A Qualitative Exploration of the Impact of Stroke on the Management of Pre-Existing Conditions

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Preface

I began undertaking the Professional Doctorate in Health Psychology at the University of West England since November 2017. In order to successfully complete this doctorate in line with UWE, the British Psychological Society, and the Health Care Professions Council's requirements I had to complete five competencies: 1) Professional Skills in Health Psychology; 2) Consultancy Skills in Health Psychology; 3) Teaching and Training in Health Psychology; 4) Psychological Interventions in Health Psychology; and 5) Research. The research component is split into 1) systematic review and 2) research thesis with reflective chapter. This thesis is the final product for the research competency.

I completed my MSc in Health Psychology at King's College London in 2014. After completion, I began working in academia for the National Institute of Stroke and Applied Neurosciences at the Auckland University of Technology, New Zealand. I worked as a Research Assistant and Teaching Assistant. Upon returning to the UK in 2016, I worked for the Stroke Association as a Stroke Recovery Co-ordinator. As part of this role, I undertook specialist training to support stroke survivors in their recovery and rehabilitation in the community. The support service I worked within included offering practical advice, emotional support, and communication support. This practice-driven post enabled me to build on my practitioner skills. However, it also allowed me to see the raw experiences of stroke survivors in the first 12-months of their recovery.

From my experiences and reviewing the literature, it was clear that this group of individuals lacked specific support for unmet needs. The "one-size-fits-all" approach that seemed to dominate care, appeared to not take the individual context into account. While assessing patient needs, it was evident that stroke survivors faced many challenges in their stroke recovery, which were multifaceted. In particular, the vast majority of patients were also managing additional long-term health conditions whilst focusing on their stroke recovery. After reviewing the literature, evidence was scarce and lacking. Working in a third sector organisation restricted the opportunity to conduct any research. Therefore, I saw the professional doctorate as an exciting opportunity to pursue this interest.

I completed a systematic review during the first year of the professional doctorate, titled ‘What Psychosocial Interventions Work for Stroke Survivors Well-Being in the First 6 Months? A Systematic Review’. Although the focus of the systematic review was interventions to support the unmet psychosocial needs of stroke survivors in the first 6-months post-stroke, it did not directly inform this research. Therefore, it has been included in Appendix A.

Abstract

Background: Stroke is a leading cause of disability in the UK with 1.3 million people living with the physical and psychosocial impact as part of their daily lives. In addition, over 85% of stroke survivors have at least one pre-existing long-term condition. Previous research on the management of long-term conditions has focussed on a single-disease approach and may not be reliably or helpfully applied to those with multimorbidity. The aim of this study was to explore the impact of having a stroke on the management of pre-existing conditions in the first 3 to 12-months post-stroke.

Method: An exploratory qualitative study was conducted. Fifteen participants (seven males and eight females; mean age 55 years) who had both experienced a stroke in the last 3 to 12-months and had been diagnosed with at least one long-term condition before the stroke, participated in virtual or face-to-face semi-structured interviews. Inductive Reflexive Thematic Analysis was used to analyse the transcribed data.

Findings: Four themes and one subtheme were identified: (1) 'I was OK I felt fine' – Positive illness representations prior to stroke. (2) 'I've had one I don't want any more' - Stroke as a 'teachable moment'. (3) Who does what? - Mismatch of expectations. (3.1) 'It's self-responsibility for every part of me' – Self management after stroke. (4) 'Nothing is going to be the same again': Acceptance and hope.

Conclusions: Participants held a positive health identity prior to their stroke, despite having pre-existing long-term conditions. The stroke experience challenged participants' health perceptions, resulting in a *teachable moment* where self-management and health behaviours changed. Participants were unclear as to who did what in terms of recovery and rehabilitation, including both management of the stroke and existing long-term conditions. Actions to improve health depended on participants’ value of health, what self-management meant to them and the support they received. Although participants had accepted their situation, they hoped their recovery would continue. Recovering from stroke in the context of pre-existing conditions provides additional challenges and considerations throughout the recovery journey. The applicability of the findings and future research are discussed.

Chapter 1 – Introduction and Literature Review

1.1 Introduction

This study aims to explore the impact of having a stroke on the management of pre-existing long-term conditions (LTCs) in the first 3 to 12-months after stroke. This chapter will include a review of the current evidence around the incidence, prevalence, and outcomes of stroke and LTCs. It will then focus on the relationship between stroke and multimorbidity. This section will provide a rationale for this study including the intended aims and research questions.

1.2 Stroke

Stroke is one of the leading causes of death and premature mortality in the UK (Bhatnagar et al., 2010; Stroke Association, 2020). In addition, there are currently 1.3 million stroke survivors in the UK, many living with neurological deficit and disability (NHS Digital, 2021). This population is considerable and growing, with 1.8% of the UK population having a stroke in their lifetime (NHS Digital, 2021), approximately 100,000 people per year in the UK (National Institute for Health and Care Excellence, 2022). A stroke occurs when the blood supply to an area of the brain is restricted, causing neurological deficits (Tadi & Lui, 2021). The neurological deficits can lead to increased disability and poor health outcomes for survivors (Feigin et al., 2010).

The abrupt onset of symptoms is a novel characteristic of stroke, presenting individuals with an acute medical crisis (Kirkevold, 2002). The commonest signs of stroke are sudden numbness or weakness on one side of the body in the face, arm, and/or leg; difficulty speaking or understanding speech; confusion; visual disturbances; trouble walking and/or lack of co-ordination; and/or a sudden severe headache (Centers for Disease Control and Prevention, 2022). With survival rates increasing over the last decade (Wafa et al., 2018), disability is a common outcome of survival (Wafa et al., 2020), and patients may experience emotional disorders, reduced functionality, communication difficulties, fatigue, and cognitive deficits (Stroke Association, 2022). Consequently, stroke has a negative impact on long-term functioning and quality of life in stroke survivors (Katan & Luft, 2018; Lincoln et al., 2012). Stroke outcomes can be influenced by the type of stroke experienced. There are three types of stroke: ischaemic stroke, haemorrhagic stroke, and transient ischemic attack (TIA). An ischaemic stroke occurs when the blood supply to the brain is restricted due to a blockage such as a blood clot (NHS, 2019). A haemorrhagic stroke occurs when there is a bleed within the brain (NHS, 2019). Ischaemic stroke accounts for approximately 85% of the prevalence with haemorrhagic strokes accounting for 15% (Musuka et al., 2015). The effects need to have lasted for longer than 24 hours or lead to death to be classified as a stroke (Feigin et al., 2021).

The causes, outcomes, and treatment strategies, differ according to the stroke type (Zhang et al., 2012). Nevertheless, it is widely recognised that all strokes are a significant cause of disability due to both initial symptoms and long-term impairments. A TIA is classified as a "mini stroke" as it shares the same medical characteristics as an ischaemic stroke, except the symptoms last for 24 hours or less (Lincoln et al., 2012). Therefore, the effects are deemed temporary. Nevertheless, TIAs are associated with a higher risk of future stroke (Lioutas et al., 2021), with stroke risk being between 2%-17% in the first 90 days after TIA (Hill & Coutts, 2011).

1.2.1 Stroke outcomes

Stroke survivors can experience a range of psychological, physical, and communication consequences, negatively impacting on quality of life, and leaving participants with long-term needs (McKevitt et al., 2011; Crichton et al., 2016). Such long-term needs include mental, emotional, daily living, communication, cognitive, physical health, financial, care and social needs (Lincoln et al., 2012), placing a burden on the individual, caregivers (Caro et al., 2018) and the NHS (Patel et al., 2020). The most common consequence of stroke is post-stroke fatigue (PSF; Baylor et al., 2014), with up to 75% of stroke survivors reporting problems within the first year (Wen et al., 2018). PSF has been reported to be influenced by time since stroke, type of stroke and geographical location (Alghamdi et al., 2021). It is distressing for stroke survivors and has been associated with poorer quality of life and an increased risk of death (Wu et al., 2015). PSF burden is exacerbated by other stroke-related symptoms, particularly post-stroke depression (PSD; Wen et al., 2018).

PSD is the most common psychological consequence affecting approximately a third of all stroke survivors (Volz et al., 2021). It tends to peak between 3-6 months after stroke onset, yet it can develop as early as hours after the stroke incident (Whyte & Mulsant, 2002). PSD reduces rehabilitation engagement (Hamid & MacKenzie, 2017), increases disability (Paolucci et al., 2019), reduces quality of life (Hilari et al., 2012) and increases mortality (Cai et al., 2019). Furthermore, anxiety affects a quarter of all stroke survivors (Knapp et al., 2020) leading to worsening functional outcomes (E. H. Lee et al., 2019). Improving Access to Psychological Therapies often reject referrals for stroke survivors due to the complexity of stroke recovery (NHS, 2017). Historically, there has been a lack of psychological support available for stroke survivors (NHS, 2017) and this study could inform the provision for support for stroke survivors.

PSD is impacted by other psychological entities such as identity and empowerment. Identity affects stroke survivors in response to their changing bodies (Nasr et al., 2016). A change in identity subsequently impacts stroke survivors' relationships such that their perspectives of how they viewed themselves in comparison to others, change. The theme of changing perspectives of the self and how others view them has been recurrent across studies and has been shown to have a detrimental impact on stroke outcomes. For example, negative identity changes can lead to lower mood and reduced quality of life and self-esteem (Lapadatu & Morris, 2017). Moreover, concepts such as power and empowerment contribute to stroke survivors' rehabilitation experience indicating a feeling of loss of control and powerlessness amongst survivors (Peoples et al., 2011). The need of enabling empowerment came from constantly assessing and reassessing the issues that arose in the rehabilitation process, such as relationships and collaborations with health care professionals, adjusting and accommodating to new limitations and changes, and the neglect of non-physical needs such as relationship support and psychological help (Peoples et al., 2011). Stroke recovery is demanding, and the additional psychological effects have detrimental impacts on recovery leading to poor outcomes (Medeiros et al., 2020).

1.2.2 Stroke recovery

Stroke recovery is gradual and can last from a few days to years. Globally, 60% of stroke survivors experience permanent damage and limitations, such as physical, cognitive, and psychological effects (Mackay et al., 2004). In a study of 9 stroke survivors across 63 interviews, the author suggested that stroke recovery follows a linear trajectory (Kirkevold, 2002). They proposed that individuals are in a "semi-stable" state approximately 6 to 12-months post-stroke, and it is within these first 12-months that stroke recovery may be divided into four phases; 1) trajectory onset: surprise and suspense; 2) initial rehabilitation: hard physical work; 3) continued rehabilitation: focus on psychosocial and practical adjustment; 4) semi-stable phase: going on with life. Current research exploring the functional recovery in the first 6-months after stroke supports this (K. B. Lee et al., 2015). Twenty stroke survivors were neurologically and functionally assessed by a physiotherapist at seven time points from 1-week to 6-months post-stroke. Stroke recovery was found to be rapid in the first 4-weeks and then decelerated in the later stage between 3 and 6-months (K. B. Lee et al., 2015). This further suggests that stroke recovery is gradual and prolonged. While there is a significant body of literature exploring the functional and psychological recovery of stroke patients, the context in which a patient is recovering is often overlooked (Kirkevold, 2002). A deeper understanding of the dynamics of the adjustment process is required to move toward more holistic and focused services.

Although a linear trajectory has been outlined by Kirkevold (2002), recent qualitative research indicates that this may not be the case (Hawkins et al., 2017). Stroke recovery has been argued to be more of a cyclical process of recovery including improvement and decline, as well as a process whereby identity is questioned (Hawkins et al., 2017). Consequently, finding a meaning, adjusting, and managing impairments all contribute to the cyclical process of recovery. This is supported by a recent qualitative study which investigated the experience of stroke in survivors the first-year post-stroke (Crowe et al., 2016). Four females and six males' mental well-being was measured using the Hospital Anxiety and Depression scale (Zigmond & Snaith, 1983) in addition to participating in semi-structured interviews. Using Interpretative Phenomenological Analysis, three themes were identified: fear of stroke, loss of self, and sense of isolation and aloneness, with underlying processes of reduced self-compassion and lack of acceptance (Crowe et al., 2016). These findings offer support for the cyclical process of stroke recovery and offers insight for potential psychological interventions. Such interventions may include identifying and addressing the underlying cause to psychological distress such as self-compassion and social isolation, as evidenced. To get the best outcomes for stroke survivors, self-management interventions have also been introduced to enhance stroke recovery (Ruksakulpiwat & Zhou, 2021). These interventions have pre-dominantly focused on the self-management of the consequences and effects of stroke as well as the self-management of recovery and prevention of a secondary stroke (Riegel et al., 2017).

1.2.3 Stroke recovery: Self-management

Self-management is related to the improvement of health outcomes and quality of life in people with LTCs (Anekwe & Rahkovsky, 2018). It also offers an overall contribution to the improvement of societal health (Ryan & Sawin, 2009) and has been argued to reduce the burden on health systems (Lorig & Holman, 2003). However, self-management is not a term with a single definition and can be an ambiguous concept for healthcare professionals and patients (Parke et al., 2015; Boger et al., 2015). Self-management has been defined as “a process in which individuals acquire skills, strategies and knowledge to manage the physical, psychological, emotional and social effects of a chronic condition” (Sadler et al., 2017, p. 1). This study has adopted the Royal College of Nursing (2022) definition of self-management, which is defined as:

> The systematic process of learning and practicing skills which enable individuals to manage their health condition on a day-to-day basis, through practicing and adopting specific behaviours which are central to managing their condition, making informed decisions about care, and engaging in healthy behaviours to reduce the physical and emotional impact of their illness, with or without the collaboration of the health care system. (para. 7)

The RCN’s definition suggests that changing health behaviours are also expected as well as acquiring skills to manage an LTC. These self-management behaviours include medication and treatment adherence, adjustment to diagnoses and consequences of conditions, as well as finding strategies to minimise disruption to life.

Current unhealthy lifestyles pose a major threat to public health (Department of Health, 2010a). Although modest changes in lifestyle choices are recommended, it is very difficult to achieve (Kelly & Barker, 2016), which could be attributed to the individualistic approach routinely adopted by institutions (Bossy et al., 2016). Typical self-management involves individuals making good lifestyle choices, often ignoring the wider societal influences on behaviour. The individual behaviours include adopting health protective and risk reducing behaviours, for example engaging in physical activity, eating fruits and vegetables, not using substances such as alcohol, tobacco, or drugs (Spring et al., 2012). Lifestyle is an extremely important modifiable risk factor for stroke (Rutten-Jacobs et al., 2018). In their cohort study across the UK, Rutten-Jacobs and colleagues (2018) found that stroke risk increased by 66% in individuals with an ‘unfavourable’ (no or one healthy lifestyle factor) lifestyle compared to those with a ‘favourable’ (three or four healthy lifestyle factors) lifestyle. Therefore, in addition to the rehabilitation process in stroke recovery, good self-management post-stroke includes engaging in rehabilitation, adhering to medication treatment, and living a healthy lifestyle (Fryer et al., 2016).

The term and concept of self-management has been found to be broadly unfamiliar to stroke survivors (Sadler et al., 2017). Sadler et al. (2017) interviewed 13 stroke survivors and 13 physiotherapists approximately 2 to 6-months post-stroke, in London. They used semi-structured interviews and used a thematic analysis approach. Stroke survivors were not familiar with the term *self-management* and were unable to link self-management with their stroke recovery (Sadler et al., 2017). Furthermore, physiotherapists viewed self-management as a process in which stroke survivors were expected to actively participate in their rehabilitation, recovery and manage their health. According to Sadler et al.’s (2017) findings, there are both individual and organisational hurdles in the early stages of self-management after stroke, with social and organisational factors also playing a role. This synthesis of qualitative research has provided insight into a mismatch of understandings between organisations, healthcare professionals and patients when it comes to self-management. This could be problematic for self-management in practice if expectations of stroke survivors and healthcare professionals are not aligned.

Although stroke survivors may not be familiar with the concept of self-management, research has shown that some self-management interventions can result in positive outcomes, such as improved quality of life for stroke survivors (Fryer et al., 2016). This is dependent on individuals acquiring the skills to successfully engage in self-management. In a systematic theory synthesis of 23 studies published after 2005, Babkair and Dickson (2017) found that stroke survivors find engaging in self-management difficult once discharged from hospital (Babkair & Dickson, 2017). They suggest that barriers to self-management in stroke survivors can be attributed to environmental, individual (such as medication non-adherence, lack of knowledge/understanding, reduced self-efficacy) and psychosocial factors. Since Babkair and Dickson (2017), little research has been conducted in understanding why people may or may not engage in self-management after stroke.

As outlined in the NHS England ‘Supported Self-Management’ (SSM) document “support for self-management is part of the shift in relationship between health and care professionals and people represented by personalised care” (NHS England and NHS Improvement, 2020, p. 5). This assumes that participants are familiar with the term *self-management* as well as having the skills needed to successfully engage in it. It also lacks the importance of addressing factors that may facilitate or hinder an individual to engage in self-management such as the psychological concepts of self-efficacy. This assumption has been recently identified in a study by Kidd et al. (2020), exploring the implementation of SSM in community-based stroke care. A secondary qualitative analysis was conducted to explore community stroke nurses' perspectives on the challenges of implementing SSM. Different levels of understandings and thus interpretations of the SSM were apparent amongst community stroke nurses (Kidd et al., 2020). The SSM assumes a one-size-fits-all model which continues to be reinforced within healthcare. Consequently, this makes it difficult for nurses to deliver tailored and person-centred self-management support. This evidence indicates that there is a clear gap between policy and practice of supported self-management in stroke survivors (Kidd et al., 2020). This gap can be minimised to strengthen the support delivered. Contextual factors need to be considered, especially as healthcare professionals tend to deliver predominantly illness-specific interventions (Breckner et al., 2021). This is still apparent within the NHS and by not having insight into the context by which stroke survivors self-manage, clinical recommendations are going to be based on a one-size-fits-all approach. The current approach lacks the crucial aspect of person-centred self-management which individuals require to succeed.

1.3 Self-management and multimorbidity

Similarly, to stroke, there has been research exploring the factors contributing to self-management in relation to other LTCs such as diabetes (Ansari et al., 2022), chronic obstructive pulmonary disease (Bauer & Schiffman, 2020) and hypertension (Yatim et al., 2019). Definitions of *chronic disease* vary greatly, as does the length of time that a sickness must be present before anything is considered chronic (Bernell & Howard, 2016). Chronic disease or illness has been defined as “prolonged, do not resolve spontaneously, and are rarely completely cured” (Dowrick et al., 2005, p.1). Furthermore, the World Health Organisation (WHO) states that chronic diseases tend to be of longer duration and cannot be passed from person to person (WHO, 2021). The WHO (2021) also acknowledge that there are four main types: cardiovascular diseases, cancers, respiratory diseases, and diabetes. While it is recognised that chronic illnesses have a “prolonged" duration, there is debate over the precise time frame needed to qualify a condition as chronic (O’Halloran et al., 2004). Three months appears to be the shortest acceptable amount of time across published research, with other definitions stretching to 6 and 12-months (O'Halloran et al., 2004; National Center for Chronic Disease Prevention and Health Promotion, 2022). Other definitions of chronic illness have been less specific such as from the Department of Health and Social Care (DHSC), formally Department of Health (DoH). They define them as conditions “that cannot currently be cured but can be controlled with the use of medication and/or other therapies” (DoH, 2010b, p. 4). As the terms chronic condition and long-term condition are often used interchangeably, the term long-term condition (LTC) will be used for the purposes of this research. In this study, LTCs are defined as prolonged conditions (minimum duration of 3-months) and require management through medication or treatment (O'Halloran et al., 2004; DoH, 2010b).

