Moreover, families were inadequately prepared to care for stroke patients at home as a result of restrictions on visitations and communication with family during hospitalisation which was also identified as a big challenge for the caregivers of stroke patients in another study in the United States [9]. Caregivers in that study thought that frequent attendance of therapy sessions

and direct communication with staff could improve their readiness for the discharge of their family members from inpatient rehabilitation. As that was impossible during the pandemic, they suggested alternative measures such as scheduled phone calls from all members of the care team and frequent video conference or footage from therapy sessions to keep the caregiver involved in the plan of care [9].

The healthcare needs of caregivers emerged strongly from participants' comments. Some carers and family members tended to display emotional vulnerability for the caring roles due to lack of social or psychological support. In a national stroke survey, 78% of the informal carers had alarmingly presented with severe mental health impacts during the pandemic [40]; psychosocial support needs to be extended to not only the stroke survivors but also their carers of people who had a stroke during the pandemic. In our study, community psychologist consultations received by a participant's family member was suggested as helpful; professional counselling might be one of the resolutions for caregivers to lessen their emotional burden and could in return benefit stroke patients' recovery [41].

The use of remote rehabilitation, online groups, and SM approaches have been found very effective for some patients in previous literature [42, 43]. During the pandemic, dependence on these approaches as the key strategy for improving recovery urges further uptake and adoption of SM during the period when the services are still catching up. However, SM was not the best option for everyone and the capacity of an individual for self-management involving remote rehabilitation should be evaluated [44]. Also, our findings confirm some challenges for the delivery of remote rehabilitation identified by previous research such as users' poor IT skills and resources, miscommunication between individuals, and safety issues [45]. The remote delivery of SM is found to work best in cases of motivated survivors, having a supporting caregiver and when therapists have a healthy relationship with their patients. These factors should be considered when planning for individual care and when planning patients' groups for therapy.

There were some limitations to this study. Some participants were unsatisfied with meeting online for the interviews, especially stroke survivors who weren't familiar with the use of technology. Consequently, the researcher had to do multiple meetings to carry out assessments and interviews in separate sessions. Most of our participants were female in both groups (only one male survivor), which might not represent the perspectives of male stroke survivors in the UK (males' prevalence (51%) > females) [46]. However, it was not feasible for this study to purposefully recruit more participants based on their gender. This study included participants from Birmingham and London areas. Hence, to develop a national recommendation for best practices there might be a need for national research that can evaluate the system more widely. Also, the study only included patients from sub-acute and chronic stages; due to this limitation, we might not be entirely sure of the challenges faced by patients in the acute settings. However, as previously explained, access to acute patients was very restricted during the Covid pandemic. The findings of this study demonstrate the situation of the stroke services during the pandemic, when the interviews were collected, and future research can evaluate the long-term impact of the pandemic on service delivery after the relaxation of the control measures and when services return to normal or the new normal practice. A key question remains as what the residual long-term impact of the pandemic is on the health care system and patients who have had stroke during this pandemic situation.

Conclusion

The findings of this study demonstrated the impact of the pandemic on stroke care and provided suggestions for optimal delivery of care in future situations. Future research is warranted

to examine the efficacy of new strategies such as reducing the time for acute care and enhancing remote delivery of rehabilitation for people with mild to moderate impairments post stroke.

Clinical messages

- Despite patients recommending face to face delivery with precautions, when offered self-management interventions, their ability to engage in self-management seemed to be activated since professional support was limited during the lockdown.
- Patients' competence to engage in self-management and remote rehabilitation should be assessed prior to delivering self-management due to challenges related to access and ability to use technology.
- According to patients, the use of technology was highly recommended as the only hope for participating in rehabilitation during the pandemic.
- Future clinical practice should consider the digital divide and improve opportunities for Information Technology education.

Supporting information

S1 File.
(PDF)

S2 File.
(DOCX)

Acknowledgments

The authors would like to acknowledge the patients and therapists who participated. AS, SR, and AAS contributed to the design of the study. AS was responsible for acquisition of data. All authors contributed to analyses and interpretation of data. All authors contributed substantially to drafting the article or revising it critically.

Author Contributions

Conceptualization: Ahmad Sahely, Andrew Soundy, Sheeba Rosewilliam.

Data curation: Ahmad Sahely, Andrew Soundy, Sheeba Rosewilliam.

Formal analysis: Ahmad Sahely, Shara Kai Ning Hew, Yik Ka Chan, Andrew Soundy, Sheeba Rosewilliam.

Funding acquisition: Ahmad Sahely.

Investigation: Ahmad Sahely, Shara Kai Ning Hew, Yik Ka Chan, Andrew Soundy, Sheeba Rosewilliam.

Methodology: Ahmad Sahely, Andrew Soundy, Sheeba Rosewilliam.

Project administration: Ahmad Sahely, Sheeba Rosewilliam.

Resources: Ahmad Sahely, Sheeba Rosewilliam.

Software: Ahmad Sahely, Sheeba Rosewilliam.

Supervision: Ahmad Sahely, Andrew Soundy, Sheeba Rosewilliam.

Validation: Ahmad Sahely, Andrew Soundy, Sheeba Rosewilliam.

Visualization: Ahmad Sahely, Andrew Soundy, Sheeba Rosewilliam.

Writing – original draft: Ahmad Sahely.

Writing – review & editing: Ahmad Sahely, Shara Kai Ning Hew, Yik Ka Chan, Andrew Soundy, Sheeba Rosewilliam.

References

1. Johnson W, Onuma O, Owolabi M, Sachdev S. Stroke: a global response is needed. Bull World Health Organ. 2016; 94(9):634. https://doi.org/10.2471/BLT.16.181636 PMID: 27708464
2. Association S. State of the nation Stroke statistics—Februrary 2018. 2018;(February). Available from: https://www.stroke.org.uk/system/files/sotn_2018.pdf
3. Douiri A, Muruet W, Bhalla A, James M, Paley L, Stanley K, et al. Stroke care in the United Kingdom during the COVID-19 pandemic. Stroke. 2021; 52(6):2125–33. https://doi.org/10.1161/STROKEAHA.120.032253 PMID: 33896223
4. Bersano A, Pantoni L. Impact of the SARS-CoV-2 pandemic on stroke care: a warning message. 2020;
5. D'Anna L, Brown M, Oishi S, Ellis N, Brown Z, Bentley P, et al. Impact of national lockdown on the hyperacute stroke care and rapid transient ischaemic attack outpatient service in a comprehensive tertiary stroke centre during the COVID-19 pandemic. Front Neurol. 2021; 12:37.
6. Aguiar de Sousa D, Sandset EC, Elkind MS V. The curious case of the missing strokes during the COVID-19 pandemic. Am Heart Assoc; 2020.
7. Rees N, Smythe L, Hogan C, Williams J. Paramedic experiences of providing care in wales (UK) during the 2020 COVID-19 pandemic (PECC-19): A qualitative study using evolved grounded theory. BMJ Open. 2021; 11(6):1–14. https://doi.org/10.1136/bmjopen-2021-048677 PMID: 34140344
8. Busetto L, Sert M, Herzog F, Hoffmann J, Stang C, Amiri H, et al. "But it's a nice compromise"–Qualitative multi-centre study of barriers and facilitators to acute telestroke cooperation in a regional stroke network. Eur J Neurol. 2022; 29(1):208–16. https://doi.org/10.1111/ene.15130 PMID: 34582614
9. Sutter-Leve R, Passint E, Ness D, Rindflesch A. The caregiver experience after stroke in a covid-19 environment: A qualitative study in inpatient rehabilitation. J Neurol Phys Ther. 2021; 45(1):14–20. https://doi.org/10.1097/NPT.0000000000000336 PMID: 33086240
10. Lee JJ, Tsang WN, Yang SC, Kwok JYY, Lou VWQ, Lau KK. Qualitative Study of Chinese Stroke Caregivers' Caregiving Experience during the COVID-19 Pandemic. Stroke. 2021;(April):1407–14. https://doi.org/10.1161/STROKEAHA.120.032250 PMID: 33588588
11. Palacios-Ceña D, Fernández-de-Las-Peñas C, Florencio LL, de-la-Llave-Rincón AI, Palacios-Ceña M. Emotional experience and feelings during first COVID-19 outbreak perceived by physical therapists: a qualitative study in Madrid, Spain. Int J Environ Res Public Health. 2021; 18(1):127.
12. Palacios-Ceña D, Fernández-de-Las-Peñas C, Florencio LL, Palacios-Ceña M, de-la-Llave-Rincón AI. Future challenges for physical therapy during and after the COVID-19 pandemic: a qualitative study on the experience of physical therapists in Spain. Int J Environ Res Public Health. 2021; 18(16):8368. https://doi.org/10.3390/ijerph18168368 PMID: 34444118
13. Palacios-Ceña D, Fernández-de-Las-Peñas C, Palacios-Ceña M, De-La-Llave-Rincón AI, Florencio LL. Working on the frontlines of the COVID-19 pandemic: A qualitative study of physical therapists' experience in Spain. Phys Ther. 2021; 101(4):pzab025.
14. Ditwiler RE, Swisher LL, Hardwick DD. Professional and ethical issues in united states acute care physical therapists treating patients with COVID-19: stress, walls, and uncertainty. Phys Ther. 2021; 101(8): pzab122. https://doi.org/10.1093/ptj/pzab122 PMID: 33956143
15. Pandian JD, Panagos PD, Sebastian IA, Sampaio Silva G, Furie KL, Liu L, et al. Maintaining stroke care during the COVID-19 pandemic in lower-and middle-income countries: World Stroke Organization Position Statement endorsed by American Stroke Association and American Heart Association. Int J Stroke. 2022; 17(1):9–17. https://doi.org/10.1177/17474930211055878 PMID: 34711104
16. Meyer D, Meyer BC, Rapp KS, Modir R, Agrawal K, Hailey L, et al. A stroke care model at an academic, comprehensive stroke center during the 2020 COVID-19 pandemic. J Stroke Cerebrovasc Dis. 2020; 29(8):104927. https://doi.org/10.1016/j.jstrokecerebrovasdis.2020.104927 PMID: 32434728

17. Smith EE, Mountain A, Hill MD, Wein TH, Blacquiere D, Casaubon LK, et al. Canadian stroke best practice guidance during the COVID-19 pandemic. Can J Neurol Sci. 2020; 47(4):474–8. https://doi.org/10.1017/cjn.2020.74 PMID: 32654680

18. Gunasekaran K, Amoah K, Rajasurya V, Buscher MG. Stroke in a young COVID-19 patient. QJM An Int J Med. 2020;

19. Avula A, Nalleballe K, Narula N, Sapozhnikov S, Dandu V, Toom S, et al. COVID-19 presenting as stroke. Brain Behav Immun. 2020; 87:115–9. https://doi.org/10.1016/j.bbi.2020.04.077 PMID: 32360439

20. British Medical Association. Rest, recover, restore: Getting UK health services back on track. 2021;

21. De Biase S, Cook L, Skelton DA, Witham M, Ten Hove R. The COVID-19 rehabilitation pandemic. Age Ageing. 2020; 49(5):696–700. https://doi.org/10.1093/ageing/afaa118 PMID: 32470131

22. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Heal care. 2007; 19(6):349–57. https://doi.org/10.1093/intqhc/mzm042 PMID: 17872937

23. Harding G, Gantley M. Qualitative methods: beyond the cookbook. Fam Pract. 1998; 15(1):76–9. https://doi.org/10.1093/fampra/15.1.76 PMID: 9527301

24. Archer MS. Reconstructing sociology: The critical realist approach. J Crit Realis. 2016; 15(4):425–31.

25. Bowling A. Research methods in health: investigating health and health services. McGraw-hill education (UK); 2014.

26. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res. 1975; 12(3):189–98.

27. Mahoney FI, Barthel DW. Functional evaluation: the Barthel Index: a simple index of independence useful in scoring improvement in the rehabilitation of the chronically ill. Md State Med J. 1965;

28. Williams LS, Weinberger M, Harris LE, Clark DO, Biller J. Development of a stroke-specific quality of life scale. Stroke. 1999; 30(7):1362–9. https://doi.org/10.1161/01.str.30.7.1362 PMID: 10390308

29. Pracheth R, Mayur SS, Chowti J V. Geriatric depression scale: A tool to assess depression in elderly. Int J Med Sci Public Heal. 2013; 2(1):31–5.

30. Mason M. Sample size and saturation in PhD studies using qualitative interviews. In: Forum qualitative Sozialforschung/Forum: qualitative social research. 2010.

31. Turner SM, Hersen M. The interviewing process. In: Diagnostic interviewing. Springer; 1994. p. 3–24.

32. Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qual Res Sport Exerc Heal. 2019; 11 (4):589–97.

33. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today. 2004; 24(2):105–12. https://doi.org/10.1016/j.nedt.2003.10.001 PMID: 14769454

34. Berger R. Now I see it, now I don't: researcher's position and reflexivity in qualitative research. Qual Res. 2015; 15(2):219–34.

35. Öhman A. Qualitative methodology for rehabilitation research. J Rehabil Med. 2005; 37(5):273–80. https://doi.org/10.1080/16501970510040056 PMID: 16208859

36. Balasch i Bernat M, Balasch i Parisi S, Sebastián EN, Moscardó LD, Ferri Campos J, Lopez Bueno L. Determining cut-off points in functional assessment scales in stroke. NeuroRehabilitation. 2015; 37 (2):165–72. https://doi.org/10.3233/NRE-151249 PMID: 26484508

37. Boulton AJ, Jordan H, Adams CE, Polgarova P, Morris AC, Arora N. Intensive care unit visiting and family communication during the COVID-19 pandemic: A UK survey. Journal of the Intensive Care Society. 2021;175114372110077. https://doi.org/10.1177/17511437211007779 PMID: 36033248

38. Lyden P. Temporary emergency guidance to US stroke centers during the COVID-19 pandemic on behalf of the AHA/ASA Stroke Council Leadership. Stroke. 2020; 10(10.1161).

39. Lucas L, Gordon S, Heyes R. Impact of COVID-19 on the stroke rehabilitation pathway: multidisciplinary team reflections on a patient and carer journey from acute to community stroke services BMJ Case Reports CP 2021; 14:e245544. https://doi.org/10.1136/bcr-2021-245544 PMID: 34815227

40. Stroke Association. Stroke Recoveries at Risk [Internet]. 2020 Sep [cited 2022 Jun 22]. Available from: https://www.stroke.org.uk/sites/default/files/campaigning/jn_2021-121.1_-_covid_report_final.pdf

41. Perrin PB, Heesacker M, Hinojosa MS, Uthe CE, Rittman MR. Identifying at-risk, ethnically diverse stroke caregivers for counseling: A longitudinal study of mental health. Rehabilitation Psychology. 2009; 54(2):138–49 https://doi.org/10.1037/a0015964 PMID: 19469603

42. Warner G, Packer T, Villeneuve M, Audulv A, Versnel J. A systematic review of the effectiveness of stroke self-management programs for improving function and participation outcomes: self-management

programs for stroke survivors. Disabil Rehabil [Internet]. 2015; 37(23):2141–63. Available from: http://www.tandfonline.com/doi/full/10.3109/09638288.2014.996674 PMID: 25579669

43. Laver KE AZCMLNAGS, Sherrington C. Telerehabilitation services for stroke. Cochrane Database Syst Rev [Internet]. 2020;(1). Available from: https://doi.org/10.1002/14651858.CD010255.pub3

44. Clark E, Bennett K, Ward N, Jones F. One size does not fit all–stroke survivor's views on group self-management interventions. Disabil Rehabil. 2018; 40(5):569–76. https://doi.org/10.1080/09638288.2016.1268653 PMID: 28034320

45. Di Lorito C, Duff C, Rogers C, Tuxworth J, Bell J, Fothergill R, et al. Tele-rehabilitation for people with dementia during the COVID-19 pandemic: a case-study from England. Int J Environ Res Public Health. 2021; 18(4):1717. https://doi.org/10.3390/ijerph18041717 PMID: 33578949

46. National Institute for Health and Care Excellence. What is the prevalence of stroke and TIA in the UK? [Internet]. United Kingdom. National Institute for Health and Care Excellence; 2022 [cited 2022 Jun 23]. Available from: https://cks.nice.org.uk/topics/stroke-tia/background-information/prevalence

Appendix 4: <u>The protocol of the systematic review (PROSPERO registration)</u>

PROSPERO
International prospective register of systematic reviews

NHS
National Institute for Health Research

University of York
Centre for Reviews and Dissemination

Systematic review

1. * Review title.

Give the working title of the review, for example the one used for obtaining funding. Ideally the title should state succinctly the interventions or exposures being reviewed and the associated health or social problems. Where appropriate, the title should use the PI(E)COS structure to contain information on the Participants, Intervention (or Exposure) and Comparison groups, the Outcomes to be measured and Study designs to be included.

Self-management interventions to improve mobility in the community after stroke: a systematic review integrating the quantitative and qualitative literature

2. Original language title.

For reviews in languages other than English, this field should be used to enter the title in the language of the review. This will be displayed together with the English language title.

3. * Anticipated or actual start date.

Give the date when the systematic review commenced, or is expected to commence.

01/10/2019

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

31/03/2020

5. * Stage of review at time of this submission.

Indicate the stage of progress of the review by ticking the relevant Started and Completed boxes. Additional information may be added in the free text box provided.
Please note: Reviews that have progressed beyond the point of completing data extraction at the time of initial registration are not eligible for inclusion in PROSPERO. Should evidence of incorrect status and/or completion date being supplied at the time of submission come to light, the content of the PROSPERO record will be removed leaving only the title and named contact details and a statement that inaccuracies in the stage of the review date had been identified.
This field should be updated when any amendments are made to a published record and on completion and publication of the review. If this field was pre-populated from the initial screening questions then you are not able to edit it until the record is published.

The review has not yet started: No

Review stage	Started	Completed
Preliminary searches	Yes	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here (e.g. Funded proposal, protocol not yet finalised).

The protocol for this review has been finalised.

The protocol for this review has been finalised.

6. * Named contact.

The named contact acts the guarantor for the accuracy of the information presented in the register record.

Ahmad Sahely

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Mr. Sahely

7. * Named contact email.

Give the electronic mail address of the named contact.

8. Named contact address

Give the full postal address for the named contact.

School of Sport, Exercise and Rehabilitation Sciences, University of Birmingham, Birmingham, B15 2TT, UK

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

University of Birmingham

Organisation web address:

https://www.birmingham.ac.uk/schools/sport-exercise/index.aspx

11. * Review team members and their organisational affiliations.

Give the title, first name, last name and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong.

Mr Ahmad Sahely. University of Birmingham
Dr Andrew Soundy. University of Birmingham
Dr Sheeba Rosewilliam. University of Birmingham

12. * Funding sources/sponsors.

Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Include any unique identification numbers assigned to the review by the individuals or bodies listed.

Not applicable

13. * Conflicts of interest.

List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review.

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members.

Mrs Carron Sintler. Stroke Services University Hospitals Birmingham and Birmingham Community Healthcare Trust

15. * Review question.

State the question(s) to be addressed by the review, clearly and precisely. Review questions may be specific or broad. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS where relevant.

What are the effects and outcomes of self-management interventions related to the rehabilitation of mobility post-stroke?

16. * Searches.

State the sources that will be searched. Give the search dates, and any restrictions (e.g. language or publication period). Do NOT enter the full search strategy (it may be provided as a link or attachment.)

2. Hand searches will be conducted using Google Scholar for the first 10 pages.

- PubMed
- MEDLINE
- EMBASE
- PsycINFO
- AMED
- CINAHL
- Cochrane Database of Systematic Reviews

- Web of Science

3. Secondary searching will include:

- Screening of references from shortlisted articles.

- A search of grey literature (unpublished studies) including conference proceedings and PhD theses will be sought for this review.

The Key words have been identified from the research question based on the PICOS strategy. These have been exploded using synonyms from related literature and identification of MeSH terms from PubMed.

The search strategy will be run using same keywords on different databases.

The filters/limiters will be applied in all databases (literature that published from 1992 to 2019 and will be restricted to the publications that are in English, related to human and include abstracts)

The Boolean operators OR and AND will be used when searching for independent components of PICOS.
The OR operator will be used when different synonyms are used for the same concept
The AND operator will be used to combine searches of different concept.

The searches will be re-run by a second researcher and the results will be discussed in a meeting with the review team.

17. URL to search strategy.

Give a link to a published pdf/word document detailing either the search strategy or an example of a search strategy for a specific database if available (including the keywords that will be used in the search strategies), or upload your search strategy.Do NOT provide links to your search results.

https://www.crd.york.ac.uk/PROSPEROFILES/151051_STRATEGY_20191016.pdf

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Yes I give permission for this file to be made publicly available

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes.

Healthcare Stakeholder Self-management

Outcome: Mobility/Walking

19. * Participants/population.

Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria.

Inclusion: Adult stroke survivors (18 years) with any type or severity of stroke, who have received any form of [illegible] intervention for other purposes where mobility is not included.

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the nature of the interventions or the exposures to be reviewed.

Interventions that used self-management solely or incorporate any of its strategies will be included for the review. Self-management is a process in which individuals can acquire skills and knowledge to manage their [illegible] management strategies are: patient education, goal setting, peer support, and self-monitoring/feedback. The studies that have any or all these examples or any related strategies will be included if they were used to improve mobility of stroke survivors. Studies will be excluded if their aim was not related to the self-management or mobility improvement.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

- [illegible] standard care or placebo/no intervention.

22. * Types of study to be included.

Give details of the types of study (study designs) eligible for inclusion in the review. If there are no restrictions on the types of study design eligible for inclusion, or certain study types are excluded, this should be stated. The preferred format includes details of both inclusion and exclusion criteria.

All types of relevant quantitative, qualitative, or mixed methods studies to the research question will be included. There will be no restrictions on the types of study design eligible for inclusion in this review.

23. Context.

Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.

24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

The studies will be included for review if they include at least one measure of functional mobility outcomes.

Functional mobility is defined as the manner in which people are able to move around in the environment in order to participate in the activities of daily living and, move from place to place.

These functional mobility outcomes are measured using outcome measures related to balance (e.g. Berg's balance test, Dynamic gait index, functional reach test, single limb stance, timed up and go), functional gait (e.g. functional gait assessment) gait speed (e.g.10 mt walk test), and distance walked (e.g 6 minute walk test).

These measures will be looked at baseline till the end of follow up in each study.

The review of the relevant qualitative studies aims at exploring the lived experiences of people with stroke regarding self-management mobility programmes. We will be exploring opinions/views, expectations, experiences, and knowledge from the participants in such self management programmes. The aim is to establish a knowledge base on which we can develop future self-management programmes for mobility.

Timing and effect measures

This review will include any evidence about the effect of self-management for stroke population at any stage (acute, subacute, chronic) of their recovery.

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

The secondary outcomes for the review are:

- Self-management related outcomes (e.g. self-efficacy scale and goal attainment scale).

- Psychological outcomes (e.g. Beck's depression inventory, Geriatric depression scale, Hospital anxiety and depression scale)

- Social and general well being measures (e.g. Stroke impact scale)

These measures will be looked at baseline till the end of follow up in each study.

Timing and effect measures

This review will include any evidence about the effect of self-management for stroke population at any stage (acute, subacute, chronic) of their recovery.

26. * Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

Study selection of the citations will be done by two independent reviewers to check the eligibility of the

studies.

- Eligible studies will be saved and transferred to Mendeley.

- The duplicated citations will be removed.

- A review of the titles, abstracts will be carried out independently by two reviewers.

- The abstracts will be screened against the inclusion and exclusion criteria independently by two reviewers.

- Full texts will be downloaded for relevant abstracts.

- Two reviewers will independently screen the articles for eligibility and check the agreement between them.

- If there is disagreement, a third reviewer will review the paper's eligibility.

- A PRISMA Flow Diagram will be used to guide the process for screening and inclusion.

Data extraction

- Data extraction will start after the studies with relevant information are reviewed and shortlisted. The extracted data will include information about participants' demographics, stage of recovery, geographical location, and type of treatment received with/without self-management. Information about study methods and findings will be extracted. Also, information about the types of self-management interventions that have been used in the study and their protocols such as intensity, duration, form of evaluation/outcome measurements of each intervention will be extracted.

- The data extraction table will be piloted using the subheadings given for the first two articles and the results will be compared between two reviewers. Any changes to the table will be finalised at this stage before further data extraction.

- Two reviewers will extract data independently and they will check their agreement and resolve any disagreements with a third reviewer.

- The plan is to contact investigators for any missing data that are required to extract data or judge the quality of an article. The reasons for exclusion will be reported in the PRISMA Flow Diagram.

- The extracted data will be recorded in an Excel spreadsheet.

27. * Risk of bias (quality) assessment.

Describe the method of assessing risk of bias or quality assessment. State which characteristics of the studies will be assessed and any formal risk of bias tools that will be used.

- The Cochrane's Risk of Bias Tool will be used to critically appraise the randomised controlled trials. This will include assessment of; sequence generation, allocation concealment, blinding of participants and personnel, blinding of outcome assessment, incomplete outcome data, selective outcome reporting and other bias. The Risk Of Bias In Non-randomised Studies of Interventions (ROBINS-I) will be used to evaluate the non-controlled trials.

- To assess the risk of bias in the qualitative studies, the Consolidated criteria for reporting qualitative research (COREQ) will be used.
- The Mixed Methods Appraisal Tool (MMAT) will be used for the quality assessment of the mixed-methods studies.
- Studies with poor quality will be excluded from the review. Poor quality will be identified as described by the used tool.
- Two reviewers will be assessing the quality of the included studies independently and will discuss their agreement and a third reviewer might be asked to review quality if needed.

- The Grading of Recommendations, Assessment, Development and Evaluations (GRADE) framework will be used to rate the quality of evidence.

28. * Strategy for data synthesis.

Provide details of the planned synthesis including a rationale for the methods selected. This **must not be generic text** but should be **specific to your review** and describe how the proposed analysis will be applied to your data.

A Narrative Synthesis (NS) of aggregate data about self-management interventions to improve mobility for stroke survivors will be done following the Cochrane guidance for data synthesis. This will include summary of data regarding participants characteristics, details of the used interventions and outcomes. If there are enough studies with homogeneous population, interventions and outcome measures and articles have low risk of bias then we will consider meta-analysis of the outcomes that can be combined. We will estimate summary e?ect size using Odds Ratio and using both ?xed and random e?ects models and construct a forest plot.

If adequate number of homogeneous studies to carry out meta analysis is not found, we will not limit synthesis of data based on numbers of studies available. If studies score a low score on quality we will highlight this fact but not limit our review to high quality studies only. The above decisions were made because our generic scoping search did not provide us with many results and we do not want to limit studies due to weak methodological quality in the narrative synthesis.

The following steps will be used for NS:

1- The data from data extraction table will be summarised under participant characteristics, study characteristics, intervention contents, outcome measures used, effectiveness of the interventions on various outcomes and summarise methodological quality of the studies included.

2- We will explore commonalities in the data between studies and combine the common findings. We will

present summarised findings for outcomes against the background of the methodological quality of the studies.

3- We will highlight the differences in the findings and explore reasons as to why that might be.

4- Content analysis will be carried out for the synthesis of qualitative data.

The result of the data synthesis will be reviewed by two senior researchers with experience in systematic reviews.

29. * Analysis of subgroups or subsets.

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

There is no initial plan for subgroup analysis. However, it might be done for specific outcome measures if there are enough studies included in the review if studies are found to be homogenous. A consideration is made for subgroup analysis to look at the efficacy of self-management interventions for stroke survivors in acute vs. chronic stage of their recovery if appropriate studies are found.

30. * Type and method of review.

Select the type of review and the review method from the lists below. Select the health area(s) of interest for your review.

Type of review

Cost effectiveness
No

Diagnostic
No

Epidemiologic
No

Individual patient data (IPD) meta-analysis
No

Intervention
No

Meta-analysis
Yes

Methodology
No

Narrative synthesis
Yes

Network meta-analysis
No

Pre-clinical
No

Prevention
No

Prognostic

No

Prospective meta-analysis (PMA)
No

Review of reviews
No

Service delivery
No

Synthesis of qualitative studies
Yes

Systematic review
Yes

Other
Yes

meta analysis will be conducted if appropriate data are found

Health area of the review

Alcohol/substance misuse/abuse
No

Blood and immune system
No

Cancer
No

Cardiovascular
No

Care of the elderly
No

Child health
No

Complementary therapies
No

Crime and justice
No

Dental
No

Digestive system
No

Ear, nose and throat
No

Education
No

Endocrine and metabolic disorders
No

Eye disorders
No

General interest
No

Genetics
No

Health inequalities/health equity
No

Infections and infestations
No

International development
No

Mental health and behavioural conditions
No

Musculoskeletal
No

Neurological
Yes

Nursing
No

Obstetrics and gynaecology
No

Oral health
No

Palliative care
No

Perioperative care
No

Physiotherapy
Yes

Pregnancy and childbirth
No

Public health (including social determinants of health)
No

Rehabilitation
Yes

Respiratory disorders
No

Service delivery
No

Skin disorders
No

Social care
No

Surgery
No

Tropical Medicine
No

Urological
No

Wounds, injuries and accidents
No

Violence and abuse
No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.
English

There is not an English language summary

32. * Country.

Select the country in which the review is being carried out from the drop down list. For multi-national collaborations select all the countries involved.

England

33. Other registration details.

Give the name of any organisation where the systematic review title or protocol is registered (such as with The Campbell Collaboration, or The Joanna Briggs Institute) together with any unique identification number assigned. (N.B. Registration details for Cochrane protocols will be automatically entered). If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

Give the citation and link for the published protocol, if there is one

Give the link to the published protocol.

Alternatively, upload your published protocol to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

No I do not make this file publicly available until the review is complete

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

35. Dissemination plans.

Give brief details of plans for communicating essential messages from the review to the appropriate audiences.

Do you intend to publish the review on completion?

Yes

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords will help users find the review in the Register (the words do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

- Population/participants: Stroke OR cerebrovascular accident* OR cerebrovascular disease OR ischemic stroke OR haemorrhagic stroke OR CVA OR Hemiplegia OR Acquired brain injury OR Cerebral Stroke OR Post stroke

AND

Rehabilitation OR Therapy OR Physiotherapy OR Physical therapy OR Intervention OR Training OR modification OR Program*

- Intervention: Self manage* OR self management OR Management, Self OR self-management OR self

efficacy OR self care OR self* OR Self Help OR Self Care

AND

Patient education OR Health education OR Educ* goal setting OR goal planning OR Therapy planning OR action

planning OR Care Planning OR Peer support OR Patient support OR Monitor OR self-monitor* OR self-feedback OR Self-evaluation OR Self- report OR Self-efficacy OR Confidence OR Knowledge OR skills OR Manage OR Coping OR Responsible OR Autonomy

- Comparator :Exercise* OR Physical Activity OR Physical Exercise OR Exercise training OR Group therapy

- Outcome: Walking OR functional mobility OR ambulation OR gait training OR mobility OR Gait*

37. Details of any existing review of the same topic by the same authors.

Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible.

38. * Current review status.

Review status should be updated when the review is completed and when it is published. For newregistrations the review must be Ongoing.
Please provide anticipated publication date

Review_Ongoing

39. Any additional information.

Provide any other information the review team feel is relevant to the registration of the review.

40. Details of final report/publication(s).

This field should be left empty until details of the completed review are available.

Give the link to the published review.

Appendix 5: Ethics approval for the feasibility study (Chapter 5)

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr Sheeba Rosewilliam
School of Sports, Exercise and Rehabilitation Sciences
University of Birmingham
Edgbaston
B15 2TT

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

17 June 2020

Dear Dr Rosewilliam

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Feasibility of a self-management intervention for improving mobility for patients following stroke in the community.**
IRAS project ID:	**269079**
Protocol number:	**ERN_19-0944**
REC reference:	**20/SW/0071**
Sponsor	**University of Birmingham**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **269079**. Please quote this on all correspondence.

Yours sincerely,
Sharon Northey

Approvals Manager

Email: approvals@hra.nhs.uk

Copy to: *Dr Birgit Whitman*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance]		01 August 2019
GP/consultant information sheets or letters	1	12 December 2019
Interview schedules or topic guides for participants	2	23 September 2019
IRAS Application Form [IRAS_Form_09032020]		09 March 2020
Letter from sponsor		09 March 2020
Organisation Information Document [Organisation Information Document]	1	
Other [Patient leaflet]	2	01 December 2019
Other [Exercise Booklet]	3	30 October 2019
Other [Usual Care document]	2	29 May 2020
Other [Patient Education]	4	01 December 2019
Other [Responses to PO]		
Other [Generic Clinical Trials Insurance]		01 August 2019
Other [Public and Product Liability]		01 August 2019
Other [Sponsor insurance letter]		09 March 2020
Other [Goal setting]	3	30 October 2019
Other [Integrated outcome measures]	1	12 December 2019
Other [Permission to contact form]	2	13 January 2020
Participant consent form [Consent form-Intervention]	5	16 May 2020
Participant consent form [Consent form-FG]	1	16 May 2020
Participant information sheet (PIS) [PIS-Main]	7	14 May 2020
Participant information sheet (PIS) [PIS- FG]	1	14 May 2020
Research protocol or project proposal [Protocol]	6	26 February 2020
Sample diary card/patient card [Recording Diary]	4	16 May 2020
Schedule of Events or SoECAT [Schedule of Events]	2	30 April 2020
Summary CV for Chief Investigator (CI) [CV for CI]		20 November 2019
Summary CV for student		29 April 2019
Summary CV for supervisor (student research)		09 March 2020
Summary CV for supervisor (student research) [Supervisor's CV]		09 March 2020
Summary CV for supervisor (student research) [Clinical Lead's CV]		29 May 2020

IRAS project ID	269079

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There is one type of participating NHS Organisation who will identify potential participants. External researchers who may obtain consent at the time of patient discharge.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	The submitted Organisation Information Document details the funding available to sites.	A Local Collaborator should be identified at the site to facilitate access arrangements for the external research team where needed.	No Honorary Research Contracts, Letters of Access or pre-engagement checks are expected for local staff employed by the participating NHS organisations. Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 6: Ethics approval for the qualitative study (Chapter 4)

From: Susan Cottam (Research Support Services) [redacted]
Subject: Application for Ethical Review ERN_21-0775
Date: 24 August 2021 at 14:44
To: Sheeba Rosewilliam (Physiotherapy) [redacted]
Cc: Ahmad Sahely [redacted]

SC

Dear Dr Rosewilliam,

Re: "Exploring the experiences, of people who had a stroke and views of therapists who managed stroke patients during the Covid-19 pandemic: A qualitative exploratory study."
Application for Ethical Review ERN_21-0775

Thank you for your application for ethical review for the above project, which was reviewed by the Science, Technology, Engineering and Mathematics Ethical Review Committee.

On behalf of the Committee, I confirm that this study now has full ethical approval.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly brought to the Committee's attention by the Principal Investigator and may necessitate further ethical review.

Please also ensure that the relevant requirements within the University's Code of Practice for Research and the information and guidance provided on the University's ethics webpages (available at https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Links-and-Resources.aspx) are adhered to and referred to in any future applications for ethical review. It is now a requirement on the revised application form (https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-Forms.aspx) to confirm that this guidance has been consulted and is understood, and that it has been taken into account when completing your application for ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's H&S Unit at healthandsafety@contacts.bham.ac.uk.

Kind regards

Susan Cottam
Research Ethics Manager
Research Support Group
[redacted]Block Dome
Aston Webb Building
University of Birmingham
Edgbaston B15 2TT
Tel: [redacted]
Email: [redacted]
Web: https://intranet.birmingham.ac.uk/finance/RSS/Research-Support-Group/Research-Ethics/index.aspx

Appendix 7: Data management plan

Self management intervention to improve walking of stroke survivors in the community

A Data Management Plan created using DMPonline

Creators: ahmad sahely, First Name Surname

Affiliation: University of Birmingham

Template: UoB short template

Last modified: 16-04-2020

Self management intervention to improve walking of stroke survivors in the community

Data description

What types of data will be used or created?

Quantitative data (clinical measurments)
Qualitative data (focus group transcripts)

How will the data be structured and documented?

Data will be in the form of tabular data (numbers), figures (graphs and flow diagrams) and text.

Data storage and archiving

How will your data be stored and backed up?

The study principal investigator (PI) and the other researcher will be responsible for the process of data collection and storage and will ensure that the data and information will be saved on a database held securely at the School of Sport, Exercise, and Rehabilitation Sciences in the University of Birmingham. The hard copies of consent forms and other measurements forms will be saved in a locked room in the Sportex building and only the PI and the PGR will have access to them. All other data will be electronic and stored in the University's server in password protected files for 10 years according to University guidelines.

Is any of the data of (ethically or commercially) sensitive nature? If so, how do you ensure the data are protected accordingly?

The collected data is sensitive ethically. However, the participants data will be anonymised and files will be password protected. They will not be shared with therapists and any other researchers not involved in data collection or analysis.
An ethical appoval will be optained prior to data collection.

Where will your data be archived in the long term?

It is proposed that the study will end in two years in March 2022. The hard copies of the consent forms will be stored in the academic's office in the University. All other data will be electronic and stored in the University's server in password protected files for 10 years according to University guidelines.

Data sharing

Which data will you share, and under which conditions? How will you make the data available to others?

Only the researchers involved in the study will have access to the anonymised data sets. Permission is being sought from the participants to use their data for secondary analysis during the consenting process.

The clinical collaborators will have periodical summary of the findings in the steering group meetings.

The anonymous data might have to be deposited in public repositories as per the open access guidelines for some journals and decision will be made by the steering group committee regarding this.

The findings of this study will be disseminated through different avenues. This will include publications in related journals, conference presentations, stroke assemblies, social media, institutional reports, summary to participants and relevant charity websites.

Appendix 8: detailed list of search terms

Keywords	MeSH
Stroke OR cerebrovascular accident* OR cerebrovascular disease OR ischemic stroke OR haemorrhagic stroke OR CVA OR Hemiplegia OR Acquired brain injury OR Cerebral Stroke OR Post stroke	("Stroke/nursing"[Mesh] OR "Stroke/physiopathology"[Mesh] OR "Stroke/rehabilitation"[Mesh] OR "Stroke/therapy"[Mesh]) Entry terms: • Strokes • Cerebrovascular Accident • Cerebrovascular Accidents • CVA (Cerebrovascular Accident) • CVAs (Cerebrovascular Accident) • Cerebrovascular Apoplexy • Apoplexy, Cerebrovascular • Vascular Accident, Brain • Brain Vascular Accident • Brain Vascular Accidents • Vascular Accidents, Brain • Cerebrovascular Stroke • Cerebrovascular Strokes • Stroke, Cerebrovascular • Strokes, Cerebrovascular • Apoplexy • Cerebral Stroke • Cerebral Strokes • Stroke, Cerebral • Strokes, Cerebral • Stroke, Acute • Acute Stroke • Acute Strokes • Strokes, Acute • Cerebrovascular Accident, Acute • Acute Cerebrovascular Accident • Acute Cerebrovascular Accidents • Cerebrovascular Accidents, Acute
Rehabilitation OR Therapy OR Physiotherapy OR Physical therapy OR Intervention OR Training OR modification OR Program*	("Stroke Rehabilitation/methods"[Mesh] OR "Stroke Rehabilitation/nursing"[Mesh] OR "Stroke Rehabilitation/psychology"[Mesh] OR "Stroke Rehabilitation/standards"[Mesh] OR "Stroke Rehabilitation/therapeutic use"[Mesh] OR "Stroke

	Rehabilitation/therapy"[Mesh] OR "Stroke Rehabilitation/trends"[Mesh])
Self manage* OR self management OR Management, Self OR self-management OR self efficacy OR self care OR self* OR Self Help OR Self Care	("Self-Management/education"[Mesh] OR "Self-Management/methods"[Mesh] OR "Self-Management/standards"[Mesh] OR "Self-Management/trends"[Mesh]
Patient education OR Health education OR Educ* goal setting OR goal planning OR Therapy planning OR action planning OR Care Planning OR Peer support OR Patient support OR Monitor OR self-monitor* OR self-feedback OR Self-evaluation OR Self-report OR Self-efficacy OR Confidence OR Knowledge OR skills OR Manage OR Coping OR Responsible OR Autonomy	- "Patient Education as Topic"[Mesh] AND "Self Care"[Mesh] - Entry terms for 'goal': Care Planning, Patient Planning, Patient Care Nursing Care Plans Care Plan, Nursing Care Plans, Nursing Nursing Care Plan Plan, Nursing Care Plans, Nursing Care Goals of Care Care Goal Care Goals - "Patient Care Planning"[Mesh] OR "Advance Care Planning"[Mesh] OR "Community Health Planning"[Mesh] - "Life Support Care"[Mesh] OR "Social Support"[Mesh] - "Self-Examination"[Mesh] OR "Self-Evaluation Programs"[Mesh] - "Self Efficacy"[Mesh] OR "Self-Examination"[Mesh] OR "Self-Evaluation Programs"[Mesh] OR "Self Care"[Mesh] OR "Self-Management"[Mesh] OR "Self-Control"[Mesh] OR "Patient Generated Health Data"[Mesh] OR "Personal Autonomy"[Mesh] OR "Self Report"[Mesh]
Exercise* OR Physical Activity OR Physical Exercise OR Exercise training OR Group therapy	Entry Terms for physical activity: - Exercises - Physical Activity - Activities, Physical - Activity, Physical - Physical Activities - Exercise, Physical

	- Exercises, Physical - Physical Exercise - Physical Exercises - Acute Exercise - Acute Exercises - Exercise, Acute - Exercises, Acute - Exercise, Isometric - Exercises, Isometric - Isometric Exercises - Isometric Exercise - Exercise, Aerobic - Aerobic Exercise - Aerobic Exercises - Exercises, Aerobic - Exercise Training - Exercise Trainings - Training, Exercise - Trainings, Exercise
Walking OR functional mobility OR ambulation OR gait training OR mobility OR Gait*	- "Walking"[Mesh] OR "Walking Speed"[Mesh] OR "Mobility Limitation"[Mesh] - "Walking"[Mesh] OR "Dependent Ambulation"[Mesh] OR "Early Ambulation"[Mesh] OR "Mobility Limitation"[Mesh] OR "Gait Disorders, Neurologic"[Mesh] - "Gait"[Mesh] OR "Gait Disorders, Neurologic"[Mesh] OR "Walking Speed"[Mesh]

The following limiters were used:

- Abstract
- Human
- Date Published (January 1992- July 2021)
- English Language

Appendix 9: Codes and themes for the systematic review

Dean et al 2018

	SR's codes	Current themes
Acceptability		
"It is ten weeks, you do it twice a week. Personally for the first say three or four weeks, I'd think well this is getting me nowhere, but then you think that you notice things, things are improving and at the end of ten weeks you want to go for twenty weeks" (4; 119–125).	Gradual improvement over time	Outcomes
"I'd tell them [another stroke survivor] to go ahead and do it and to take it step by step and not to worry about it. Because you are treated with great respect, it was wonderful and they were. I'll never be able to speak highly enough of them." (25; 388–390).	Motivating peers respectful treatment	Theoretical basis Delivery of intervention
Intervention approach		
"It opened my eyes to what can be done you know. How can I put it? It wasn't as if I believed that I couldn't do something it was being pointed in the right direction…heh I can do it……Great you've done it, you did it and you do it again. Yeah it was great" (4; 358–361).	Motivation and direction	Theoretical basis
"It wasn't easy at first, but I used to manage it" (5; 246).	Persistence	Theoretical basis
"It was the way they addressed how you do your exercises. What it is doing to you and all the rest of it. Now to me that was absolutely important, because it made sense of why you are doing all this pumping up and down, and if you can't do that, do this" (22; 252–255).	Knowledge of exercise	Delivery of intervention
"It was you felt as if you were a human being with them. You know and you were treated with respect…and although you couldn't do things and you felt a bit of an idiot, they never let you feel like that" (25; 567–572).	respectful treatment positive support	Delivery of intervention Delivery of intervention
"It's a bit like playing scales…it's not creative but as I gradually realise it, it could potentially be creative…doing something that I had been doing without thinking before and now couldn't. …Now and again I walk without my stick without realising it, that's creative I think" (6; 354–392).	gradual improvement	Outcomes
Impact of programme: psychologically		
"I suppose it is attitude of mind as much as anything. I mean I felt I'd gone through that stage of training and that I was going to get better. It built my spirit up…I felt as if it, well it was worth the three months you know and at the end of the day I hope I'm going to get back to something like normal" (16; 358–365).	Belief of recovery gaining hope	Outcomes

"It really helped me mentally, you know I thought right I can do this because before I was going into my shell, thinking I can't do this and I can't do that. Oh I am not going out. Then I went on that [ReTrain] and it gave me an element of confidence" (43; 562–565).	confidence	Outcomes
Impact of programme: physically "You started to notice they are actually starting to fall into place. I don't remember doing that last time. But I am doing it now great get on with it I am doing it faster now" (4; 189–190).	Improvement in speed	Outcomes
"I know if I went down which I did one day in the hall in the early stages of coming back home and I did manage to get up and walk upstairs…but I wouldn't have been able to do that had I not had that [training]" (16; 475–477).	knowledge of fall	Outcomes
Homework adherence "Trainers were always on about doings exercises at home…I could never pin him down to how long that should be for though" (6; 624).	uncertainity of dosage	Delivery of intervention
Programme technique adherence "I think that was the big thing you saw the benefits after the second, well the first or second session we had.' 'Oh we can do."	Belief of recovery	Outcomes

Portz et al 2018

We identified three major themes; these are positive change, no change and continued exercise. Overall the participant's responses were fairly positive, and few statements indicated negative experiences related to physical fitness or activity. The themes and supporting quotations are outlined below.	brriers and facilitators (factors affecting SM based training)	NEW THEME: Barriers and facilitators
Positive change Participants expressed positive change regarding both physical fitness and physical activity. Under the category of physical fitness, improvements were noted in multiple areas:		

endurance "I definitely have more endurance"; strength "I think I'm stronger"; gait speed "Something is letting me walk —more relaxed, confident, something"; flexibility"It's definitely made me more flexible"; and balance"I think I feel more balanced."

positive change in mobility as a physical fitness (improvement in speed, balance, and endurance) — Outcomes

In general, participants expressed improvements in all areas of physical fitness.

Positive changes were also seen for the category of physical activity. Participants reported improvement in walking, both ability and duration.

Positive chane in walking as a PA (improvement in walking ability and duration) — Outcomes

For example one participant said, "I think I can walk easier and go farther now." There was also an increase in movement as suggested by the comment,

"I had a lot of positive physical changes that gave me confidence to keep coming here."

positive change that improve confident (SE) — Outcomes

Lastly, participants viewed their ability to engage in yoga as a positive change. As such, several participants made statements such as, "I thought the yoga was

fantastic. I mean, I've taken yoga before but I didn't realize how helpful it was." Participants were very enthusiastic about yoga and experiences. Additionally, we found that when asked by the interviewer if there was improvement or change some participants agreed affirmatively with "yes" responses.

Yoga as a helpful training in addition to SM — outcomes

gradual improvement — Outcome

No change

While seven of participants found that they had benefitted from positive changes, there were some participants that reported experiencing no change in physical fitness or physical activity. Some of their statements regarding a lack of change

lack of improvement — Outcome

included: "Oh, I don't know. I feel about the same, really," "As far as I'm concerned, about the same," and "No. No change." Participants reported that it was difficult to recognize changes in themselves, stating, "I can't see it in here. I can't see it helping me. Maybe it did. But I can't see it."

Difficulty recognising change — Challenges

Continued exercise

Participants expressed a desire to either continue at their current level or increase their exercise, one participant said, "I was doing three times a week, and I need to make it four or five times." There was also an interest in both increased walking and continuing with yoga poses learned in the class. One participant stated, "It's made me want to set up a walking routine," while another indicated, "I love yoga. . .I will continue to do with certain poses." Participants also expressed an increase appreciation and understanding the benefits of exercise; as a participant stated "Well, as you do the exercises, you know that the whole body works together and you have a new appreciation of what each and every exercise helps you accomplish, and it's all important."

Persistance and desirability to continue exercising — Outcomes

increased knwoledge — Outcomes

White et al 2013

Loss of roles post stroke

All participants reported experiencing role loss and lifestyle change as a result of the impact of residual physical, cognitive or communicative impairments from their stroke. Participants stated they were unable to resume everyday tasks and previously

enjoyed activities, for example walking and golf. The inability to return to work and driving were significant areas of expressions of loss.

"I'm home bound and I can't drive yet." (Participant 3, male, 76)

"I stopped working; I had a good job, good income. That's all gone and I had to learn how to walk, talk, and breathe." (Participant 4, male, 60)

All participants spoke of how their symptoms were experienced on a continuum of lesser to greater role restrictions and loss. Greater experiences of loss were closely linked with a cycle of inactivity and frustration. This was evident in participants' expressions of frustration regarding the experience of restriction.

"I mean I just get frustrated. I can't do things I used to do and . . . [you] just try to work your way around it." (Participant 2, male, 67)

Feelings of frustration were often attributed to feelings of increased dependency as a result of ongoing residual symptoms. Most participants were required to rely on other people to assist them to maintain involvement in prestroke roles.

" . . . it's like you're a bird having its wings clipped, I mean I'm completely relying on my wife to take [me] to go out . . . " (Participant 3, male, 76)

Participants who took initiative for adapting to their circumstances were able to modify activities to maximise independence and reported feelings of greater control over their circumstances. For many, feelings of control were closely aligned with recovery, increased independence and a gradual

walking as a commonly reported problem post-stroke — walking is an important goal of rehabilitation

the need for walking training post-stroke — walking is an important goal of rehabilitation

SM can help increase independence — Outcomes

feeling of self-management and control highly affected their recovery, level of independence and resuming of their life — outcomes

resumption of the demands of normal life and previously valued life roles.
"The other day I got out of the car and walked to the bank, normally I would have gone with someone pushing me in a wheelchair . . . now I walk it." (Participant 4, male, 60)

Stroke onset/knowledge of risks factors pre stroke

There was evidence in the interviews that most participants lacked knowledge of stroke risk factors, warning signs and "did not even know what a stroke was really" (Participant 6, male, 52). Poor knowledge of stroke was evidenced by the failure of the majority of participants to respond to their stroke symptoms as an emergency. As a result many participants continued to conduct their daily activities and postponed seeking medical attention or depended on family members to instigate contact with the health system.
"During the night I sort of felt a bit funny. I thought it might have been the way I was sleeping, the position of the head. So I went back to bed. I got up in the morning and I still felt something strange . . . ." (Participant 3, male, 76)
However this was not always the case and some participants reported familiarity with education campaigns or had previously read information regarding stroke warning signs and symptoms and thus responded appropriately.
"I had read I don't know if it was in Readers Digest or some magazine, what the symptoms were . . . and in answer I said I think I'm having a stroke. So straight away she [my wife] phoned the hospital." (Participant 8, male, 80)
A concerning finding was the extent to which participants perceived themselves to be in good health and not at risk of

stroke, or recurrent stroke, despite having multiple risk factors such as high blood pressure and diabetes and other significant comorbidities, such as heart disease. With further exploration

the importance of patient education
Lack of knowledge

the need for SM strategies
barrier/challenge

wrong perception
lack of knowledge negatevely affect people

theoritical basis
the need for education

it was apparent that participants were in fact not familiar with modifiable and non modifiable risk factors for stroke and the way in which these could be addressed to improve health.
"I didn't think I was terribly much at risk to be honest . . . I always felt my diet was pretty good and fairly varied . . . but yes, I had high blood pressure." (Participant 8, male, 80)

Benefit of Masterstroke

Knowledge

Most participants reported an increase in their knowledge about stroke, management of risk factors and lifestyle modification as a result of attending the Masterstroke program. The most commonly reported knowledge gains pertained to diet and making wiser food choices such as, "how to recognise what was good for you" (Participant 8, male, 80) through an increased understanding of food labels, nutritional value and dietary intake.
" . . . .just the things you learn about diet and all stuff like that was incredible" (Participant 6, male, 52)

Exercise

The incorporation of an exercise component into the program was highly valued by all participants. As a result participants reported improvements in regards to their levels of personal exercise as a result of Masterstroke. In particular, participants reported increased strength, endurance and exercise tolerance.
"I think I'm actually stronger now in the top half [of my body] than I was before I had the stroke." (Participant 6, male, 52)
The impact of regular exercise meant that many were now

Knowledge helps to adapt new life — Outcomes

SM increased participants capability for mangement of life — outcomes

incorporation of SM into exercise programmes is highly valued by stroke survivors — outcomes

increased level of exercise (strength, endurance, and tolerance) — outcomes

able to complete exercises and activities of daily living that they could not initially complete post stroke.
"I'm definitely stronger in the legs, I get up and down [off a chair] a lot easier . . . without increasing leg strength I wouldn't have been able to do that and also it helps with the stamina cause I did tend to get out of breath very quickly." (Participant 4, male, 60)

However the amount of exercise undertaken by participants varied considerably depending on severity of impairments and exercise tolerance. For example some participants

had impaired mobility and balance as a result of their stroke

which impacted participation in contrast to other participants with milder impairments who were able to more fully participate.

uncertainity of dosage/the dosage is varied and there is no one ideal exercise programme

delivery of intervention

people with impaired mobility are less participating

walking is an important goal of rehabilitation

Group benefits

Participation in Masterstroke also provided an opportunity for increased socialisation among participants; sharing the common experience of stroke meant that participants felt less isolated. Overall, participants reported that being in a group with others in a similar situation was also an optimal way to find out how others have managed to negotiate life after stroke.
"Being with other people that have had similar incidents was good to talk to them and find out how they've managed." (Participant 4, male, 60)
In addition, participants were able to empathise with each other and gain encouragement and motivation from seeing

increased socialisation

outcomes

working in groups is more benificial

brriers and facilitators

Motivation and encouragement (by other survivors and by health professionals)

theoritical basis

improvements in other group members over the course of Masterstroke.

"What was good is you got to know them and know that you're not alone." (Participant 3, male, 76)

"One of them there, his walking from the first day to the last day improved 100%." (Participant 2, male, 67)

walking improvement — outcome

There was a common experience of participants benefiting from the opportunity to compare themselves with other participants in terms of stroke symptoms and severity of impairments. As a result, participants were able to appreciate their own circumstances and their personal progress.

"Well one of the things that really hit me was how bad a lot of younger people were and how lucky I'd been in comparison. That really hit me." (Participant 8, male, 80)

Participants also reported that constant encouragement by the health professionals was advantageous and a source of motivation to improve and be "pushed." (Participant 2, male, 67).

self-appreciation — outcomes

Motivation to modify lifestyle

A major benefit of Masterstroke reported by participants was the opportunity to make lifestyle changes and improve one's physical health. Following the initial onset of stroke, participants expressed feelings of fear that they would experience a subsequent stroke. Participants reported a desire to make lifestyle modifications in order to manage risk factors and reduce their risk of secondary stroke. Feelings of fear were a key motivator for attending Masterstroke and for making lifestyle changes to reduce risk factors for stroke. As a result many participants reported that making changes to their lifestyles was in fact not difficult considering their "life was involved" (Participant 6, male, 52).