Health Psychology research has focused on patient adjustment to LTCs for many years. There has been a substantial amount of psychological research exploring conditions such as type 2 diabetes (e.g., Tang & Gao, 2020), chronic obstructive pulmonary disease (e.g., Scharloo et al., 2007), HIV (e.g., Norcini Pala & Steca, 2015), cancer (e.g., Hopman & Rijken, 2015), and rheumatoid arthritis (e.g., Flurey et al., 2018). Although these illnesses present different symptoms, aetiology, and treatments, what they all have in common is that all individuals diagnosed with a LTC are often encouraged to self-manage due to the increased pressure healthcare systems are experiencing (Wagner et al., 2001; Rodham, 2020). Consequently, these challenges manifest regardless of whether a cause for the condition is known, whether the primary issue is physical or psychosocial, or what age the individual was at onset of the condition (Wagner et al., 2001). A further challenge to self-management and adjustment to LTCs, is the experience of having two or more, placing a major burden on individuals (Wallace et al., 2015) and healthcare systems (Soley-Bori et al., 2021).

With an ever-increasing aging population in the UK, a greater percentage of people are being diagnosed with more than one LTC; referred to as multimorbidity. Multimorbidity and co-morbidity are terms that have been used interchangeably within health and medicine (Gallacher et al., 2019). Someone with multimorbidity is living with a minimum of two long-term conditions (NICE, 2016; Johnston et al., 2019; Gallacher et al., 2019). Moreover, co-morbidity is a term used to describe a medical condition which co-exists alongside another medical condition in the same person (Nicholson et al., 2019). This study will use the term multimorbidity when referring to an individual with two or more pre-existing LTCs.

Approximately 27.2% of the English population, and 23% of the Scottish population have two or more LTCs (Cassell et al., 2018; Barnett et al., 2012). Although multimorbidity increases with age (Barnett et al., 2012; Yarnall et al., 2017), 30% of people with 4 or more LTCs were below the age of 65 years (Stafford et al., 2018), highlighting that multimorbidity is not just an issue for older adults. However, there appears to be a gap in the literature addressing multimorbidity in contrast to the wealth of research on the exploration of single-disease adjustment (Taylor et al., 2014).

Multimorbidity can exacerbate physical and psychosocial issues evidenced in patients with a single LTC, due to the increased treatment burden (Skou et al., 2022). The increasing treatment burden on patients with multimorbidity may result in individuals lacking engagement in medication and treatment adherence (Gallacher et al., 2019). Consequently, this may have a detrimental effect on the individuals' quality of life and healthcare costs in the long term. Multimorbidity has also been associated with many negative health outcomes such as reduced quality of life, high treatment burden, greater health service use (Cassell et al., 2018) and higher mortality (Nunes et al., 2016).

Patients with multimorbidity have also reported unmet needs in relation to emotional management, changing habits and loss of independence (Breckner et al., 2021). Breckner and colleagues (2021) conducted a qualitative study interviewing 17 patients with multimorbidity and 7 healthcare practitioners in Germany. They identified a need for further support from healthcare professionals to cope with the disease. This research suggests that healthcare professionals need to be clear as to who bears the responsibility for self-management and communicate these with patients (Breckner et al., 2021). Moreover, further research recommends that healthcare professionals and patient views should be consistent for patients to feel supported in the management of their conditions (Freilich et al., 2020).

People with multimorbidity consider their LTCs incommodious due to the impact on quality of life and physical function, the consequences of health problems and challenges with self-management (Slightam et al., 2018). Consistently, it appears that participants tend to prioritise one LTC over others (Cheraghi-Sohi et al., 2013). Cheraghi-Sohi and colleagues (2013) conducted a qualitative secondary analysis of four existing data sets, which consisted of a total of 41 participants with multimorbidity. They found that individuals tended to focus on those LTCs that they perceived to have a potential future risk. Furthermore, patients' priorities of LTCs change at fundamental points and as a result they change their level of engagement with self-management (Morris et al., 2011). Interestingly, individuals with multimorbidity do not seem to perceive their illnesses as an increasing burden but more a factor of change (Morris et al., 2011).

Therefore, research focusing on the mechanisms through which LTCs interact is important for understanding the origin and management of multimorbidity (Valderas et al., 2007). In Stafford et al.'s (2018) two-year study, individuals with four or more

LTCs were found to attend significantly more outpatient appointments (average 8.9 vs 2.8), GP appointments (average 24.6 vs 8.8) and be prescribed more medication (average 20.6 vs 5.6) compared to those with a single LTC, respectively. Consequently, this increases costs for the NHS and presents an opportunity to foster supported self-management and community intervention where appropriate. This epitomises the need to explore the experiences of individuals with multimorbidity. It is evident that individuals with complex health problems such as multimorbidity need support to self-manage (Stafford et al., 2018; Barker et al., 2018). Therefore, understanding of multimorbidity must be better understood to develop preventative interventions, lessen its burden, and consider patients' needs in developing health-care services (Barnett et al., 2012).

1.4 Stroke and Multimorbidity

There are many reasons why multimorbidity in stroke warrants attention. In addition to psychological, societal, and contextual factors, multimorbidity needs to also be considered within the stroke context due to the added complexities it brings (Gallacher et al., 2019). LTCs can often be present when patients have a stroke, which adds a layer of complexity to the treatment journey and patient experience. Multimorbidity prevalence estimates vary from 43-99% in stroke survivors (Gallacher et al., 2019), with over 85% of stroke survivors reporting at least one long-term condition (Gallacher et al., 2018), rendering patients more likely to have a stroke within the context of a LTC, than in isolation. Current literature has evidenced that multimorbidity can lead to an increased hospital stay, poorer functional outcomes, and mortality in stroke survivors (Gallacher et al., 2013). This can have an impact upon medical treatment, with previous research identifying treatment burden after stroke due to polypharmacy, reduced care continuity and uncoordinated appointments (Aquino et al., 2019). The most reported definition of polypharmacy in research considers the number of medications prescribed daily as five or more. However, some definitions have included more than eleven medicines (Masnoon et al., 2017).

Furthermore, Gallacher et al. (2019) recently concluded that the knowledge of multimorbidity in stroke is limited. However, they identified potential health-related issues with stroke and multimorbidity, such as polypharmacy (Gallacher et al., 2014), which is associated with non-adherence to secondary preventative medication in stroke survivors (Al AlShaikh et al., 2016). Age, alcoholism and multimorbidity including diabetes, previous stroke, congestive heart failure, myocardial infarction and pulmonary heart disease in individuals have been shown to contribute to an increased length of stay in hospital after stroke (Johansen et al., 2006). These results highlight the importance of considering the impact of pre-existing LTCs in stroke survivors.

Multimorbidity can also inhibit post-stroke recovery by interfering with recommended treatments. For example, having arthritis has been evidenced to have a detrimental impact on stroke recovery due to mobility issues, pain, frustration and additional coping needs (Wood et al., 2009). Further studies have begun to look at the association of specific co-morbidities in the context of stroke. For example, a recent retrospective analysis of prospectively collected data among 23,579 stroke admissions, investigated post-stroke outcomes in adults admitted for their first ischemic stroke (Ouk et al., 2020). In this study, the presence of diabetes and depression prior to stroke was associated with increased need for long-term care and heightened risk of dementia in women. Depression and diabetes mellitus were also associated individually with long-term care admission, incident dementia, stroke/TIA readmission and all-cause mortality. Furthermore, co-morbidity burden and patient-rated perceived impact of stroke in the first year have been found to be independently associated (Sewell et al., 2021). Identifying reasons that contribute to poorer outcomes for stroke survivors with co-morbidities is fundamental to further understand the context in which people recover.

Clinical guidelines remain disease-specific which could contribute to increased burden to patients and healthcare professionals (Aquino et al., 2019). The studies outlined above (Ouk et al., 2020; Sewell et al., 2021) provide clinical markers of the detrimental impact co-morbidities have on stroke recovery and outcomes. Yet understanding the context of the individual is lacking. Exploring the reasons as to why these poorer outcomes occur is imperative to improve quality of patient care.

Clearly, it is paramount that stroke and multimorbidity are considered in order to understand healthcare use and outcomes for stroke survivors (Aquino et al., 2019). However, in a review of 428 randomised controlled trials (RCTs) exploring the stroke research that included patients with multimorbidity, found that these patients have been explicitly excluded from inclusion (Nelson et al., 2017). This oversight may result in a domino effect on the lack of consideration of multimorbid care and context in which stroke survivors rehabilitate. Although Nelson et al.'s (2017) review only included RCTs, it is concerning that the vast amount of research excludes patients with co-morbidities rendering evidence-based policy in stroke care reductive.

There has only been one qualitative study which was the first to identify the stroke experience in the context of more than one LTC (Rutherford et al., 2018). The authors aimed to explore the challenges to stroke recovery to support the refinement of self-management programmes. The researchers had a large sample size for a qualitative research design and interviewed 53 stroke survivors and 26 significant others. They interviewed participants at 6-months post-stroke, although there is evidence that stroke survivors continue to respond and adjust to their stroke past this time point

(Arntzen et al., 2015; Theadom et al., 2019). Rutherford and colleagues (2018) used minimally structured open-ended questions and analysed using inductive thematic analysis to explore patient challenges during stroke recovery. The stroke experience was described as frightening and shocking by participants leading to difficulties managing the effects of their stroke. Stroke survivors' management of the consequences of their stroke was viewed as challenging as they had to manage more than one long-term condition alongside the competing demands of everyday life. Seemingly due to participants' perceived lack of cause of stroke, they were unsure on the actions they needed to take to reduce their risk of future stroke and cope with effects. Consequently, the authors recommend that self-management programmes for individuals with stroke and co-morbidities would benefit from specifically targeting the individuals' health beliefs to provide a foundation for recovery post-stroke. Rutherford et al. (2018) did not exclude individuals with cognitive or communication difficulties and offered additional support, rendering their study more inclusive compared to previous studies. However, the aim of Rutherford et al.'s (2018) study was to explore the challenges to stroke survivors 6-months post-stroke, limiting the findings to beyond this timepoint. Research suggests that stroke recovery slows down after 6-months but continues up to 12-months (Mayo et al., 1999). Furthermore, Rutherford and colleagues (2018) aimed to explore only the challenges to self-management in stroke recovery, overlooking the understanding of potential facilitators to recovery beyond self-management. In-depth understanding of how the stroke impacts the management of pre-existing conditions is also lacking. Therefore, the current research looks to explore the experiences of stroke survivors specifically in the context of increased depth up to 12 months post-stroke.

1.5 Health Psychology Theoretical models

There are many health psychology theories that may be relevant for exploring the impact of having a stroke in people with pre-existing long-term conditions. However, three models were pertinent and considered particularly relevant. A Shifting Perspective Model of Chronic Illness by Paterson (2001), a transactional model of illness, the Common-Sense Model (Leventhal et al., 2016); and a contextual model, the working model of adjustment to chronic illness (Moss-Morris, 2013), which have been described below.

1.5.1 The Shifting Perspective Model of Chronic Illness

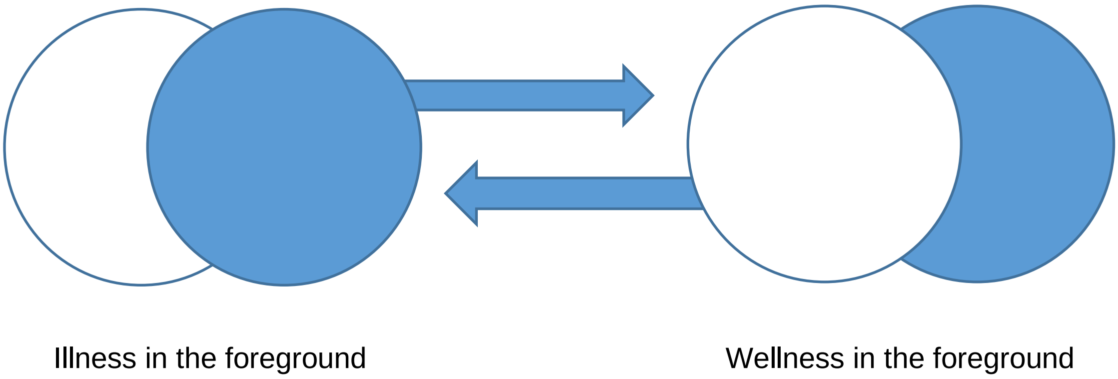
A considerable amount of research in stroke has stemmed from Bury's (1982) theory of Biographical Disruption (Faircloth et al., 2004). This theory suggests that being diagnosed with a LTC is seen as a critical situation, which results in an interference and a disturbance of an ongoing life, creating an inconsistency in equilibrium. Consequently, the individual questions their biography and identity. Although Bury's (1982) theory was originally applied to people with rheumatoid arthritis, it has dominated the literature across long-term illnesses (Paterson, 2001). Biographical disruption has been criticised to lack acknowledgement and consideration of the influence of other mitigating factors when presented with long-term illness (Faircloth et al., 2004). It is postulated that the acute onset of stroke indicated more of a biographical flow in contrast to biographical disruption for stroke survivors (Faircloth et al., 2004). Rather than disrupting one's biography, the illness results in an adaptation and the significance of the condition will depend on the context of the individual (Faircloth et al., 2004).

In line with the evidence reviewed above, the reoccurring themes of reprioritising and shifting perspectives suggests that the Shifting Perspective Model of Chronic Illness

(Paterson, 2001) may be appropriate in understanding the experiences of stroke survivors. The Shifting Perspective Model (Paterson, 2001) is an ongoing continual shifting perspective of chronic illness developed (see figure 1). According to Paterson (2001), adjusting and adapting to chronic illness is a continuous process in which the patient shifts' their focus from one aspect of their illness to another. This is how individuals attempt to make sense of the current experience or world in which they are living. Paterson's model can be applied to those with more than one long-term condition as individuals' perspectives and priorities may change with regards to self-managing their multiple conditions.

Figure 1

Shifting Perspectives Model of Chronic Illness



Note. This figure was adapted from Paterson (2001)

The Shifting Perspective Model of Chronic Illness (Paterson, 2001) hypothesises that the increasing disease-related deficits and problems can result in the individual shifting to illness-in-the-foreground. It is during this process that individuals focus on the illness, associated symptoms, and negative consequences of disease (Paterson, 2003). This, therefore, suggests that people with more than one long-term condition could potentially have illness-in-the-foreground most of the time potentially resulting in more negative attitudes. Paterson (2001; 2003) suggests that having wellness as the forefront perspective involves the individual’s focus “being as well as possible” (Paterson, 2003; p. 989), thus appreciating the role of the self rather than the illness. Paterson argues that individual perspectives are neither correct or incorrect, but rather reflect their own needs and circumstances. Consequently, the role of healthcare professionals shifts to assisting people with long-term illness identify and understand their perspectives on the illnesses. Practitioners must commit to hearing what people consider to be important (Paterson, 2001).

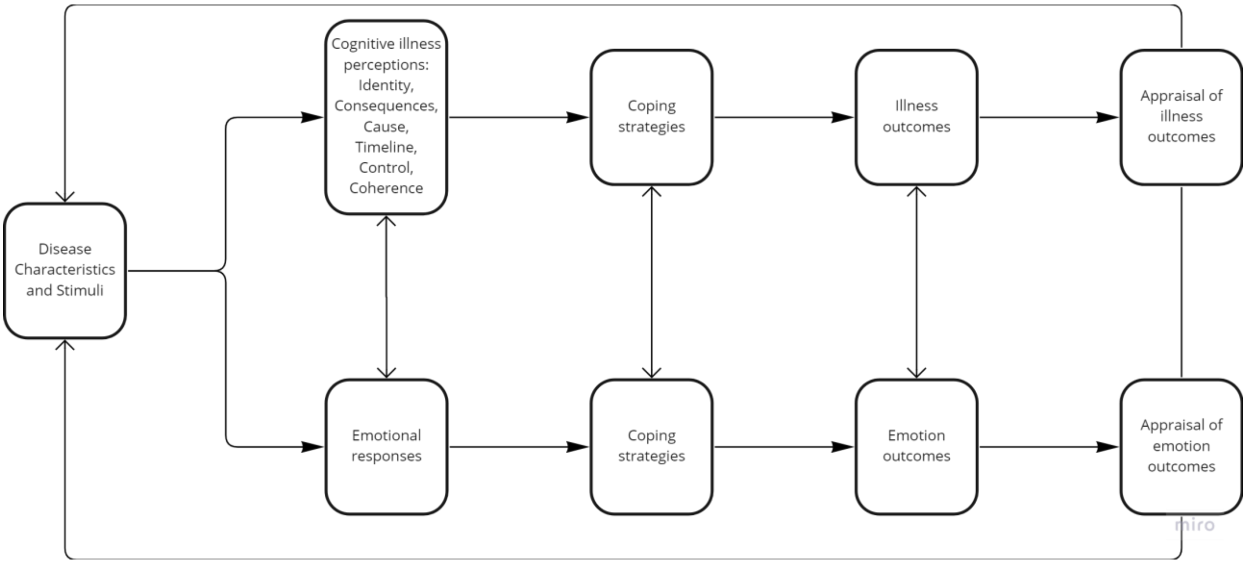
Supporting Paterson’s (2001) model, Bourland et al. (2011) interviewed 6 stroke survivors between 21-months and 11-years post-stroke and found that they reported experiencing an *awakening* after their diagnosis, thus shifting their perspectives. The authors reported that quality of life was described by survivors as a dynamic construct that constantly changed. The process of change was seen to have occurred when activities once valued by participants were lost or gained. The study brings a useful longitudinal perspective to long-term recovery post-stroke. However, the study lacks consideration for survivors' short-term perspective changes and how these impact on health behaviour. Therefore, researchers should seek to understand how stroke survivors view their ongoing illnesses as part of the awakening described by Bourland et al., (2011) and understand *how* their perspectives shifted from one LTC to another. These initial responses to a health threat could be explained by the Common-Sense Model of Self-Regulation (Leventhal et al., 2016).

1.5.2 Common-Sense Model

The Common-Sense Model of Self-Regulation (Leventhal et al., 1992; Leventhal et al., 2016; see figure 2) is a theoretical framework that is highly utilised in Health Psychological research and practice (Minshall et al., 2021). The Common-Sense Model (CSM) addresses the relationships between illness representations or perceptions and illness-related experiences. The model explicates how illness perceptions and emotional reactions drive the responses to the illness-related experiences (Cameron & Moss-Morris, 2010). The CSM theorises the perceptual, behavioural, and cognitive processes by which individuals become aware of a health threat and explains how these processes influence individual actions such as the self-management of ongoing and future health threats. The cognitive, emotional, and behavioural responses are self-regulatory in that they are influenced by and affect the individual's self-concept (Petrie & Weinman, 1997). As such, the model is a dynamic, multi-level and interactional.

Figure 2

Common-Sense Model of Self-Regulation



Note. This figure was created and adapted from Leventhal et al. (1992) and Hagger et al. (2017)

The CSM (Leventhal et al., 2016) identifies five key components of illness perceptions: identity, cause, timeline, consequences, and control/cure. Identity beliefs concern the diagnosis or illness label and the associated symptoms. Causal beliefs are the attributing factors or conditions supposed to have caused the illness. The expected duration of the illness are the drivers for the timeline beliefs. They can vary from acute, to episodic or chronic/long-term duration. The beliefs about consequences concern the effects of an illness such as psychological, physical, or social effects. Finally, the control or cure perceptions are concerned with the extent to which the illness or disease can be treated or managed through treatment measures and behaviours (Cameron & Moss-Morris, 2010). The five illness perception components were increased to six when coherence was added to explain the understanding and knowledge of an illness (Moss-Morris et al., 2002). The model indicates that illness perceptions can induce emotional responses as well as behavioural and vice versa. The emotional response or reaction are typically negative such as fear and worry.