SM increased participants capability for mangement of life — outcomes

reduced risk of secondary stroke — outcome

"I don't want to have another stroke anytime soon so I'm gonna do the darn best I can to make sure I don't." (Participant 8, male, 80)
However some participants were not highly motivated to make lifestyle changes and were more dependent on external sources for motivation. In particular there was an expressed benefit towards attending Masterstroke as a source of motivation.
"I committed myself to go there, so once I got there I got stuck into it." (Participant 8, male, 80)

Goal setting

Goal setting was central to the Masterstroke program and participants reported that this provided a means to learn how to set measurable and achievable goals for the duration of Masterstroke. Most participants expressed a common goal towards making physical gains, such as walking better and increasing endurance, which in turn impacted on functional abilities.
"Well I had a goal to try and start walking without the stick so the program was basically set-up to help me build up certain muscle groups in the leg, hip and knee." (Participant 4, male, 60)
Despite the benefit of goal setting the majority of participants stated that they had not achieved all of the goals that they identified as the commencement of Masterstroke which resulted in concerns for the future. However overall, participants were motivated to achieve their goals and reported that Masterstroke was seen as a stepping stone towards improved outcomes.
"I think I'm on my way to it, I wouldn't say I've achieved it because I don't think [I have] . . . I think you've got to keep working at it."

Goal setting is central for SM — theoritical basis

walking as a common goal — walking is an important goal of rehabilitation as it affect participation

not all goals achieved — challenges

SM leads to improved outcomes — outcomes

(Participant 2, male, 67)

Lifestyle modification post Masterstroke

Interviews explored ongoing implementation of knowledge and lifestyle modification. Some participants reported persisting

low motivation as a barrier to lifestyle modification

specifically with regards to maintenance of a regular exercise regime. This was closely linked to no longer having a formal routine which promoted accountability.

"I just wasn't feeling motivated . . . it's just so easy on your own [because you say] 'yeah I'll do it tomorrow'." (Participant 8, male, 80)

However, some participants had decided to continue attending the same gym where Masterstroke was held.

Participants reported motivation was facilitated by having

familiarity with the staff and the gym setting.

"I'm not exercising much at all at home but I'm trying to get back into the program they run up there at John Hunter Hospital and going up there once or twice a week." (Participant 2, male, 67)

Participants who reported having a tolerance of exercise

and a regular exercise routine prior to Masterstroke were more likely to continue with exercise than those who had no previous exercise tolerance. This was heightened in individuals who had the support of others to achieve this, routines such as a daily walks with their partners or use of home gym equipment.

"We've got a little home gym here so I keep the exercises up most

motivated people can do better with SM	brriers and facilitators (factors affecting SM based training)
social support increases motivation	brriers and facilitators (factors affecting SM based training)
previous level of exercise make a difference	facilitators

morning. I'm doing the cross trainer for half an hour and then I do weights...I've been trying to pick up some muscle tone again." (Participant 7, female, 64)

For other participants the experience of comorbidities was an additional barrier to ongoing exercise due to conditions such as lower back pain.

"Well I'm motivated but I'm usually de-motivated by the [back] pain." (Participant 5, male, 81)

Participants reported that education about diet and nutrition was major benefits of Masterstroke which led to positive modifications to diet and "keeping my weight down" (Participant 2, male, 67). Participants stated they had increased the amount of salad and vegetables consumed and paid more attention to lowering levels of salt, sugar and fat content within their diets in order to make healthy modifications.

"I pay much more attention to you know, salt content and sugar content and things like this." (Participant, 8, male, 80)

Comorbidities might be a barrier to PA — barriers

education is essential for SM — the need for SM strategies

SM leads to positive change — outcomes

DePaul et al 2019

Patient perceptions

All patients (10/10) reported that the program helped them practice more walking, and helped them achieve their walking goals. Six of 10 indicated that the IMPACT program was easy to complete. Every participant was able to identify one goal, although this some- times took more than one session or needed adjustment over the 2 weeks. One participant indicated that they had difficulty completing the program due to fatigue and pain,

two other participants indicated difficulty completing their program due to lack of available supervision. A number of participants reported asking nurses and other non-therapy staff to supervise them as they walked rather than accepting a ride in the wheelchair to the bathroom, or common dining room. While all 10 participants felt that they could complete the program on their own, the two participants who identified difficulties due to a lack of supervision also reported as a barrier to completion that the therapist and other

SM helps patients to improve walking and to attain their walking goals — Outcomes

the need for therapist support is required in some cases — challenges

team members were concerned for their safety, indicating an apparent difference between perceived safety by patients and the team.

they also indicated that they would continue to practice walking-related activities beyond the coaching period.	desirability to continue exercising	Outcomes
Therapist perceptions Despite participating in a period of self-study (reading manual and supporting literature) and 4h of face-to-face training, the IMPACT Therapist reported an initial lack of self-confidence in their ability to apply the IMPACT training approach in a post-study interview; particularly the shift from prescription of exercises to engaging patients in development of their own practice plan. They reported feeling comfortable and confident in the role of coach after the 3rd participant. The IMPACT Therapist found it particularly challenging to help lower functioning patients identify walking-related tasks that they could complete without therapist supervision. They reported that over the course of the study, they learned to engage families or informal caregivers from the first visits, which helped facilitate their involvement in patient practice activities and allowed more depend- ent patients to complete more challenging walking-related activities outside of therapy sessions.	Lower functioning can be a barrier for SM	Barriers

Huijbregts et al., 2009

Perceived Programme Benefits In general, participants' expectations about the programme were met; the main exceptions were the participants with stroke who were hoping for a more individualized exercise programme that would meet more personal needs, as reflected in the following comments: I thought that the exercise program was going to be a little bit more extensive, . . . I pulled through it [the stroke] a lot better than some other people, so I could have maybe did a little more rigorous exercise. (T-MOST Participant with Stroke #7) For myself, I think I was doing a light workout with this group. I was holding back. (WLC Participant with Stroke #2)	individualised therapy leads to better outcomes	Outcomes
Both participants with stroke and their care partners described numerous benefits of the MOST programme. The most commonly discussed benefits were information sharing, participation in exercise, increased motivation and determination, a sense of comfort from the realiza- tion that they were not "on their own," understanding the needs of their care partners, a sense of making a con- tribution to the community by helping others, and a decreased sense of isolation through peer support received from the group, either in person or via videoconferencing:	preceived benefits	outcomes

I thought it was a very interesting program, because when I got out of the hospital, you hadn't had a chance to really meet a whole lot of stroke survivors and talk to them: what's in common, what isn't, what's been affected by their stroke, and what's been affected by your own stroke; to pass on the information to them, and receive some information from them. So far as I'm concerned, it's a very good program, and if it stretches out into the area, talking to you on the TV was like you being here. (T-MOST Participant with Stroke #3)

social support increases motivation — facilitators

Some care partners reported that the participants with stroke appeared to gain insight and self-awareness and that they became more aware of the needs of care partners:

I sensed when he came back, there was a lot of, Think about how you behave this week, and how did you behave last week. And his growth of insight into his abilities and what he could do, and what he had to work on grew from this course, and this was a wonderful thing for us. I think knowing what you can do, and the effort to try to do something extra, it's a real balance to do this, and safely. This program did help us this way. It helped us be able to talk about it. (T-MOST Caregiver #7)

I do find he's a little bit easier to live with since he's been coming here, and he realizes that he's not the only one in the world that's had a stroke. (WLC Caregiver #1)

inreased awarness about new life — outcomes

Process Findings: Attendance and Feasibility of Videoconference Delivery

During the focus groups, programme participants commented on the videoconferencing aspect of the programme. Participants reported that by allowing the Toronto-based MOST programme to be delivered in Thunder Bay, the videoconferencing decreased their sense of isolation and allowed for sharing of information across a large geographical distance: Because we're away from the Greater Toronto Area, we appreciate anything like that … it is a wonderful thing, because people are isolated out here. It's one of our greatest problems, is isolation. (T-MOST Caregiver #7)

preceived benefits — Outcomes

Participants also provided ideas for expanding the videoconferencing aspect of the programme and suggested that videoconferencing could also be used to include other participants with stroke who live in more remote areas, and not only to connect a remote facilitator:

videoconferencing can help delivery of SM and other aspects of rehabilitation to remote areas — facilitators

It's a very good program and if it stretches out into the area, talking to you on the TV was like you being here . . . If you can put care out . . . to the district, and hook up with a whole bunch of these smaller places that don't have ten stroke victims in one day, and only have a few of them in a couple of months, and you can hook up with these people so they don't have to travel. And as you know, in Northern Ontario, we travel miles and miles to get anywhere. And for the people coming in from the north, it's a much more convenient for them

just to get it by TV instead of them packing up, coming here—some people just can't do it after a stroke. (T-MOST Participant with Stroke #3)

Appendix 10: GRADE Table for the systematic review

Certainty assessment							Impact	Certainty	Importance
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations			
Walking Speed (assessed with: 10-Meter Walking Test)									
9	4 RCTS and 5 Observational	serious [b]	serious [c]	not serious	not serious	publication bias strongly suspected [b]	- There was a significant improvement in the intervention groups in 3 studies - Other studies had some trends towards improvement in the intervention groups but were not statistically significant - No significant changes between groups were reported in any study	⨁◯◯◯ VERY LOW	CRITICAL
Physical activity (assessed with: number of steps per day)									
8	1 RCT and 7 observational	serious [e]	very serious [f]	not serious	serious [g]	publication bias strongly suspected [b]	- The number of steps per day has improved significantly in the intervention groups in 2 studies and reduced in the control group in one study - One study wasn't powered enough to detect any change - Other studies had no significant change	⨁◯◯◯ VERY LOW	CRITICAL
Endurance (assessed with: 6 Minutes Walking Test)									
10	4 RCTs and 6 Observational	serious [b]	serious [c]	not serious	serious [e]	none	- Statistically increased in the intervention groups in 6 studies and in the control group in one of them - A moderate effect size was found in one of the studies - One study had insufficient participants to reach statistical significance - Two studies had no significant change between the 2 arms of the study - There was a qualitative evidence to support the positive effect	⨁◯◯◯ VERY LOW	CRITICAL
Balance, gait speed, and mobility (assessed with: Timed Up and Go)									
8	5 RCTs and 3 Observational	serious [g]	serious [c]	not serious	serious [f,g]	none	- 5 studies had significant improvement - One study was not powered enough to detect the change - 2 studies had no significant difference between groups - There was a qualitative evidence to support the positive effect	⨁◯◯◯ VERY LOW	CRITICAL
Mobility (assessed with: Rivermead Mobility Index)									
4	randomised trials	not serious	not serious	not serious	serious [g]	none	- No significant changes were reported - Sample size was relatively small across studies	⨁⨁⨁◯ MODERATE	CRITICAL
Functional Mobility (assessed with: Stroke Impact Scale - Mobility Domain)									
2	randomised trials	serious [j]	not serious	not serious	serious [g]	none	- No significant time x group interaction effect was found in both studies	⨁⨁◯◯ LOW	CRITICAL
Self efficacy									
10	5 RCTs and 5 Observational	serious [b]	serious [c,f]	not serious	serious [e]	none	- Different measurements were used - 3 studies had significant improvement in the intervention groups - There is a qualitative evidence from 2 studies to support the positive effect	⨁◯◯◯ VERY LOW	
Quality of Life									

Certainty assessment							Impact	Certainty	Importance
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations			
11	observational studies [l]	serious [b]	serious [c]	not serious	serious [e,f]	none	- Different measurements were used - Significant improvements in the intervention groups in 5 studies - Moderate effect size for change in SIS in one study - Other studies showed some trends toward improvement but were not statistically significant	⨁◯◯◯ VERY LOW	

CI: Confidence interval; **MD:** Mean difference

Explanations

b. due to study designs
c. the effect of intervention was inconsistent across all studies
d. 1 RCT
e. due to study designs and sample size
f. due to heterogeneity in participants and intervention characteristics
g. small sample size that can affect the confidence in the effect
j. both had a relatively small sample size and lack of participants blinding
l. 4 RCTs and 7 Observational

Appendix 11: Topics covered in the therapists' interviews.

Experience of delivering services:

a) Can you please tell me about stroke care and rehabilitation delivery services since the first wave of the pandemic?
b) What services did the NHS or other community services provide to the people after stroke?
c) What modified systems were in place at your workplace for people with stroke?

Impact and needs of patients:

a) *What do you think were the problems for people who had a stroke during the pandemic in accessing services?*
b) *What do you think is the impact of the pandemic on rehabilitation services for people with stroke?*
c) *How do you think this might affect them in terms of their mobility and recovery in the long-term?*
d) *From a therapist's perspective, please can you tell me about the patients' needs during this pandemic in terms of rehabilitation?*

Management strategies:

a) *What were the strategies used to manage access to services?*
b) *What were the strategies that have been used to deliver rehabilitation for patients during the pandemic?*
c) *Any examples of good practice used?*
d) Was there any efforts to introduce self-management programmes to the patients for their recovery? Were any specific efforts taken to improve their mobility? Did the patients benefit and how?

Outlook:

a) *When the health services start to reopen what do you consider as priorities for stroke services?*
b) *What can the healthcare system do to ensure optimal services in the future waves of the pandemic in delivering care and rehabilitation?*
c) *What can the healthcare system do to ensure optimal services for people in isolation?*

Appendix 12: Topics covered in the stroke survivors' interviews.

Experience of stroke:

a) Please tell me about your experience of having a stroke
b) Please tell me how the stroke has affected you and your daily activities.
c) What do you think were the main challenges that you experienced as a result of the pandemic in accessing services?
d. How did the stroke affect you in terms of your mobility?

Care received:

a) Tell me about the care provided by the NHS or other community services after the stroke.
b) What do you think was the impact of the pandemic on your care and rehabilitation services?
c) Tell me about the things or people that you feel were helpful to manage your situation?

Needs and goals:

a) Can you tell me about your needs during this period in term of healthcare and rehabilitation services? Which of your needs were not fulfilled?
b) What is your main goal for rehabilitation?

Management:

a) Did the healthcare professionals teach you any strategies (to self-manage) that you could use or build on, for your recovery at home after stroke?
b) Apart from the self-management strategies that professionals taught you, please tell me what else have you been doing to manage your situation since the onset of your stroke? Were any specific efforts taken to improve your mobility?
c) More specifically, what have you been doing either on your own (self-management) or with the help of others to achieve your rehabilitation goal?
d) Were the self-management strategies useful for you and in what way?

Future care:

a) When the health services start to reopen what do you think are your priorities for your rehabilitation?
b) How can we ensure services are tailored to people affected by stroke in the future waves of the pandemic or when you have to isolate?

Appendix 13: Information sheet for patient participants

UNIVERSITY OF BIRMINGHAM

Study Information Sheet for participants (Patients)- Version 3

Study title: Exploring the experiences, of people who had a stroke and views of therapists who managed people with stroke during the Covid-19 pandemic: A qualitative exploratory study.

Please read the following material and decide if you would like to participate. You can discuss the information with others and the researcher involved before you agree to take part in the study. We thank you in advance for the time and effort spent on considering participation in this study.

Why are we doing this study?

Stroke is a major cause of disability worldwide. Prior to the pandemic approximately 110,000 people were reported to have a stroke each year in the UK (Stroke Association 2018). Since the start of the Covid-19 pandemic several studies indicated that number of people admitted due to stroke was markedly reduced. The impact of the covid pandemic on the care of stroke patients in terms of their rehabilitation and recovery is still not known. It is important to understand factors that influenced peoples' experience of having a stroke, hospitalisation and rehabilitation during the pandemic.

When the health services start to reopen there will be a need for rehabilitation for patients with various conditions including stroke as a major illness. There are calls to identify what patients missed during the pandemic and their priorities to ensure services are tailored in the future waves of the pandemic. There is a need to be proactive and identify what patients' rehabilitation needs are, to be prepared for the reopening of rehabilitation services.

This study aims to gain insight into stroke patients' and therapists' experiences, needs and rehabilitation priorities after their first stroke during the pandemic.

Who is doing the study?

This is a project done by researchers from School of Sport, Exercise and Rehabilitation Sciences at the University of Birmingham. University of Birmingham is the sponsor for this study. Dr. Sheeba Rosewilliam is a lecturer and physiotherapist registered with the Health and Care Professions Council who teaches at the University of Birmingham and is carrying out this work with Dr. Andrew Soundy and Mr. Ahmad Sahely as part of his PhD program.

Are you eligible to join the study?

If you had a stroke anytime since March 2020, if you are able to communicate to a reasonable extent (not having severe aphasia) via phone or using internet meeting apps such as zoom or skype, have the mental capacity to give informed consent which will be screened using a simple measure, if you are willing to share your experience of your care and rehabilitation following your stroke please consider participation in this study.

What happens if you decide to participate?

If you decide to participate in the study, you will be given an opportunity to ask questions/ clarifications about the study. Once your questions have been clarified, the simple measure to assess mental capacity will be carried out. If you meet the eligibility criteria set out above, you will be asked to sign a consent form to participate in the study through email. If you feel uncomfortable to sign and scan the consent documents, the consent forms will be mailed to you by post. In case you find it difficult to sign the consent, there are two ways to collect the consent; you can ask somebody to sign it on your behalf or you can consent verbally before the interview.

You will be asked to arrange for a time for an interview that will last approximately 45-60 minutes. You will have the choice to do the interview online Via Zoom or Skype or on the phone. Before the interview, the researcher will collect some information about your type of stroke, age, gender, time since stroke, functional ability and quality of life after stroke using questionnaires. Please note that there will be some personal questions/tests about ability to function/daily life post-stroke which may be upsetting or slightly difficult to answer; perhaps a carer or relative can help you to answer. The questionnaires will be administered in a video call with the researcher and one of the tests will require a pen and a piece of paper. These tests using questionnaires will be done to assess the status of your ability to do function, mental capacity and social functioning following your stroke. You can ask the researcher to know your scores for these assessments if you wish to. During the interview, we will ask you about your experience and thoughts regarding:

- Experience of having a stroke during the pandemic
- Experience of accessing health services.
- Care and therapy after stroke
- Your needs for rehabilitation when services re-open.
- Strategies you suggest to manage access and delivery during another wave of the pandemic or during isolation.

Please note that you have the right to stop your participation or have a break at any time during the interview. You also have two weeks after your interview to withdraw from the study and in this case your information will be removed and not included for data analysis. After 2 weeks of your interview, you cannot withdraw your data and you will receive a shopping vouchers (£20.00 per person) as a reimbursement for your time. You will not get the £20 voucher if you withdraw from the study.

The interview will be digitally recorded in a secure recorder and transcribed into written text by a transcription service on the UoB recommended list (with confidentiality clauses). All your data will be made anonymous and stored securely in the university's secure servers.

How will we use information from you?

Data will be handled securely and in line with the data protection act (2018). The consent forms will have your name and contact details. The data will be stored safely in secure servers at the University of Birmingham. All information from the interviews and questionnaires will be made anonymous and stored securely in password-protected computers. All personal data will be made anonymous using codes. Data will not be shared with any person other than those involved in the project. Reports for the University and published data will not include your personal details. If direct quotes are published from the group discussion, the researcher will ensure that you cannot be identified from the data that is published. Your service providers will also be anonymised in the write up. Please note that the anonymous data will be securely stored for 10 years at the University and contact details will be stored for 3 years. After this time the data will be destroyed or deleted.

Where can you find out more about how your information is used?

You can find out more about how we use your information by asking one of the research team listed below

- by sending an email to [redacted] Mr. Ahmad Sahely, or [redacted] Dr. Sheeba Rosewilliam or
- dataprotection@contacts.bham.ac.uk
  - by ringing us on [redacted].

Why should I participate in the study?

Your contribution to this study is highly valued as it could help identifying and discussing patients' needs and problems that have been affected by the restricted services during the pandemic period. When the health

services start to reopen there will be huge demand for rehabilitation for various conditions of which stroke will be a major illness. With the knowledge that you share with us through the interview, we hope to further refine the processes and improve the quality of care delivered for future patients with stroke.

Are there any risks?

The are no major risks involved in participating in these interviews. There might be a slight risk of you, remembering your stroke and getting upset about it. The interviews will be stopped if you're upset and then we can resume at a later point when you feel better. Please note that the presence of a carer or a family member during the interview is optional if you want and if you feel more comfortable. You can also speak to the senior researcher (Dr. Sheeba Rosewilliam) who will reassure you. Further help for psychological support can be gained from:

1. Stroke association at https://www.stroke.org.uk/AZw OR stroke helpline at: https://www.stroke.org.uk/ncZ OR call 0303 3033 100
2. You can call the Samaritans on 116 123 to talk to someone, and you can also email them at jo@samaritans.org.
3. The Silver Line for Information, friendship and advice to older people. Tel: 0800 470 80 90
4. You can make an appointment through the practice to speak to your GP about mental health and wellbeing problems.

In case you have any concerns about the conduct of your interview, you will be referred to Dr. Rosewilliam who is the chief investigator for this study for further help. Regardless of this, if you wish to complain, or if you have any concerns about any aspect of the way you have been approached or treated during the study, please write to the research governance email address given below.

What happens at the end of the study?

At the end of the study, the findings will be written up. These findings will then be published in health journals and presented at conferences. The findings will also be disseminated in the local NHS trusts in the form of presentations and posters. If you would like to know the findings of the study please feel free to contact the researchers involved and copies of reports will be sent to you. Anonymous data from this study will be used to support other similar research in the field of rehabilitation.

Thank you

Thank you for taking time to read the information sheet and considering participation in the study.

Contacts

1. **Dr. Sheeba B Rosewilliam**, School of Sport, Exercise, and Rehabilitation sciences, University of Birmingham, B15 2TT. Email: , (Sheeba Rosewilliam)Tel:
2. **Dr. Andrew Soundy,** School of Sport, Exercise, and Rehabilitation sciences, University of Birmingham, B15 2TT. Email: , (Andy Soundy) Tel:
3. **Mr. Ahmad Sahely**, School of Sport, Exercise, and Rehabilitation sciences, University of Birmingham, B15 2TT. Email: , (Ahmad Sahely) Tel:
4. Research Governance , University of Birmingham, email: ADM-researchgov@adf.bham.ac.uk

Appendix 14: Information sheet for therapist participants

UNIVERSITY OF BIRMINGHAM

Study Information Sheet for Participants (Therapists)- Version 3

Study title: Exploring the experiences of people who had a stroke and therapists who managed people with stroke during the Covid-19 pandemic: A qualitative exploratory study.

Please read the following material and decide if you would like to participate. You can discuss the information with others and the researcher involved before you agree to take part in the study. We thank you in advance for the time and effort spent on considering your participation in this study.

Why are we doing this study?

Stroke is a major cause of disability worldwide. Prior to the pandemic approximately 110,000 people were reported to have a stroke each year in the UK (Stroke Association 2018). Since the start of the covid pandemic several studies indicated that number of people admitted due to stroke was markedly reduced. Fear of covid infections, lockdown isolation, advice from doctors and media to stay home could have reduced peoples' willingness to seek prompt medical help. This situation could have been worsened by the reallocation of stroke beds and reallocation of staff and resources to covid pandemic potentially affecting rehabilitation. The impact of the covid pandemic on the care of stroke patients in terms of their rehabilitation and recovery is still not known.

When the health services start to reopen there will be a need for rehabilitation for patients with various conditions including stroke as a major illness. There

are calls to identify what patients missed during the pandemic and their priorities to ensure services are tailored in the future waves of the pandemic. There is a need to be proactive and identify what patients' rehabilitation missed needs are, to be prepared for the huge deluge for rehabilitation.
This study aims to gain insight into stroke patients' and therapists' experiences, needs and rehabilitation priorities after their first stroke during the pandemic.

Who is doing the study?

This is a project done by researchers from School of Sport, Exercise and Rehabilitation Sciences at the University of Birmingham. University of Birmingham is the sponsor for this study. Dr. Sheeba Rosewilliam is a lecturer and physiotherapist registered with the Health and Care Professions Council who teaches at the University of Birmingham and is carrying out this work with Dr. Andrew Soundy and Mr. Ahmad Sahely as a part of his PhD program.

Are you eligible to join the study?

Therapists who have had to manage stroke patients during the ongoing pandemic, working in the NHS or private practice and at the level of band 5 to band 9 are eligible to participate in this study.

What happens if you decide to participate?

If you decide to participate in the study, you will be asked to sign a consent form electronically. You will be asked to arrange for a time and place for an interview that will last approximately for an hour. You will have the choice to do the interview online Via Zoom or Skype or phone. During the interview, we will ask you about your experience with the management of post stroke rehabilitation during the pandemic period and patients' needs/problems for rehabilitation during the lockdown and when services reopen. We also would like to get your perspectives on identifying strategies to manage access and delivery during another wave of the pandemic or during isolation. The interview will be guided by questions about these themes and probing questions will be added while the interview wis going on. Please note that you have the right to stop your participation at any time during the interview. You also have two weeks after your interview to withdraw from the study and in this case your information will be erased and not included for data analysis. After 2 weeks of your interview, you will receive a shopping vouchers (£20.00per person) as a reimbursement for your time. If you decide to withdraw your data within two weeks of data collection then the vouchers will not be sent to you.
The interview will be digitally recorded in a secure recorder and transcribed into written text by the transcription service on the UoB recommended list

(with confidentiality clauses). All your data will be made anonymous and stored securely in the university's secure servers.

How will we use information from you?

Data will be handled securely and in line with the data protection act (2018). The consent forms will have your name and contact details. These will be stored safely in secure servers at the University of Birmingham. All information from the interviews and questionnaires will be made anonymous and stored securely in password-protected computers. All personal data will be made anonymous using codes. Data will not be shared with any person other than those involved in the project. Reports for the University and published data will not include your personal details. If direct quotes are published from the interviews, the researcher will ensure that you cannot be identified from the data that is published. The service providers/employers will also be anonymised in the write up.

Please note that the anonymous data will be securely stored for 10 years at the University and contact details will be stored for 3 years. After this time the data will be destroyed or deleted.

Where can you find out more about how your information is used?

You can find out more about how we use your information by asking one of the research team listed below

- by sending an email to [redacted] Mr. Ahmad Sahely, or [redacted] Dr. Sheeba Rosewilliam or
- dataprotection@contacts.bham.ac.uk
- by ringing us on [redacted].

Why should I participate in the study?

Your contribution to this study is highly valued as it could help identifying and discussing patients' needs and problems that have been affected by the restricted services during the pandemic period. When the health services start to reopen there will be huge demand for rehabilitation for various conditions in the elderly of which stroke will be a major illness. With the knowledge that you share with us through the interview, we hope to identify strategies to refine the processes and improve the quality of care delivered for future patients with stroke.

Are there any risks?

The are no risks involved in participating in these interviews. In case you have any concerns about the conduct of your interview, you will be referred to Dr. Sheeba Rosewilliam who is the chief investigator for this study for further help. Regardless of this, if you wish to complain, or if you have any concerns about

any aspect of the way you have been approached or treated during the study, please write to the research governance email address given below.

What happens at the end of the study?

At the end of the study, the findings will be written up. These findings will then be published in health journals and presented at conferences. The findings will also be disseminated in the local NHS trusts in the form of presentations and posters. If you would like to know the findings of the study, please feel free to contact the researchers involved and copies of reports will be sent to you. Anonymous data from this study will be used to support other similar research in the field of rehabilitation.

Thank you

Thank you for taking time to read the information sheet and considering participation in the study.

Contacts

Dr. Sheeba B Rosewilliam, School of Sport, Exercise, and Rehabilitation sciences, University of Birmingham, B15 2TT. Email: , (Sheeba Rosewilliam) Tel:
Dr. Andrew Soundy, School of Sport, Exercise, and Rehabilitation sciences, University of Birmingham, B15 2TT. Email: , (Andy Soundy) Tel:
Mr. Ahmad Sahely, School of Sport, Exercise, and Rehabilitation sciences, University of Birmingham, B15 2TT. Email: , (Ahmad Sahely) Tel:
Research Governance , University of Birmingham, email: ADM-researchgov@adf.bham.ac.uk

Appendix 15: Consent form for patients

UNIVERSITY OF BIRMINGHAM

School of Sport, Exercise, and Rehabilitation Sciences

CONSENT FORM FOR PATIENTS PARTICIPANTS

Study title: Title: Exploring the experiences of people who had a stroke and therapists who managed people with stroke during the Covid-19 pandemic: A qualitative exploratory study.

(Please tick either yes or no) (Please initial box)

1. I confirm that I have read the study information sheet dated: 20/8/2021 Version 3.
2. ☐ I confirm that I understand the above information sheet about the study.
3. ☐ I confirm that I have had the opportunity to ask questions about this study and all my questions have been satisfactorily answered.
4. I understand that **my participation is voluntary** and that I am **free to withdraw at any time**, **without giving any reason**, without my medical care or legal rights being affected or compromised in any way. I am under no obligation to partake in the study. (I understand that if I withdraw from the study, before the data analysis (after two weeks), my data will be erased. If not, my data will still be used for research purposes, but no further data will be collected from me after my withdrawal from the study).
5. I agree to take part in the individual interview, and I understand that my views will be audio recorded. Yes/No
6. I agree to anonymous quotations from the interview being used for research purposes.
7. I want to see any quotations before they are used. Yes/NO
8. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.
9. I understand that the data collected during the study, may be looked at by individuals from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.
10. I agree to take part in this study.

(Participant's name) *(Participant's signature)*

……

(Date)

Witness/Carer Name: Witness/Carer signature:

(Researcher's
name)
(Researcher's signature)…… (Date)

Appendix 16: Consent form for therapists



School of Sport, Exercise, and Rehabilitation Sciences

CONSENT FORM FOR PATIENTS PARTICIPANTS

Study title: Title: Exploring the experiences of people who had a stroke and therapists who managed people with stroke during the Covid-19 pandemic: A qualitative exploratory study.

☐ (Please tick either yes or no) (Please initial box)

1. I confirm that I have read the study information sheet dated: 20/8/2021 Version 3.
2. ☐ I confirm that I understand the above information sheet about the study.
3. ☐ I confirm that I have had the opportunity to ask questions about this study and all my questions have been satisfactorily answered.
4. I understand that **my participation is voluntary** and that I am **free to withdraw at any time**, **without giving any reason**, without my medical care or legal rights being affected or compromised in any way. I am under no obligation to partake in the study. (I understand that if I withdraw from the study, before the data analysis (after two weeks), my data will be erased. If not, my data will still be used for research purposes, but no further data will be collected from me after my withdrawal from the study).
5. I agree to take part in the individual interview, and I understand that my views will be audio recorded. Yes/No
6. I agree to anonymous quotations from the interview being used for research purposes.
7. I want to see any quotations before they are used. Yes/NO
8. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.
9. I understand that the data collected during the study, may be looked at by individuals from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.
10. I agree to take part in this study.

(Participant's name) *(Participant's signature)*

……

(Date)

Witness/Carer Name: Witness/Carer signature:
(Date)

(Researcher's name) (Researcher's signature)……

(Date)

Appendix 17: Priorities for care identified by participants

Priority (Frequency)	Supporting quote
Inpatient setting	
- Allow family visit and contact time (5)	*"The first one is find a way for family to come, I would say that is definitely a priority." (P5)*
- More interactions between patients and healthcare professionals (1)	*"The ward sister hasn't got time to talk, I never had a conversation with her ever. I would have liked to have known, how am I doing, am I doing well, will I get over this, will I ever walk again, would I be able to look after myself again." (P6) "In reality on the ward, you know, the precautions are there, you're wearing a mask, we didn't really interact as patients that much." (P3)*
- More conversations or information regarding mental health with patients (1)	*"I think they should talk to you more, tell you about what's happening, what the prospects are, what you can do to help your mental health, give you more encouragement." (P6)*
- Allow more time for staff to develop continuous professional development (1)	*"… the extra studying, the time for this study, time for people's well-being, helping people succeed. So put in time for the well-being stuff." (P5)*
- Improve information technology in NHS (2)	*"I had got an iPad but they got no Wi-Fi. Wi-Fi wasn't working so I couldn't use my iPad or watch films. There was no TV in the ward at all. Nothing to pass the time away. I got nothing to do." (P6)*
Inpatient and Community Settings	
- Provide more therapy sessions (3)	*"I hope there would be more OT [Occupation Therapy], I hope there will be more physio. I really like to be in a gym, I'd like to be able to use equipment to do things." (P5)*
Community Setting	
- Receive therapies and treatments in a timely manner (1)	*"I would wish everyone got immediately the treatment I got and immediately all the services." (P1)*
- More follow-up community support, e.g. daily check-in services on phone (3)	*"I think even if just, calling you, check that you are okay, because he [stroke charity representative] might not always ring, and, you know, reach out just to check that you're okay." (P2) "… the biggest need was to have support and to have somebody who work with you on a daily basis." (P4)*
- More support from independent stroke organisations (2)	*"I definitely think more support from organisations like Stroke Association. And I know it's difficult, but during the pandemic, just a phone call, I found really, really difficult to deal with." (P4)*
- More support to family and caregivers (2)	*"They [the family] had no idea what was going on for me, and they were certainly not prepared for me." (P5) "My sister would have said support from like the council or social services." (P4)*
- Resume face-to-face general practitioner (GP) consultations (2)	*"That is not only me but this is a national situation, is I don't have access to GP." (P1) " If it wasn't a pandemic, they would have been able to see me and… I think that might be the stroke may be may not even have happened." (P2)*
- Provide education regarding stroke to the general public (1)	*"There needs to be more education in the public… I feel like I missed signs as well. And as well as the hospital missing signs." (P2)*

Appendix 18: COREQ Checklist for the qualitative study (Chapter 4)

Manuscript: Exploring the experiences of people who had a stroke and therapists who managed people with stroke during the Covid-19 pandemic: An exploratory qualitative study.

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group?	Page 6
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Page 6
3. Occupation	What was their occupation at the time of the study?	Page 1 and 6
4. Gender	Was the researcher male or female?	Page 1
5. Experience and training	What experience or training did the researcher have?	Page 1
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Page 6 .
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Page 6
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Page 6

Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Page 1,4 and 6
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Page 5
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Page 5
12. Sample size	How many participants were in the study?	Page 1 and 7
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Page 7
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Page 6 .
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Page 5
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Page 5 and 6
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 5 and 6 (copy of the guides attached as appendices A and B)
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No Page 5
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 6
20. Field notes	Were field notes made during and/or after the inter view or focus group?	Page 6
21. Duration	What was the duration of the interviews or focus group?	Page 6
22. Data saturation	Was data saturation discussed?	Page 6
23. Transcripts returned	Were transcripts returned to participants	Page 7

	for comment and/or correction?	
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Page 7
25. Description of the coding tree	Did authors provide a description of the coding tree?	Page 7
26. Derivation of themes	Were themes identified in advance or derived from the data?	Page 7
27. Software	What software, if applicable, was used to manage the data?	NA
28. Participant checking	Did participants provide feedback on the findings?	Page 7
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Page 9 to 21
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Page 9 to 21
31. Clarity of major themes	Were major themes clearly presented in the findings?	Page 9 to 21
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Page 9 to 25

Appendix 19: Exercise booklet (chapter 5)

Exercises to Improve Walking for People with Stroke

This booklet includes different types of exercises for:

A) Warm up and cool down

B) Strength

C) Endurance (stamina)

D) Balance

- The exercises are classified into 3 levels (I, II, & III). The exercises will become slightly more challenging as you get better in the next few weeks.
- The researcher will circle the exercise that you should do at home in this booklet
- You can take this booklet home and follow it.
- Your progress will be assessed every 2 weeks.
- Please read the instructions and safety precautions given below before starting your exercises.

IRAS Number: 269079 Version 3, Dated 30.10.2019

Instructions

Remember: Safety comes first!

1. Your safety is very important. If you become tired or develop pain – Stop immediately.
2. If you feel dizzy or faint, you should stop your exercises immediately and inform your family member or carer.
3. If you experience chest pain, or severe breathlessness, please call 999 for help.
4. If you experience leg pain or tiredness which does not subside in the next 24 hours please speak to your GP about these symptoms and report these or any other problems in your recording diary.
5. Please note that while you are doing the balance exercises you might feel unsteady; to be safe and avoid a fall while you are doing the exercises please follow the following safety precautions:

- Don't wear slippers or loose-fitting shoes while doing the exercises.
- Do wear comfortable clothing which is not restrictive or could cause a trip over.
- Do the exercises close to a wall or near stable furniture such as the back of a chair.

6. You should always start to warm-up your body before the planned exercises and then cool-down at the end.

General Instructions:

7. Exercises should be done at least once a day. Though these exercises can be done at any time of the day, it is better if you can do it in the morning before your daily schedule starts. Please use the booklet to guide your exercise session.

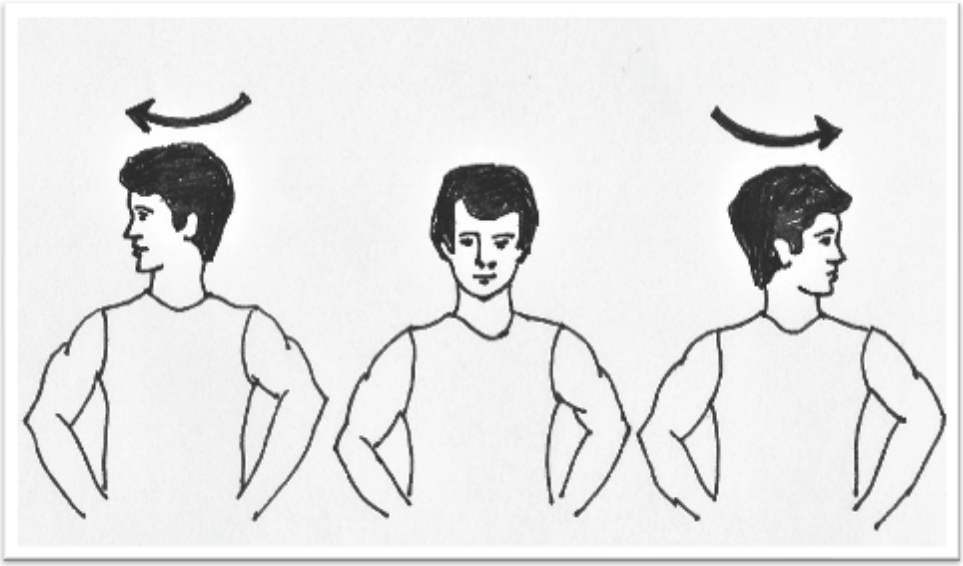
8. It will take between 30 to 40 minutes to complete the entire set of exercises.

A) Warming up and cooling down Exercises

Warm up exercises are done to prepare muscles and joints for the strength and balance training. Warm up increases the circulation and reduces risk of exercise related injuries.

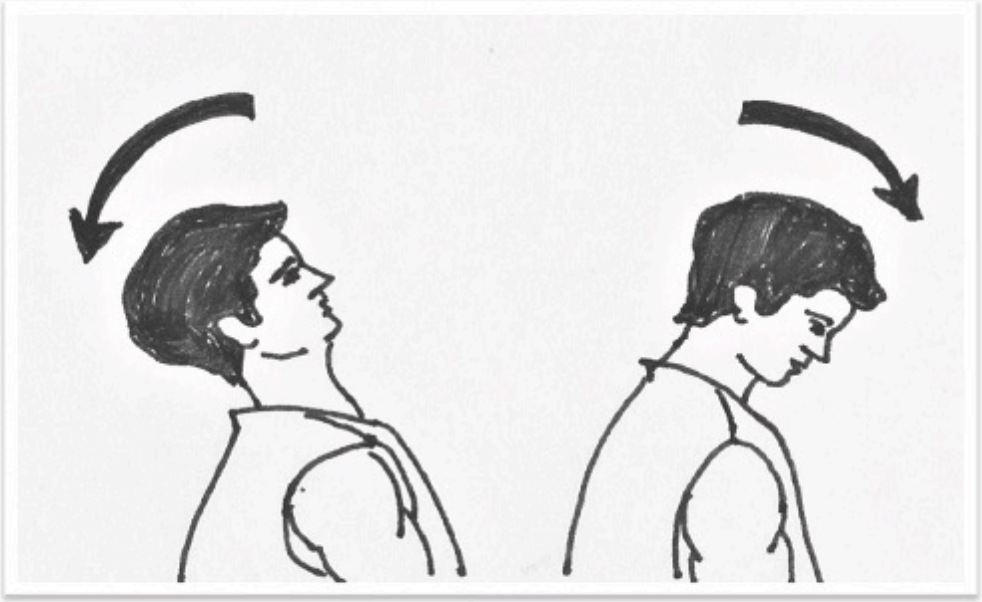
Cool down exercises help to relax the muscles after exercising them and it also help to improve flexibility.

1) Seated-Head Turns – Side to Side



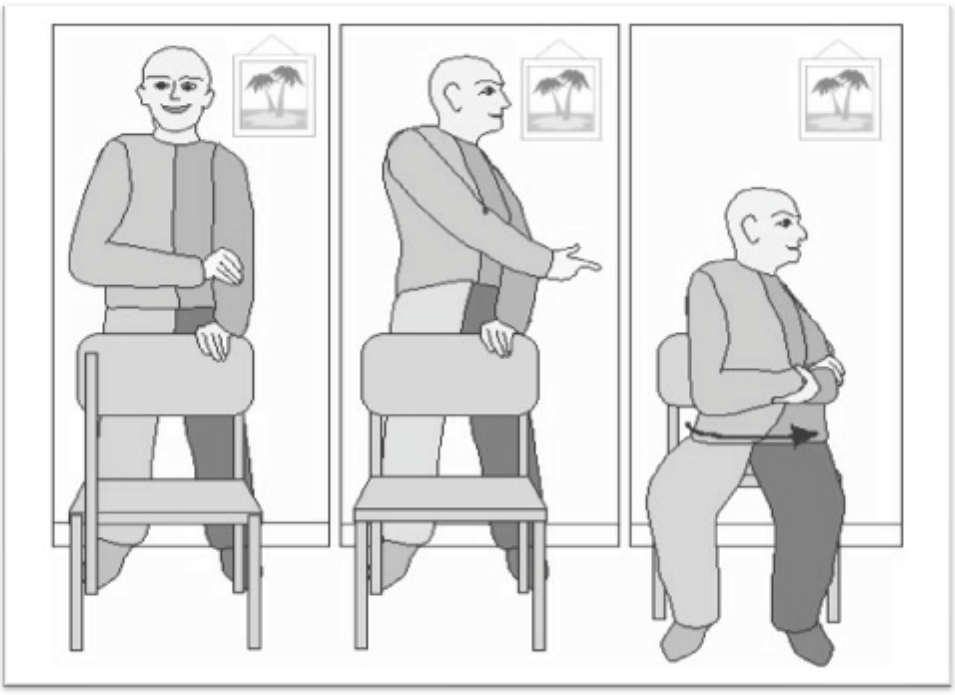
a) Move your head to right and left as far as possible at a slow speed.
b) Continue this at a smooth pace for 30 seconds to 1 minute.
Precaution: If you suffer from neck pain and/or dizziness this exercise might bring these symptoms back. However, do these exercises as much as you can. This will help reduce these symptoms over a period of time.

2) **Seated-Head Turns- Up and Down**



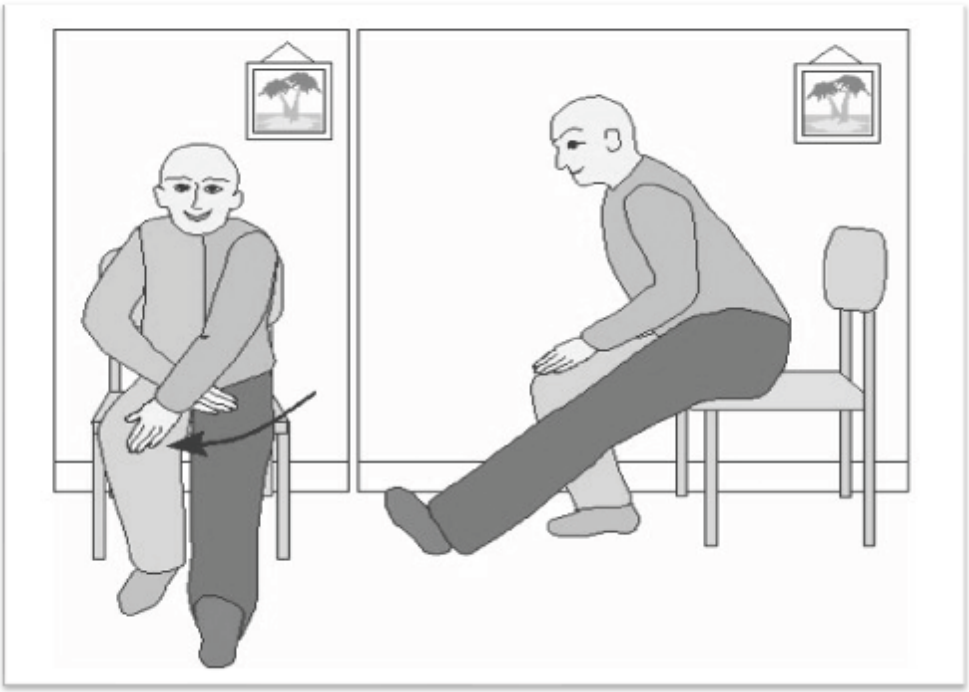
a) Move your head up and down as far as possible at a slow speed.
b) Continue this at a smooth pace for 30 seconds to 1 minute.
Precaution: If you suffer from neck pain and/or dizziness this exercise might bring these symptoms back. However, do these exercises as much as you can. This will help reduce these symptoms over a period of time.

3) Trunk Twist



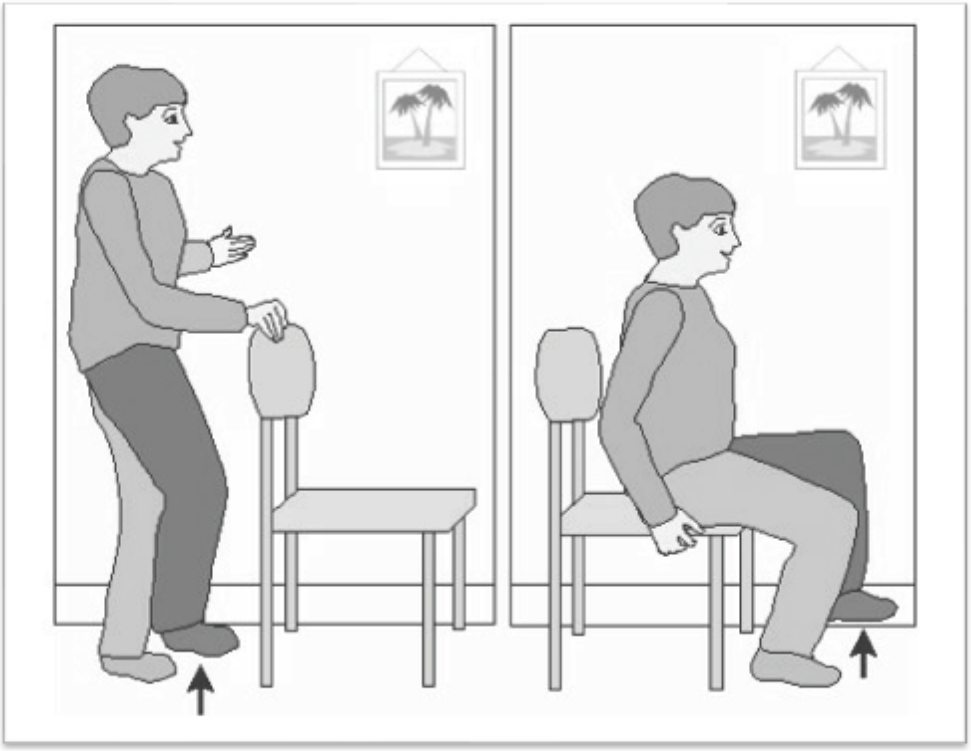
a) In seated or standing.
b) Use light support of a chair if needed.
c) Twist the upper body to the side.
d) Only turn the upper body (not the hips).
e) Return to the start position and repeat to the other side.
f) Repeat 4 times on each side alternating left and right. Do 8 turns in total.

4) Back of thigh stretch



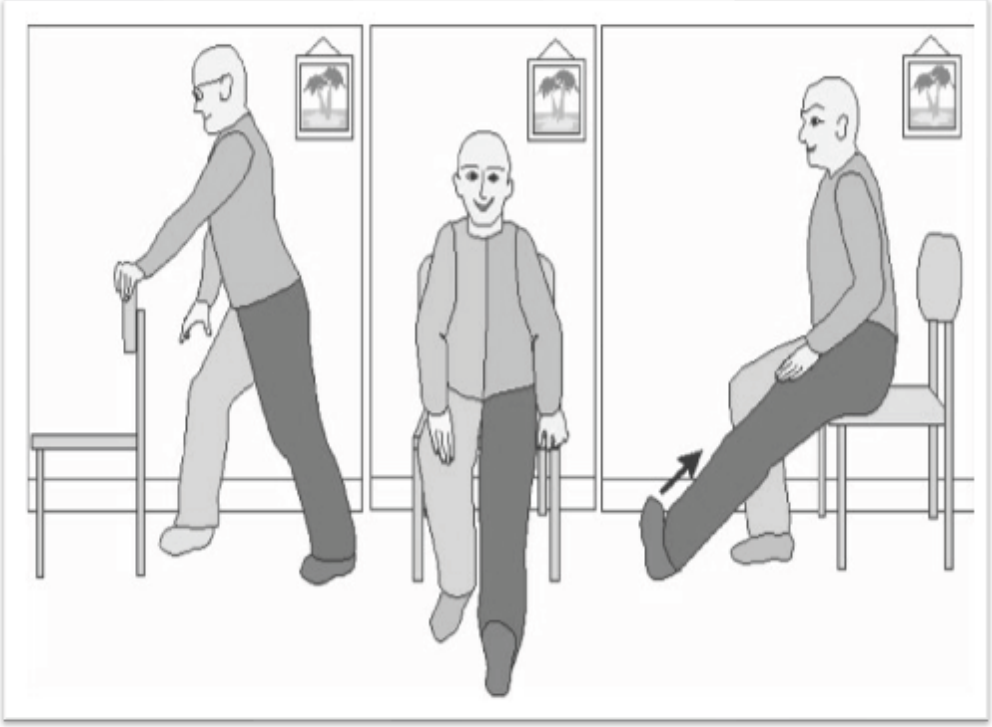
a) Sit in the front half of the chair, but not too far forwards.
b) Straighten one leg and place the heel on the floor.
c) Place both hands if able to on the bent leg.
d) Try to sit up straight in the chair.
e) Lean your body forward while keeping your back as straight as possible. You will feel a stretch behind the thigh.
f) Hold the stretch position for 10 - 20 seconds, breathe normally throughout.

5) Marching & Arm swing



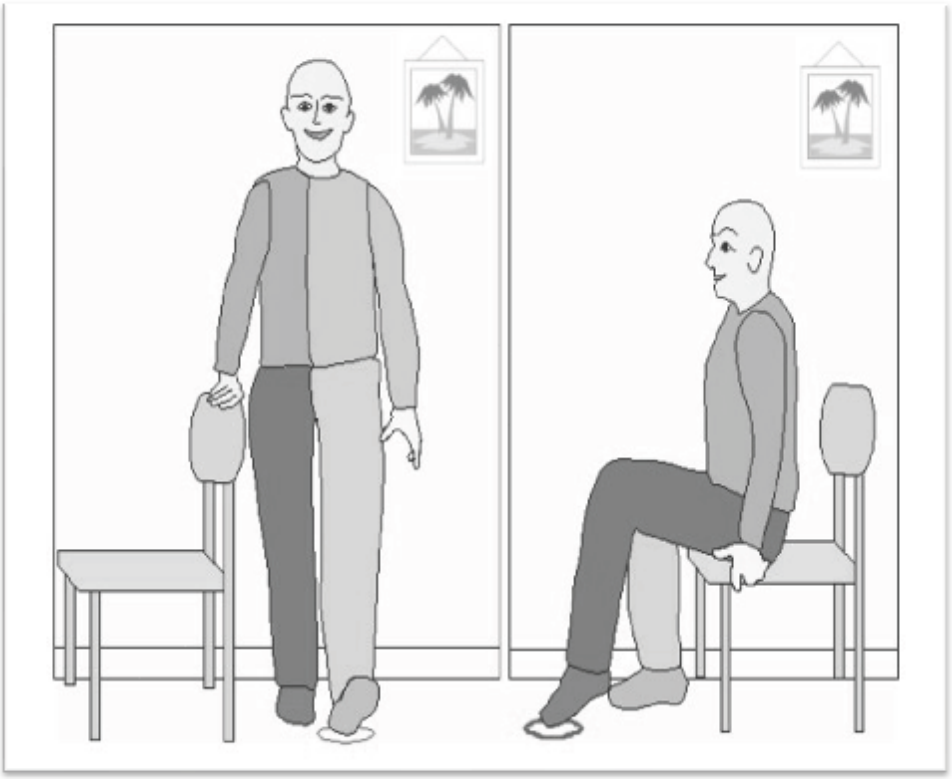
a) In seated or standing, keep your back as straight as possible.
b) Begin marching your legs.
c) Try to lift both knees evenly.
d) Continue marching for 10 seconds progressing to 30 seconds when you feel able.
e) Add an arm swing with one or both arms.
f) Breathe normally throughout.

6) Calf Stretch



a) This exercise can be done while being seated or standing
b) Stand behind the chair holding on for a little support if needed
c) Step back with one leg and press the heel down to the floor,
d) If seated, straighten your leg and try to pull your toes towards your nose.
e) Feel the stretch in the back of your leg
f) Hold for 10 - 20 seconds and repeat on the other leg.