There has been a plethora of research investigating the tenets of the CSM using illness perceptions, coping, and illness outcome measures (Hagger & Orbell, 2022; Hagger et al., 2017). Although there are no studies to date that have explored illness perceptions in the context of stroke recovery and multimorbidity simultaneously, there has been some early research applying the CSM to patients with multimorbidity (Bower et al., 2012). Bower et al. (2012) sought to investigate patients' perceptions of multimorbid long-term conditions. They interviewed 28 adults with at least 2 LTCs. The authors were selective with the conditions and participants had self-reported being diagnosed with 2 or more of the following: chronic obstructive pulmonary disease (COPD); coronary heart disease (CHD); non-insulin-dependent diabetes, chronic arthritis, or depression. Positively, having healthcare staff identify potential participants mitigated or reduced the risk of accuracy and bias associated with self-reported medical conditions (Hansen et al., 2014). Bower et al. (2012) found that perceptions of individual conditions were affected by multimorbidity. Identity, beliefs about cause, coherence/understanding and consequences were all impacted by the presence of multimorbidity (Bower et al., 2012). This offers solid rationale for looking at single LTCs in the context of multimorbidity; which this current study seeks to achieve.

The CSM has also been applied to the stroke population (Aujla et al., 2019). In their longitudinal study of 50 stroke survivors, Aujla et al. (2019) asked participants to complete self-reported measures on health-related quality of life using the EQ-5D-5L (Brooks, 1996), mood using the Patient Health Questionnaire-9 (Kroenke & Spitzer, 2002) and disability using the Nottingham Extended Activities of Daily Living Scale (Nouri & Lincoln, 1987). The authors measured illness perceptions using the Stroke Illness Perception Questionnaire-Revised (Aujla et al., 2018) and analysed using Spearman’s correlations. Aujla et al. (2019) reported that baseline illness beliefs were not significantly related to 3-month post-stroke health-related quality of life or disability. However, they did find that baseline illness beliefs were associated with mood issues 3-months post-stroke (Aujla et al., 2019). Their study offers the recommendation that illness beliefs as well as mood should be clinically assessed immediately after stroke. Furthermore, depression and anxiety have been found to mediate the relationship between illness perceptions and quality of life (Minshall, et al., 2021), therefore supporting Hagger and Orbell (2022). However, it is unclear as to how and why these illness perceptions occurred for stroke survivors and how having other long-term conditions influenced their illness perceptions.

Furthermore, illness perceptions have been shown to impact on stroke recovery (Della Vecchia et al., 2019; Minshall, et al., 2021). Della Vecchia and colleagues (2019) investigated illness beliefs and emotional responses in 24 stroke survivors, on average 7.5-months post-stroke, with mild disabilities. The authors found that the participants reported difficulties in dealing and coping with the consequences of stroke, specifically the hidden disabilities. Identity beliefs were not developed during the acute phase of the stroke, which was associated with the lack of information given by healthcare professionals. This lack of information was also attributed to the cognitive issues the participants experienced during the stroke episode. Participants further struggled to construct an illness identity in the chronic phase of stroke due to the cognitive challenges faced at acute phase. These are interesting findings as constructing a strong identity has been found to have a positive effect on psychological distress (Hagger & Orbell, 2003).

Hagger and Orbell (2022) have recently proposed an extension of the CSM whereby they define additional dimensions and mechanisms for explaining how lay perceptions of health threats influence coping behaviours, responses, and health-related outcomes. They propose that there is a lack of understanding in how the processes within the CSM model influence individual's behaviour to engage in their own treatment regimens and self-management (Hagger & Orbell, 2022). More research is needed to explore how patients manage the increasing burden of the responsibility of their own health management, based on their illness perceptions and emotional responses thus forming the basis of this research.

The CSM outlines the process underlying people's response to and management of health threats (Leventhal et al., 1992; 2016; Hagger & Orbell, 2017). The model outlines that the adaption to health threats originates from an examination of threat from the perspective of the individual, which is driven by external stimuli. However, the model lacks explanation regarding the process of external stimuli or factors influencing responses and adaptation (Hagger & Orbell, 2022). Moss-Morris (2013) has proposed a unified theory specific to the multifaceted process of adaption and adjustment to chronic illness: The working model of adjusting to chronic illness.

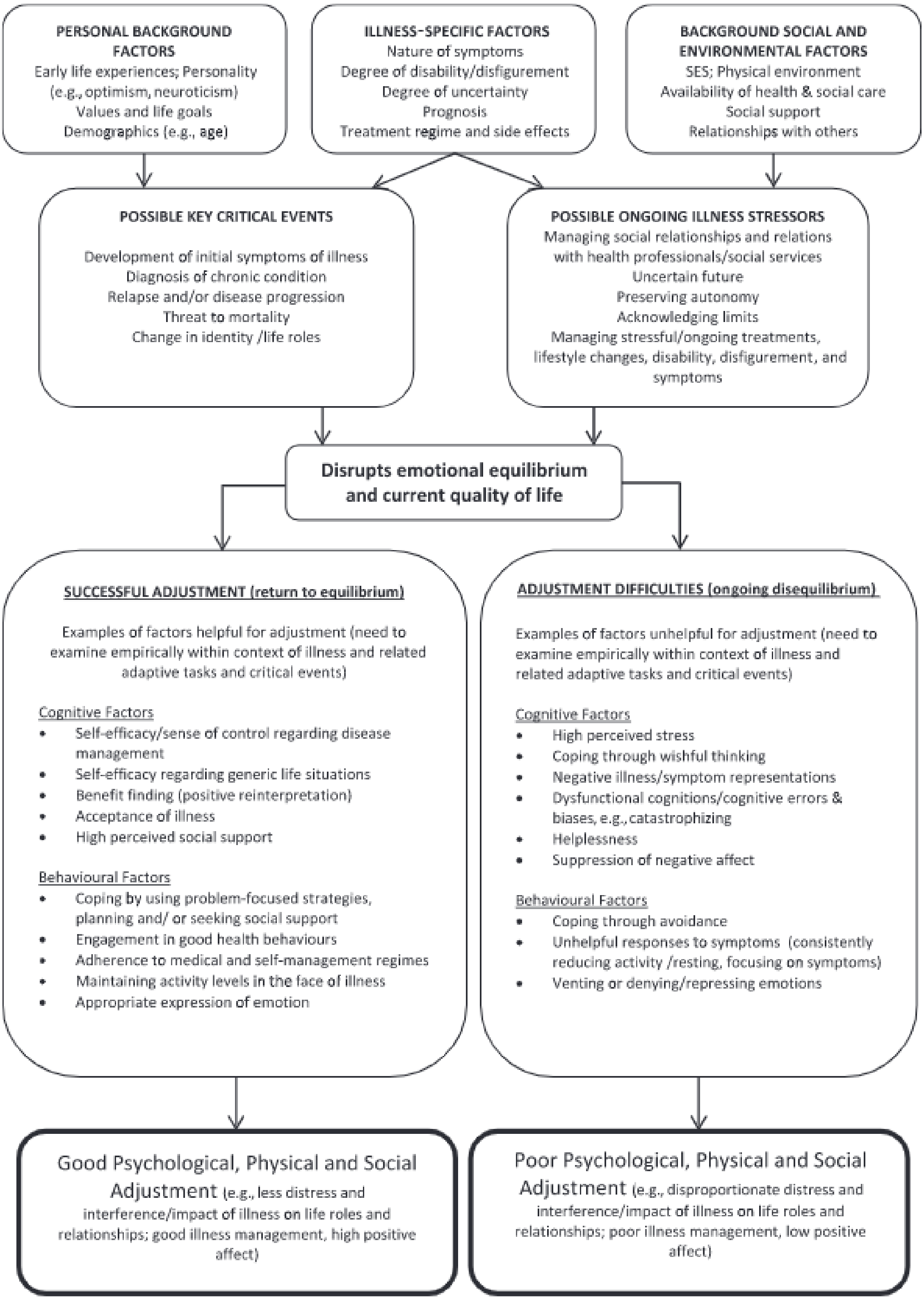
1.5.3 The working model of adjusting to chronic illness

Moss-Morris (2013) has argued for a new consistent overarching theory that specifies the process of chronic illness adjustment and adaptation: The working model of adjustment to chronic illness. Definitions of adaptation and adjustment to chronic illness has been inconsistent which has led to difficulties in measuring these constructs. Therefore, a unified theory is proposed by Moss-Morris (2013). This theory stipulates that individuals' responses to health and illness stressors and threats are influenced by background factors. These factors include a) personal background factors (such as early life experiences, demographics, and personality; b) illness-specific factors (such as symptoms, nature of disability, uncertainty; and c) background social and environmental factors (such as socioeconomic status, physical environment, social support).

Personal background factors and illness-specific factors influence possible key critical events, for example the development of the initial symptoms of the illness or diagnosis of condition. Whereas illness-specific factors with background, social and environmental factors lead to possible ongoing illness stressors, such as managing social and health relationships, uncertain future and managing ongoing treatments. The adjustment process for the critical events and illness stressors requires maintaining equilibrium in the context of chronic stressors or returning to equilibrium in the case of critical events. The model (see figure 3) outlines some examples of factors that are helpful and unhelpful for adjustment (Moss-Morris, 2013).

Figure 3

A Working Model of Adjustment to Chronic Illness



Note. Permission to use image was granted from the author *(Moss-Morris, 2013; p. 684).*

This new working model offers standardisation when considering and researching adjustment to chronic illness. It also highlights the complexities to self-regulation and adjustment to chronic illness. However, it misses some of the explanations on the drivers for changes to adjustment and how adjustment outcomes may change during the process of adjusting to chronic conditions. Nevertheless, this has been further conceptualised and explained by adding the potential mediating responses that the acute and ongoing illness stressors induce (Dekker & de Groot, 2018). Dekker & de Groot (2018) propose that the stressors induce cognitive, emotional, and behavioural responses that in turn, impact on health outcomes. This model strengthens the argument for context in chronic illness adjustment. This study hopes to further this understanding by exploring the impact of a single disease, stroke, on the management of pre-existing LTCs; a novel approach that has been largely unexplored to date.

1.6 The current study

It has been recommended by existing research that understanding patient perspectives in relation to their MTLCs needs to be addressed (Skou et al., 2022; Valderas et al., 2009). There is a lack of research which investigates the experiences of stroke survivors with pre-existing long-term conditions in relation to how they respond to and manage their multiple health conditions. This is an important topic to explore since these individuals are at an increased risk of poor health due to their more complicated treatment plan making self-management more difficult (Gallacher et al., 2019).

The aim of this research is to explore the impact of having a stroke for people with pre-existing long-term conditions. The findings will be important as evidence in this area of multimorbidity in the context of a specific health condition, such as stroke, is scarce. The findings will also provide understanding for healthcare professionals and clinicians working with newly diagnosed stroke survivors with pre-existing long-term health conditions to make certain that appropriate, sensitive, and comprehensive care is given.

The complexity of managing more than one LTC has been outlined in the literature where there is clear evidence of a single-disease focus approach to research and treatment. This study aims to explore the impact of having a stroke for people with pre-existing conditions, it also aims to identify the factors which make it difficult for stroke survivors to self-manage and to explore the health beliefs of stroke survivors in relation to their stroke and pre-existing long-term conditions. Consequently, the findings will offer insight into potential recommendations for healthcare professionals working clinically to support stroke survivors in their self-management of multiple long-term conditions throughout their recovery and beyond.

1.6.1 Research aims

1. To explore the impact of having a stroke for people with pre-existing long-term conditions.
2. To identify the factors which make it difficult for stroke survivors to self-manage their stroke and long-term health conditions.
3. To explore the health beliefs of stroke survivors in relation to their stroke and pre-existing long-term conditions.

Chapter 2a – Methodology

2a.1 Theoretical Standpoint

Understanding of conceptual underpinnings of the qualitative method used is crucial for methodological integrity and is underpinned by the researchers ontological and epistemological assumptions (Braun & Clarke, 2006; 2013; 2022a). Ontology concerns our beliefs and what we think about the kind and nature of reality (Al-Saadi, 2014; Fletcher, 2017). Ontological positions specify the relationship between our human practices and interpretations and the world in which we live (Braun & Clarke, 2013). Epistemology is a branch of philosophy concerned with theory of knowledge (Willig, 2022). It is concerned with the knowledge that we think we can know and how we can go about understanding it; and as such, epistemological approaches align with the ontological positions of realism, critical realism, and relativism (Braun & Clarke, 2022b).

Realism and relativism sit at either end of the ontological continuum (Willig, 2022). At one end of the continuum, realism assumes a pre-social reality that exists independently of the researcher's and participant's knowledge and views (Willig, 2022). At the other end of the continuum, rather than a single pre-social reality that realism assumes, relativism assumptions suggest there are multiple constructed realities we will never comprehend beyond these constructs (Braun & Clarke, 2013). A critical realist (CR) stance sits between realism and relativism in the continuum. Braun and Clarke (2022b) suggest CR can be understood as "combining ontological realism with epistemological relativism to provide a position that retains a concept of truth and reality but recognises that human practices always shape how we experience and know this" (p. 169). Therefore, CR assumes an objective reality, yet knowledge and understanding are subjective, such that it is transitive and dynamic social construction (Vincent & O'Mahoney, 2017). CR does not deny that there is a social world that exists independently of the researcher's ideations (Fletcher, 2017) nor do critical realists uphold the idea of multiple realities; however, a mediated reflection of reality is posited to be accessed through research using this lens (Fletcher, 2017; Braun and Clark, 2022b).

This research adheres to the critical realist approach. This research assumes that people hold an external reality that we can partially access through research; that the way we believe in something is our truth based on our experiences, events and how we make sense and give meanings to situations and circumstances. These perceptions of reality are subjective and can vary over time. This study holds the view that the truth of knowledge claims varies in line with the contexts in which those claims are made. Meanings behind individuals' experiences are created but also the ways in which the broader social context affects those meanings (Braun & Clarke, 2006). This study acknowledges the external reality of having a stroke alongside having pre-existing long-term conditions but also recognises that individuals perceive and experience this subjectively.

Chapter 2b – Method

2b.1 Design

Qualitative research is widely used in Health Psychology research (Shaw et al., 2019). Qualitative research is an approach that allows researchers to answer exploratory research questions and to "focus on making sense of human experience, how people communicate with each other, and how they operate within a social system" (Shaw et al., 2019; p. 739). Braun and Clarke (2013) explain that qualitative analysis is concerned with meaning and therefore cannot provide a single answer to a research question. The theoretical stance and philosophical underpinnings aid investigators to conduct research using methods suitable to these approaches (Fletcher, 2017).

According to Braun and Clarke (2013) there are two main classifications in qualitative research: experiential and critical. Critical qualitative researchers do not take the data at face value and aims to understand the factors influencing the meanings expressed as well as the effects of the representations expressed (Braun & Clarke, 2013). Consequently, experiential qualitative researchers prioritise the participants' interpretations and therefore, accept and focus on them in the analysis. This desire to understand participants' perspectives and meanings drives experiential research (Braun & Clarke, 2013). This study adopted the experiential research approach to explore and make sense of the experiences of stroke survivors with long-term conditions.

2b.1.1 Rationale for Reflexive Thematic Analysis

Qualitative research offers a diverse range of approaches to data analysis (Braun & Clarke, 2013; 2020). A critical realist position underpins several qualitative approaches and has been used to underpin research using Grounded Theory (Bunt, 2018), Discourse Analysis (Sims-Schouten & Riley, 2007), and Interpretive Phenomenological Analysis (IPA; Fade, 2004). Due to the ontological and epistemological approach of this thesis taking a critical realist assumption, IPA was considered as well as Thematic Analysis (TA). IPA is an alternative qualitative approach which aims to examine and explore how people make sense of major life experiences (Smith et al., 2009), which could be argued to fit the research objectives of this thesis. However, TA was ultimately decided as the most appropriate method due to the ontological assumptions of the research as well as the methodological considerations of TA. TA involves "later theme development, with themes developed from codes, and conceptualised as patterns of shared meaning underpinned by a central organising concept” (Braun & Clarke, 2020, p. 39). It can be used to both reflect reality and to unpick or unravel the surface of reality. There are many approaches to TA and it can be thought of as an overarching term for a range of methods (Braun & Clarke, 2020). This method is useful for answering questions about an individual’s beliefs, perceptions and experiences (Braun & Clarke, 2022a; 2022b) which fits suitably with the research question.

Braun and Clarke (2019) have recently relabeled their TA approcah to reflexive TA, highlighting the importance of being explicit in the outlining assumptions and consideration of the “centrality of reseracher subjectiveity and reflexivity” (Braun & Clarke, 2019, p. 590). They have provided clear guidelines on the process of what reflexive TA entails (Braun & Clark, 2022b). This study adhered to Braun and Clarke (2022b) reflexive TA methodology and my reflexivity throughout the process can be found in table 3 and in the Reflective Chapter (Appendix B). As the aim of this thesis was to explore the impact of stroke on pre-existing LTCs as it has not been explored before, an inductive approach to reflexive TA was selected.

2b.2 Sampling and Selection Process

2b.2.1 Recruitment process

The research project was advertised using online adverts/posters (Appendix C). I used my own social media accounts to promote the study on Facebook, Instagram, LinkedIn, and Twitter. As well as posting the information about my study, I also contacted charities through their social media accounts. Stroke Information (www.strokeinformation.co.uk) and Headway West London (www.headwaywestlondon.org.uk) posted information about the study on their Twitter accounts which were consequently reshared by social media users.

Facebook also offer platforms known as groups or pages where stroke survivors or family members of stroke survivors can join to access peer support. These pages are used by researchers and healthcare professionals to recruit participants for their research. During April–October 2021 I posted on relevant stroke-related Facebook pages or groups (Appendix D). I received more interest than I had anticipated, however a lot of the interest was from people who did not meet the inclusion criteria, for example, they were not living in the UK. I also tried to promote the study through charities. I contacted 18 local and national charities via email (Appendix E), however, I only received five responses. Four charities apologetically declined supporting the study. Nevertheless, I received one response from the Stroke Association, who gave me the opportunity to attend two of their online stroke support groups and promote my study. Unfortunately, I did not manage to recruit any participants through this method.

Therefore, as recruitment through charities was not as successful as I had hoped, all participants were recruited through Facebook. Snowball sampling was also optimised by asking participants if they knew of other individuals who may be interested in being in the research study.

Throughout the recruitment phase, all participants were offered an incentive of being in a prize draw to win a £50 voucher of their choice, which was outlined on the poster. Participants were asked to opt into the draw when their interview had concluded.

2b.2.2 Inclusion/Exclusion criteria

Due to incomparable health systems across the world, only participants living in the UK were included in the study. This assumed that all participants had been, or were, currently being treated within the NHS. Moreover, participants had to be 18-years old or over; been diagnosed with a stroke within the last 3 to 12-months; and had been diagnosed with at least one long term condition prior to their stroke. Table 1 outlines the inclusion and exclusion criteria for recruiting participants in this study.

Table 1

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
• Diagnosed with stroke between 3-12 months ago • Diagnosed with at least one long-term condition prior to the stroke • Individuals with mild-moderate aphasia • Over 18 years old • Resides in the UK	• Diagnosed with stroke < 3 or > 12 months ago • Diagnosed with TIA rather than a stroke • Had no diagnosis of a long-term condition prior to stroke diagnosis • Individuals with severe receptive or expressive aphasia • Individuals with severe cognitive deficit whereby consent cannot be given • Does not reside in the UK

The definition of *long-term condition* (LTC) adopted for this study is that it is a condition “that cannot currently be cured but can be controlled with the use of medication and/or other therapies” (DoH, 2010b, p. 4). I ascertained whether participants had a LTC if the participant reported having to manage the condition on daily basis for a minimum of 3-months (O’Halloran et al., 2004). For example, this included having to take medication and/or reports of physical or emotional limitations as well as managing functional symptoms and conditions that could lead to further medical complications if left untreated.

It was decided to only include individuals at least 3-months and maximum 12-months after stroke. Evidence suggests that stroke survivors are in the acute and subacute phase of stroke from onset to approximately 3 to 4-months (Kirkevold, 2002; K. B. Lee et al., 2015). During these phases, stroke survivors experience the most debilitating consequences of their stroke. Therefore, it was considered that stroke survivors who had experienced a stroke less than 3-months prior may still be experiencing a more intensive recovery and as such may still be in hospital, be experiencing significant cognitive deficits, or still be adjusting to the acute event. Moreover, it has been argued that stroke survivors seem to experience the most recovery from their stroke in the acute phase and the recovery continues but slows 6 to 12-months post-stroke (Mayo et al., 1999). It is at this point in their recovery that participants must engage in their stroke recovery as well as readjusting to day-to-day living.