7) Toe and heel lift

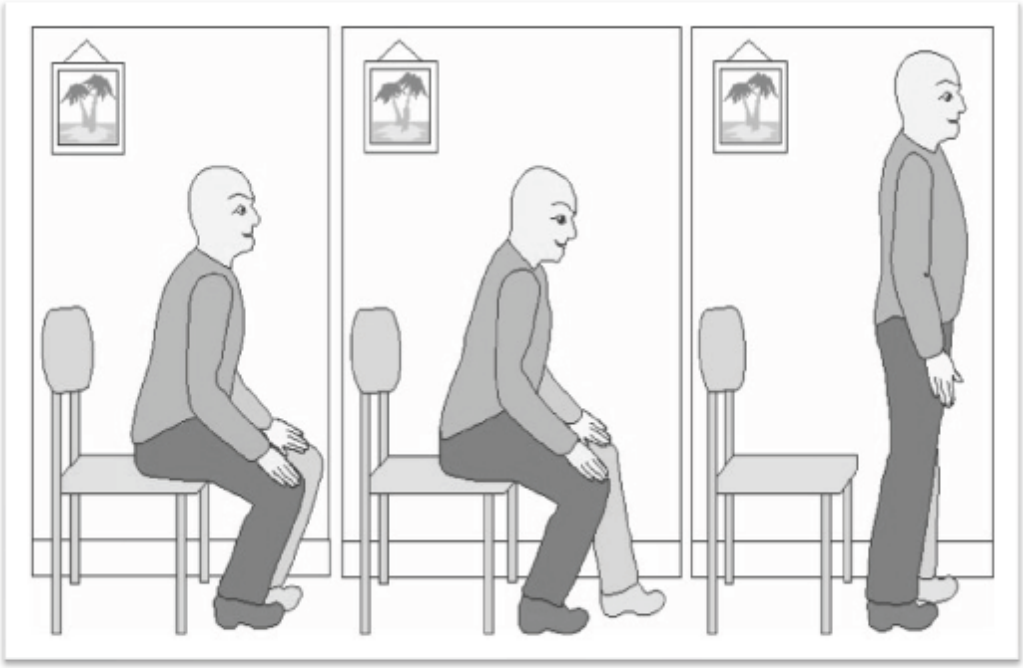


a) In sitting
b) Place the foot on the floor, lift the knee and the heel off the floor.
c) Point the toe to the same spot.
d) Lower your knees and place heel on floor.
e) Now pick your toes off the floor and point them towards your knees.
f) In standing place one leg in front. Do the same as above.
g) Repeat 4 times on each leg.

I. LEVEL I Exercises

B) Strength Exercises

8) Sit to Stand



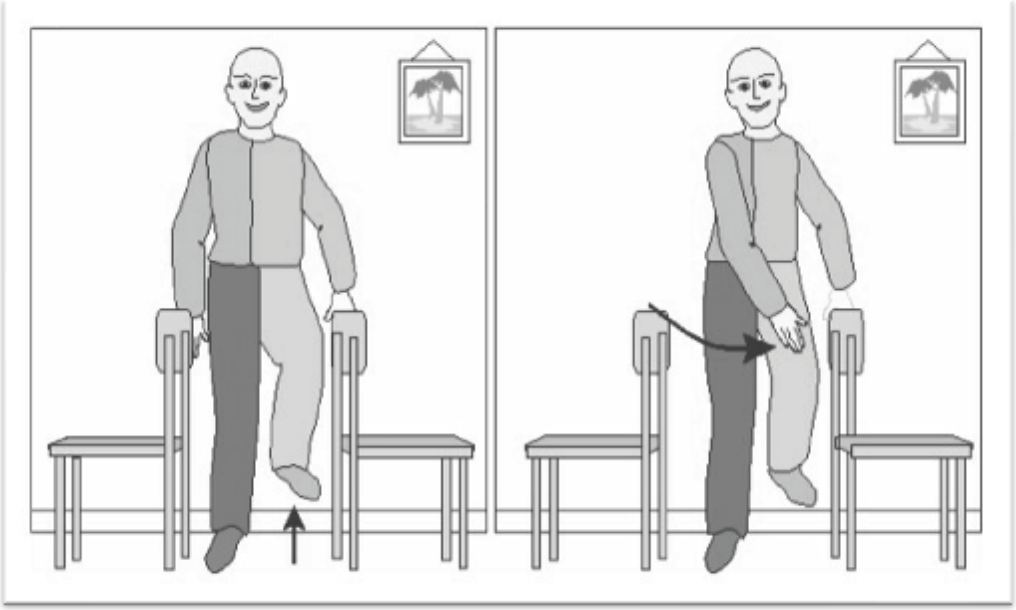
a) Stand up slowly and sit down.
b) If you can, try this exercise without using your arms to push up.
c) Repeat this 5 to 10 times.

9) Step Ups



a) Use a wide step or stair.
b) Use support for balance.
c) Step up with your affected leg.
d) Hold for 5 -10 seconds
e) Step back to the floor with your affected leg, with control.
f) Step up with the other leg.
g) Step back to the floor.
h) Repeat the exercise for 10 times.

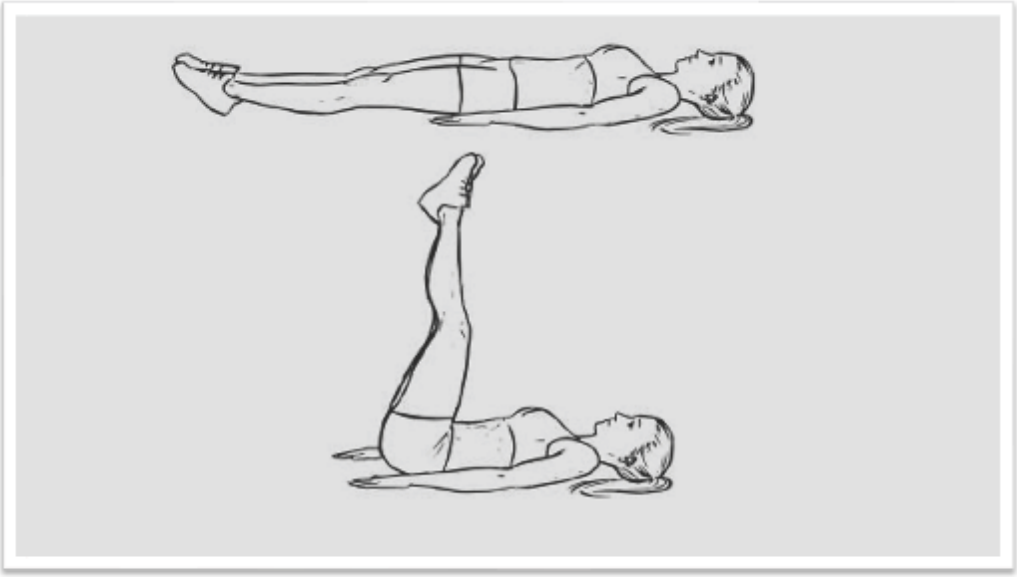
10) Hand to Knee



a) Perform this exercise standing with your back close to a wall.
b) Practise marching on the spot.
c) Raise your knees high.
d) Aim for even height knee raises.
e) Progress to add hand touching opposite knee.
f) Aim for even movement to the left and right.

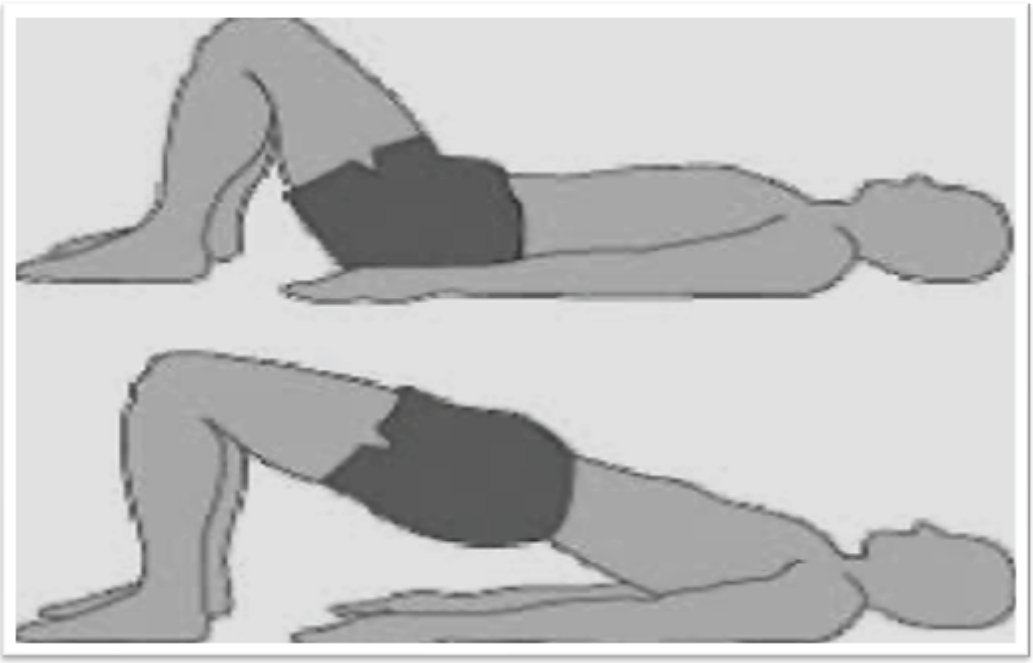
Precaution: this exercise may challenge your balance so use reliable support if needed.

11) Leg Raises (only for home)



a) Lay on your back with your hands on the sides or under your lower buttocks.
b) Keep your leg straight and ankles together.
c) Raise your legs upward by flexing the hip as much as you can.
d) Hold for 5 counts and relax your leg.
e) Repeat for 10 times

12) Bridging exercise (only for home)



a) Lying on your back with your knees bent and feet on the bed or mat.
b) Lift your hips up toward the ceiling.
c) Hold this position for 5 seconds and lower your hips down.
d) Repeat for 10 times.

C) Endurance Exercise

13) Shuttle Walking

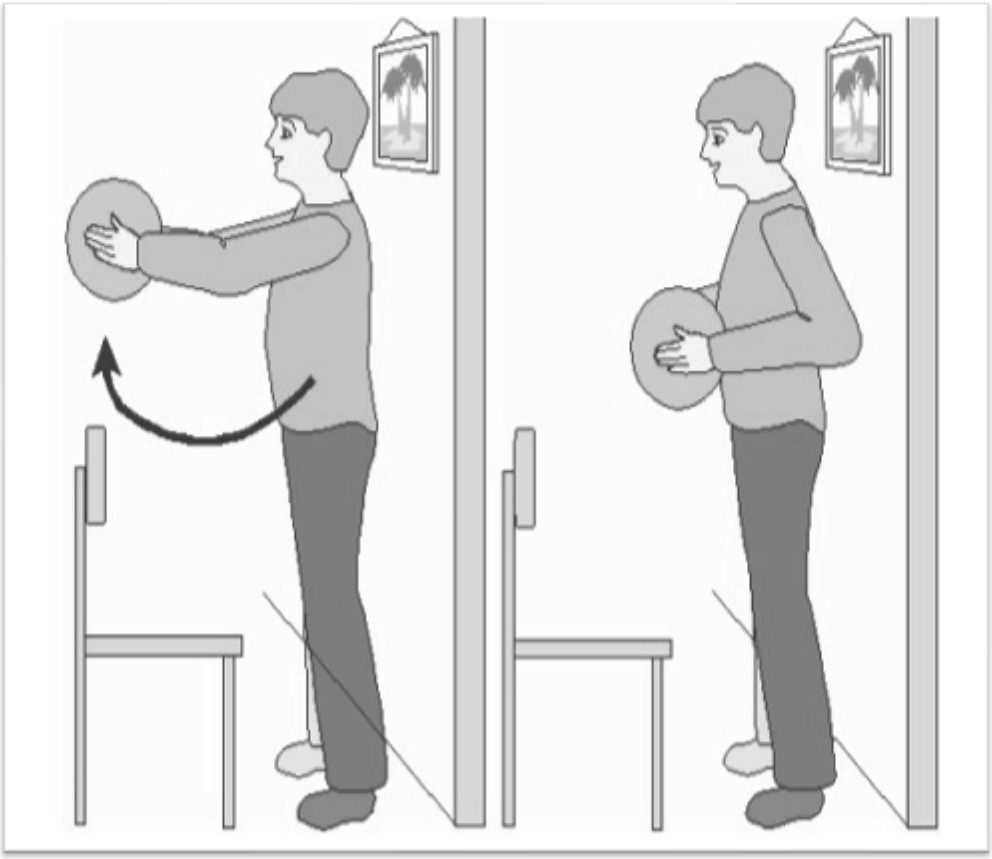


You can practice walking indoors or outdoors. Stand upright.

a) Try to lift your knees as you walk, to have a longer step.
b) Lift your feet and place the heel down first as you walk.
c) Try to take even steps.
d) Look at where you place your foot if this helps.
e) Start out with 5 to 15 minutes, or ¼ mile, once per day.
f) Increase your time and/or distance gradually.

Precaution: Use an area free of obstacles where you can walk safely.

14) Ball Raise (or similar object)

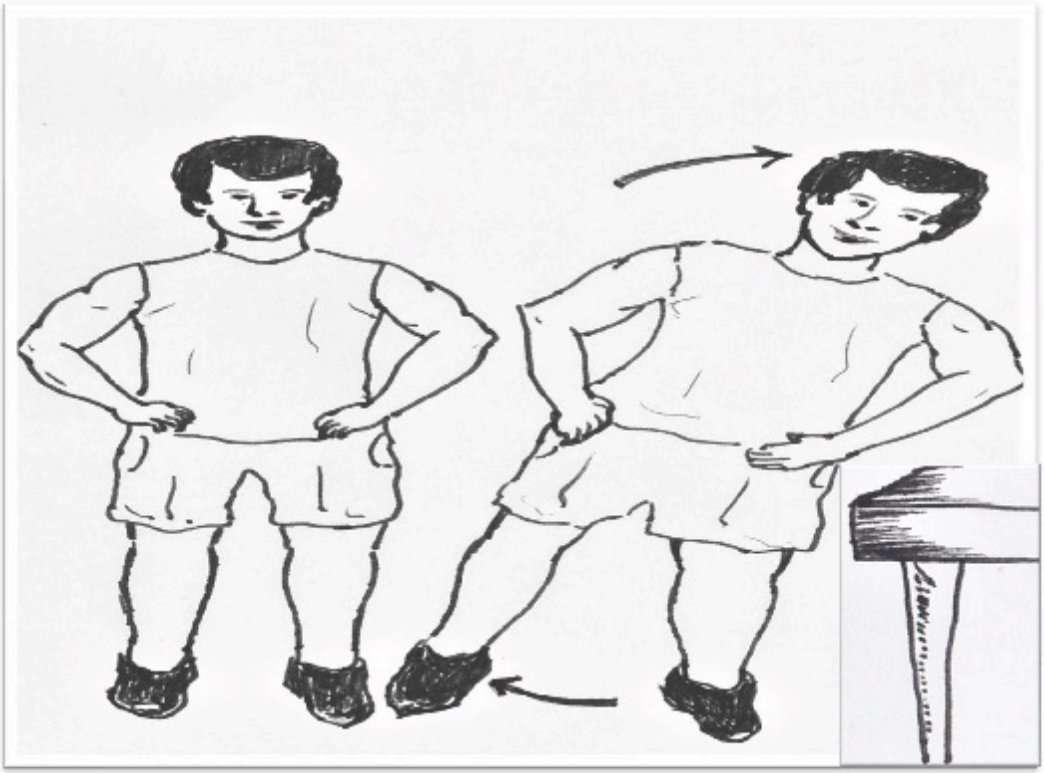


a) Place feet shoulder width apart.
b) Put equal weight across both feet.
c) Pick-up the ball and stand upright.
d) With arms straight, raise the ball to just under shoulder height.
e) Repeat this movement, reaching outwards and upwards as if you are passing the ball to a person next to you.

II) Level II Exercises (For patients who show improvement in their assessment)

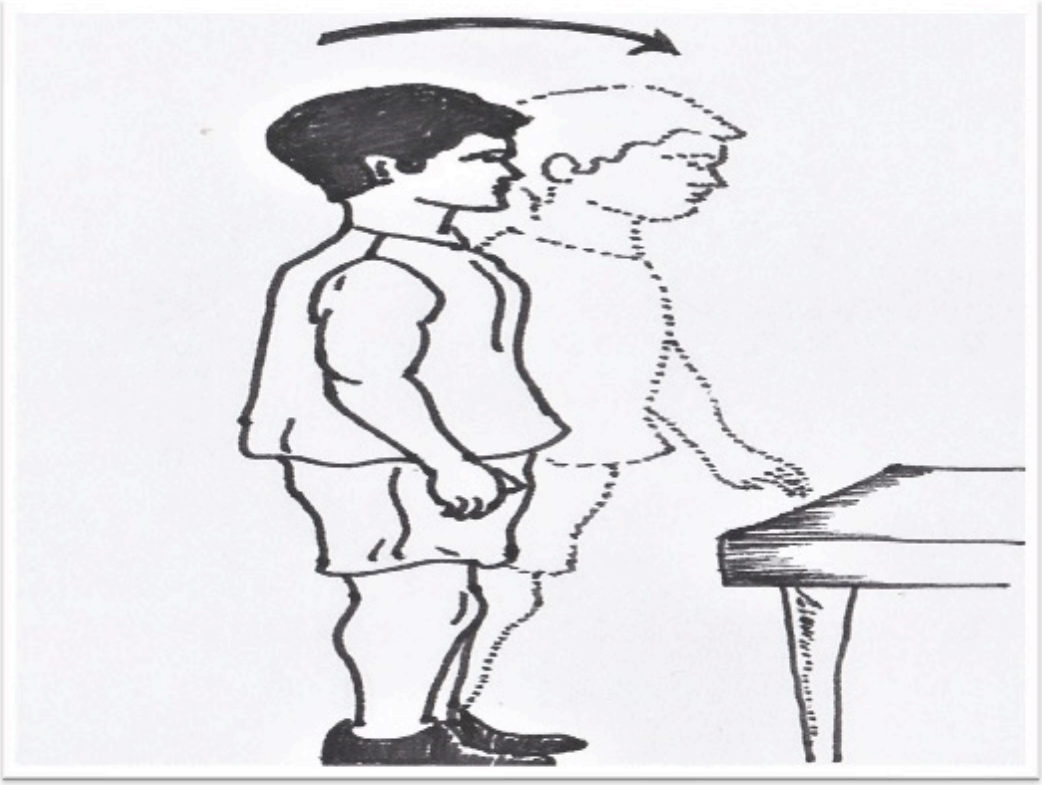
C) Balance Exercises

15) Sway- Right and Left



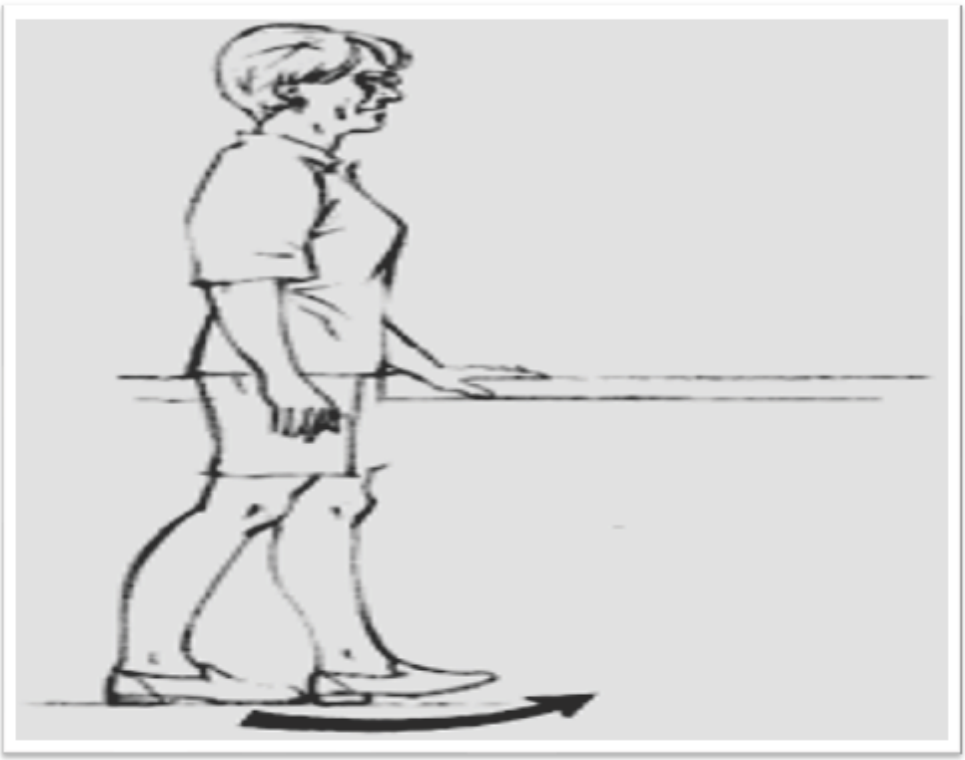
a) **Stand behind a chair or table** with your feet shoulder width apart.
b) Sway on to one side (don't sway too far) and hold on to this position for 5 to 10 seconds.
c) Come back to the middle.
d) Sway on to the other side and hold on to this position for 5 to 10 seconds
e) Repeat this for 5 to 10 times.

16) Sway- Forward-Middle- Backward



a) **Stand behind a chair or table** with your feet hip width apart.
b) Sway forward (not too far) without lifting heels up, when you feel pressure on the toes stop and stay in this position for 5 to 10 seconds.
c) Sway backward (only a little bit) to feel the pressure in the middle of the feet and stop in this position for 5-10 seconds.
d) Sway little bit more backwards so that the pressure is more pronounced on the heels and stay in this position for 5 to 10 seconds.
e) Repeat this for 10 times.

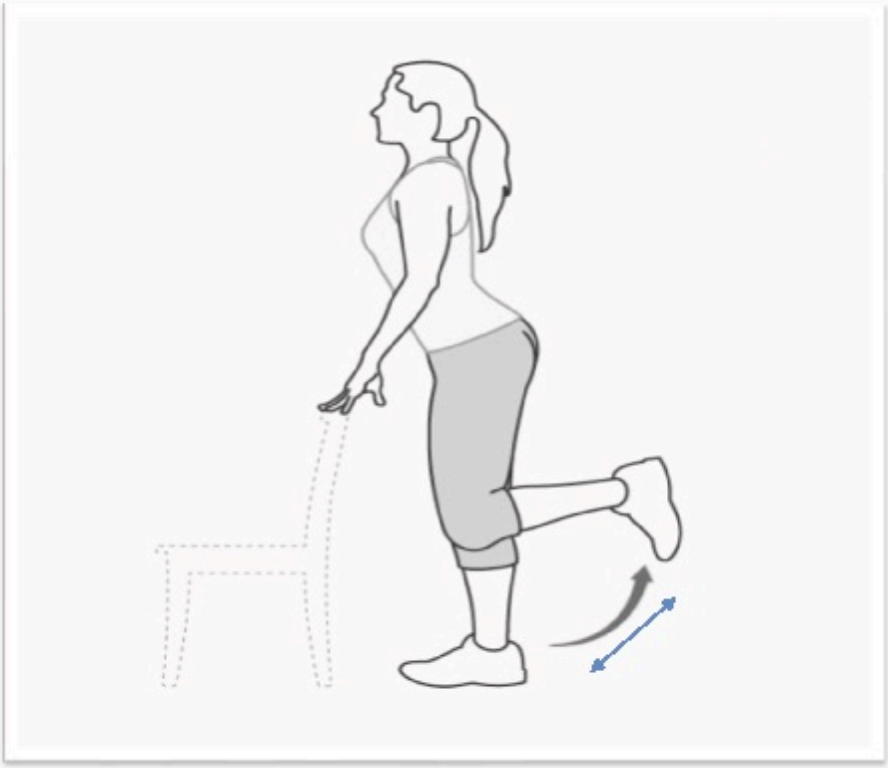
17) Heel-and-Toe Walking (Holding On)



a) Use a counter or ledge to hold on to, or ask someone to give you a hand to hold for balance.
b) Walk forwards slowly by placing one foot in front of the other.
c) Walk 5 to 10 steps forwards.
d) Repeat *3 sets of 10*

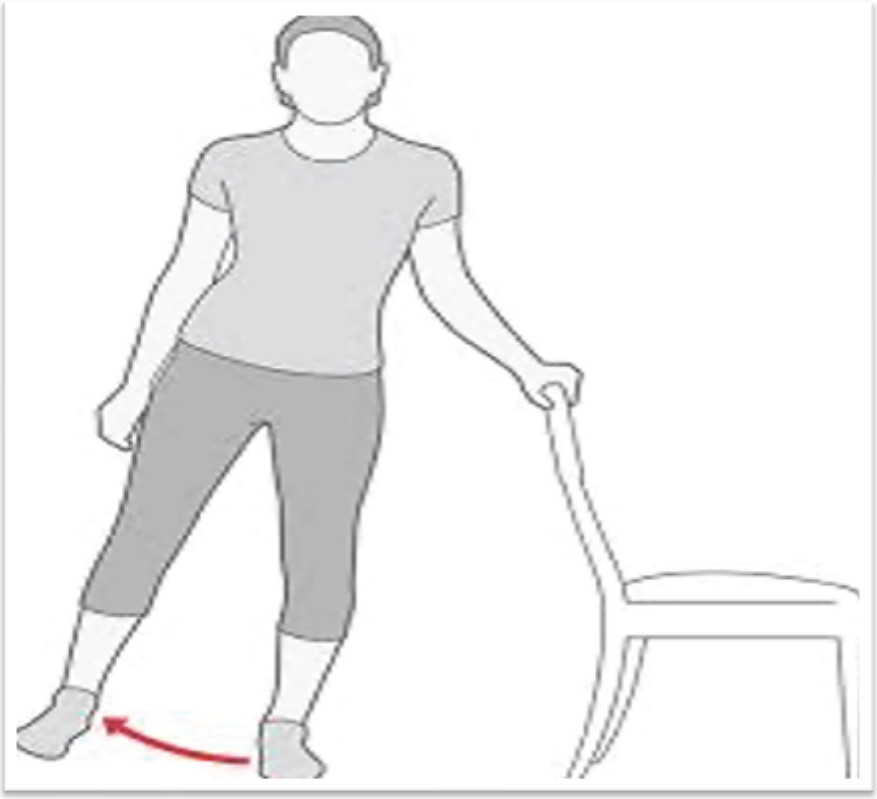
B) **Strengthening Exercises**

18) Standing Knee Extension



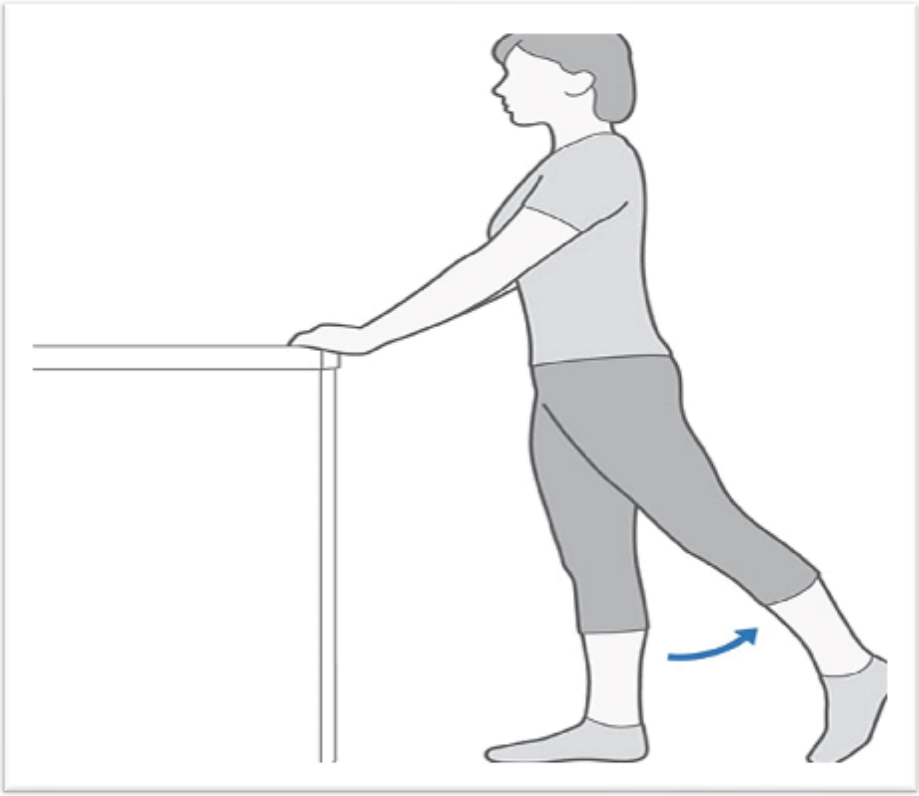
a) Holding on to a stable surface
b) bend and straighten the affected leg as if kicking
c) Repeat 3 sets of 10

19) Hip Abduction in Standing



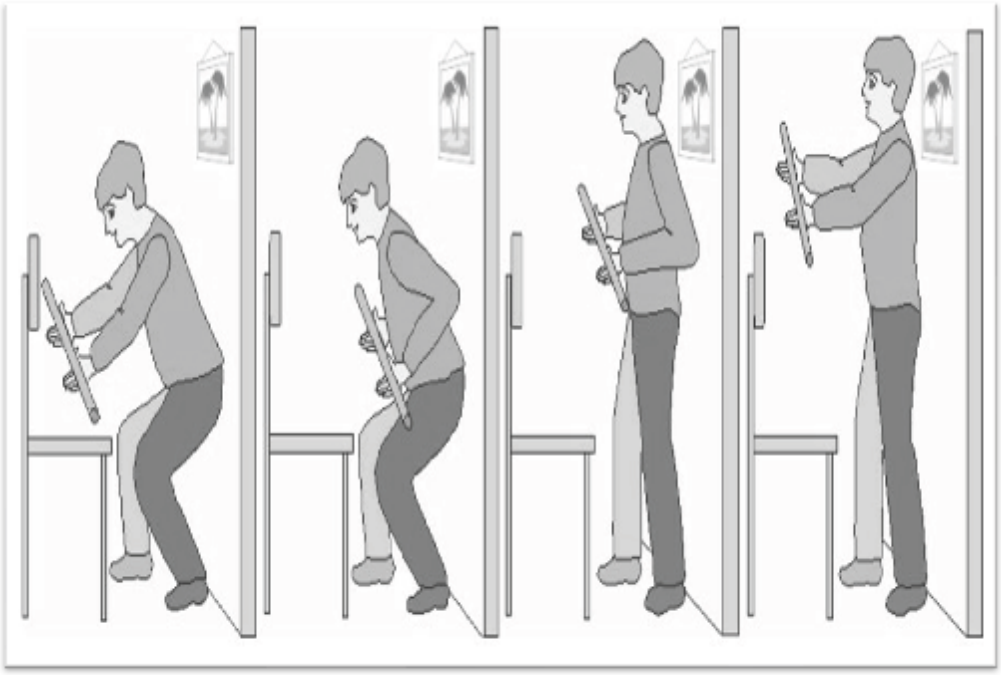
a) Holding to a stable surface
b) Lift the affected leg out to the side and back down
c) Repeat 3 sets of 10

20) Hip Extension in Standing



a) Holding to a stable surface
b) raise the affected leg backwards and back down (attempting to keep the knee straight)
c) Hold for 10 seconds, if you can, and lower it back down slowly
d) Repeat and switch legs

21) Pole Lift

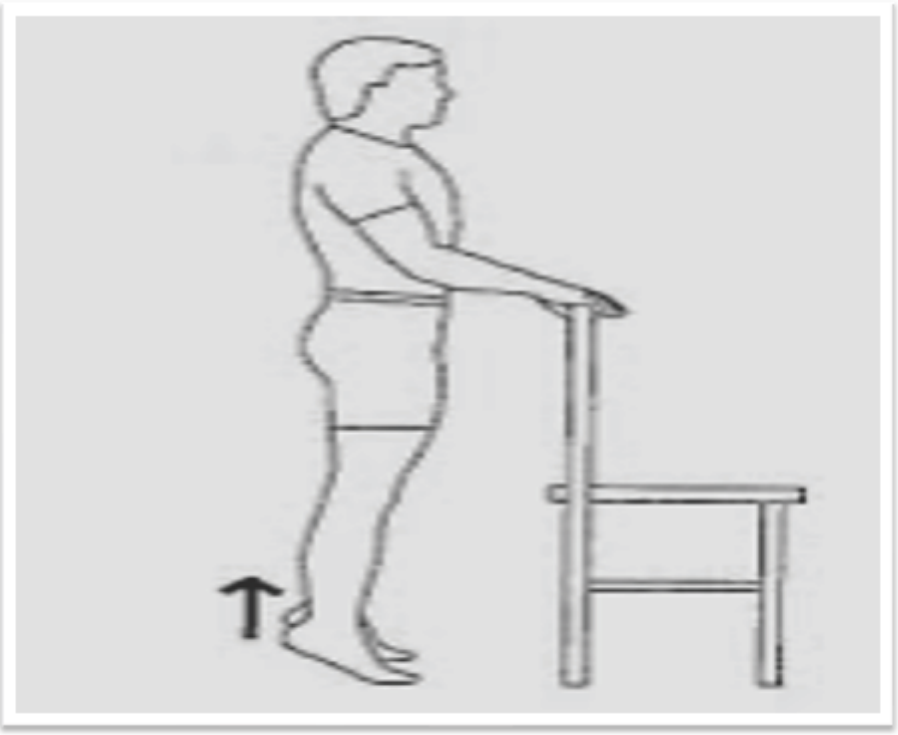


a) Hold the pole with both hands if possible.
b) Stand in front of a chair (use it as a target).
c) Bend your knees and reach the pole towards the chair.
d) Return to upright standing, and now reach the pole forwards and upwards to shoulder height.
e) Try to keep weight equal across both feet, and body symmetrical.
f) Breathe normally.
g) Start with 2 - 3 times, progressing to 8.
h) If you wear a splint, step this foot forwards, keep the heel down.

Level III. Exercises for later stage of recovery

(B & D) Balance and Strengthening exercises

22) Heel Rise with or without support



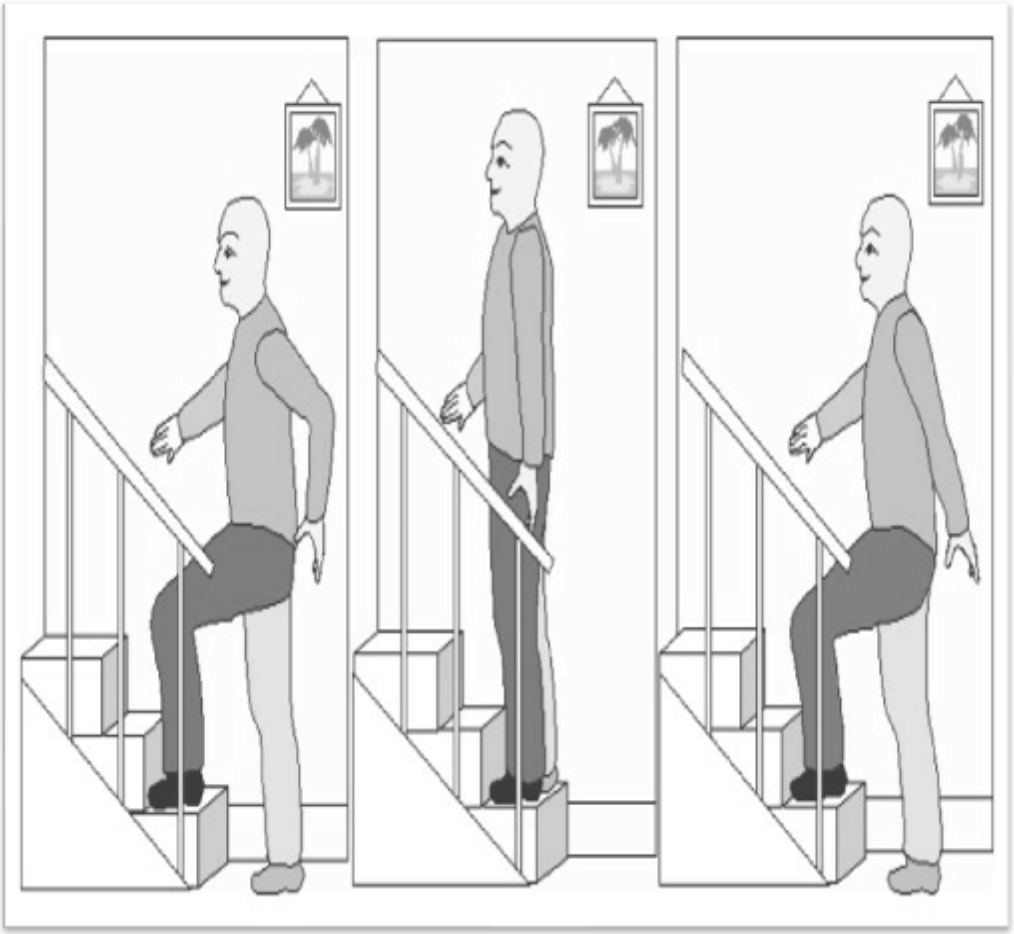
a) Holding on to a stable surface raise up on the toes and back down.
b) Hold for 10 seconds, if you can, and lower it back down slowly.
c) Repeat 3 sets of 10.

23) Squats



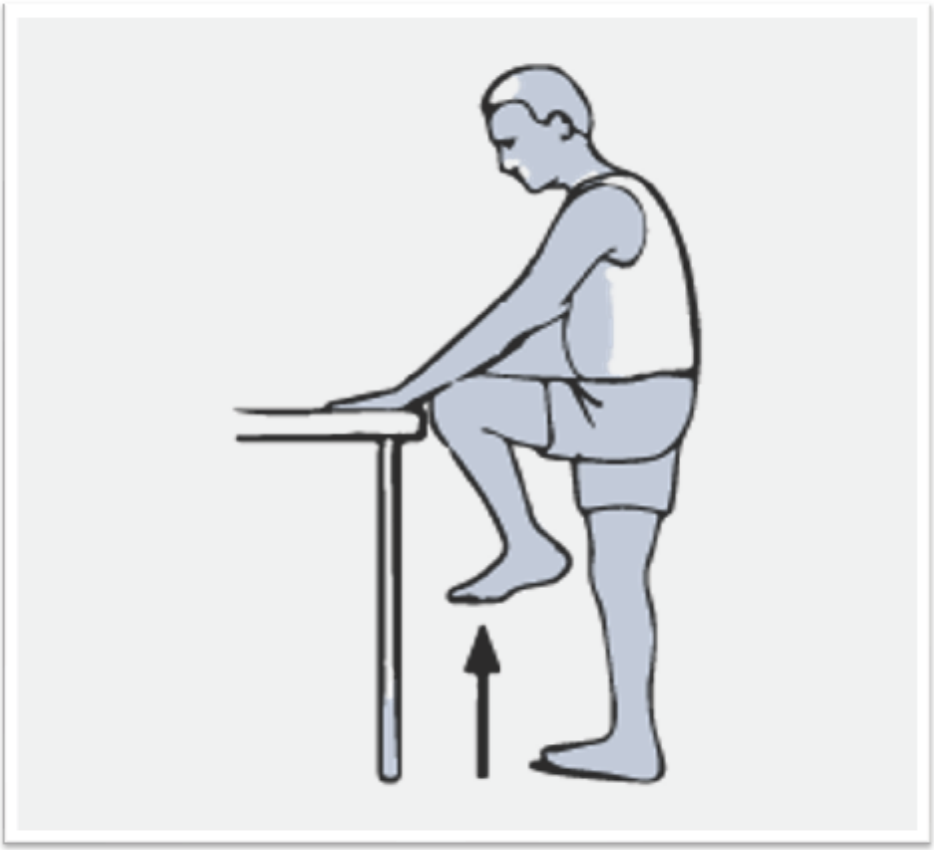
a) Holding to a stable surface.
b) Partially bend the knees as if sitting back on a chair and then stand back up straight.
c) Repeat 3 sets of 10.

24) Step Ups



a) Use a wide step or stair, Use support for balance.
b) Step up with your strongest leg.
c) Bring the other leg to join it.
d) Stand with equal weight across both feet on top of the step.
e) Step back to the floor with your 'weaker' leg, with control.
f) Start with 10 seconds progressing to 2 minutes.

25) Knee lifts



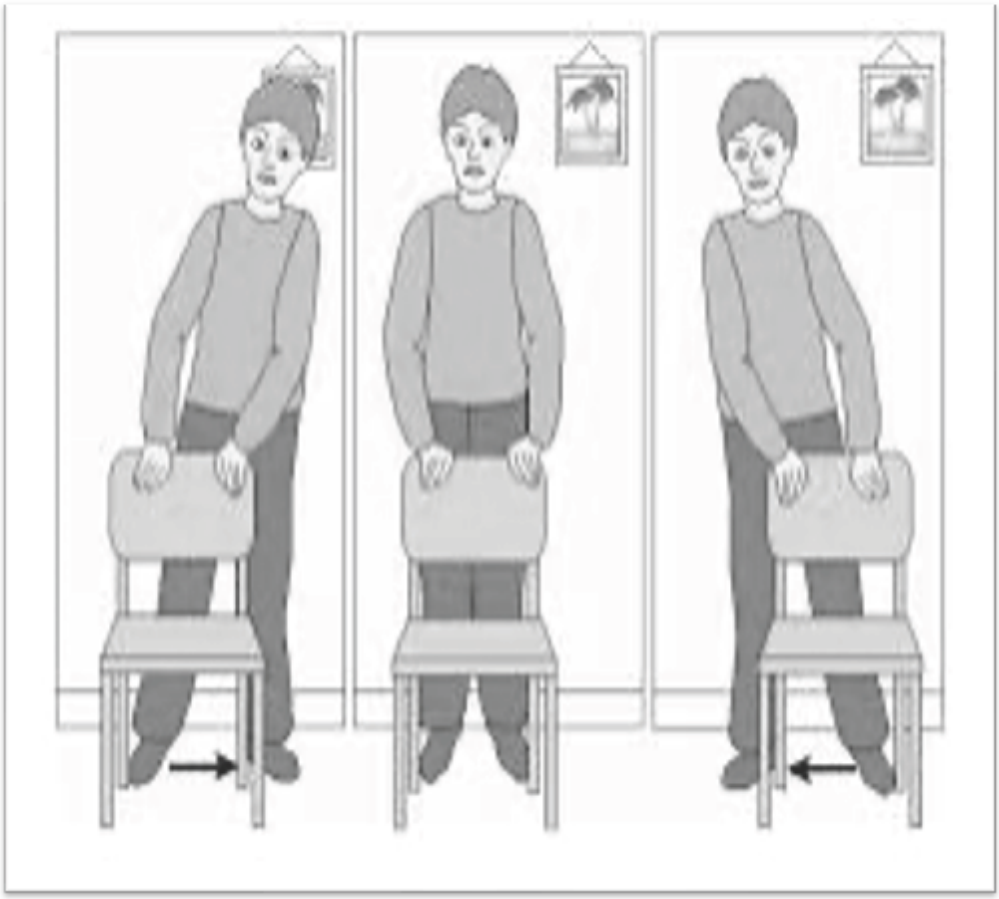
a) Hold on to a stable surface, keeping your back tall and straight.
b) Transfer your weight to one leg, and bring the other leg up in front of you, bending the knee.
c) Hold this position for a count of 10, and slowly lower it back down.
d) Repeat, then switch legs.

26) Hamstring Curl



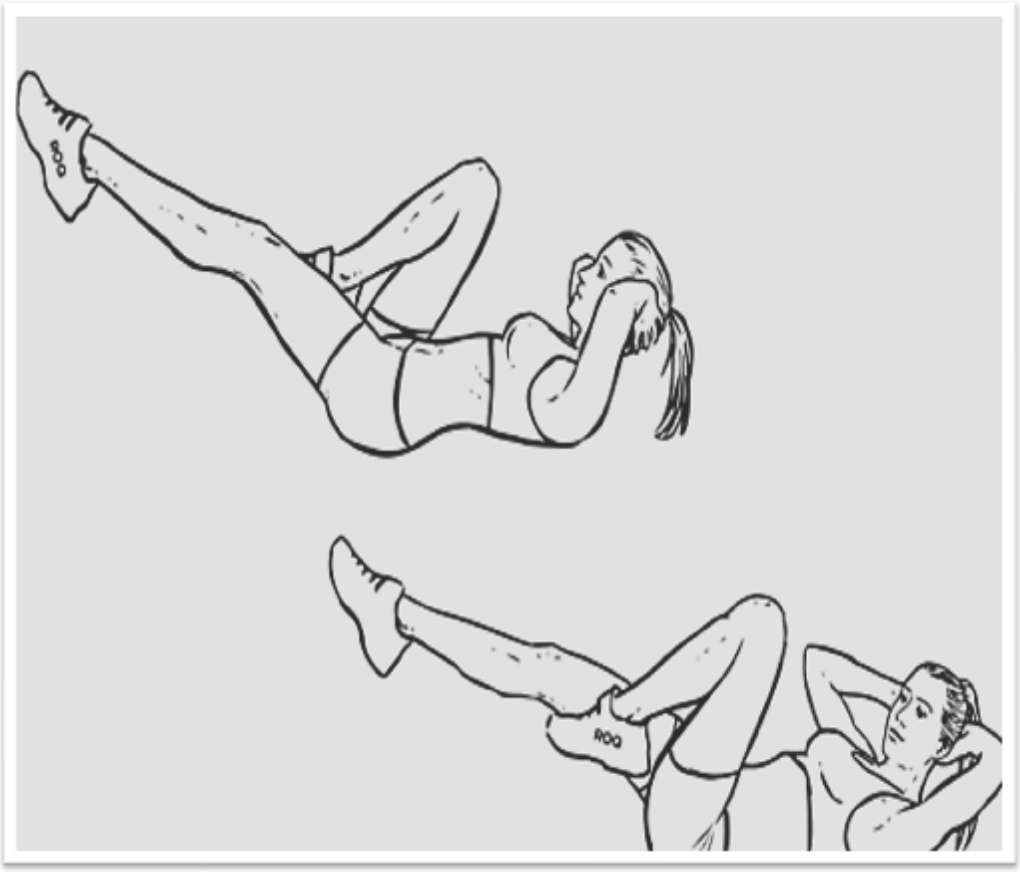
a) Holding to a stable surface.
b) Try to bring the heel of the affected leg toward the buttocks and back down.
c) Repeat 3 sets of 10.

27) Walking sideways



a) Hold on to chair in front (if needed).
b) Step sideways and walk a few steps.
c) Now walk sideways in the other direction.
d) Hold on to kitchen counter if needed at home.
e) Start with 10 seconds progressing to 2 minutes.

28) Bilateral Leg Cycling (Home only)



a) Lie on the floor and lift the legs off of the ground, holding them in a cycling position.
b) Then, cycle as if you are riding a bicycle in the air.
c) Rest and repeat 10 times.

***AT THE END OF YOUR TRAINING:**

REPEAT COOL DOWN EXERCISES GIVEN AT THE BEGINNING.

Appendix 20: Usual care report for each participant in chapter 5

Participant's ID	When did your NHS therapy start after your discharge from hospital?	How often do you receive therapy to improve walking from the NHS therapists?	Can you please tell us what have you been receiving from the NHS therapists to help improve your walking?	Are you having any private therapy since discharge? If yes, how often? What are you doing with your private physiotherapist?	Where have you been doing your walking training? (Hospital, outpatients department or Home)
1 I	Immediately after discharge PT for 8 weeks & OT for 5 weeks)	Once a week	Walking and stairs climbing	No	Home but had one session at hospital for balance
2C	After 2 weeks of discharge	Once a week for 3 weeks and then once every 2 weeks for 7 weeks (total =10 weeks)	Walking with stick-UL exs	No	Home-walking outside with physio-walking outside independently with husband- using bike at home
3 C	After a couple of weeks of discharge	-PT once a week for 6 weeks -OT 2 phone calls +one home visit	-Walking and standing exs -leg strengthening and balance exs -stairs climbing and descending exs	No	Home
4I	After 12 weeks of discharge	Once a week for 6 weeks	-Exercises (home program) -arm exs -mobility exs (strengthening and balance exs)	No	-Home (walking indoors & take steps downstairs) -has a walker to local shops
5I	After 6 weeks of discharge	Random (only 4 sessions)	Walking and UL exs	One session with private physio	Home
6C	Immediately	Once a week for 7 weeks	Walking and UL exs	No	Home and the care home building
7I	After one week of discharge	PT Once a week for 6 weeks	Adaptations, LL strengthening and stretching exs, and walking exs	No	Home and outdoors

8I	Immediately after discharge	PT and OT 3 times a week for 6 weeks	-Sensory reeducation -walking to shop and back -no exs given	no	Home (walking in the garden uphill and downhill)
9I	One week after discharge	Once a week (in outpatient department) and few community visits	Walking exs including Stepping exs, walking in therapy department, treadmill, LL strengthening exs	Private physio once a week with focus on ULexs	Home and Therapy department
10I	Immediately after discharge	Twice a week for 8 weeks	Balance, strengthening and endurance exs and walking frame to be used outdoor	No	Home and outdoors (taking bus and going to shop)
11I	Immediately after discharge	Once a week for 8 weeks	L.L and U.L exs	No	Home
12C	Immediately after discharge	Twice a week for 6 weeks stopped after that and resumed for once a week for another 6 weeks (total 12 weeks)	Balance and strengthening exs, stairs climbing and OT for UL	No	Home
13I	Immediately after discharge	Twice a week for 16 weeks	Bed exs, walking and balance exs	No	Home with few steps in the garden
14C	Immediately after discharge	Twice a week for 8 weeks PT and OT	Walking and strengthening exs and OT for UL	No	Home and around the home with physio
15C	After 7 weeks of discharge	Once or twice a week for 11 weeks	Stretching, strengthening and walking exs	No	Home and walk around the house
16C	After a couple of weeks	2-4 times a week for 13 weeks	Strengthening, balance and walking exs and OT for UL	Yes , traditional therapy but wasn't helpful	Home including garden, go to the shop
17C	After 4 weeks of discharge	Twice a week for 12 weeks PT and OT	Walking with a frame and then a stick, strengthening and balance exs and OT for UL	No	Home, outdoors with physio
18C	After 3 weeks of discharge	Once a week for 8 weeks PT and OT	Bed exs, walking and balance exs and OT for UL	No	Home
19C	After 4 weeks of discharge	Once or twice a week for 8 weeks	Walking, strengthening exs, walking outside with physio, and OT for UL	No	Home and park close to the house
20C	Immediately after discharge	Once a week for 8 weeks, stopped and started again last week	Stretching, strengthening, and balance exs	No	Home
21I	After 4 weeks of discharge	2-3 times a week for 8 weeks	Walking with walker and stick, balance exs, Sensory re-education, OT for UL	No	Home

22I	Immediately after discharge (within 5 days)	Once a week for 6 weeks	PT and OT (UL exs, Walking exs, strengthening exs)	No	Home
23I	Immediately after discharge	Once to 3 times/week for 6 weeks	PT and OT for UL and LL	No	Mostly home, but did sometimes at the outpatient Dpt.

Appendix 21: Focus group guide for participants in chapter 5

Self-management integrated intervention for improving walking in the community

Focus Group Guide

Thank you for agreeing to talk about the newly developed self-management programme for improving walking in the community. We really appreciate your participation in this study and the time that you are giving us. Today we would like to discuss with you how the study was and how we can make it better. We would like to understand whether the intervention was accepted by you as the end users and whether we can sustain it in the long run.

It might be important to know we could have interviewed everyone individually, but we purposefully decided to do focus group so we can have rich discussion about different aspects of your experience with our new intervention.

This meeting will take about an hour. We will be audio recording our meeting so that we don't miss any information. Please state your name for the record. We will not use your name in any of our reports. It is just to make data analysis easier and we can contact you if we need further information about your experience. Please remember there are no right or wrong answers, we simply want to hear your opinions. We welcome all perspectives. Feel free to critique our work, to give suggestions, or comment on anything that you think is related to the study.

Do you have any questions before we start?

Warm Up	Introductions	1. First, can we go around the table and you give me your full names please?
	Evaluation of the motivations	2. Why did you agree to participate in this project? 3. In general, do you think this programme was useful for you?
Fidelity and Acceptability of the Intervention	Feedback on the intervention components (Education sessions)	4. To what extent was the education session helpful for you? 5. How easy was it to understand the information provided in the education sessions?
	Feedback on the implementation of other components (goal setting, action planning, peer support, group sessions, and self-evaluation and feedback)	6. What do you think of the structure and content of the intervention? 7. How did you find your involvement in setting the goals and planning the activities for your walking recovery? 8. What were the difficulties in setting your own goals? 9. What do you think of having peer +/- carer support while carrying out your planned activities?

		10. How was the group sessions, would you suggest that for other stroke survivors? 11. How did you find doing your exercises at home and evaluating your performance without therapists? 12. What challenges did you face while you carrying out the programme? 13. What helped you to participate in the programme to the best of your ability?
	Methodology	14. What do you think of the design of the study i.e. that some people had planned intervention and others had only education session? 15. Do you think the used outcomes reflect what is important for you to obtain from rehabilitation? 16. Did you discuss any exercises or information from this project with people from other group who did not get this intervention?
	Feasibility and sustainability	17. Was any part of the programme (education, goal setting, action planning, peer support, group sessions, and self-evaluation and feedback) hard for you to understand or carry out? 18. How can we help you with these gaps? 19. How does this programme fit in with other care plans provided by the NHS for your rehabilitation? 20. Would you like to continue doing the same programme on your own in the future? i.e. setting goals ..etc 21. What are your thoughts about communication with research team, transportation, availability/suitability of the venue? 22. How do you think we can improve this programme?

For the participants from the control group:

1. Did you discuss any information from your talks with people from other group who have had experience the new intervention? Did they discuss their exercises with you? Did they influence you to do more physical activity than you would normally do? Did they talk to you about self-management?

2. What do you think of the design of the project i.e. that some people have had experience the new intervention and others had only education sessions?

Appendix 22: Amendments and Notification of Confirmation of Capacity and Capability for the feasibility study (Chapter 5)

Notification of Confirmation of Capacity and Capability

Dear Sheeba, Carron and Ahmad,

Study Information	
Research Title:	Feasibility of a self-management intervention for improving mobility for patients following stroke in the community
Sponsor:	University of Birmingham
Local collaborator:	Carron Sintler, Consultant Physiotherapist for Stroke Services
BCHC Ref.:	BCHCASR269079.NonPortfolio
IRAS Ref.:	269079

Birmingham Community Healthcare NHS Foundation Trust has reviewed your application for the research study described above. The review was based on the information described in the application form, protocol and supporting documents. The documents reviewed are listed below:

Document:	Version:	Date:
HRA Approval Letter		17.06.2020
REC FO		12.06.2020
IRAS form		
Protocol	V10	28.04.2021
Patient leaflet	V4	12.05.2021
Permission to contact form	V3	25.08.2021
Guidance for clinicians		
NSA 01 30.11.2020 Due to the COVID pandemic and restrictions with face to face administration of the various elements of the study protocol, we propose that the face to face interactions such as recruitment, self-management interventions and assessments will be carried out over phone calls or online meeting applications such as zoom. All consenting processes will be converted to verbally recorded or electronic methods. The delivery of assessment tool such as the pedometer and any other material will be done through post. We expect that these amendments will be applied till the covid restrictions are in place and will revert to the original protocol after the covid restrictions ease.		HRA Approval email 10.12.2020
AM 01 14/05/2021		HRA Approval email 16.06.2021

This study involves approaching participants in the sub-acute hospital and recruiting them after their discharge in the community. However due to the pandemic, non-covid studies are not being prioritised in the NHS and hence recruitment has been delayed. In order to improve recruitment for this study we would like to amend two aspects of the study. 1) We would like to open up the inclusion criteria to recruit participants who are within 6 months post stroke rather than just within the 3 months previously proposed. 2) We would like to extend our recruitment strategy to the community using the following methods: Through the Stroke Association and Different Strokes websites, Advertisements in local magazines/newsletters in Birmingham, Leaflets and posters placed in identified GP surgeries and GPs handing out study leaflets to patients with stroke.	
NSA 02 25/08/2021 Minor updates to the consent to contact form as requested by the NHS site	

Confirmation of Capacity and Capability

Birmingham Community Healthcare NHS Foundation Trust is pleased to confirm that the Trust has the capacity and capability to deliver your research. Please find attached approved organisation information documents as confirmation.