Individuals who had been diagnosed with a Transient Ischaemic Attack (TIA) only were also excluded. A TIA is considered a 'mini-stroke' or a warning sign for a future stroke and the effects are considered to last less than 24 hours (Lincoln et al., 2012). Although the psychological, cognitive, and physical impacts of a TIA have been reported (Turner et al., 2019), it was not considered suitable or in line with the aims of this current study as medically it does not require any longer-term adjustment or rehabilitation.

2b.2.3 Participants

Braun and Clarke (2013) suggest a minimum sample size of 10 participants when using TA for a professional doctorate thesis. For this study, between 10 and 15 participants were sought. This is because meaning is generated through interpretation of data and as such, the quantity of data items or when to stop collecting data is subjective and difficult to determine prior to analysis (Braun & Clarke, 2021). Moreover, the concept of *data saturation* in reflexive TA has been criticised that it is not representative with the assumptions underlying the approach (Braun & Clarke, 2021; 2022b). However, further participants would have been considered if the data acquired did not sufficiently address the research question.

2b.2.3a Participant Demographics

In total, 15 participants were recruited to participate in this exploratory study. The mean time since stroke at interview was 7.5 months. The participants were evenly split with respect to gender with 8 (53%) participants identifying as female and 7 (47%) identifying as male. Participants were between the ages of 26 and 72 years old (mean age at time of interview: 55 years). Thirteen (86%) participants identified themselves as White British, one participant identified as British Pakistani, and one participant identified as Black African. At the time of stroke, 7 of the participants were married, 4 were divorced, 3 were co-habiting and one participant was widowed. Three participants lived alone, while 12 participants either lived with their spouse/partner or family members. Four of the participants were retired, 5 were unemployed, 5 were working (full-time, part-time, self-employed) and one was on sick leave at the time of interview.

A total of 22 pre-existing long-term conditions were reported by the participants; 33% of participants had 2 pre-existing LTCs, the commonest number of pre-existing LTCs. Moreover, 27% of participants reported having 1 LTC, 20% reported 3 LTCs, 13% reported 4 LTCs and 7% reported 5 LTCs. Conditions such as stroke or myocardial infarction which consist of an episodic event were classified as a single condition despite some participants reporting a diagnosis of more than one. The most common pre-existing long-term condition was hypertension, more commonly known as high blood pressure, with 9 (60%) of the participants reporting a diagnosis. Three participants reported a diagnosis of underactive thyroid and 3 reported a diagnosis of type 2 diabetes, making these the second most reported pre-existing long-term conditions. Two participants reported a diagnosis of asthma and 2 reported a diagnosis of B12 deficiency, making them the third most reported conditions. An aggregated table outlining the demographic information of participants can be found in table 2. To ensure patient confidentiality when using small sample sizes aggregated information is strongly recommended (Morse & Coulehan, 2015). Furthermore, to protect participants' identity, pseudonyms will be used throughout the findings.

Table 2

Participant demographic information

	n	*%*
Time since stroke (months)		
3	2	13
4	0	-
5	1	7
6	2	13
7	2	13
8	3	20
9	2	13
10	1	7
11	0	-
12	2	13
No. of pre-existing conditions prior to stroke		
1	4	27
2	5	33

	n	%
3	3	20
4	2	13
5	1	7
Age at interview (years)		
18-29	1	7
30-39	0	-
40-49	1	7
50-59	9	60
60-69	2	13
70-79	2	13
Gender		
Male	7	47
Female	8	53
Ethnicity		
Black African	1	7
British Pakistani	1	7
White British	13	86
Marital Status		
Co-habiting	3	20
Divorced	4	27
Married	7	47
Widowed	1	7
Living Status		
Lives alone	3	20
Lives with spouse/partner	8	53
Lives with family	4	27

	n	%
Employment Status		
Unemployed	5	33
Working full-time	2	13
Working part-time	1	7
Sick (employed)	1	7
Self-Employed	2	13
Retired	4	27
Pre-existing conditions		
Acute Angina	1	7
Aneurysm	1	7
Asthma	2	13
Atrial Fibrillation	1	7
B12 deficiency	2	13
Coeliac Disease	1	7
COPD	1	7
Depression	1	7
Fabrys Disease	1	7
Fibromyalgia	1	7
High Cholesterol	1	7
Hypertension	9	60
Hypertrophic cardiomyopathy	1	7
Nocturnal incontinence	1	7
Pre-diabetic	1	7
Previous Mis	1	7
Psoriasis	1	7
PV bleeding	1	7

	n	%
Stroke	1	7
Thalassemia	1	7
Type 2 Diabetes	3	20
Underactive thyroid	3	20

2b.2.4 Materials

Several resources were developed to aid the delivery of this research project:

- Consent form (standard and aphasia-friendly) (Appendix F)
- Eligibility Form (Appendix G)
- Information sheet (standard and aphasia-friendly) (Appendix H)
- Demographic questionnaire (Appendix I)
- Topic guide for interview (standard and aphasia-friendly) (Appendix J)
- Debrief/thank you letter (standard and aphasia-friendly) (Appendix K)
- Lay summary (Appendix L)
- Privacy notice (Appendix M)

The aphasia-friendly resources were developed using the Stroke Association Accessibility Guidelines (Stroke Association, 2012). The guidelines recommend keeping the messages short and in a logical order. Furthermore, sentences must be clear and simple, and everyday words should be used. The aphasia-friendly materials developed can be found in the appendices (H.2, J.2, K.2).

2b.3 Data Collection

2b.3.1 Interview topic guide design

To understand participants' experiences over time the interview topic guide was developed based on Hawkins et al.'s (2017) questions and prompts. Hawkins and colleagues (2017) investigated the post-stroke recovery trajectory by interviewing stroke survivors. They understood that recovery is dynamic, shifting, and multifaceted and therefore developed their interview topic guide taking these factors into consideration. The language identified and used in their questions and prompts were appropriate for the focus of this study and therefore they were used as inspiration to develop this topic guide. Additional open-ended questions were incorporated to explore the experiences of stroke survivors more in-depth and to include specific focus on pre-existing conditions. The Shifting Perspectives of Chronic Illness model and the Common-Sense Model of Self-Regulation were also drawn upon and considered in the design of the questions. However, care was taken to ensure an inductive approach was adhered to through the use of open-ended questions and a semi structured approach.

The topic guide was developed and built upon with collaboration with my supervisors in the initial phases (CG and KC). It was also reviewed by a colleague at King's College London who is an experienced qualitative researcher; she offered her expertise as someone who was not involved in the development of the research study design. Further patient and public involvement are discussed in section 2b.6.

2b.3.2 Interviews

The two most common approaches to conducting interviews in research is either using structured or semi-structured methods (Low, 2013). Structured interviews are a method of data collection involving asking questions in a specific order. They are characterised as being rigid and inflexible due to often using closed-ended questions (Adhabi & Anozie, 2017; Gill et al., 2008). Alternatively, semi-structured interviews mitigate the rigid nature of a structured interview as it allows more flexibility for the interviewer (Howitt, 2019), such that interviews are focused while still offering the researcher the opportunity to explore pertinent topics (Adeoye-Olatunde & Olenik, 2021). Therefore, semi-structured interviews allow for a variety of analytic approaches to be used (Willig, 2022). In-depth research interviews typically involve one interviewer asking questions to one interviewee. This is particularly useful when conducting interviews about experiences. Another data collection method used in qualitative research are focus groups. Using focus groups requires one or more researchers (moderators) asking questions to a group of approximately 6 to 10 interviewees (Howitt, 2019). Focus groups involve dynamic interactions between the interviewees, of which is missing when using an individual interview approach. However, interviews are deemed more effective at generating a deeper insight into sensitive topics compared to focus groups (Guest et al., 2017). Due to the nature of this study, disclosure of sensitive information especially around health and illness was likely.

As this is a doctoral study, the logistics of conducting interviews versus focus groups were considered. If conducting a focus group, several participants would have had to be available on the same time, date, and location. Comparably, interviews are easier to arrange (Willig, 2022). This consideration, as well as making the process as easily accessible and convenient for participants, contributed to the decision to conduct interviews.

2b.3.3 Remote interviews

Due to the Covid-19 pandemic, remote interviews were warranted. This was the safest option for both the researcher and potential participants. Remote/online interviews are useful as they offer a quicker solution to recruitment compared to face-to-face interviews (Engward et al., 2022). This method also allowed for geographical spread and increased inclusivity.

The potential participant was able to decide whether they would like to be interviewed via the telephone or via video link. All participants chose to conduct the interview via video link using Zoom. However, near the end of the recruitment period, lockdown had eased, and laws had changed, therefore the final participant requested to be interviewed in person and this was arranged. All safety protocols outlined in the Risk Assessment for the researcher were adhered to (Appendix N).

2b.3.4 Procedure

During the recruitment period, the study was advertised using online adverts/posters. Participants responded to the advertisements by either messaging me on the social media platform, completing the form on Qualtrics (www.qualtrics.com) or emailing to arrange a time for further discussion. I then contacted potential participants to arrange a time to assess eligibility for inclusion using the eligibility form (Appendix G). In between expressing an interest and being assessed, I sent all the relevant documents to participants via email (see appendices F, H, L).

At point of eligibility assessment, if the participant met the inclusion criteria, I repeated the aims of the research and further explained what participating would mean for the participant. I gave each participant the time needed to make the decision to participate or not. If the participant decided to partake in the interview, they signed the consent form. All participants signed the consent form digitally and emailed it to me. At this stage, the interview was arranged at a time and date suitable for the participant and a Zoom link was sent.

Before the interview began, I gave the rationale for the study again. I also reminded participants that the interview was going to be recorded. Furthermore, I reminded the participant that they could withdraw at any time without reason. Demographic information was collected using the form in Appendix I; collecting information about:

- Age
- Gender
- Marital status
- Living status
- Employment status
- Ethnicity

Collecting demographic information for each of the participants served to explore whether different groups of people have different beliefs, attitudes or perceptions that impact their coping mechanisms and self-management strategies.

Each semi-structured interview took approximately one hour. The topic guide was used to guide the interview, however as it was a semi-structured interview, the questions were only used as prompts. At the end of the interview, each participant was thanked and was emailed a debrief letter.

The interviews were recorded using a dictaphone. The recording was immediately transferred to the UWE cloud, stored in my password protected One Drive folder, and was deleted off the dictaphone, in line with GDPR requirements. Identifiable information (e.g., name and contact details) were safely stored separately to the interview data and destroyed approximately 6-months after participation. This was to allow time for the participant to withdraw if they wish. A flow diagram illustrating the procedure can be found in figure 4.

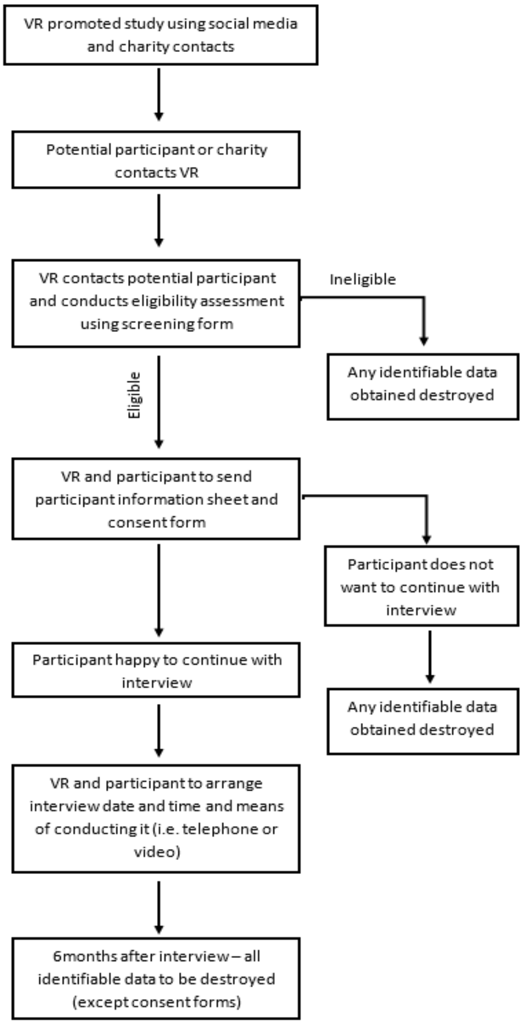
During one interview, the spouse of the participant was present as the participant had aphasia and requested her partner be present to assist her throughout the interview.

Written consent from the participant was obtained prior to the interview and verbal consent for the participant's partner was obtained at the start of the interview.

After the final interview had been conducted, all participants were contacted and asked if they would like to be entered into a raffle to win a £50 voucher of their choice as a thank you for participating. Eight out of the 15 participants replied. An online random name generator was used, and each participant was contacted with information about whether they had won or not.

Figure 4

Flow diagram of procedure



2b.4 Data Analysis

2b.4.1 Thematic Analysis Process

After each interview, the audio file was transcribed verbatim. Reflexive TA as outlined by Braun and Clarke (2022b) was used to analyse the data. The six step guidelines from Braun and Clarke (2006; 2013; 2022b) informed the analysis and application of each phase is outlined in table 3:

1. Familiarising the data / Familiarising yourself with the dataset
2. Initial coding / Coding
3. Searching for themes / Generating initial themes
4. Reviewing themes / Developing and reviewing themes
5. Naming and defining themes / Refining, defining, and naming themes
6. Writing and producing the report / Writing up

Table 3

Reflexive Thematic Analysis Guidelines and Application

Reflexive Thematic Analysis Phase		Application
Phase 1	Familiarising the data / Familiarising yourself with the dataset	Familiarisation began when I transcribed each of the interviews. Although transcription can be seen as laborious, it was when I truly started making sense of the data. Listening to the audio back several times to ensure the transcription was correct allowed me to reconnect with the interview. I took this opportunity to create notes which included reflections, comments and potential initial codes and I was able to identify potential points of analytical interest.

Reflexive Thematic Analysis Phase		Application
Phase 2	Initial Coding/ Coding	The data was coded using a mix of digital software (Nvivo v1.5) and manually. During my training, I attended a two-day course on Nvivo to ensure full competence when using this software for analysis. Moving between the two techniques prompted new reflections and insights. I used Nvivo in the first instance to conduct the initial coding. I used a mix of semantic (surface meanings) and latent (underlying ideas, patterns, and assumptions) codes, thus producing both descriptive and interpretive codes. I returned to the coding phase a few times based on Braun and Clarke's (2022b) recommendation. I found myself getting very caught up in the coding phase and I got to a point when I realised, I had to stop as I felt that my codes and labels had captured and differentiated diverse meaning. During the multiple rounds of coding, I was able to ensure a thoroughness and review the consistency of the coding. During this phase, I was aware of my existing knowledge of health psychological models and theories, which in turn will have shaped my interpretations of the data. I reflected

Reflexive Thematic Analysis Phase		Application
		on this throughout the interview phase by engaging in reflexive journals.
Phase 3	Searching for themes/ Generating initial themes	Moving onto this phase was challenging as I was comfortable in the coding phase, and I was not quite sure where to start. Initially, I used Nvivo to cluster codes. I also used physical sticky notes on the wall and drawing arrows to create links between codes, so I was able to see the mapping visually. This helped me generate the initial themes. This research undertook a more experiential approach to analysis. The initial approach produced robust patterns that described participants' experiences and perceptions around stroke recovery and management of LTCs. As such, the initial themes I generated felt more like *topic summaries* which did not reflect the interpretation of the data. I presented these to my supervisors, and we had an in-depth discussion about the narrative and interpretation of the data I had analysed. We discussed that themes are more conceptual rather than descriptive which helped me move onto the next step.

Reflexive Thematic Analysis Phase		Application
Phase 4	Reviewing themes / Developing and reviewing themes	While developing and reviewing themes, I had to continue going back and forth to the codes. I created multiple thematic maps in order to make sense of the codes. I found this stage challenging as I wanted to do the participants justice by telling their story well. I struggled with uncertainty and anxiety during this process, and I occasionally had to take a step back. The whole process of developing themes took me through a journey of not getting too attached to the themes. The themes changed many times throughout this step as I wanted to ensure they told a coherent and interpretive story.
Phase 5	Naming and defining themes / Refining, defining, and naming themes	When naming the themes, I created a table identifying the key messages of each one. This allowed me to be very clear about the concept I wanted to report on and enabled me to refine each theme. I found this process a lot more challenging than I thought I would, particularly when naming the themes. Initially I named the themes without using quotes, however after discussion with my supervisor we felt that by using quotes, it would allow the reader to observe the key concept quickly. This also gave me reassurance that the theme name was

Reflexive Thematic Analysis Phase		Application
		informative, concise, and representative of the theme's concept.
Phase 6	Writing and producing the report / Writing up	I began writing throughout phases 4 and 5. Writing is fundamental to the process, as this is where the analysis takes shape (Braun & Clarke, 2022b). This phase allowed me to refine the themes even further, such as restructuring and removing subthemes. I found this phase the most satisfying as I was able to see the analysis and findings come together to tell a coherent narrative. Although I enjoyed the process, this phase still required patience and focus. I struggled to focus and concentrate by reading and editing themes in the conventional way, so another strategy I used was creating a Powerpoint presentation of the themes and key findings. It was during this activity that I was able to finalise my thematic map as I could see the links between themes clearly, as well as the flow of the story.

2b.4.2 Analytic Narrative

The reporting style within this study manifests a blended analytic narrative demonstrating both an illustrative and analytical narrative (Braun & Clarke, 2022b). I have structured my analysis to include both descriptive and interpretative elements when discussing the findings. The analytical ‘so what’ is mentioned in the analysis however the in-depth interpretations in relation to the current literature and psychological theory is found in the discussion chapter. During the analysis, the data extracts were used both illustratively and analytically. By using quotes illustratively, the extracts are considered examples of the analytical points. By using the extracts analytically, the extracts helped me to “comment on and make sense of the specific features of a particular data extract in order to advance [my] analytic narrative” (Braun & Clarke, 2022b, p.138). This is where I focused on the specific detail within the quotes to develop and strengthen the claims and narrative.

2b.4.3 Ensuring Quality in the Qualitative Process

Researchers have put forward a range of checklists and guidance in order to guide quality in qualitative research (Braun & Clarke, 2020; Walsh & Downe, 2006). This study utilised the criteria set out by Tracy (2010) to ensure eight key quality markers were used to assess the quality of this research: (a) worthy topic, (b) rich rigor, (c) sincerity, (d) creditability, (e) resonance, (f) significant contribution, (g) ethics, and (h) meaningful coherence. Table 4 outlines the quality assessment criteria and how it was applied to this research.