Your research can commence as of today (29.09.2021).

Please also ensure that you notify the R&I team with the following information:

1. Any amendment made to this research.
2. Any incident or complaint relevant to the conduct of the research within this Trust. This includes any event that could have, or did, lead to loss of data, a confidentiality breach, damage to property, and/ or harm to participants.
3. A summary of the research findings when available.

Details of this research are held on the Trust research database "EDGE".

Please contact the R&I team if you need any support with your research or if you have any queries regarding the above.

May we take this opportunity to wish you success with your research.

Kind regards
Research and Innovation

Priti Parmar
Research and Innovation Manager

Address: Research and Innovation, Medical Directorate, Birmingham Community Healthcare Foundation NHS Trust, 1st Floor, 3 Priestley Wharf, Holt Street, Birmingham. B7 4BN
Mobile: 07714 847 549
Email:
Web: www.bhamcommunity.nhs.uk

Please consider the environment before printing this e-mail

Reminder: R&I Showcase Event will take place **12.45-14.30pm** from the **11 - 15th October 2021**. Please **register** to join us for this exciting opportunity to learn about

Appendix 23: Consent forms for participation in the feasibility study

UNIVERSITY OF BIRMINGHAM

School of Sport, Exercise, and Rehabilitation Sciences

CONSENT FORM FOR PARTICIPANT FOR INTERVENTION

Study title: Feasibility of a self-management intervention for improving mobility for patients following stroke in the community

(Please tick either yes or no) (Please initial box)

1. I confirm that I have read the information sheet dated 24/4/2021 version 10 about this study.

2. ☐ I confirm that I understand the above information sheet about this study.

3. ☐ I confirm that I have had the opportunity to ask questions about this study and all my questions have been satisfactorily answered.

4. ☐ ☐ I understand that **my participation is voluntary** and that I am **free to withdraw at any time**, **without giving any reason**, without my medical care or legal rights being affected or compromised in any way. I am under no obligation to partake in the study. (I understand if I withdraw from the study, my data will still be used for research purposes but no further data will be collected from me after my withdrawal from the study).

5. I agree to being contacted about taking part in a discussion group following the program. YES/NO

6. ☐ I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.

7. ☐ I agree to my General Practitioner being informed of my participation in the study. I agree to my General Practitioner being involved in the necessary exchange of information about me between my GP and the research team.

8. ☐ ☐ I understand that the data collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.

9. I agree to take part in this study.

(Patient name)	*(Patient signature)*	*(Date)*
…….		
(Witness name)	*(Witness signature)*	*(Date)*
(Researcher name)	(Researcher signature)	(Date)

UNIVERSITY OF BIRMINGHAM

School of Sport, Exercise, and Rehabilitation Sciences

CONSENT FORM FOR PARTICIPANT FOR FOCUS GROUP

Study title: Feasibility of a self-management intervention for improving mobility for patients following stroke in the community

(Please tick either yes or no) (Please initial box)

1. I confirm that I have read the information sheet dated……. version …about the Focus group part of the study.

2. ☐ I confirm that I understand the above information sheet about the focus groups.

3. ☐ I confirm that I have had the opportunity to ask questions about this study and all my questions have been satisfactorily answered.

4. ☐ I understand that **my participation is voluntary** and that I am **free to withdraw at any time**, **without giving any reason**, without my medical care or legal rights being affected or compromised in any way. I am under no obligation to partake in the study. (I understand if I withdraw from the study, my data will still be used for research purposes but no further data will be collected from me after my withdrawal from the study).

5. ☐ I agree to take part in the focus group following the program and I understand that my views will be recorded on zoom. YES/NO

6. ☐ I agree to anonymous quotations from the focus groups being used for research purposes.

7. I want to see any quotations before they are used. YES/NO

8. ☐ I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.

9. ☐ I agree to my General Practitioner being informed of my participation in the study. I agree to my General Practitioner being involved in the necessary exchange of information about me between my GP and the research team.

10. ☐ I understand that the data collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.

11. I agree to take part in this study.

(Patient name) *(Patient signature)* *(Date)*

……

……
(Witness name) *(Witness signature)* *(Date)*

(Researcher name) (Researcher signature) (Date)

Appendix 24: Information sheets for participation in the feasibility study



Study Information Sheet for Participants - Version 10
Study title: Feasibility of a self-management intervention for improving mobility for patients following stroke in the community -Intervention information.

Why are we doing this study?

After a stroke, individuals' lives can be affected by various disabilities. They are cared for in the NHS by a team of doctors, nurses, and therapists. But when they get discharged, many people feel confused or feel left out by the healthcare services. They may struggle to cope with their condition in the community.

One way to help a person cope better with the after-effects of stroke is by teaching them to manage their health and rehabilitation by themselves with some support from health professionals. This means of self-help is called Self-management (SM). Self-management programs can empower patients by providing the knowledge and skills to better understand and manage their condition.

Walking is affected in 75% of people following a stroke. Gaining the ability to walk after having a stroke has been mentioned as their most important goal for rehabilitation. The purpose of the study is to test the use of a self-management intervention to improve mobility for people with stroke after their discharge from hospital.

This project is part of a PhD study. We invite you to take part in this project which will give you opportunities to gain better knowledge about your walking ability. So please consider participation in this project. Please read the following material and decide if you would like to participate. You can discuss the information with others and the researcher involved before you agree to take part in the study. We thank you for the time and effort spent on considering your participation in the study.

Who is doing the study?

This is a project done by researchers from the University of Birmingham in collaboration with the Birmingham Community Hospitals NHS foundation trust. University of Birmingham is the sponsor for this study. Dr. Sheeba Rosewilliam is a lecturer and physiotherapist registered with the Health and Care

Professions Council who teaches at the University of Birmingham and is carrying out this work with Mr. Ahmad Sahely as part of his PhD program. Mrs. Carron Sintler is a consultant physiotherapist who works in the Moseley Hall hospital and will be working on this project with the researchers.

Are you eligible to join the study?

All stroke survivors who are medically stable, within the first six months post-discharge from hospital, able to communicate reasonably, and have a device that can launch ZOOM programme if they need to participate remotely from home are eligible to take part in this study. It is important to note that your participation is entirely voluntary and you are not obliged to support this study. The standard of care you receive or your legal rights will not be affected in any way if you do not wish to participate in this study. Even if you decide to take part you will have the right to change your mind and may withdraw at any time without giving any reason. Even after you begin to participate, if you decide to withdraw at any time, this will not affect the standard care provided by the NHS. Any data collected up to withdrawal may still be used for research purposes. But no further data will be collected from you. You can find out more about how we use your information by asking one of the research team by sending an email to the researchers below.

What happens if you decide to participate?

If you decide to participate in the study, you will be given more information about your role in the study. We will read out the consent forms over zoom or on the phone and ask you for consent for each statement. We will send the consent forms electronically and you can either sign it electronically or send an email stating you are consenting to participate. You will be asked to sign consent forms electronically by one of the persons conducting the project. Your GP will be informed of your participation using a letter.

In order to be able to test the effectiveness of the self-management program you will be randomly allocated to either one of the two following groups:

1) a control or a standard care group that gets the opportunity to attend (in person or on zoom) a talk on improving walking ability and safety in walking

OR

2) a treatment group where you will participate in the self-management for walking program. You will attend an education session about the mobility training and safety. You will participate in setting goals and develop action plans for your walking. You will attend group exercise sessions every two weeks for twelve weeks and evaluate your own progress. The group exercise session will include exercises for warm up and cool down such as stretching, strengthening, endurance (stamina) and balance which will take between 30 to

45 minutes to perform. Due to the COVID pandemic, the intervention will take place over zoom or in person if government restrictions permit.

The treatment group will also be given a booklet with similar exercises to complete at home and a diary to record the activities you perform in an electronic copy. Or these documents can be posted to you as hard copies if you prefer. You can do as much exercises as possible at home and you are not forced to complete the training every day. However, regular exercise training has been shown to improve recovery and we would encourage you to try and complete the exercises as often as you can. Please make sure that you involve your family or carer in carrying out the activities at home for your own safety reasons. Once every two weeks the researcher will call you over the phone to review your progress.

Each participant in both the treatment and standard care groups will be assessed for their walking performance, confidence and emotional status three times during the project (at the start when you join the study, after 12 weeks and after 6 months). We will do assessments of your self-efficacy or confidence, goal-achievement, and the ability for self-monitoring your progress. This will be done using questionnaires, validated scales and recording diaries/documents that will be given to you either in an electronic format or completed over the phone. Other physical assessments include your physical function (time taken to walk 6-metres, maximum walking speed, distance walked in the community using a small pedometer sent to you by post), emotional and social performance using validated tests and questionnaires. The assessments will be done by a researcher who has had training in doing these assessments. Additionally, type of stroke, gender, date of birth, marital status and cognitive status will be recorded. Due to the COVID pandemic the data can be collected on electronic copies of the forms using emails or using zoom and telephone questioning.
All assessment and interventional activities can take place over zoom.
Assessments will be arranged at a time convenient to the participants. Please note that there will be no financial reimbursement for this part of the study.
The total length of your involvement in this study will be 6 months.

How to Join A Zoom Meeting?
If you are unfamiliar with the zoom, the researcher will call you on your phone to help you set up zoom on a suitable electronic device. They will also have trial zoom meetings before the actual study meetings to make sure you can use zoom.
Here's a step-by-step guide to join a Zoom meeting quickly:

Note: The same steps apply to both your laptop and your phone.
To join Using A Meeting Link, if you have a meeting link, just click on it or paste it into your web browser to join the meeting.

With your agreement we may invite you to participate in a group discussion about your experience in this project and further details of this will be provided at the three-month assessment.

How will we use information from you?

We will need to use information from you for this research project. We will have your name and contact details for communication purposes. We will keep all information about you safe and secure. All your assessment information will be made anonymous and stored securely in the researcher's office.
The electronic consent forms will have your name and contact details. These will be stored safely in password protected computers at the University of Birmingham. All information from assessment questionnaires and focus groups will be made anonymous and stored securely in password-protected computers and hard copies will be stored in filing cabinets in the University office. All personal data will be made anonymous using codes. Data will not be shared with any person other than those involved in the project. Reports for the University and published data will not include your personal details. Please note that the anonymous data will be securely stored for 10 years at the University and contact details will be stored for 3 years in case we need to share findings with you. After this time the data will be destroyed or deleted.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- leaflet available from Mr.Ahmad Sahely
- by asking one of the research team listed below
- by sending an email to [redacted],

or [redacted] or

- [redacted]
- by ringing us on [redacted].

Why should I participate in the study?

Your contribution to this study is highly valued since it will help us to identify whether the new self-management intervention is feasible and effective in improving confidence and walking ability for stroke survivors. It is possible that you will personally benefit by improving your knowledge about improving your

walking as well as confidence to manage your rehabilitation if you are in the group having the self-management intervention. With the knowledge that you share with us we hope to further refine the processes and improve the quality of care delivered for future patients with stroke.

Are there any risks?

The risks involved in participating in this study are minimal. You may feel fatigue which is a common symptom during the recovery after stroke, but no major problems have been found with people who have used similar training programs. You will be supervised in group sessions by the researcher and at home by a family member to keep you safe. If you live alone, exercises of a level suitable for your capacity that you can do unsupervised will be prescribed for you. In case you have any concerns about the conduct of the study, you will be referred to Dr. Sheeba Rosewilliam who is the chief investigator for this study for further help. Regardless of this, if you wish to complain, or if you have any concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the research governance email address given below. The University has in force a Public Liability Policy, which provides cover for claims for "negligent harm", and the activities here are included within that coverage.

What happens at the end of the study?

If this new intervention is found to be effective, then it will be recommended for wider practice. The findings will be written up. These findings will then be published in health journals and presented to professionals at conferences. The findings will also be disseminated in the local NHS trusts in the form of presentations and posters. If you would like to know the outcome of the study please feel free to contact the researcher involved and copies of reports will be sent to you. Anonymous data from this study will be used to support other similar research in the field of rehabilitation.

Thank you

Thank you for taking time to read the information sheet and considering participation in the study.

Contacts

1. **Dr. Sheeba B Rosewilliam**, School of Sport, Exercise, and Rehabilitation sciences, University of Birmingham, B15 2TT. Email: , Tel:
2. **Mr. Ahmad Sahely**, School of Sport, Exercise, and Rehabilitation sciences, University of Birmingham, B15 2TT. Email: , Tel:

3. **Mrs. Carron Sintler,** Consultant Physiotherapist, Moseley Hospital, Alcester road, Moseley Birmingham. Phone:
4. Research Governance , University of Birmingham, email: ADM-researchgov@adf.bham.ac.uk

UNIVERSITY OF BIRMINGHAM

Study Information Sheet for Participants for focus groups- Version 3
Study title: Feasibility of a self-management intervention for improving mobility for patients following stroke in the community - Focus group.

Why are we doing this study?

After a stroke, individuals' lives can be affected by various disabilities. They are cared for in the NHS by a team of doctors, nurses and therapists. But when they get discharged, many people feel confused or feel left out by the healthcare services. They may struggle to cope with their condition in the community.

One way to help a person cope better with the after-effects of stroke is by teaching them to manage their health and rehabilitation by themselves with some support from health professionals. This means of self-help is called Self-management (SM). Self-management programs can empower patients by providing the knowledge and skills to better understand and manage their condition.

Walking is affected in 75% of people following a stroke. Gaining the ability to walk after having a stroke has been mentioned as their most important goal for rehabilitation. The purpose of the study is to test the use of a self-management intervention to improve mobility for people with stroke after their discharge from hospital.

This project is part of a PhD study. This project has two phases for data collection. The first phase involved being randomly allocated to a self-management programme for mobility or to a group with only education and assessment. We invite you to take part in this second phase of this project which will give you opportunities to voice your opinions about the study. Please read the following material and decide if you would like to participate. You can discuss the information with others and the researcher involved before you agree to take part in the study. We thank you for the time and effort spent on considering your participation in the second phase of this study.

Who is doing the study?

This is a project done by researchers from the University of Birmingham in collaboration with the Birmingham Community Hospitals NHS foundation trust. University of Birmingham is the sponsor for this study. Dr. Sheeba Rosewilliam is a lecturer and physiotherapist registered with the Health

and Care Professions Council who teaches at the University of Birmingham and is carrying out this work with Mr. Ahmad Sahely as part of his PhD program. Mrs. Carron Sintler is a consultant physiotherapist who works in the Moseley Hall hospital and will be working on this project with the researchers.

Are you eligible to join the study?

You were previously asked to join the self-management study and kindly agreed to participate in the study. We want to let you know that your participation is much appreciated. You also have a device that can launch ZOOM Programme which you can use for this group discussion. We would like to find out your views since you took part in the first phase of the study. We would like to know about your reasons for participating in the study, your views on the feasibility of implementing the intervention, the components of the intervention and how they can be improved. We plan to collect views of participants through focus groups. Your participation in the focus groups is entirely voluntary and you are not obliged to support this work. The standard of care you receive or your legal rights will not be affected in any way if you do not wish to participate in this study. Even if you decide to take part you will have the right to change your mind and may withdraw at any time without giving any reason. Even after you begin to participate, if you decide to withdraw at any time, this will not affect the standard care provided by the NHS. Any data collected up to withdrawal may still be used for research purposes. But no further data will be collected from you. You can find out more about how we use your information by asking one of the research team by sending an email to the researchers below.

What happens if you decide to participate?

If you decide to participate in the study, you will be given more information about your role in the study. You will be asked to sign consent forms specifically for the focus groups by one of the persons conducting the project. Due to COVID pandemic, for the focus group study we will gain verbal consent on zoom in separate recordings. We will also keep the verbally recorded consents in an audio format in a password protected file on the University server for 10 years. You will be asked to participate in a single focus group which is a group discussion about your experience in this project. You will be asked to discuss your motivation, feedback on the components of the program, the feasibility and sustainability of the program and any other aspects of the study. The group discussion will last for about 45 mins to 1 hour. If you agree to participate, the focus group will be set up at a time suitable for participants and take place in the community center or at the University of Birmingham. Due to the COVID pandemic the group discussion will be held on zoom rather than in person. The researcher will first contact you over phone to guide you on using

zoom and then set up the group discussion on zoom. Focus groups will be recorded on zoom. These zoom recordings will be transferred to the University server and deleted on zoom within 3 days. Recordings will be deleted from the server after being transcribed. All the text data will be made anonymous and stored securely in the researcher's office or on University server. We will reimburse the time for participants who attend these focus groups using shopping vouchers (£20.00per person).
How to Join A Zoom Meeting?

If you are unfamiliar with the zoom, the researcher will call you on your phone to help you set up zoom on a suitable electronic device. They will also have trial zoom meetings before the actual study meetings to make sure you can use zoom.
Here's a step-by-step guide to join a Zoom meeting quickly:
Note: The same steps apply to both your laptop and your phone.
To join Using A Meeting Link, if you have a meeting link, just click on it or paste it into your web browser to join the meeting.

How will we use information from you?
We will need to use information from you for this research project. We will have your name and contact details for communication purposes. We will keep all information about you safe and secure.
The consent forms will have your name and contact details. These will be stored safely in locked cabinets at the University of Birmingham. All information from assessment questionnaires and focus groups will be made anonymous and stored securely in password-protected computers and hard copies will be stored in filing cabinets in the University office. All personal data will be made anonymous using codes. Data will not be shared with any person other than those involved in the project. Reports for the University and published data will not include your personal details. If direct quotes are published from the group discussion, the researcher will ensure that you cannot be identified from the data that is published. Please note that the anonymous data will be securely stored for 10 years at the University and contact details will be stored for 3 years in case we need to share findings with you. After this time the data will be destroyed or deleted.
Where can you find out more about how your information is used?
You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- leaflet available from Mr.Ahmad Sahely
- by asking one of the research team listed below

- by sending an email to [redacted],

or [redacted] or

- dataprotection@contacts.bham.ac.uk
- by ringing us on [redacted].

Why should I participate in the study?

Your contribution to this study is highly valued since it will help us to identify whether the new self-management intervention is feasible and effective in improving confidence and walking ability for stroke survivors. With the knowledge that you share with us through the focus groups we hope to further refine the processes and improve the quality of care delivered for future patients with stroke.

Are there any risks?

The are no risks involved in participating in these focus groups. In case you have any concerns about the conduct of the focus groups, you will be referred to Dr. Sheeba Rosewilliam who is the chief investigator for this study for further help. Regardless of this, if you wish to complain, or if you have any concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the research governance email address given below. The University has in force a Public Liability Policy, which provides cover for claims for "negligent harm", and the activities here are included within that coverage.

What happens at the end of the study?

If focus groups participants identify that this new intervention is found to be effective, then it will be recommended for wider practice. The findings will be written up. These findings will then be published in health journals and presented to professionals at conferences. The findings will also be disseminated in the local NHS trusts in the form of presentations and posters. If you would like to know the outcome of the study, please feel free to contact the researcher involved and copies of reports will be sent to you. Anonymous data from this study will be used to support other similar research in the field of rehabilitation.

Thank you

Thank you for taking time to read the information sheet and considering participation in the study.

Contacts

1. **Dr. Sheeba B Rosewilliam**, School of Sport, Exercise, and Rehabilitation sciences, University of Birmingham, B15 2TT. Email: [redacted], Tel: [redacted]

2. **Mr. Ahmad Sahely**, School of Sport, Exercise, and Rehabilitation sciences, University of Birmingham, B15 2TT. Email: [redacted] , [redacted]
3. **Mrs. Carron Sintler,** Consultant Physiotherapist, Moseley Hospital, Alcester road, Moseley Birmingham. Phone: [redacted]
4. Research Governance , University of Birmingham, email: ADM-researchgov@adf.bham.ac.uk

Appendix 25: Permission to contact form for participants in the feasibility study

Permission to Contact Form

Title of Study: Self-Management Integrated Intervention for Improving Walking In the Community after Stroke

Name of the chief investigator: Dr Sheeba Rosewilliam (Physiotherapist/lecturer in the School of Sport, Exercise and Rehabilitation Sciences, University of Birmingham)
Local Researcher: Mrs. Carron Sintler Consultant Physiotherapist, Stroke services, Moseley Hall hospital.
Ahmad Sahely (PhD student at the School of Sport, Exercise and Rehabilitation Sciences, University of Birmingham)
Email:

Staff member who approached you about this research (Name and Job Title):
……
…….

I would like to receive more information regarding this study of self-management support to improve walking in the community after stroke. I agree to the research team contacting me to set an appointment date and time to take part in the study or discuss further information.

Please complete how you would prefer to be contacted below and return to a member of your therapy team as soon as possible.

I agree to be contacted by telephone: Yes / No
Telephone number: ……

I agree to be contacted by email (I am aware that email communication is not a secure form of communication): Yes / No
Email: ……

I agree to be contacted by letter at the following address: Yes / NO
Full postal address:
……
……
……

Patient Name……..
Date…….
Patient
Signature……
……

Appendix 26: Data management document sent to participants in the feasibility study

NHS
Health Research Authority

This document explains how health researchers use information from patients. If you are asked to take part in research, you can ask what will happen in the study.

What is patient data?

When you go to your GP or hospital, the doctors and others looking after you will record information about your health. This will include your health problems, and the tests and treatment you have had. They might want to know about family history, if you smoke or what work you do. All this information that is recorded about you is called patient data or patient information.

When information about your health care joins together with information that can show who you are (like your name or NHS number) it is called identifiable patient information. It's important to all of us that this identifiable patient information is kept confidential to the patient and the people who need to know relevant bits of that information to look after the patient. There are special rules to keep confidential patient information safe and secure.

What sort of patient data does health and care research use?

There are lots of different types of health and care research.

If you take part in a clinical trial, researchers will be testing a medicine or other treatment. Or you may take part in a research study where you have some health tests or answer some questions. When you have agreed to take part in the study, the research team may look at your medical history and ask you questions to see if you are suitable for the study. During the study you may have blood tests or other health checks, and you may complete questionnaires. The research team will record this data in special forms and combine it with the information from everyone else in the study. This recorded information is research data.

In other types of research, you won't need to do anything different, but the research team will be looking at some of your health records. This sort of research may use some data from your GP, hospital or central NHS records. Some research will combine these records with information from other places, like schools or social care. The information that the researcher collects from the health records is research data.

Why does health and care research use information from patients?

In clinical trials, the researchers are collecting data that will tell them whether one treatment is better or worse than other. The information they collect will show how safe a treatment is, or whether it is making a difference to your health. Different people can respond differently to a treatment. By collecting information from lots of people, researchers can use statistics to work out what effect a treatment is having.

Other types of research will collect data from lots of health records to look for patterns. It might be looking to see if any problems happen more in patients taking a medicine. Or to see if people who have screening tests are more likely to stay healthier.

Some research will use blood tests or samples along with information about the patient's health. Researchers may be looking at changes in cells or chemicals due to a disease.

All research should only use the patient data that it really needs to do the research. You can ask what parts of your health records will be looked at.

How does research use patient data?

If you take part in some types of research, like clinical trials, some of the research team will need to know your name and contact details so they can contact you about your research appointments, or to send you questionnaires. Researchers must always make sure that as few people as possible can see this sort of information that can show who you are.

In lots of research, most of the research team will not need to know your name. In these cases, someone will remove your name from the research data and replace it with a code number. This is called coded data, or the technical term is

pseudonymised data. For example, your blood test might be labelled with your code number instead of your name. It can be matched up with the rest of the data relating to you by the code number.

In other research, only the doctor copying the data from your health records will know your name. They will replace your name with a code number. They will also make sure that any other information that could show who you are is removed. For example, instead of using your date of birth they will give the research team your age. When there is no information that could show who you are, this is called anonymous data.

Where will my data go?

Sometimes your own doctor or care team will be involved in doing a research study. Often, they will be part of a bigger research team. This may involve other hospitals, or universities or companies developing new treatments. Sometimes parts of the research team will be in other countries. You can ask about where your data will go. You can also check whether the data they get will include information that could show who you are. Research teams in other countries must stick to the rules that the UK uses.

All the computers storing patient data must meet special security arrangements.

If you want to find out more about how companies develop and sell new medicines, the Association of the British Pharmaceutical Industry has information on its website.

What are my choices about my patient data?

- You can stop being part of a research study at any time, without giving a reason, but the research team will keep the research data about you that they already have. You can find out what would happen with your data before you agree to take part in a study.
- In some studies, once you have finished treatment the research team will continue to collect some information from your doctor or from central NHS records over a few months or years so the research team can track your health. If you do not want this to happen, you can say you want to stop any more information being collected.

- Researchers need to manage your records in specific ways for the research to be reliable. This means that they won't be able to let you see or change the data they hold about you. Research could go wrong if data is removed or changed.

What happens to my research data after the study?

Researchers must make sure they write the reports about the study in a way that no-one can work out that you took part in the study.

Once they have finished the study, the research team will keep the research data for several years, in case they need to check it. You can ask about who will keep it, whether it includes your name, and how long they will keep it.

Usually your hospital or GP where you are taking part in the study will keep a copy of the research data along with your name. The organisation running the research will usually only keep a coded copy of your research data, without your name included. This is kept so the results can be checked.

If you agree to take part in a research study, you may get the choice to give your research data from this study for future research. Sometimes this future research may use research data that has had your name and NHS number removed. Or it may use research data that could show who you are. You will be told what options there are. You will get details if your research data will be joined up with other information about you or your health, such as from your GP or social services.

Once your details like your name or NHS number have been removed, other researchers won't be able to contact you to ask you about future research. Any information that could show who you are will be held safely with strict limits on who can access it.

You may also have the choice for the hospital or researchers to keep your contact details and some of your health information, so they can invite you to take part in future clinical trials or other studies. Your data will not be used to sell you anything. It will not be given to other organisations or companies except for research.

Will the use of my data meet GDPR rules?

GDPR stands for the General Data Protection Regulation. In the UK we follow the GDPR rules and have a law called the Data Protection Act. All research using patient data must follow UK laws and rules.

Universities, NHS organisations and companies may use patient data to do research to make health and care better. When companies do research to develop new treatments, they need to be able to prove that they need to use patient data for the research, and that they need to do the research to develop new treatments. In legal terms this means that they have a 'legitimate interest' in using patient data.

Universities and the NHS are funded from taxes and they are expected to do research as part of their job. They still need to be able to prove that they need to use patient data for the research. In legal terms this means that they use patient data as part of 'a task in the public interest'. If they could do the research without using patient data they would not be allowed to get your data.

Researchers must show that their research takes account of the views of patients and ordinary members of the public. They must also show how they protect the privacy of the people who take part. An NHS research ethics committee checks this before the research starts.

What if I don't want my patient data used for research?

You will have a choice about taking part in a clinical trial testing a treatment. If you choose not to take part, that is fine.

In most cases you will also have a choice about your patient data being used for other types of research. There are two cases where this might not happen:

1. When the research is using anonymous information. Because it's anonymous, the research team don't know whose data it is and can't ask you.
2. When it would not be possible for the research team to ask everyone. This would usually be because of the number of people who would have to be contacted. Sometimes it will be because the research could be biased if some people chose not to agree. In this case a special NHS group will check that the reasons are valid. You can opt-out of your data being used for this sort of research. You can ask your GP about opting-out, or you can find out more.

Who can I contact if I have a complaint?

If you want to complain about how researchers have handled your information, you should contact the research team. If you are not happy after that, you can contact the Data Protection Officer. The research team can give you details of the right Data Protection Officer.

If you are not happy with their response or believe they are processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

Appendix 27: Staying safe document

Copyright: www.safeexerciseathome.org.au Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License.



SAFE EXERCISE AT HOME

STAY SAFE USING ONLINE EXERCISE RESOURCES

Before you start:

- ❑ Do you have the necessary technology? A laptop or tablet (eg iPad) is ideal. The screen of a phone may be too small.
- ❑ Do you have a reliable internet connection? If not print the exercise sheets.
- ❑ Can you see your screen easily while you exercise? Set your computer or tablet up somewhere stable where you can easily see the screen. Rest it on a few large books on the kitchen bench to make the screen the right height.
- ❑ If applicable, can you hear the instructions? Try turning up the volume on your device.
- ❑ Get your equipment ready (eg weights, sturdy support, water bottle, etc).
- ❑ If you are doing a live online class, make sure you have the correct app downloaded (eg Zoom, Skype). Contact your instructor if you're unsure.
- ❑ Have a clear space to exercise. Remove obstacles (eg rugs, cords) so you don't trip.
- ❑ Remove potential distractions and risks such as pets.
- ❑ Exercise in a well-lit area that is not too hot or cold.
- ❑ Wear comfortable clothing you can move in and well-fitting shoes or runners.

While exercising and watching your screen

- ❑ Only have one exercise on your screen at a time.
- ❑ Exercise at your own pace. Don't try to keep up with the exercise demonstrator.
- ❑ Balance exercises must be done safely. If needed, use a bench, table, or sturdy chair next to you or in front and a wall close behind to steady you.

Copyright: www.safeexerciseathome.org.au. Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License.

- ❑ Listen to your body! If an exercise causes you pain, discomfort, or you feel unsteady or unsafe, either modify the exercise (eg do an easier version, hold on for balance support) or leave it out. Seek advice, if you need, from an exercise specialist (physiotherapist/exercise physiologist).
- ❑ Have someone else nearby when you exercise if possible, especially for the first time (respecting any social distancing recommendations). Alternatively keep your phone in reach if you live alone.
- ❑ Start any new exercise slowly and carefully. If there is a video, watch the video before you try the exercise. If the exercise has an 'easy' and a 'hard' option, try the easy option first.
- ❑ If you are doing a live online class (eg one run by a health professional or exercise instructor) make sure you can see the instructor and they can see you. It may be distracting if you can also see other people exercising.

Stop exercising immediately *If you become dizzy, develop chest pain or feel unwell. You should discuss these problems with a professional.*

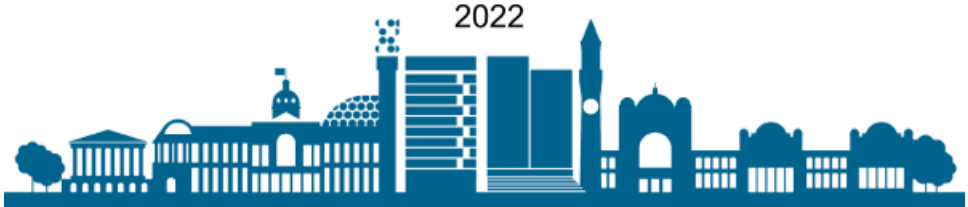
Appendix 28: Slides for the education sessions

UNIVERSITY OF BIRMINGHAM

Self-Management Integrated Mobility Training to Improve Walking in the Community Following Stroke

Patient Education
IRAS Number: 269079

Ahmad Sahely
2022



Version 5 Dated: 30/10/20 IRAS Number: 269079

Agenda

- Why are we doing this session?
- How can a stroke affect your mobility?
- Why is it important to recover mobility after having a stroke?
- What can we do to improve our mobility?
- How can you be safe when you are walking around?
- How can you learn to manage this part of your rehabilitation on your own?
- Time for open questions.



Version 5 Dated: 30/10/20 IRAS Number: 269079

Why are we doing this session?



- Only 50% of people with stroke leave the hospital with a complete assessment of their needs and goals set for their rehabilitation.
- Almost half (45%) of stroke survivors feel lost or abandoned after they leave hospital.
- The main goal of this education session is to help you to increase your self confidence and ability to be independent in performing your daily activities.

How can a stroke affect your mobility?



A stroke can affect how well you sit, move, balance, stand and walk

<u>The main problem causing inability to walk is to do with your muscles:</u>

- This includes weakness of the muscles and tightness on one side of your body.
- This can result in the joint becoming fixed in one position.
- You might have a high tone which makes your muscles stiff and tight or low tone where the muscles may be floppy or loose.

UNIVERSITY OF BIRMINGHAM

How can a stroke affect your mobility?

- Difficulty in walking because of having pain in your legs
- You may feel your movement is slow or clumsy.
- Feel very tired after walking even a short distance.
- Difficulty keeping your balance, feeling unsteady or dizzy.
- Losing sensation or having pins and needles
- You may have swelling on your foot or leg.



UNIVERSITY OF BIRMINGHAM

Version 5 Dated: 30/10/20 IRAS Number: 269079 Today

Why is it important to recover mobility after having a stroke?



What can you do to improve your mobility?

If you are under NHS care

Your physiotherapist will assess how well you move, sit, stand and walk.

They will then work with you to set goals and

They will develop a rehabilitation program to meet your goal of walking.

If you are not under NHS care:

Practice walking with your carer.

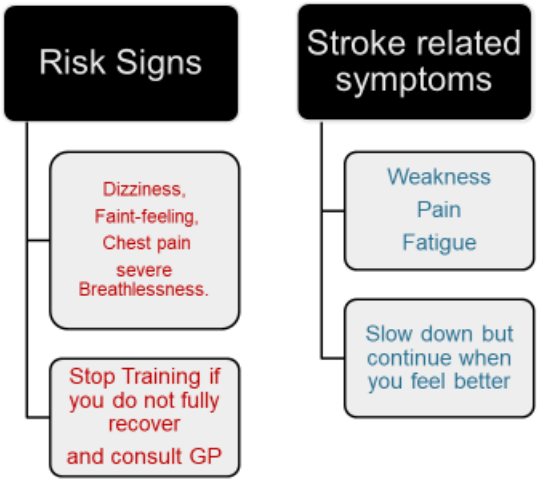
The more you do it is better for you.

BE SAFE

UNIVERSITY OF BIRMINGHAM

Safety in walking

There are two types of risks:



UNIVERSITY OF BIRMINGHAM

Version 5 Dated: 30/10/20 IRAS Number: 269079

How can you be safe when you are walking around?

- **Safety is first.**

Please note that while you are walking please follow the safety precautions:

- Avoid walking in socks, slippers or loose fitting shoes.
- Wear comfortable clothing which is not restrictive and could cause a trip over.
- If you have a walking aid, don't forget to use it.

- If you feel tired while training, consider to keep your training within the tolerable level.
- Keep your home clutter-free so that you don't trip
- Wear your glasses if you have one.
- Remove loose rugs
- Make sure you don't have loose wires or pets in your way.
- If you walk outside, you should consider walking with another person
- Be aware of uneven and slippery surfaces.

UNIVERSITY OF BIRMINGHAM
Version 5 Dated: 30/10/20 IRAS Number: 269079

- **Repetition** is key to improvement, so try to walk short distances but as often as possible.
- Movement and exercises can help to reduce muscle stiffness and pain.
- Do exercises to improve your balance and strength to help with walking.

- While you may make the most improvement in the first six months, regular activity will help you to continue your recovery.
- Exercise improves your fitness, your general health and reduces your risk of having another stroke.
- You could join an exercise group at your local community health centre or a fitness centre.

UNIVERSITY OF BIRMINGHAM
Version 5 Dated: 30/10/20 IRAS Number: 269079

Self-management (SM) Programs

- Self management is when we take control of our health and manage our recovery by ourselves
- We can be supported a little bit by therapists, family or friends.
- Main need for this is –OUR CONFIDENCE!

Self-management (SM) Programs

- Self-management can improve your ability to do more general activities like dressing.
- It can help to socialise more.
- It will also make us feel happy and proud about ourselves.

UNIVERSITY OF BIRMINGHAM
Version 5 Dated: 30/10/20 IRAS Number: 269079

Self-Management for walking

With a focus on walking:

- Improve your knowledge about your stroke,
- Improve your knowledge about what is required for walking in the community
- Gain the required skills to perform walking.
- Practice the activities repeatedly.
- Progress your training.

How will the study help you?

In this program you will be engaged in selecting goals for your rehabilitation in consultation with a researcher.

<u>You will also have the opportunity to:</u>

- ✓ Develop an appropriate plan for your training at home
- ✓ monitor your daily training and progress
- ✓ receive feedback and support from the therapist and peers
- ✓ Participate in group exercise sessions

UNIVERSITY OF BIRMINGHAM
Version 5 Dated: 30/10/20 IRAS Number: 269079

What will happen in the next 12 weeks?

Week 1: (Group and Individual)

a) Education sessions on zoom due to the covid pandemic

b) Self-management strategies:

- Individualised goal-setting and action-planning for mobility training.
- Patient will be taught home exercises using a booklet and self-monitoring of mobility training using a recording diary.

Week 2, 4, 6, 8 &10: (Group)

- The researcher will conduct one group session every other week for 10-12 people where participants are taught exercises for strengthening, balance, and mobility. (5 sessions in total on zoom due to covid pandemic)
- Patient-experts (trained stroke-survivors) will provide peer-support during the group sessions.



Week 3, 5, 7, 9 &11: (Individual)
Phone calls by a researcher to review goals and progress.

Week 12: (Group)
Reiteration of safety, reviewing mobility-training and positive reinforcement.

Assessments:
at recruitment, after 3 months, and after 6 months over zoom due to pandemic.

There will be 2 types of outcome measures (self-management and functional performance)



Common Challenges

To reduce the risk of physical symptoms that are related to stroke such as fatigue, weakness, and pain you should:

- ✓ Start with warm up and end with cool down exercises
- ✓ Keep your training within the tolerable (mild to moderate) level especially if feel unsteady while practising the exercises.
- ✓ Consult your therapist if you need to modify your training plan.

Time for open questions





UNIVERSITY OF BIRMINGHAM

Version 5 Dated: 30/10/20 IRAS Number: 269079

Appendix 29: Goal setting and action planning documents

Your Goals and Action Plans

Participant id: Date:

- Before you start your exercise programme to improve your walking, we want you to think of what you want to achieve related to walking in the community (**your goal**).
- Once you decide on your goal then your researcher will help you decide on what exercises you must do to achieve your goal. This is your **action plan** to reach your goal.
- In your action plan, it is important to mention what exercises, when they will be done and how many will be done.
- You can review your goals and action plans regularly along with the researcher.
- Please complete this form either on your own or get help from a family member if you have difficulty in writing.

SET YOUR OWN GOAL:

1. I would like my carer to be present and involved in every step of this process.
   Yes/ No

2. Who is your carer that you would like to be involved for discussing your goals and participation in this study?

3. Future goals for walking
   a. In terms of walking, what would you like to achieve at the end of three months? (Long term goal)

   b. Why is it important for you to achieve the above goal (Motives/Values)?

c. What skills do you think, you need to reach the above goals?

d. What barriers do you think you need to overcome to achieve these goals?

Session no.	**Date**	**Goals** (within the next couple of weeks, what activity related to walking do you want to be able to do?)	**Action plan** (how to achieve goal)
Week 1			
Week 3			
Week 5			
Week 7			

Week 9			
Week 11			
Final review			

To be completed by the researcher after follow up calls

At baseline

……
……
……
……

Week 3

……
……
……
……

Week 5

……
……
……
…..

Week 7

……
……
……
….

Week 9

……
……
……
…..

Week 11

……
……
……
……

Final review:

……
……
……
……
……..

Appendix 30: Recording diary for intervention group

Participant Recording Diary

Participant Study ID: ……
Starting Date……

This is a diary to record what exercises you are doing every week. Please note that this record will help you, the researcher and your carer to keep track of your improvement.

- Write the name or number of the exercise that has been suggested from the exercise booklet given to you, in the first column.
- Please put a tick (√) against the days when you do the exercises or put (X) if you do not.
- Score your confidence in doing the exercises

I believe that I was totally unable to do the exercise.

I believe that I was able to do the exercise extremely well.



To indicate your confidence in doing an exercise use a simple scale from 0-10. Use the picture below as guidance.

- Researcher will discuss the notes in your diary every two weeks.
- Please keep this diary for future review. Please return this recording diary at the end of the project to help us analyse your progress.

Week 1 **Exercise** (name or number):	**Date**	**Completed (check √ or x)**	**Confidence in performing the exercise (0-10)**	**Any problems with completing your exercise**	**Number of steps** **(Pedometer readings)**
	Sunday				
	Monday				
	Tuesday				
	Wednesday				
	Thursday				
	Friday				
	Saturday				

Week 2 **Exercise** (name or number):	**Date**	**Completed (check √ or x)**	**Confidence in performing the exercise (0-10)**	**Any problems with completing your exercise**	**Number of steps** **(Pedometer readings)**
	Sunday				
	Monday				
	Tuesday				
	Wednesday				
	Thursday				
	Friday				
	Saturday				

Week 3 **Exercise** (name or number):	**Date**	**Completed (check √ or x)**	**Confidence in performing the exercise (0-10)**	**Any problems with completing your exercise**	**Number of steps** **(Pedometer readings)**

	Sunday				
	Monday				
	Tuesday				
	Wednesday				
	Thursday				
	Friday				
	Saturday				

Week 4 **Exercise** (name or number):	**Date**	**Completed (check √ or x)**	**Confidence in performing the exercise (0-10)**	**Any problems with completing your exercise**	**Number of steps** **(Pedometer readings)**
	Sunday				
	Monday				
	Tuesday				
	Wednesday				
	Thursday				
	Friday				
	Saturday				

Week 5 **Exercise** (name or number):	**Date**	**Completed (check √ or x)**	**Confidence in performing the exercise (0-10)**	**Any problems with completing your exercise**	**Number of steps** **(Pedometer readings)**
	Sunday				
	Monday				
	Tuesday				
	Wednesday				
	Thursday				
	Friday				
	Saturday				

Week 6 **Exercise** (name or number):	**Date**	**Completed (check √ or x)**	**Confidence in performing the exercise (0-10)**	**Any problems with completing your exercise**	**Number of steps** **(Pedometer readings)**
	Sunday				
	Monday				
	Tuesday				
	Wednesday				
	Thursday				
	Friday				
	Saturday				

Week 7 **Exercise** (name or number):	**Date**	**Completed (check √ or x)**	**Confidence in performing the exercise (0-10)**	**Any problems with completing your exercise**	**Number of steps** **(Pedometer readings)**
	Sunday				
	Monday				
	Tuesday				
	Wednesday				
	Thursday				
	Friday				
	Saturday				
Week 8 **Exercise** (name or number):	**Date**	**Completed (check √ or x)**	**Confidence in performing the exercise (0-10)**	**Any problems with completing your exercise**	**Number of steps** **(Pedometer readings)**
	Sunday				
	Monday				
	Tuesday				
	Wednesday				

	Thursday				
	Friday				
	Saturday				

Week 9 **Exercise** (name or number):	**Date**	**Completed (check √ or x)**	**Confidence in performing the exercise (0-10)**	**Any problems with completing your exercise**	**Number of steps** **(Pedometer readings)**
	Sunday				
	Monday				
	Tuesday				
	Wednesday				
	Thursday				
	Friday				
	Saturday				
Week 10 **Exercise** (name or number):	**Date**	**Completed (check √ or x)**	**Confidence in performing the exercise (0-10)**	**Any problems with completing your exercise**	**Number of steps** **(Pedometer readings)**
	Sunday				
	Monday				
	Tuesday				
	Wednesday				
	Thursday				
	Friday				
	Saturday				

Week 11 **Exercise** (name or number):	**Date**	**Completed (check √ or x)**	**Confidence in performing the exercise (0-10)**	**Any problems with completing your exercise**	**Number of steps** **(Pedometer readings)**

	Sunday				
	Monday				
	Tuesday				
	Wednesday				
	Thursday				
	Friday				
	Saturday				
<u>Week 12</u> **Exercise** (name or number):	**Date**	**Completed (check √ or x)**	**Confidence in performing the exercise (0-10)**	**Any problems with completing your exercise**	**Number of steps** **(Pedometer readings)**
	Sunday				
	Monday				
	Tuesday				
	Wednesday				
	Thursday				
	Friday				
	Saturday				

Appendix 31: The TIDieR (Template for Intervention Description and Replication) Checklist

TIDieR
Template for Intervention Description and Replication

The TIDieR (Template for Intervention Description and Replication) Checklist*:

Information to include when describing an intervention and the location of the information

Item number	Item	Where located **	
		Primary paper (page or appendix number)	Other † (details)
	BRIEF NAME		
1.	Self-Management Intervention to Improve Mobility in the Community after Stroke (SIMS)	____137___	_____
	WHY		
2.	SM interventions have increasingly shown a positive effect on survivors' self-efficacy, emotional and functional recovery, and social participation.	___ 141___	Ref (Parke et al., 2015; Sahely et al., 2022; Warner et al., 2015)
	WHAT		
3.	Materials: Patient education (slides/safety tips brochure), goal setting (GAS form), action planning (exercise booklet), group sessions (physical or online), self-monitoring (pedometer/recording diary).	__145,146__	Appendices (19,27-30)

4.	Procedures: ***<u>Week 1: (Group and Individual)</u>*** • Education about impact of stroke, improving gait, self-management and safety. • Self-management strategies including individualised goal setting for mobility goals and action-planning using exercises from a booklet based on their baseline assessment. • Patient were taught home exercises using the same exercise booklets and self-monitoring of mobility training was done using a recording diary. A safety tips documents with resources for guidance was provided prior to the start of exercise plan. ***<u>Week 2, 4, 6, 8 &10: (Group)</u>*** An online meeting every two weeks for group exercise sessions and peer support provided by an experienced stroke patient. Participants are taught exercises for strengthening, balance, and mobility from the exercise booklets. Patient-experts will provide peer-support during the group sessions. The patient-experts are stroke-survivors who were paid from the PPI costs. ***<u>Week 3, 5, 7, 9 &11: (Individual)</u>*** A follow up call by the research therapist for reviewing goals, updating exercise plan and patient's progress in the programme every fortnight. ***<u>Week 12: (Group)</u>*** A reiteration of safety, review of mobility-training and positive reinforcement for long term sustainability.	__145,146__	_____ _

	WHO PROVIDED		
5.	Physiotherapists (researcher/students).	__145,146__	_____
	HOW		
6.	Education session delivered mainly online (face to face on request), goal setting and action planning delivered face to face (online on request), group sessions delivered remotely, follow up calls through phone calls and assessment done face to face unless requested by participants to be online.	__145,146__	_____
	WHERE		
7.	All activities were done at participants homes or online via Zoom meetings.	____144_____	_____
	WHEN and HOW MUCH		
8.	Patients recruited to participate within 6 months of discharge from acute care. The intervention lasted for 3 months. Exercises to be done and recorded every day. The intensity and duration of daily exercises depends on the level of recovery of the participant and describe in more details in the exercise booklet.	___145____	Appendix 19
	TAILORING		
9.	The intervention was planned to be personalised for each participant based on their baseline assessment. The exercise booklet has 3 levels of exercise. Also, therapist can discuss individual goals based on level of recovery.	___145_____	_____

	MODIFICATIONS		
10.‡	To improve safety in zoom classes as all participants chosen to meet online for the group sessions (because of COVID restrictions), a qualified researcher and a registered therapist were both present to deliver the classes. Some education sessions were presented to participants with communication/technical challenges by the research therapist at home instead of remote delivery.	__158-162__	_____
	HOW WELL		
11.	Planned: the intervention adherence and fidelity was assessed by the research team from the University of Birmingham (2 professors and a PhD student) in collaboration with senior clinicans and patients with expertise in stroke rehabilitation.	__147,148__	_____
12.‡	Actual: The intervention was delivered as planned with some flexibility in the mode of delivery (face to face vs. online). Overall, the participants appreciate the support they received during the period of intervention, reported some perceived improvements in their functional mobility and psychosocial parameters and showed their desirability to follow the protocol after finishing the programme.	__158,166__	_____

** **Authors** - use N/A if an item is not applicable for the intervention being described. **Reviewers** – use '?' if information about the element is not reported/not sufficiently reported.

† If the information is not provided in the primary paper, give details of where this information is available. This may include locations such as a published protocol or other published papers (provide citation details) or a website (provide the URL).

‡ If completing the TIDieR checklist for a protocol, these items are not relevant to the protocol and cannot be described until the study is complete.

* We strongly recommend using this checklist in conjunction with the TIDieR guide (see *BMJ* 2014;348:g1687) which contains an explanation and elaboration for each item.

* The focus of TIDieR is on reporting details of the intervention elements (and where relevant, comparison elements) of a study. Other elements and methodological features of studies are covered by other reporting statements and checklists and have not been duplicated as part of the TIDieR checklist. When a **randomised trial** is being reported, the TIDieR checklist should be used in conjunction with the CONSORT statement (see www.consort-statement.org) as an extension of **Item 5 of the CONSORT 2010 Statement.** When a **clinical trial protocol** is being reported, the TIDieR checklist should be used in conjunction with the SPIRIT statement as an extension of **Item 11 of the SPIRIT 2013 Statement** (see www.spirit-statement.org). For alternate study designs, TIDieR can be used in conjunction with the appropriate checklist for that study design (see www.equator-network.org).

Appendix 32: Rationale and psychometric properties of the used outcome measures

Outcome measures	Why they have been used	Psychometric properties
The Stroke self-efficacy questionnaire (Jones, Partridge and Reid, 2008; Riazi, Aspden and Jones, 2014).	To evaluate participant' self-efficacy in relation to functional performance and self-management. It is recommended for use in clinical and research interventions, and in evaluating stroke self-management interventions.	The new SSEQ has good psychometric properties and is a clinically useful assessment of self-efficacy after stroke. - Has a good face validity. - Has a strong linear relationship with the Falls Efficacy scores suggesting good criterion validity. - Has a good internal consistency (Cronbach Alpha 0.90) - The SSEQ is able to discriminate between participants who can/cannot walk.
The Goal Attainment Scale (GAS) (Hurn, Kneebone and Cropley, 2006; Rockwood et al., 2003; Stolee et al., 1999)	To measure participants' ability to achieve their goals	- Excellent interrater reliability in geriatric patient population (IRR= 0.88-0.93) - Responsiveness for mobility in older adults (effect size = 4.43; standardized response mean = 0.91; relative efficiency >100; Norman's responsiveness = 0.32).
The Patient Specific Functional Scale (Evensen et al., 2023; Stratford, Kennedy and Wainwright, 2014; Mathis et al., 2019)	To assess participants' ability to perform specific daily activities related to mobility.	- Excellent test-retest reliability (ICC = 0.81 for stroke patients and 0.82 for community-dwelling older adults). - Satisfactory content validity for stroke (80% of the PSFS items were classified as activities and participation in the ICF). - Convergent validity (Excellent correlation with the Lower Extremity Functional Scale for community-dwelling older adults (r=0.81)).
Functional Gait Assessment (FGA)	To determine the impact of SIMS on participants'	For stroke population: - Excellent test-retest reliability (ICC = 0.95).

(Lin et al., 2010; Thieme, Ritschel and Zange, 2009)	mobility. Particularly, it was used to assess postural stability during walking and ability to perform multiple motor tasks while walking.	- Excellent interrater reliability (ICC=0.94). - Excellent intrarater reliability (ICC=0.97). - Criterion and construct validity: FGA has a n excellent correlation with Functional Ambulatory Category, 10MWT, Gait Speed, Berg Balance Scale, and Rivermead Mobility Index. - Moderate responsiveness in detecting change at the 2 and 5 months of rehabilitation.
Timed Up and Go (Flansbjer et al, 2005; Knorr et al, 2010)	To assess mobility, balance, walking ability, and fall risk in older adults.	- Excellent test-retest reliability (ICC = 0.96). - Criterion validity (excellent correlation with 6MWT (r = -0.92)). - Construct validity (excellent association with Berg Balance Scale (-0.70, $p < 0.001$)).
10-meter Walking Test (Collen et al., 1990; Flansbjer et al., 2005; Perera et al., 2006; Tyson and Connell, 2009)	To assess walking speed (meters/second) over a short duration.	- Excellent test-retest reliability (ICC = 0.95 to 0.99) - Excellent intrarater reliability; ICC = 0.87 to 0.88 - Excellent interrater reliability; (ICC = 0.998) - Criterion validity: a. Excellent correlation with dependence in instrumental activities of daily living (r = 0.76) b. Excellent correlation with Barthel Index (r = 0.78) - Construct validity (Excellent correlation with Berg Balance Scale (r = 0.627)). - Responsiveness (small meaningful change = 0.05 m/s and substantial meaningful change = 0.10 m/s).
Six Minutes Walking Test (Flansbjer et al., 2005; Fulk et al, 2008; Kosak and Smith, 2005)	To assess the distance walked over 6 minutes (walking distance and endurance).	- Excellent Test-retest reliability (ICC = 0.86 - 0.99). - Adequate Intra-rater reliability (ICC=0.74). - Adequate Inter-rater reliability (ICC=0.78).

		- Criterion validity (excellent correlation with TUG, 10 mWT, and 12 MWT).
Number of steps walked per day using pedometer (Gebruers et al., 2010; Negrini et al., 2020; Young Lee et al., 2018)	To track level of physical activity.	- In stroke rehabilitation, pedometers found to be valid and had good test-retest reliability in a large number of settings. - Numerous studies demonstrated correlations between accelerometery and common stroke scales.
The Montreal Cognitive Assessment (MoCA) (Cumming et al., 2018; Toglia et al., 2011)	For the screening and assessment of cognitive ability of participants	For stroke population: - Interrater reliability between original and blind scoring for the visuospatial/executive MoCA items was the following: • Almost Perfect for trail-making (Kappa=0.94, 95% confidence interval [CI] 0.92-0.96) • Substantial for cube copy (Kappa=0.80, 95% CI 0.76-0.83) • Substantial for clock numbers (Kappa=0.67, 95% CI 0.62-0.73) • Moderate for clock hands (Kappa=0.46, 95% CI 0.42-0.51) • Moderate for clock contour (Kappa=0.49, 95% CI 0.40-0.58) - Internal consistency: Excellent internal consistency, higher than Mini Mental State Examination (Chronbach's alpha = 0.78 Vs. 0.60). - Criterion validity: a. Excellent correlation of MoCA with MMSE (r = 0.79) and Cognitive FIM scores (r = 0.67). b. Adequate correlation with discharge status (r = 0.40), which is higher than MMSE (r = 0.30).

		c. Stronger relationship of MoCA scores to rate of functional improvement (formula using admission and discharge FIM scores, LOS) than the MMSE. d. MoCA visuo-executive. sub score was strongest predictor of functional status and improvement in FIM scores.
The General Health Questionnaire (GHQ-12) (Rompple et al., 2013; Hardy *et al.*, 1999; Petkovska et al., 2015;)	To assess the psychological well-being of participants.	- The GHQ-12 has a good reliability and convergent validity in multiple contexts. - High internal consistency for general population (alpha coefficient of 0.86 -0.89). - The test–retest correlation (0.73). - The GHQ-12 correlated most highly with other mental health measures (such as the Brief Screen for Depression) and least with the Muscle Fatigue scale, providing evidence of discriminant validity.