Table 4

Tracy (2010) Quality Assessment Criteria and Application

	Quality Marker	Application to this study
Worthy topic	The topic of the research is: • Relevant • Timely	The initial research idea and design of this research was formed based on professional practice and

	Quality Marker	Application to this study
	• Significant • Interesting	evidence. There is minimal understanding of how stroke survivors adapt and manage their stroke recovery alongside managing other pre-existing conditions. Multimorbidity is a topical area for public health and the NHS as it results in reduced quality of life for the patient (Wallace et al., 2015) and has a large economic burden (Soley-Bori et al., 2021). As such, the topic is not only interesting and relevant, but it is timely and significant.
Rich rigor	The study uses sufficient, abundant, appropriate, and complex: • Theoretical constructs • Data and time in the field • Sample(s) • Context(s) • Data collection and analysis processes	Multiple psychological theoretical constructs formed part of the rationale for the research such as illness perceptions, and self-management, thus highlighting complex and appropriate theoretical constructs. The 15 participant interviews were conducted over a 6-month period. They were between 30 – 60 minutes in length, indicating enough

Quality Marker		Application to this study
		time was spent collecting sufficient data. All participants met the inclusion criteria demonstrating appropriate samples and contexts. Both the data collection and analysis processes were rigorous throughout the research. This is evidenced by the description of the collection of data and the phases of reflexive thematic analysis undertaken, demonstrating transparency, and offering replicability.
Sincerity	The study is characterized by: • Self-reflexivity about subjective values, biases, and inclinations of the researcher(s) • Transparency about the methods and challenges	Due to the data analysis being reflexive thematic analysis, reflexivity was not only demonstrated by completing a research diary, but it also formed an integral part of the analytical process. Biases and influences were identified in the journal entries and reflections including challenges were captured in the reflexive report.
Creditability	The research is marked by:	Ongoing supervision formed part of the analytical process during the

	Quality Marker	Application to this study
	• Thick description, concrete detail, explication of tacit (non-textual) knowledge, and showing rather than telling • Triangulation or crystallization • Multivocality • Member reflections	research. The supervisory support offered a place for triangulation and discussions. The results include detailed descriptions of each theme, whereby the interconnectedness of themes was represented visually in a thematic map. Relevant quotes were also used to demonstrate both the analytical and illustrative points made in the findings.
Resonance	The research influences, affects, or moves particular readers or a variety of audiences through: • Aesthetic, evocative representation • Naturalistic generalizations • Transferable findings	The findings from the study can be transferable to individuals diagnosed with stroke and pre-existing diagnoses of long-term conditions. Part of the findings can be transferable to stroke survivors without co-morbidities.
Significant contribution	The research provides a significant contribution: • Conceptually/theoretically • Practically • Morally • Methodologically • Heuristically	Recommendations from the findings have been provided to improve practice and to gain a deeper understanding of participants' experiences while recovering from a stoke alongside managing other pre-existing

	Quality Marker	Application to this study
		conditions. The findings offer key messages for individuals, organisations, and systems. Additionally, the findings have been discussed in line with existing research and health psychological theory. This research has heuristic significance as potential avenues for future research was discussed.
Ethics	The research considers • Procedural ethics (such as human subjects) • Situational and culturally specific ethics • Relational ethics • Exiting ethics (leaving the scene and sharing the research)	Ethical approval was sought for the research as procedural and ethical considerations were considered. The necessary documents (Participant Information Sheet & Privacy Notice) were presented to each participant to ensure they understood the study before offering written and verbal consent to participate. Procedural ethics were also considered through developing a distress protocol.
Meaning coherence	The study: • Achieves what it purports to be about	The study's research and method were carefully designed. The theoretical standpoint also helped inform the research design. The rationale for each decision has

	Quality Marker	Application to this study
	• Uses methods and procedures that fit its stated goals • Meaningfully interconnects literature, research questions/foci, findings, and interpretations with each other	been documented thoroughly throughout the report to ensure that the methods and procedures matched the purpose of the project, goals, and aims. In-depth findings were developed and written, with interpretations evidenced in the discussion section.

Note. This table was adapted with permission from the author (Tracy, 2010).

2b.5 Ethical Considerations

The research received ethical approval from University of West England via the UWE Faculty Research Ethics Committee (FREC).

2b.5.1 Informed consent and voluntary participation

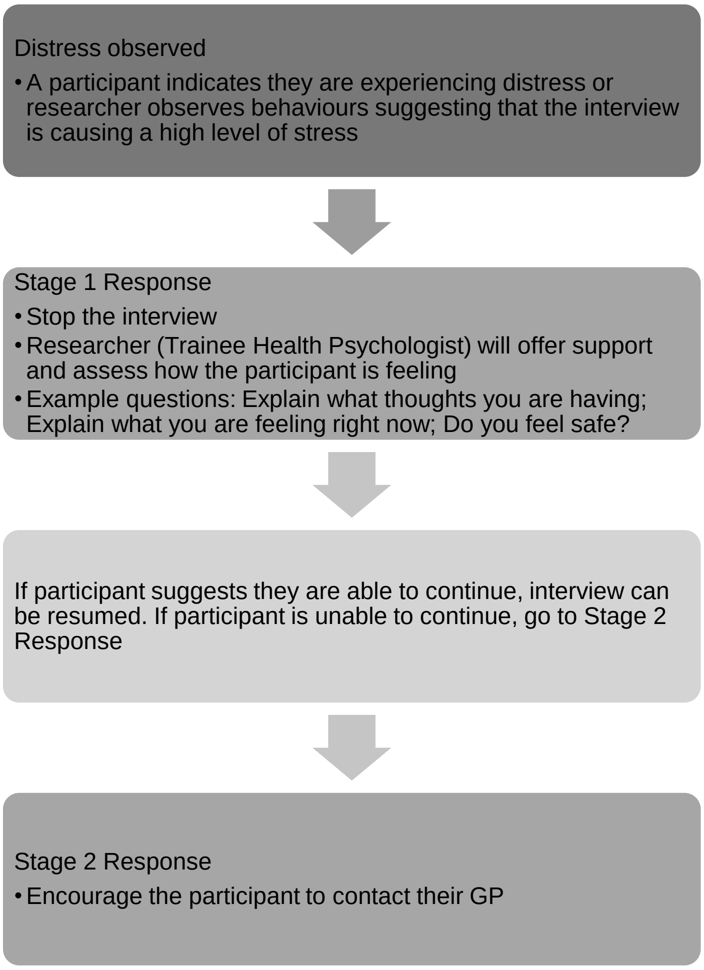
As per the ethical guidelines, each participant was given all the necessary documentation at the first point of contact. It was clearly explained verbally and written in the consent form that this was voluntary, and participants could stop or withdraw at any point either during, or up to 6-months after, the interview. Once the interview had concluded, each participant was given a brief verbal debrief, in addition to a written debrief letter emailed to them.

2b.5.2 Distress protocol

Due to the potential sensitive nature of the interview, a distress protocol was developed to ensure the safety of the participants. Although the risk of distress was considered unlikely in the design of this study, it was acknowledged that participants may have found talking about their illnesses and discussing experiences emotionally distressing as they could be deemed as sensitive topics. Moreover, common mental health conditions such as anxiety and depression were considered to be long-term conditions and were therefore included in this study. Consequently, it was deemed appropriate to develop a distress protocol (see figure 5), in the event that the participant experienced distress or difficulties during the interview.

Figure 5

A Protocol for Managing Distress During Interviews



Distress observed
- A participant indicates they are experiencing distress or researcher observes behaviours suggesting that the interview is causing a high level of stress

Stage 1 Response
- Stop the interview
- Researcher (Trainee Health Psychologist) will offer support and assess how the participant is feeling
- Example questions: Explain what thoughts you are having; Explain what you are feeling right now; Do you feel safe?

If participant suggests they are able to continue, interview can be resumed. If participant is unable to continue, go to Stage 2 Response

Stage 2 Response
- Encourage the participant to contact their GP

Note. This protocol was developed using templates provided by Haigh & Witham (2015) and Draucker et al. (2009).

2b.6 Patient and Public Involvement

Patient and Public Involvement (PPI) in the design and conduct of research projects, especially in health, has been gaining momentum in recent years (Biggane et al., 2019). The first two participants interviewed were asked their feedback on the questions being asked. This helped further inform the questions and allowed any changes to be made. The feedback was that I had included all relevant questions based on the aims of the study and that no further questions were needed. Additionally, the aphasia-friendly resources developed for this project were developed with a Stroke Coordinator working for the Stroke Association and a Speech and Language Therapist working within an Integrated Community Therapy Team for stroke survivors in the NHS. This was to ensure that the research fitted the needs of the community stroke survivors. No participants wanted use of the aphasia-friendly documents.

2b.7 Reflexivity

Reflexivity is deemed an essential requirement for good qualitative research (Braun & Clarke, 2013), it is also at the core of reflexive TA (Braun & Clarke, 2019; 2022a; 2022b). It encourages us to “foreground, and reflect upon, the ways in which the person of the researcher is implicated in the research and its findings” (Willig, 2022, p. 27). Reflexivity was therefore an essential component to conducting reflexive TA in line with the guidance; it allows for transparency as well as exploring critical self-reflection (Ortlipp, 2008). I kept a journal throughout the process and have written a reflective piece outlining my position as a health psychologist trainee while conducting this research (Appendix B). Within the journals, I reflected on each interview to outline the impact of a researcher in an interview setting; as such making the researcher visibly part of the research process (Braun & Clarke, 2013; 2022b).

Chapter 3 – Findings

Four themes and one subtheme were identified (see figure 6). '"I was OK I felt fine" - Positive illness representations prior to stroke' focuses on the stroke survivors' health and illness perceptions before stroke. Participants' health identity was shaped by their ability to engage in meaningful activities, despite having been diagnosed with at least one long-term condition (LTC). As participants did not consider themselves unwell, they described perceptions of themselves as at low risk of stroke and attributed the stroke to external factors. This lack of health threat appeared to influence participants' health behaviours.

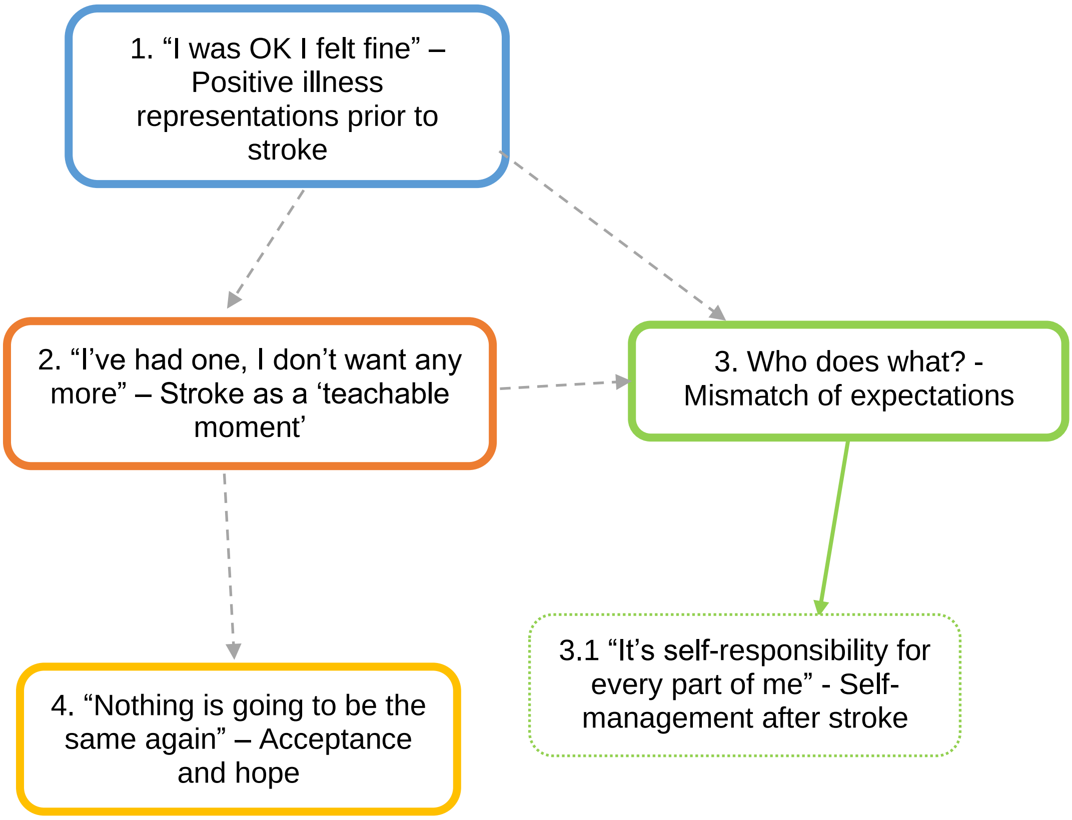
'"I've had one I don't want any more" - Stroke as a 'teachable moment'' relates to the stroke event, the participant perceived consequences of the stroke and how these were described as having driven a shift in their health identity. The stroke survivors explain their search for meaning behind new or recurring symptoms. The direct impact of the stroke on pre-existing conditions was also discussed in relation to the timing of the stroke and intentions to take medication. The fear of having another stroke was described as fuelling participants' uncertainty of the future.

The third theme 'Who does what? – Mismatch of expectations' concentrates on the stroke survivors' expectations of their follow-up care and subsequent stroke journey. Stroke survivors' expectations of who was responsible for their care was expressed as ambivalent, which created uncertainty around how to manage their health in the future and where this support could be sourced. This theme also contained a subtheme '"It's self-responsibility for every part of me" – Self-management after stroke', which details participants' intentions and behaviour change in relation to having to assume self-management since the stroke.

'"Nothing is going to be the same again" - Acceptance and hope' focuses on the conflicted nature of hoping for more progress in their recovery but accepting what has happened to them and the consequences associated with the stroke. Participants' acceptance of their situation was not mutually exclusive of hope of future recovery and better health.

Figure 6

Thematic Map of Themes and Subthemes



Theme 1: "I was OK I felt fine" – Positive illness representations prior to stroke

This theme focuses on participants' perspectives regarding their pre-existing LTCs prior to their stroke. Participants described that they felt well despite their pre-existing conditions, and that these perceptions influenced their beliefs about the cause of the stroke. Participants reflected on their life and experiences of managing their other

LTCs before the stroke, which included risk perception and their causal beliefs regarding the stroke. Although all participants had been diagnosed with at least one LTC prior to their stroke diagnosis, most participants seemed to identify themselves as being well. For some participants, health was described as and identified in terms being able to engage in meaningful activities. This included physically being able to do what they wanted to do, seeing themselves as 'active' and being able to live a 'normal' life.

> *"Busy" (Deborah, Female)*
>
> *"Very active very very active she was always on the go" (Deborah's Carer, Male)*

Having the ability to be active gave participants a sense of comfort that their health was not cause for concern. Paul talked about going to the gym and enjoying gardening in his spare time. His ability to be able to participate in these activities led him to describing himself as fit, suggesting good health.

> *"Yeah I was pretty fit erm we had the lockdown prior to my stroke lovely weather last year so I was in the garden at the time I'd demolished some old sheds and built new ones erm I filled two massive skips" (Paul, Male)*

Mimi was a young stroke survivor. She wasn't working at the time of her stroke but her ability to be able to look after her four children contributed to the perception of her own health as fit and healthy before the stroke occurred.

> *"I was normally I would say I was quite fit and healthy I wouldn't say fit as in like I was very in caring into fitness but just normal person really just getting on day by day I I didn't have like a routine of fitness or anything or like a diet*

> *erm so I would say I was pretty normal I had four kids so erm I felt like I was yeah healthy enough to have the kids" (Mimi, Female)*

Moreover, some participants were working at the time of their stroke and being able to work shaped their perceptions of living an active life and not perceiving themselves as unwell.

> *"I did work very long hours I used to work six days and six nights a week" (Ian, Male)*

For some participants, their health identity was influenced by the disruption pre-existing conditions, symptoms and treatments had on their lives. The level of impact and disruption of pre-existing conditions to life was minimal for most participants. Simon had been diagnosed with a heart issue when he was in his 20s. Up until having to take medication for his conditions recently, he did not feel restricted by his condition as he was able to do everything he wanted to do.

> *"Well erm the hypertrophic cardiomyopathy was detected after a family screening because my erm niece when she was about two she they detected a problem with her heart and they said the rest of family need to be screened and I picked the short straw and they found it on me but erm up since then I've been okay I've done everything a 25-year-old wanted it's never ever stop me from doing anything" (Simon, Male)*

For many participants the lack of daily symptoms experienced caused them to perceive themselves as not having 'anything wrong' with them. For Michael, taking medication and following a healthier diet was described as protecting his health and keeping things ‘under control’ despite being diagnosed with diabetes and high blood pressure.

> *“I was OK I felt fine I didn't think there was anything wrong with me I except that I had to take medication for high blood pressure I I needed to take medication for diabetes but er I felt that er my diabetes was under control with the er with the dieting” (Michael, Male)*

Not *feeling* unwell in terms of symptoms seemed to be central to participants identifying themselves as well overall despite the earlier diagnosis.

> *“I exercised a lot I walked a lot my job was rel- relatively physical I didn't feel unwell ever you know I had the odd cold and that otherwise I seem good and but I I did keep an eye on my blood pressure mind I I didn't want I didn't want it to go too high” (Edward, Male)*

Others described being skeptical of the impact having anything worthy of treatment or concern, highlighting that you *“have to live your life” (Hannah, Female)* and not engage with an illness identity. Mimi had previously been diagnosed with an underactive thyroid and was prescribed daily medication. However, she expressed a lack of understanding as to why and how the medication helps and a dismissal of its importance.

> *“In terms of health wise I don't understand what it does for me anyway like how does it affect my life at all” (Mimi, Female)*

Jane’s lack of diabetes management prior to her stroke was represented by her flippant attitude to her pre-existing LTC.

> *“It was uh it was kind of like an attitude like ‘oh there's a pill for that’ … do you know what I mean so if it gets worse there’s a pill for that you know and and I and that attitude that that I think lead to where I was” (Jane, Female)*

The dismissive attitude towards pre-existing conditions reflects the health identity of being ‘well’ that participants described. Furthermore, participants described contrasting experiences of their pre-existing conditions, with some experiencing minimal disruption and others experiencing significantly more. Yet, participants’ health identity seemed to be entrenched in physical capabilities of being able to engage in hobbies, be an active parent and work. Participants viewing themselves as active, fit, and healthy led to them a reduced perception of risk of stroke prior to being diagnosed. In the following quote, Robert alludes to the notion of risk perception which could have been a precursor for the cause of his stroke.

> *“I didn't really think I was in you know at risk” (Robert, Male)*

Causal beliefs also offered some explanation as to why participants did not identify themselves to be in poor health prior to their stroke, despite having pre-existing LTCs. Some participants believed it was the responsibility of healthcare professionals to prevent the stroke or acknowledge it was happening, suggesting the stroke was out of their control. In one instance, Edward was told he should have experienced some symptoms to indicate something was not right and that he should have seen the signs. As a result, he spent time ruminating about whether he had experienced these symptoms but concluded that he had not. This suggests a mismatch of understanding between healthcare professionals and the participant. The expectations of what people should be feeling or experiencing prior to their stroke created self-doubt.

> *“I had no symptoms of the AF at all ‘cause I was told I should have been breathless well I I can’t I sit here trying to remember was I breathless and nothing” (Edward, Male)*

Similarly, Deborah also blamed the healthcare professionals for over prescribing medication, which has led to a dispute.

> *“She was over prescribed the medication which consequently er caused a stroke or clots” (Deborah’s carer, Male)*

This quote reflects the importance of not perceiving herself as unwell as it led to them not taking responsibility for their health and blamed others. Other external causal factors were described by Robert. He believed that if he had not been put on a program to manage his diabetes, then there is a chance he may have not experienced the stroke.

> *“The consultant at that erm that saw me a man that dealt with the stroke said that it was negligible the risk was really negligible and that he was surprised that I was put on a program so in a sense I may not have had a stroke by being put on the program but then it could the stroke could have been a lot worse if when I had one so you know it's it's one of those things” (Robert, Male)*

Another participant suggested that their GP should have seen the signs and prevented it. He expressed his lack of knowledge should not have been the reason why he had the stroke, however, he shifted the responsibility onto himself and others that *“they should know about these things and gain awareness” (Richard, Male).*

Consequently, other participants, however, when looking back at pre-stroke behaviour and attitudes appeared to blame themselves. It was their responsibility to have prevented the stroke.

> *"Because if I could control my blood pressure I wouldn't have had the stroke" (Diane, Female)*

In hindsight, some participants believed that if they had controlled their pre-existing conditions, they could have prevented the stroke. This alludes to an internal focus of cause, rather than the external factors mentioned above. Subsequently, participants felt angry with themselves, believed they should have looked after their health prior to their stroke and felt they should have taken their pre-existing conditions more seriously.

> *"It wasn't hard do you know what I mean if I didn't and I that's the bit I'm really cross with myself thinking everything I put in place was not hard to do I should have done it years ago and it took a stroke to make me realize that… They said my erm so my diabetes contributed to the stroke along with high cholesterol and I didn't know I had high cholesterol and stress" (Jane, Female)*

Interestingly, a few participants also could not understand what caused it, suggesting it could have happened by chance. However, a few participants also discussed the impact of the pandemic on the ability to engage in health behaviours such as going to the gym, which they believed contributed to the etiology of their stroke. The pandemic seemed to encourage participants to adjust their lifestyle for example, drinking more alcohol at home which could have contributed to the cause of their stroke.

> *"What I think happened is when the lockdown kicked in gyms shut my lifestyle changed as regards I couldn't go work because of the injections it's an immune suppressive so they stopped me from going to work even though it's on full pay which is happy days er but the fact is that er the gym has stopped as I say and I was at home a lot probably drinking more than I should have done and you know all everything changed and I suppose I was on a good balance and then my balance went out of kilter that's what I suspect anyway"* (Richard, Male)

> *"I probably drank too much alcohol tended to drink too much during that lockdown that first lockdown the weather was nice we were all sitting out on our patios"* (Paul, Male)

A few participants were also questioned by healthcare professionals and friends about the prospect of the Covid-19 vaccination causing their stroke.

> *"I thought 'I've got to have this [vaccination] like people that have it and do you catch COVID are normally at a lot lower risk than people who haven't been jabbed' and I just thought 'get it done' so and then of course I had the second one in June then of course a stroke in August and then I've got the anti-vaccine people getting on me going 'are you sure it wasn't the jabs that gave you your stroke' I said 'no I'm not a hundred percent sure but I would again I'll have the heart attack first the stroke second and COVID finally last' because I said 'I don't want to be on a oxygen whatever'"* (Ian, Male)

Simon also specified that there was an indication that the Covid-19 vaccination could have caused his stroke, as he did not know what caused it.

> *“The only one thing I had different was I had a Pfizer jab… and a month later I had a stroke so it could I don't know if it is related to the jab or what but I don't know” (Simon, Male)*

The causes of stroke were speculative and unclear. Participants attributed many external factors such as being able to see the warning signs or healthcare professionals being able to prevent it, the consequences of the Covid-19 pandemic or the vaccine.

Participants’ perceptions of their health prior to their stroke were determined by factors such as being able to engage in meaningful activities, being able to physically do what they wanted to do and consequently not considering themselves at risk of stroke due to their functionality and lack of symptoms. Participants’ positive health identity drove them to perceive the stroke as being caused by external factors outside of their control, such as healthcare professionals, medication, and the Covid-19 pandemic. These are interesting findings considering all participants had at least one existing LTC.

Theme 2: “I’ve had one I don't want any more” - Stroke as a ‘teachable moment’

Participants described experiencing a shift in their identity from perceiving themselves being well prior to their stroke, to having poorer health post-stroke. As discussed in theme 1, participants often described their health as that of a healthy individual despite their pre-existing LTCs. After the diagnosis of stroke, health and wellness was defined in terms of successful management of both the stroke and the existing LTCs, where recovery, adjustment and functionality after stroke needed to be synced with self-management of their existing LTCs.

According to participant accounts, the stroke impacted the participants' daily lives and functioning. Participants talked about losing their independence and not being able to do what they have always done, for example gardening and driving. Participants described being hit with the realisation that they could not do what they used to be able to do, and that they had to shift their mindset to that of someone with a diagnosis of stroke. The subsequent experience of recovery from stroke prompted participants to make a shift to requiring recovery and support, leading them not perceiving themselves to be well anymore. The shift was often subtle and was depicted throughout the dataset by the use of past tense in participants' language.

> *"I felt as I* ***was*** *in really quite good condition" (Richard, Male)*

> *"I didn't have any health issues at all I* ***was*** *very quite active" (Mary, Female)*

Some participants explicitly compared their health from before and after their stroke diagnosis. These realisations were in relation to consequences of illnesses, importance placed on conditions and the treatments they received. After the stroke, these factors were used to compare pre- and post-stroke health. Edward described how before his stroke he did not consider and value his health as often and much as he does now.

> *"Cause before [the stroke] I wouldn't say I didn't give I didn't give erm two hoots about my health I did like but you would do things that wasn't good for you wouldn't you and not have a second thought like you know" (Edward, Male)*

Ian had experienced five heart attacks before his stroke. However, the stroke meant that he was no longer able to work full-time. This significant disruption incited him to change his perspective on his self-management and realise what was best for him to look after his health. This was evidenced in his recognition of what was causing him to feel like he had overdone it, which consequently left him needing to recover.

> *"When did I come back I can't remember what date in August it was but I came back and I tried to jump straight back in and work full time the very first full day that I'd done was a Tuesday so I was in at nine o'clock in the morning worked till about five er then came back in for six and then worked till one…lucky enough the next day the Wednesday was my day off I slept for twenty three hours so I'd totally overdone it… it done me a favour because then I realised I have to get like Barry in to do the cleaning" (Ian, Male)*

Furthermore, the salience of symptoms and conditions participants experienced led them to consider the impact this had on their lives. The experience of having a stroke had a major impact on participants' perceptions of symptoms and subsequent behaviours. Many participants discussed how sensitive they were to physical sensations and had difficulties making decisions about how the deal with the symptoms experienced. Having a stroke drove participants to be more aware of symptoms which they would not have ordinarily noticed and tried to understand why they were experiencing them.

> *"I don't like that feeling and erm and the thought of having a headache I've only have a couple of headaches since the stroke and it's quite frightening when you get a headache you think 'oh what's going on' you know" (Paul, Male)*

Participants questioned whether the symptoms they were experiencing attributed to their stroke or their other LTCs.

> *“Now I'm thinking is the pain Fibromyalgia or is it stroke should I go to A&E well I won’t go to A&E erm so it's all just about resting you know” (Julie, Female)*

Some participants had no hesitation in going to the hospital if they experienced a sensation, which they had not previously done. Others overcame previous patterns of attempting to avoid medical care.

> *“I started having chest pain again and erm automatically I thought ‘I don't know what this is going to lead up to so I'm going to get checked out’ … I think you just worry over everything like and you want to catch it before it happens again” (Mimi, Female)*

> *“The slightest little thing I think is wrong with me I'm on the phone to them I must seem like a right nag” (Edward, Male)*

> *“Oh well it's just like where you try and control it all yourself but then if you notice any signs straight away your phone the doctors up” (Diane, Female)*

As a result of the stroke, Simon reflected on the mind-body link and used this to cope with his symptoms, which was also apparent for other participants. He talked about managing the thoughts around any physical sensation to reduce the anxiety.

> *“I mean managing your like your mind I think coz you're worried about like any little pain or anything you think ‘oh this it's a symptom’” (Simon, Male)*

For many participants, the stroke sparked a drive to be more health conscious. This was particularly true in participants that experienced more severe consequences of their stroke. This perceived severity was based on consequences including physical, cognitive, and psychological effects. Edward described feeling trapped as a consequence of his stroke.

> “*I get anxious and depressed and my mind isn't as sharp as it used to be, you know… I’m so scared of having another stroke… I’m not free to do what I want to do” (Edward, Male)*

For some where the severity was deemed minimal, the stroke seemed to have less of an impact on attitudes towards health, illness, and symptoms, compared to those participants who perceived severe effects of stroke; thus, reducing the saliency of the stroke.

> *“I just had the headache you know that was all … you do feel realise you are sort of mortal and you know things happen but I don’t really feel at huge risk I suppose” (Robert, Male)*

The beliefs about the severity of the stroke came from participants comparing themselves to other stroke survivors and seeing how they were impacted. Mimi saw her stroke as minor which was a belief she held when comparing her own stroke effects with other stroke survivors who were in the hospital at the same time as her.

> *“And it’s just counted as like a little stroke so I can’t imagine what people with major strokes go through” (Mimi, Female)*

Although the perceptions of the severity of the stroke contributed to saliency and importance of the stroke for some participants, the majority of participants discussed the impact the stroke had on their pre-existing conditions. The impact was specific to the situation the stroke had left the participants in and what this meant in terms of managing their pre-existing conditions. Being in hospital, the timing of their stroke and the ongoing effects of their stroke all contributed to their consideration of their LTCs.

Simon discussed the difficulty he experienced managing his pre-existing condition while in hospital at the time of his stroke. He felt there was a lack of understanding of what his condition meant. However, he did not seem to think the stroke impacted on his ability to manage his physical health conditions but understood how the stroke could impact someone psychologically.

> *"So, I'm a celiac as well so I have to be careful what I eat… So it was a bit strange in and you know bit difficult in hospitals cause some people don't understand that that it's a gluten free diet so… I don't think [stroke] impacts my condition I don't know I don't know it's just there it's there you have to erm it could impact your mind I suppose if you let it" (Simon, Male)*

Similarly, Hannah discussed the timing of the stroke indicating that the routine she had established, and the pre-existing condition already being so embedded in her life, that it was something she managed easily. She discussed the treatment of her pre-existing condition and believed that if she had to manage her treatment for her pre-existing disease at the same time as her stroke or after, she believed she may have found this challenging.

> *"I think if I'd started if I'd had the stroke and then started my treatment for my [disease] then I think it would have impacted on my memory because it was*

> *something new but because it's something that's already stored in my memory and is stored in the back it doesn't affect" (Hannah, Female)*

In Hannah's quotation, the ability to be able to manage her pre-existing condition was characterised and defined based on the timing of her stroke. She recognised how impactful the consequences of her stroke could have been on the management of her other conditions. However, some participants discussed the negative impact the stroke had on managing their pre-existing conditions. Tracey explained how her pre-existing conditions worsened which made managing other health issues more difficult.

> *"My diabetes got worse afterwards yeah that came back with a vengeance but that's but also I've not slept since the stroke I think because I had a stroke in the night whilst asleep…I wasn't a very good sleeper before so it seems to have made all the things I had a bit of a problem with much worse" (Tracey, Female)*

Contrastingly, a few participants discussed the stroke improving symptoms. Deborah talked about some health benefits after the stroke diagnosis. A significant symptom she was having to manage before her stroke did not seem to be something she needed to manage since her stroke.

> *"It totally stopped the bleeding" (Deborah's carer, Male)*
> *"It stopped when I was in (hospital)" (Deborah, Female)*

Similarly, participants talked about how the pre-existing conditions could cause another stroke. They showed knowledge and understanding about what may cause more health issues for them in the future since their stroke diagnosis, highlighting the interconnectedness of illnesses.

> *“I think if I am having an asthma attack or the a COPD infection I don’t think that would help the stroke because that would send my blood pressure high again…so I think by keeping those two more under control to a degree that I can that's also gonna help me not to have another stroke” (Diane, Female)*

> *“The most important one to be managed is blood pressure you know and er well blood pressure and your cholesterol was the de- that combination of high blood pressure and high cholesterol is a killer you know it is a killer and unchecked it’ll creep up behind you and then slap you right down when you least expect it” (Richard, Male)*

These realisations became apparent purely because of the stroke event, suggesting the importance the stroke had in shifting health and illness perceptions. Furthermore, despite participants experiencing positive and negative consequences of their stroke on their other LTCs, there was a shift in the importance they placed on medication taking since their stroke. Michael described how he had ignored his diabetes prior to his stroke and was not very good at taking his medication for it. However, since his stroke he is more regimented in taking the medication for his diabetes.

> *“Before this stroke I was neglecting my diabetes too but since then I am religiously taking all my medication… I now I have I actually considers er it's really important to take all my medication on time” (Michael, Male)*

The barriers to taking medication were discussed however, interestingly the importance of the particular condition the medication was for, directly impacted on the participants' willingness and motivation to take the medication at the correct time.

> *“I don't see as important I know it doesn't sound good but erm I don't see that as an important medicine otherwise I'll be always having it on time the same way I think erm what it is with the under active thyroid medication is that you've got to have it first thing in the morning and that's really hard to remember with that one and the Warfarin is an evening medication and even though it's hard to remember I still make sure I remember I’ll put an alarm clock on and everything like that so there's a big difference yeah” (Mimi, Female)*

In this quote, Mimi struggles to understand how beneficial the medication for her underactive thyroid is. By not considering it important, she had difficulty remembering to take it in the morning. This highlights how influential health beliefs are on health behaviours. Similarly, Edward’s importance of taking medication shifted after his stroke.

> *“I knew it was important to control it erm my father's couple of heart attacks due to high blood pressure so I knew it was important to control it erm I wouldn't say I was brilliant at taking my medication but I I took them ninety-five percent of the time but now now I take them a hundred percent time I'm regimented to take them you know” (Edward, Male)*

Despite the difficulties participants faced, they also utilised coping mechanisms and strategies to increase medication adherence. Such strategies were driven by their motivations to reduce risk and have better health. This was often in contrast to their behaviours before their stroke in managing their LTCs.

> *“I mean with all my medication that I take at which I have to take everyday it’s in a daily pop pill and it sits by the kettle so when I get up I know that I need to take you know Monday AMs and its all and erm and then I do it all myself so it's all set up for two weeks worth of medication” (Hannah, Female)*

On top of managing the consequences of their stroke such as the physical, cognitive, and psychological impacts, for some the stroke led to participants being diagnosed with other conditions that they also needed to manage. A result of the stroke meant that all participants were on more medication as well as the new diagnoses. Most had been diagnosed with new conditions such as high cholesterol at the time of their stroke.

> *“I only discovered in hospital they've got cholesterol well I was really shocked I never for a million years ever thought I had cholesterol” (Diane, Female)*

The new diagnoses on top of the stroke highlighted a disappointment of having to take more medication. Having another condition to have to manage highlights the increased complexity of stroke and the subsequent rehabilitation and recovery journey. The complexity of managing stroke in the context of pre-existing conditions was a core concept throughout the participant accounts. Participants shifted their thinking about importance of medication taking.

> *“Thyroxine I need I need to take and I desperately take it permanently and my blood pressure obviously I take my tablets religiously now I probably didn't take them properly before I put my hands up to that” (Julie, Female)*

> *“More important now because some of the medication that I'm on erm because of the stroke is causes complications with liver and stuff so it's important” (Robert, Male)*

Participants expressed anxiety and worry regarding having another stroke. These concerns contributed to their shifting view on health and consider how they might manage their health in future. The reflections led to participants describing their intentions to look after their health better in the future.

> *“You know just concentrate on just managing this diabetes and becoming this reformed person if you know what I mean” (Jane, Female)*

As a result of the stroke being a teachable moment, participants discussed their motivations to change their behaviour based on their newfound health identity. Participants discussed why the stroke led to them changing their behaviour. Clear motivational intentions had changed and shifted towards wanting to take their health more seriously, which included managing their other LTCs better. Jane reflected on what she was like before her stroke and her lack of health focus, she understood that her previous behaviour was not in her best interest and consequently she shifted her attitude due to the stroke.

> *“I mean to be fair it was like if I was working late so I was really lucky 'cause work in a military environment they erm you have like and I was I was able to be part of the officers mess or still am so I'd perhaps work late till seven o'clock that's that's bad in itself now looking back on it but then I'd go and have my dinner and the mess then come home and my tablets have to be taken before food but I'd have them when I got home do you know what I mean and I would never take out carry around with me any medicine 'cause it gets in the way*

> *and it was a weakness to me that I'd got it you know but looking back it's my fault the way I was living you know so erm yeah that's so that's so it's a better attitude towards it now" (Jane, Female)*

Participants shared that they engaged in more risk reducing behaviours such as quitting smoking and cutting down on alcohol, as a result of the stroke.

> *"I drink really low alcohol beers at weekends and I I knock it up with naught percent beer so I trick my brain into thinking I'm drinking lots where I'm not" (Richard, Male)*

Participants discussed different motivations as to why the changed their behaviours, such as conversations with healthcare professionals.

> *"The drinking I remember erm before I got discharged the Pharmacist came to speak to me about the medication and he really highlighted the erm danger of drinking too much with the blood thinners I'm on so that was enough for me then" (Edward, Male)*

Most participants who were smoking at the time of stroke took it upon themselves to quit. Participants reflected on the consequence of their stroke as motivation to stop.

> *"I just look at me hand when I want a fag it's a good reminder" (Diane, Female)*

One participant had not quit smoking and although he had cut down considerably since his stroke, he had no intention of quitting fully.

> *"I wanted to reduce anyway I mean I used to smoke erm a hundred grammes a week which is like two big packets and not only one it was costing me fifty pound a week but two was I just felt that I was smoking too much so then I reduced it to one packet a week before I had the stroke so I reduced it by fifty percent and then now one packet last me ten eleven sometimes twelve days" (Ian, Male)*

Participants who attributed their pre-existing LTCs to the cause of the stroke resulted in a specific focus to manage those conditions better. For example, Michael expressed always being mindful of his diet for his diabetes; however, he shifted his intention to watch his diet even more closely to reduce his risk of having another stroke.

> *"One of the things er I have always said to do is is watch my dieting for the diabetes and I am doing that I have to do it even more now because I don't want the diabetes to cause me a second stroke"* (Michael, Male)

The fear expressed by Michael was shared. Sarah described how she resented how the stroke had affected her daily life in comparison to her pre-existing condition. She talked about having to wait to get back to work due to the advice she had received. Sarah became passive and discussed wanting to just get on with life with the attitude that "*there was nothing I [she] could do about it".* She spoke about feeling frustrated by the anxiety of having another stroke.

> *"It's just frustrating because I think I worry that will it happen again"* (Sarah, Female)

Sarah was aware that no one truly knew what the future held, but she looked for reassurance about what to expect in the future and understanding of how much her medication could help reduce the risk of another stroke.

> *“I know no one's got a magic wand but it be quite nice for someone to say this medication that yours on will stop you having erm another stroke” (Sarah, Female)*

Tracey also discussed feeling lucky with the consequences she experienced from her stroke, yet she still held a fear of having another stroke. She appeared to be in a vicious cycle of worrying about having another stroke and that worry and stress causing her another stroke. She described how she managed that fear through her usual coping mechanism of eating.

> *“I do realise that I was very very lucky very lucky and it could have been so much worse so I mean in not sleeping worries makes ‘cause I think ‘oh my God am I gonna have another stroke through the stress of not sleeping’ and it makes me eat I eat because I can't sleep when I get stressed” (Tracey, Female)*

Julie talked about how she coped with managing that fear, especially on the anniversary of her stroke.

> *“Last weekend when it was a year anniversary every little thing I just stayed in bed because I'm so scared of taking another one you know they can't tell you if it's gonna happen again” (Julie, Female)*

The fear of having another stroke and concern about death was expressed by Diane. She described panicking when she thought about it the first time she came home after hospital. She too found coping mechanisms to manage the overwhelming anxiety by engaging in self-talk.

> *"When I went to bed Thursday night and I lied there and I got out of bed my husband said 'what's wrong' and my son was there one of my sons no they were both there no all three of them were there sorry and er I said 'I'm scared I'm scared of it happening again and I die I'm scared' and I started getting in a bit of a panic and I was like 'no just leave me a minute leave me a minute leave me a minute' and I went and sat in the awning on me own and then gave meself a talking to" (Diane, Female)*

The experience of having a stroke was so significant to some participants they described preferring experiencing a heart attack over having another stroke, as there was the belief that it would be less impactful.

> *"Last May when I was well if somebody said to me 'you can choose between a heart attack and a stroke' I think I would take my chances of a heart attack" (Edward, Male)*

Ian, who had experienced many heart attacks, felt similarly to Edward. The consequences of the stroke and the significant impact the event contributed to his need to avoid future strokes. Ian even expressed a preference for another heart attack in comparison to another stroke.

> *"I have said to people when they ask me especially friends I say 'I'd rather have a heart attack than have a stroke' that stroke made me feel so*

> *uncomfortable and not know what was going on whereas a heart attack was just pain pain I can deal with" (Ian, Male)*

The perceived severity of the symptoms of (another) stroke was described by Ian, and others, as a catalyst for understanding how and when to engage in behaviours to protect their health.

This theme highlights a clear *teachable moment* stroke survivors experienced as a result of the stroke. The stroke was described as providing an opportunity for participants to learn and reflect on their health, which subsequently led to a shift in mindset to be more health conscious. The stroke experience was expressed as impacting on their individual motivations and attitudes towards health, resulting in positive changes in health behaviours compared to pre-stroke. An increase in symptom perception following this experience appeared to contribute to judgements as to whether to seek help or not, and despite some participants even experiencing positive effects from the stroke, such as reduced symptoms from other LTCs, it still led to a shift in mindset towards seeking to engage in healthier behaviours. The importance participants placed on the management of their existing LTCs as well as the fear of having another stroke, and now perceiving themselves to be more at risk of negative health outcomes, were significant contributing factors to this shift and subsequent change in behaviours

Theme 3: Who does what? - Mismatch of expectations

This theme concentrates on the concept of expectations, particularly in relation to responsibility of health and care. It incorporates one subtheme '"It's self-responsibility for every part of me": Self-management after stroke', which focuses on participants understanding of self-management, their intentions to self-manage and what actions they have subsequently taken to self-manage.

Participants held expectations in relation to their follow-up care, stroke recovery, and the management of their pre-existing LTCs. The expectations were shaped by previous experiences as well as the Covid-19 pandemic. Participants felt there was a lack of clarity about who was responsible for recovery and health management of all their conditions after stroke, and participants felt that they were left somewhat alone. Participants who did not seem to get the input expected from services felt abandoned by the NHS and that they were just *"left to get on with life" (Hannah, Female*). Although participants' expectations did not seem to be met, participants discussed the ways they had taken personal responsibility for their recovery. Participants identified barriers to medication adherence and provided insight into the coping strategies to overcome those barriers.

The expectations participants held in relation to their stroke and subsequent health were described as not met. Participants reported a mix of good and bad experiences throughout the stroke episode and rehabilitation, even as early as when the participant was having the stroke.

> *"The day I went to A&E it was two hundred and seventeen over a hundred and twenty-three and they sent me out of that A&E they watched me walk out in tears and get into my daughter's car they watched me from the door I should never have been let out of hospital that day and even my GP said and even the er stroke specialist said 'you should never have been let out of hospital that day and I hope you complain' I did put a complaint in but I've had nothing back whatsoever" (Julie, Female)*

Disappointment was evident across participants accounts from those who stayed in hospital. Participants discussed an expectation of more rehabilitation time and input from healthcare professionals. As a result, participants took it upon themselves to start their recovery and rehabilitation while they were in hospital.

> *“I managed to sit up on the bed and then get me legs out of the bed then I was tapping my right leg and foot on the floor continuously I ain’t got nothing on my feet so it was quiet erm then I'm practicing the speech ‘cause I saw some speech things papers on the table and I've grabbed to look at them ‘ah exercises to do’ right so I started the speech ones” (Diane, Female)*

Similarly, Ian’s rehabilitation was restricted due his pre-existing condition. He was unable to get rehabilitation and although he knew why, he did not understand the reasoning behind it and as a result, he began his own rehabilitation.

> *“I was a good few weeks just laying in bed not doing nothing at all not getting up not sitting in chair I do my own exercises in the bed like pushing my bad leg up against the bottom of the bed trying to lift my leg up bending the knee and the arm and then doing sorta hand and what have you exercises to strengthen it up 'cause I just thought ‘you’re not doing nothing for me’ I was quite upset with that to be honest” (Ian, Male)*

Participants were dissatisfied with the reasons given as to why they could not go home. Due to the perceived lack of support, they stated that they believed they would have been able to do just as much as home as within hospital.

> *“In hospital I kept saying ‘can I go home can I go home’ ‘no you need physio’…in there I was lucky if I got it twice a week so of course I could have*

> *been doing that at home what they had me doing I could have been doing at home" (Julie, Female)*

Similarly, some participants took it upon themselves to seek answers about what was going on with their health, despite feeling satisfied with the NHS and the care they had received at the time of their stroke.

> *"I did go and see a private neurologist because even though I I I I went and had all the scans and everything I and the MRI they didn't give me no results back and I ended up having that sent to a private neurologist to tell me 'cause it seemed to take ages for the NHS to actually tell me 'yeah you've had a stroke' 'cause it wasn't definitive they said 'we're going to put you in the stroke category 'cause that's what it looks like you've had but it might not be' so after the MRI it they took ages seem to give me a a result back so a couple of things I've had done myself privately you know so but all in all I've been pretty satisfied with the er NHS" (Richard, Male)*

It was evident throughout patient accounts that the pandemic had a deleterious impact on most of the participants' experience within hospital. Although participants were understanding of the staff shortages, it led to a decrease in the care that they received.

> *"Yeah they were really short staffed 'cause where they had to er erm spread out the the normally the ward the ward could be staffed for about thirty fourty people but when COVID hit they had to like spread them out so they're coming in at different times just try to try and eliminate any er cross infection and things like that" (Deborah, Female)*

It was clear the Covid-19 pandemic had a detrimental impact on healthcare services and consequently the follow-up care for the participants was not what was expected. Participants also had expectations about what they wanted from follow-up care and the management of their pre-existing LTCs.

> *"The thing is I think because of Covid everything was really delayed so erm I'm supposed to have a stroke follow up erm I'm sure they were supposed to ask me like where I am in terms of recovery but that appointment keeps getting erm cancelled and cancelled cancelled erm rescheduled" (Mimi, Female)*

> *"They weren't really interested (laughs) I've not seen erm I've only had one follow up from hospital and I've got follow up at the end of this month erm in the hospital to see the stroke team erm my last follow up was with a nurse and that was about a month ago yeah" (Tracey, Female)*

Alternatively, some participants also felt that they did not want to seek help due to the pressures the health services were facing because of the ongoing pandemic.

> *"Because of this scenario with the National Health Service at the moment you do feel that unless it's something really vital I'm not gonna bother you know I'll just carry on as best I can and I don't really have any enormous concerns so just things that would be nice to know but I'm not gonna ask any questions at the moment" (Robert, Male)*

The lack of care perceived by participants caused a dismissive attitude towards their previous LTCs and follow-up care.

> *"I did have a heart monitor fitted for a while afterwards erm in February but that was for a week and I've never had any results or anything so I assume there's nothing to worry about" (Robert, Male)*

For others, the lack of input from health services led to a sense of helplessness. One participant felt there was no point in accessing support because she believed there was nothing the HCPs could do to help her.

> *"If I go to a doctor and explained that to them that I I can't sleep at night but really tired erm because since I've had the stroke or erm I'm I'm just my arms a bit dead they can't actually do anything about it if you think about it you just got to get on with it and be strong mentally in order to get better I think sometimes you think you're doing so well and then you wake up in the morning or and I'm like 'where's my arm gone' I can't even feel it and it is there but you just gotta get on with it" (Mimi, Female)*

Participants described feeling abandoned and being *"left to get on with it" (Hannah, Female)* and *"left to my own devices" (Edward, Male).* Additionally, this sense of abandonment contributed to participants not realising the impact the stroke had on their body.

> *"I really feel I've been abandoned by the NHS you know I've read a lot about stroke so I didn't know nothing about it til I had it (it's occurred to me the) trauma my my body's been through" (Edward, Male)*

In addition to expectations in the stroke rehabilitation phase, participants also alluded having expectations regarding follow-up care with their pre-existing LTCs. Although the focus on stroke recovery was more salient compared to other conditions, following hospital admissions, and returning home, there was an expectation across participants that they should have received more follow-up support and care from their GPs regarding their pre-existing LTCs.

> *“Honestly and nobody wanted to see me erm I phoned them up and I did manage to speak to her actually but that was my instigation…in terms of healthcare afterwards I've had nothing” (Mary, Female)*

In this quote, Mary discussed getting no support regarding her pre-existing LTCs. This was also true for most other participants, insinuating that although stroke care was not adequate, it took priority over their pre-existing LTCs. For example, Deborah explained that the treatment for her B12 deficiency had stopped because of her stroke.

> *“The B12 has fallen by the wayside” (Deborah, Female)*

Contrastingly, Michael did receive care regarding his diabetes, however it was similar levels to pre-stroke times.

> *“My GP er we touch base from time to time regarding the diabetes but not more frequently than before” (Michael, Male)*

The saliency and importance of conditions seemed to spark differences in beliefs about service provisions. For example, Edward, who had not experienced a heart attack seemed to think someone with a heart attack would have had more access to support compared to what he received after having a stroke.

> *“And you know people who have heart attacks and whatever they do get a lot more support or er follow up then the stroke victims I got I think” (Edward, Male)*

The pandemic had caused some participants to feel abandoned by their healthcare professionals especially in relation to managing their pre-existing conditions.

> *“Yeah it's a diagnosis yeah every year I get tested but yeah I've not been tested properly for a year and a year and a bit now because of Covid” (Simon, Male)*

There was an overwhelming sense of frustration from the lack of support and dismissive attitudes participants described that they had received from some healthcare professionals.

> *“He just weren’t listening to me he just told me to stop taking my er clot clotting tablet 'cause I was losing blood for my teeth when I cleaned them my nunny [vagina] and from the back so he told me to stop taking it but he never offered me a substitute to take and he said ‘we’ll get you some blood tests done” (Diane, Female)*

As a result, participants felt that they had to seek their own support and care for all their conditions, which showed evidence of engaging in self-management. Some participants ended up seeking care from other sources, such as charitable organisations like the Stroke Association. There was an overwhelming sense of gratitude described for these services at a time when they felt alone.

> *“No it's just like my disappointment at the the kind of (left) care I’ve had think that that's a big big bed bugbear of mine erm the Stroke Association have been brilliant to me I got to admit that” (Edward, Male)*

Self-management was not deemed a choice, instead it was described as something participants had to participate in. This was exacerbated by the perceived lack of care participants received in relation to their stroke and pre-existing LTCs.

> *“Self-management is essential 'cause there's no other management at all erm in the sense that I haven't heard from anybody with the health service for ages” (Robert, Male)*

Only one participant discussed her excellent care in relation to her diabetes management since her stroke. Prior to her stroke, Jane expected that healthcare professionals would do everything. However, since her stroke she took self-responsibility after being given the tools and information to move forward.

> *“Now they give me all these tools and stuff and it's down to me you know it's not and I and I was and it was kind of like ‘oh the nurse will tell me what to do’ and I you know I didn't really help myself” (Jane, Female)*

This quote highlights the importance of collaborative working and how expectations of responsibility played a huge role in individuals being able to successfully engage in self-management.

The mismatch of expectations that participants experienced through their stroke journey resulted in participants feeling helpless and frustrated, and consequently unclear about who should be doing what in taking responsibility for their health care needs. Expectations varied but overall participants expressed a level of disappointment regarding their care after their stroke, including disappointment in the care of their pre-existing LTCs. This subsequently drove participants to feel that their only option was to seek opportunities for self-management, to varying degrees of success. Charitable organisations were discussed as being helpful in offering guidance in self-management of the impact of their stroke, but often their existing long-term condition was described as relegated.

Subtheme 3.1 “It's self-responsibility for every part of me” - Self-Management after stroke

This subtheme concentrates on what self-management meant for participants as well as how they engaged in self-management of both their existing LTCs, and their stroke recovery simultaneously. Some participants described taking responsibility to look after their health and engaging in new health behaviours. The concept of taking responsibility for health was common across accounts, with some participants feeling that they had no choice but to self-manage and deal with the situation they were experiencing.

Participants’ understanding about what self-management meant was mixed. Some participants had a vague idea to the concept of self-management however, others had very limited understanding of it. Two participants who had not heard of the term self-management, discussed utilising self-management skills however, they did not make the association to the term self-management specifically. Self-management was discussed in terms of stroke recovery, looking after their health beyond the stroke, as well as gaining independence back and being able to engage in daily activities such as work.

Participants discussed self-management in the way that meant they had to simply accept and manage the situation they were in. It also included being in control of and listening to their body. Therefore, highlighting a need to take personal responsibility to move forward in their recovery.

> *“Well I suppose not over doing it I suppose now you have to make sure you don't overdo stuff and listen to your body really” (Simon, Male)*

> *“It’s up to me to take this forward to make myself better it’s self-responsibility for every part of me so it’s the recovery it’s my medicine it’s my attitude towards my body in all sense and my own wellbeing” (Jane, Female)*

For others, self-management meant looking after their health by engaging in new health behaviours.

> *“Probably watch my diet erm drink obviously taking my medication exercising control my weight erm control my stress levels erm make sure I relax try not to get angry” (Paul, Male)*

Aside from stroke recovery, participants acknowledged this sense of needing to watch their health and look after themselves, suggesting the responsibility lying with them.

> *“I should be erm doing the best for myself” (Tracey, Female)*

> *“Getting on with it” (Simon, Male)*

Independence and agency were values held by most participants. They talked about self-management in terms of having and regaining their independence, which appeared pivotal in having a successful recovery.

> *“Well one of the things I would like to do is get back to driving is and er for that I will I will need to be able to use my hand to be able to to rely on my foot to know that er I will not get easily tired er and also so to to make sure that my mind stays alert” (Michael, Male)*

Despite participants discussing their abilities to self-management, ‘total self-management’ was referred to as being able to do absolutely everything they could do before their stroke. This draws on the concept of health identity discussed in the first two themes. Health identity was measured by what activities participants could engage in for example work, hobbies and being a parent.

> *“I would say I can manage anything except getting myself from A to B and that would be erm total self-management” (Mary, Female)*

To some participants, self-management meant being aware of their limitations. Therefore, by being aware of limitations, they could find strategies to cope and manage them.

> *“Well it’s it’s just a self-management is just being in control of everything you put in your body I would say you know knowing the self-management knowing your limits knowing your limit limits with stress er not not to over indulging in things that isn't good for you food wise and drink wise you know it's just a basic discipline isn’t it really” (Richard, Male)*

Some participants considered self-management as being their own responsibility to get better, but some aspects required healthcare professional support. For example, medication management required healthcare professionals to get it right before individuals can work on improving their health.

> *"As you've got medication that brings it back down it's that sustaining high blood pressure that's the killer I think so that's what I've got in my head I think I would if it flies up a bit or it goes up don't think to say you're gonna hit something and so you're gonna go bang and that's your lot keel over it's just you gotta get it back down again and get it to a level so you're not constantly high so that that's the way I see it" (Richard, Male)*

> *"If I look now where I have this er I get phone call every fortnight from the specialist diabetic nurse at the hospital … I played at it if that makes sense rather than manage it" (Jane, Female)*

In this quote, Jane explains the support she received. Although she took responsibility to improve her health, she received the support to be able to do this. Having the support available contributed towards successful self-management.

Although participants talked about it being their responsibility to manage their health and recovery, they discussed barriers to medication adherence whilst also addressing additional difficulties to engaging in self-management and treatment adherence. Difficulties were driven by physical and cognitive barriers as well as motivational barriers. Physical barriers were caused as a direct consequence of the stroke for example, unable to get medication out of the packets due to hands being affected. This not only affects stroke medication but also the medication for the other long-term conditions.

> *"You know the blister packs of tablets there's no way no way I can o- well I can open them but the tablets seem to go flying with one hand like you know" (Edward, Male)*

> *"It's silly even opening a packet of medicine to get me tablets out it's really hard" (Diane, Female)*

Additionally, one participant discussed the difficulties of physically being able to get the medication and also not being able to use the internet to order her prescription. She described an expectation from the healthcare professionals that the participant's family member would get the medication for her.

> *"Doctors aren't very helpful 'cause obviously I can't write prescriptions can only be done if they're put in the internet… and I asked them to make an exception obviously because I'm not able to use the internet but their idea is 'you've got a daughter who can do it' so that's another thing put on (daughter)" (Julie, Female)*

An additional physical barrier was work commitments, especially shift working.

> *"Only doing the night shifts coz they're all over the place yesterday so I took them even took him at four o'clock in the afternoon my tablets instead of the morning because I think they stop you from sleeping in the in the daytime" (Simon, Male)*

In this quote, Simon refers to the side-effects of the medication too and the situation that he was in with work and needing to sleep. This highlights the complexity of self-management, such as needing to consider weighing up the benefits of taking the medication with the side effects, and how they may impact the situation.

Furthermore, cognitive barriers were identified such as remembering to take the medication.

> *"I do have a medication box so I do like to fill it in make sure I have it every day but once that box is finished you gotta refill it (laughs) so that's why I think it's taken long this time" (Mimi, Female)*

> *"No sometimes I quite often forget the evening and then I think 'oh oh what what can I take'" (Julie, Female)*

As self-management was defined in terms of taking responsibility to look after their health, participants discussed how they have since changed their behaviour. They discussed the actions they have now taken to self-manage, for example being aware of and engaging in health promoting behaviours such as watching their nutrition.

> *"My diet has changed it's erm become I don't even meat very often" (Paul, Male)*

Engaging in exercise and increasing physical activity were also actions some participants decided to take.

> *"I've taken up swimming which I really enjoy so I try to do three times a week now" (Jane, Female)*

Although participants discussed engaging in new behaviours to improve their health, for some the consequences of the stroke made this difficult. For example, Mary discussed how it is her responsibility to continue being active but the confusion of being *“active but not too active” (Julie, Female)* makes being able to do this difficult. The somewhat conflicting advice from healthcare professionals added another layer for participants to consider.

> *“We invested in an exercise bike in in the house so I do that the days I don't go swimming just so when I spoke to the stroke consultant he said to me ‘at the moment don't get your heart going over a hundred beats a minute’ so it's got a thing pulsometer thing so keep your heart rate down at the moment so erm so yeah so so that's new for me” (Jane, Female)*

This quote further signifies the complexity of self-management. Similarly, Edward discussed the difficulties he experienced when managing his weight as he was unable to exercise due to the consequences of his stroke. He managed this by taking responsibility of his eating and drinking behaviours.

> *“I stopped smoking stopped drinking erm I look at what I eat although I put on a load of weight because I just sat here but I watch what I eat I don't eat anything fatty and whatever oh yeah in our terms 'cause before I wouldn't say I didn't give I didn't give erm two hoots about my health I did like but you would do things that wasn't good for you wouldn’t you and not have a second thought like you know” (Edward, Male)*

Likewise, Hannah discussed how she has now adopted healthier eating habits, but also expressed the importance of feeling satisfied.

> *“They ask you to eat healthily and not eat loads of erm processed foods but I mean you know you have to live a normal life don't you” (Hannah, Female)*

Some participants also discussed self-management in the context of work. The stroke had steered participants to re-evaluate their work-life balance and therefore decided to cut down hours to enable them to focus on their health.

> *“When did I come back I can't remember what date in August it was but I came back and I tried to jump straight back in and work full time the very first full day that I'd done was a Tuesday … I'd totally overdone it and I turned round and I arranged a meeting with the committee I said and they actually said ‘we knew you'd come back too soon but no good telling you you're too stubborn’” (Ian, Male)*

Simon spoke about the support he received from work when he returned on a phased approach.

> *“Well I went phased return so that was helpful that was very kind of them that so and now and now I'm back full time I just done two night shifts” (Simon, Male)*

This subtheme clearly demonstrates the complexity of self-management within this context. There was variation as to what self-management meant to each stroke survivor, a concept largely unfamiliar to participants despite all having at least one LTC requiring management. However, most participants decided to take personal responsibility for their recovery and health. Stroke survivors described the need to manage their pre-existing conditions, stroke, and new diagnoses by taking more medication despite barriers, as well as adjusting to the effects of their stroke and engaging in new health behaviours. Participants showed an understanding of what actions needed to be taken to improve health and look after themselves. They had to compromise on certain activities such as returning to work to focus on their health and recovery, factors that contributed to participants health identity prior to their stroke. Self-responsibility was evidenced across this cohort of stroke survivors, perhaps because of the lack of follow-up support identified post-stroke.

This theme demonstrates the complexity of self–management of pre-existing conditions, stroke recovery and adjusting to additional diagnoses since their stroke. Clearly, although stroke survivors took personal responsibility managing their conditions, at times support is necessary to feel successful in managing their health and recovery.

Theme 4: "Nothing is going to be the same again" - Acceptance and hope

This theme focuses on what having a stroke meant to participants in relation to the future. In response to the stroke event and diagnosis, participants reflected on the stroke, the acceptance of where they were in their journey, as well as their hope for their future health. Acceptance of a new normal and hope of recovery were also noteworthy; whereby there seemed to be a contradictory stance of acceptance where participants were in terms of their recovery, yet still held a glimpse of hope that their situations may improve with time.

The participants described re-evaluating many aspects of their social and working life, including the opportunity for travel or retirement. There was an apparent concern discussed when participants thought about what the future might hold when engaging in such activities. Although there was hope amongst participants about going away in the future and being able to live a more normal life, Mary spoke about the fear of being abroad and her health taking a turn for the worse.

> *"I think it's it's worrying me slightly about erm being somewhere in a third world country and be- being ill erm that that does worry me"* (Mary, Female)

However, Julie talked about living her life even with her current health situation and despite the beliefs her husband held about them going on holiday.

> *"'I still got a life to lead love' coz I said about 'I know we're not allowed to go on holiday yet' he said 'they'll be no more holidays abroad for us' I said 'what do you mean (husband)' you know we've still got to live"* (Julie, Female)

Like Julie, many participants discussed being optimistic and refocussed about what the future could hold. Paul reflected on his stroke experience as being a life changing moment which led to a realisation of what he wants in life.

> *"I think having not quite a near death situation but a life changing moment I want to make sure that I get the most out of life erm 'cause you don't know when it's going to finish no one no one knows when their life is going to finish but when you've been in this situation it focuses you even more so there's still a lot of travelling I want to do erm I think the next ten years I'd like to do a lot of that erm we've got grandchildren so I want to be around to see them growing up and help them erm probably those things I wanted to do anyway but erm it just focuses your mind a little bit more"* (Paul, Male)

Mimi expressed a precariousness about what the future might hold, emphasising the importance of each individual journey. She said that she thought she would be better by now yet accepted that her life will not be the same again.

> *“I think this arm is never gonna be the same in my opinion erm they they even say to you like we don't know actually because everybody is different like they could be days weeks months erm so I feel like I wish I had my arm back again erm that constant dizziness all time I think erm to me it feels like it's going to be a long time because I feel like I should have got a lot better by now because it’s been six months plus... I think nothing is going to be the same again yeah” (Mimi, Female)*

Richard also had an accepting attitude. He was not going to let his stroke impact his life and create fear. He accepted the uncertainty of what may or may not happen.

> *“This is what life’s all this is what growing old’s all about that's why people live so long now no doubt ‘cause of tablets I guess you know you can't predict your lifestyle I mean look at that football player he’s fit as a fiddle and everything one minute then he's down and had a heart attack and you know so I don’t’ know I don’t know what to make of it” (Richard, Male)*

Julie also discussed that she too needed to use this as a life lesson and realised the need to accept the situation she is in to be able to move forward with her life.

> *"It's learning to take my time and accept help” (Julie, Female)*

By accepting their situation, participants stated they were able to cope with, manage and adjust to the consequences of their stroke. However, some participants described that they felt they had no choice but to accept what had happened and move on otherwise it could result in emotional distress.

> *"You have to I think when you're diagnosed with these things I could stay at home and well I'll be my own pity but what's the point to be honest" (Sarah, Female)*

> *"Carry on as normal really that's why I'm going gone back to work and that and get on with life really I'm trying to stay positive because you could get depressed over it thinking 'oh you're gonna gonna have another stroke someday' but try and put that out of your mind I've always had a strong personality really to try if there's a problem get a kick myself and carry on" (Simon, Male)*

The obligation of acceptance was discussed in terms of recovery and managing ongoing effects of stroke being *"something I have to get used to" (Julie, Female).*

> *"I think this is it now I think this I think this is what I got to accept" (Edward, Male)*

Robert reflected on the stroke experience by accepting that his situation was not going to get better. As a result, he felt he had no choice but to make the best out of a difficult situation.

> *"Because you just think er you do feel like er it's irretrievably bad so there's not it's not going to get better er you have to try to to make the most of what you've got in terms of your ability" (Robert, Male)*

Edward experienced many physical disabilities yet held out hope in getting better. This hope led him to avoid getting aids to help manage his situation better. On the contrary to other participants, he talked about giving in rather than accepting the aids and support.

> *"I got to make the best of it erm I've been putting off things like getting a scooter and that like you know 'cause think 'cause I've been thinking I'm not gonna be like this forever somethings bound to happen I'm going to all of a sudden do what I used to do but I've got myse- but I've given in I got myself a little scooter now so we see how that goes and things like erm like the chair it's a low chair I'm sitting in I've given in now I know I've got it out one of these chairs that help me to stand up help me out and and recline" (Edward, Male)*

In this quote, Edward alludes to his journey of acceptance. He put off getting himself a mobility aid as he believed his circumstance would change. Over time, he accepted his situation, yet still held a hope for the future.

A pertinent concept throughout was the ongoing discussion of health, and what that meant for the future of participants, which included a contrast of hope and hopeless for the future across participants. A sense of hope complemented the notion of acceptance. Hope was discussed in relation to stroke recovery, health, and life. Some of the participants shared how they hoped their recovery would continue. Deborah discussed her recovery and that she hopes and expects her rehabilitation to continue so she will be able to walk again.

> "*I should be walking in the next couple of months" (Deborah, Female)*

There was also hope from Ian that his *“memory will sort itself out”.* In contrast, Edward expressed a sense of acceptance of what he has achieved in his recovery despite his hope to walk again.

> *“I do try to walk in the hope that it might get better but I don’t think it’s erm I don't think there's much hope for that now” (Edward, Male).*

This quote epitomises the concept of this theme; Edward had not given up on his recovery despite offering a sense of hopelessness for the future. In a similar manner, the contrast of hope and hopelessness was apparent when discussing overall health. Despite sharing a sense of hopelessness that he will never be well again, Paul shared his uncertainty of what might happen in the future.

> *“I think it’ll go on forever I think I don't know I don't think I’ll ever be well I don’t know we don't know what's going to happen” (Paul, Male)*

However, Julie stated that she believed that if she kept on looking after her health and managing the way she was, she would stay alive.

> *“So no I'm okay I manage on with everything plod on hopefully I’ll still be here next year plodding on the same” (Julie, Female)*

Participants discussed that they hoped to get back to work; but this depended on several factors. For example, following healthcare professional advice, staying positive or perhaps getting support from the Council.

> *“Oh yeah I would like to get back to some kind of work if I if I don't I would hope that the Council gives me a patch to go gardening I I need to get active I I know I get er bored with er just sitting around” (Michael, Male)*

However, Diane evidenced a sense of hopelessness yet acceptance that perhaps going back to work was not going to happen. Diane enjoyed work however, as a cleaner it was a physically demanding job. She discussed finding smaller tasks more difficult since her stroke and felt that her recovery had not progressed as much as expected. Nevertheless, she seemed to accept that she will not be going back to work.

> *“I was hoping eventually to go back to work but I think with time going on that's not going to happen even typing on your phone messages with your left hand it’s really hard I can’t clean these nails they’re filthy because you can't hold a nail brush and clean your nails on that hand you know silly things like that” (Diane, Female)*

Despite feeling like everything had been taken away from her, Diane expressed a desire to not give up and to continue to adjust and adapt to the consequences of her stroke.

> *“I knew life before my independence my work my hobbies my interests they've all been taken away and it's like shit (laughs) and you you got to learn to readjust you can either try and adjust adapt or give in and I don’t think I’m ready to give in yet” (Diane, Female)*

Accepting their current situation and circumstance was fundamental for participants to talk about their future. This theme distinguishes the different values participants held, therefore despite adjusting and accepting the implications of their stroke, participants shared hope in many areas of their life, from health to work to living life to the fullest.

This theme offers insight into how participants reflected on their recovery and viewed their health in the future. Acceptance of their current situation was key for participants to discuss the future. Hope was also evidenced throughout, and this theme shows that it can co-exist alongside acceptance.

Summary of findings

Experiencing a stroke in the context of pre-existing long-term conditions was a significant event in all the participants lives. Where participants often held a positive health identity prior to stroke even in the context of their existing LTCs, this was challenged by having a stroke. Participants described a shift in health identity after stroke, with a re-evaluation of their health and what health means to them. For many, it was described as a *teachable moment* or pivotal point where self-management began, or health behaviours changed. Participants were unclear as to who does what in terms of recovery and rehabilitation, including both management of the stroke, and existing LTCs. This was described as leading to dissatisfaction with care due to unmet expectations, particularly in the context of this study during the Covid-19 pandemic. The actions they felt they needed to take to ensure a successful improvement in health after stroke depended on many factors such as the value of their health, what self-management meant to them, what support they received and their acceptance and hope regarding their situation.

Chapter 4 – Discussion

This research aimed to explore the impact of stroke on the management of pre-existing long-term conditions (LTCs). To the researcher's knowledge, this study is the first to explore the impact of stroke in the context of multimorbidity. Four themes and one subtheme were identified: (1) "I was OK I felt fine" – Positive illness representations prior to stroke; (2) "I've had one I don't want any more" - Stroke as a 'teachable moment'; (3) Who does what - Mismatch of expectations; (3.1) "It's self-responsibility for every part of me" - Self-management after stroke; (4) "Nothing is going to be the same again" - Acceptance and hope.

4.1 Discussion of findings and application to Health Psychology

4.1.1 Theme 1: Discussion of "I was OK I felt fine" – Positive illness representations prior to stroke

Participants discussed their health identity, where participants did not see themselves as having ill health prior to their stroke, despite having been diagnosed with at least one pre-existing LTC. The influences driving identity perceptions were that participants were able to engage in meaningful activities, thus being able to physically do what they wanted to do, resulting in a reduced perception of risk.

The findings of this study illustrate the subjective nature of health identity. If applying the biomedical model, the individuals participating in this study would have been deemed 'ill' prior to their stroke as illness or disease "corresponds to failures or disturbances in the growth, development, functions, and adjustments of the organism as a whole or of any of its systems" (Engel, 1960, p. 459). This reductionist view omits the individual's perception of health and illness as well as the environmental factors influencing the behaviours associated with health and illness. Psychological and biomedical theories have since been intertwined to both broaden and challenge the traditional biomedical model and as such brought about the Biopsychosocial Model (Engel, 1977). The Biopsychosocial Model indicates that disease and illness result from the organism, interpersonal and environment levels. It is a scientific model created to account for the missing factors of the Biomedical Model (Engel, 1981), thus taking more of the context of the individual into account. Arguably, the findings here underscore the importance of viewing stroke and LTC care through a biopsychosocial lens.

Participants' health identity prior to stroke was depicted through their attitudes and perceptions of their pre-existing LTCs. Despite all participants having at least one LTC they identified themselves as well. Their identity was driven by their ability to be able to engage in meaningful activities such as work and hobbies. Some participants had established routines and strategies to manage their pre-existing conditions, so they did not seem to disrupt their lives. These findings could be explained by the Common-Sense Model (CSM; Leventhal et al., 2003). The CSM (Leventhal et al., 2003) proposes that when faced with a health threat, perceptions based on the identity, cause, control, consequences, or timeline of the illness influence the response to the threat. Identity is an illness representation within the CSM (Leventhal et al., 2003) and relates to the symptoms and illness label. In this study, participants viewed themselves as well despite being diagnosed with pre-existing LTCs, thus seemingly rejecting illness labels, and having positive illness perceptions. Although this study offers some explanation to why participants thought this, identity has previously been stipulated to be ambiguous in individuals with multimorbidity (Hagger & Orbell, 2003). Moreover, individuals with multimorbidity have varied perceptions of consequences (Bower et al., 2012). Furthermore, perceiving more negative consequences in multimorbidity predict better adherence (Schüz et al., 2014). This study supports this as participants perceived fewer negative consequences of their pre-existing LTCs and thus did not take their health as seriously, which was evidenced in their attitudes to their health prior to the stroke.

Previous literature has outlined how individuals with multimorbidity hold several social identities, such as daily life, professional life, and capacity for handling multimorbidity (Sand et al., 2021). The findings from this study support Sand et al. (2021) as participants' perceptions of their health identity were driven by their ability to engage in daily meaningful activities including, hobbies, work and being a parent. Contrastingly however, Sand et al. (2021) suggests that the participants in their study experienced physical limitations and psychological distress, which impacted on their ability to engage in work and social relationships. This current study however, found that participants were still able to engage in all these activities prior to their stroke, therefore suggesting they held a positive health identity. The differences could be attributed to the type of conditions participants had. Most of the participants in this study had hypertension, with the next two common conditions being type 2 diabetes and underactive thyroid. The participants in Sand et al.'s (2021) study commonly had musculoskeletal and gastrointestinal diagnoses, suggesting that perhaps the type of long-term condition is influential on experiences and health beliefs.

Participants' positive health identity of being well influenced their causal beliefs regarding their stroke. Interestingly participants' beliefs about the causes for their stroke were mixed, yet the majority of participants attributed the cause to external factors. As they did not view themselves as ill, participants struggled to identify a cause for their stroke but rather offered external reasons about why the stroke may have happened, including healthcare professional behaviour, their medication, and the Covid-19 pandemic. This supports research specifically exploring stroke survivors' causal attribution whereby a quarter of stroke survivors perceived the cause of stroke was due to stress, fatigue, or worries (Groeneveld et al., 2019). Similarly, stroke survivors have also attributed stroke cause to external factors such as fate or uncontrollable stress (Runions et al., 2006).

This concept could be explained by Health Locus of Control (HLC; Rotter, 1966). HLC was initially developed by Rotter (1966) and relates to the expectancy that a behaviour would lead to specific outcome in a particular situation. Perceptions of control were originally separated into two factors along a continuum: internal and external. Perceptions that an individual has control over their life and events that occur is considered as holding an internal locus of control. An external locus of control perceives life and events to be determined by powerful others, chance, or external factors (Rotter, 1966). Some of the participants in this study held an internal locus of control whereby the prevention of their stroke was down to their own behaviours. On the other hand, others saw it as the healthcare professionals' responsibility to see the signs and in turn prevent the stroke from happening. These participants held an external locus of control in relation to their health.

A further example of external locus of control apparent in these findings related to some participants attributing their reduced ability to engage in routine health behaviours to the Covid-19 pandemic rather than a lapse in self-management. For those participants, the external factor of lockdown and a change in circumstance was seen as beyond their control and therefore, did not translate to a change in health behaviour. This is consistent with previous health psychology research which has linked external health locus of control to an increased risk of multimorbidity (Mounce et al., 2018) and a reduction in engagement in health behaviours such as medication adherence (Náfrádi et al., 2017). Some participants described having little concept of what may have caused their stroke. This could be problematic for the prevention of a secondary stroke as beliefs about what caused a stroke has been found to be a necessary basis for action in stroke survivors (Rutherford et al., 2018).

Cause is another one of the five core illness perception components in the CSM (Leventhal et al., 2003). The beliefs about what cause the stroke also contributed to participants shifting their health identity from well to unwell. This supports Della Vecchia et al.'s (2019) qualitative research study exploring illness perceptions in stroke survivors. Causal beliefs were attributed to medical causes such as pre-existing diagnosed and undiagnosed conditions. However, the beliefs that behavioural risk factors cause their stroke were lacking (Della Vecchia et al., 2019). This is inconsistent with this study's findings, whereby some participants attributed their stroke to not taking their health seriously enough prior to their stroke and therefore not engaging in health promoting behaviours or managing their pre-existing LTCs. These differences might be explained by the type of pre-existing LTCs the participants had been diagnosed with. These were not recorded by Della Vecchia et al. (2019) as it was not the focus of the research. In this study, participants had a range of LTCs including hypertension, diabetes, and previous stroke. A recent study found a significant an increase in irrational health beliefs and external HLC increased the likelihood of having hypertension (Afsahi & Kachooei, 2020). These findings highlight the importance of understanding a person's HLC and health beliefs and perceptions as they could be modified to increase the prevention and management of long-term conditions.

4.1.2 Theme 2: Discussion of "I've had one, I don't want any more" – Stroke as a 'teachable moment'

This study found that the stroke event was a pivotal moment that shaped the participants' future perceptions of health and identity. Participants realised that they should have taken their health more seriously and as a result led them to reconsider how they should manage their health in future. This included the intentions to manage their pre-existing conditions better and engage in more health promoting behaviours.

Participants attributed the stroke to a disruption to daily activities and increased awareness of symptoms because of their diagnosis and treatment. In this study, participants also described the disruption to the management of their pre-existing conditions. These findings support Bury's (1982) model of biographical disruption, whereby a critical situation creates a disturbance in an individual's life. These disturbances seemed to influence a moment of learning or *teachable moment* (TM) for the participants in this study. A TM has been described as naturally occurring health situations, events or circumstances which can lead to positive behaviour change (McBride et al., 2003; Lawson & Flocke, 2009). TMs have been researched in health for specific conditions such as cancer (Frazelle & Friend, 2016), more generally in chronic disease (Xiang, 2016), for specific treatments such as surgery (Robinson et al., 2020), and in health behaviours for example smoking cessation (McBride et al., 2003). However, there has been limited evidence of the emergence of TMs in stroke or in multimorbidity. The findings in this study suggest that these TMs could be vital for stroke survivors, how they view health and illness and subsequently manage their health.

The TM resulted in participants shifting their identity from well to unwell. These findings could be explained by Paterson's (2001) Shifting Perspectives of Chronic Illness Model. Paterson (2001) emphasises a dynamic response to illness and wellness. As disease and illness related problems occur, individuals shift illness to the foreground of their mind. Paterson (2003) argues that it is at this point that an individual will focus on the negative consequences of the disease and associated symptoms. This study supports Paterson's (2001) model as participants predominately experienced wellness in the foreground prior to their stroke, which shifted to illness in the foreground after the stroke.

Deciding to seek help after experiencing symptoms seemed to be driven by the severity of stroke consequences for the participants in this study. Participants described being more aware of symptoms after their stroke which contributed to their decision-making around seeking help. Most participants who experienced symptoms sought medical attention through uncertainty of what the symptom meant. This supports previous research whereby stroke survivors were more likely to seek care compared to individuals who did not have a stroke diagnosis (Howard et al., 2008). Reasons for this help-seeking behaviour were not investigated however, in this study the decision to act on symptoms seemed to be a conscious process. Participants sought understanding and reasoning for the symptoms, whether it was their stroke or other LTCs. Although, symptom perception has not been explored post-stroke, it has been found to drive help-seeking behaviour in people with co-morbidities for possible cancer symptoms (Salika et al., 2018). However, this is dependent on the pre-existing condition and nature of the presenting symptom (Renzi et al., 2019). Symptom perception could be a significant driver for help-seeking behaviour, which could in-turn improve health outcomes in stroke survivors, however research into specific effects of long-term conditions is warranted to understand the mechanisms driving the behaviour.

The findings in this study highlighted participants' perception of risk of another stroke varied, supporting previous research (Wong et al., 2021). In this study, most participants described feeling at high risk of future stroke and fear of another stroke drove participants to engage in health promoting behaviours. These findings also support recent evidence which suggest that stroke survivors' fear of recurrence and knowledge of stroke were associated with engagement in health behaviours (Choi et al., 2017). Similarly, control and health motivation influenced fear of stroke recurrence (Chung & Kim, 2015). Overall, these studies and current findings illustrate the possible benefits of healthcare professionals understanding fear recurrence in stroke survivors to aid their engagement in health behaviours.

This current study was conducted in stroke survivors 3 to 12-months post-stroke. It has been recommended that the optimal timing to support stroke in health behaviour change post-stroke is directly after the stroke, meaning less than 3-months. This was due fear of another stroke being significantly higher at 6-weeks post-stroke compared to 3-months later (Brouwer-Goossensen, Lingsma et al., 2021). However, the current findings suggest that fear is still prevalent past this timeframe and contributed to motivations to change behaviour.

4.1.3 Theme 3: Who does what? – Mismatch of expectations

As participants seemed to re-evaluate health and what it meant to them, the question of how to manage their health became apparent. The initial care following stroke is a fundamental point within recovery for patients to be able to continue to take their recovery forward (Zeiler, 2019). However, participants in this study seemed to feel dissatisfied with the care they received immediately after their stroke. They said they anticipated more rehabilitation and support during the stroke recovery phase for both their stroke and pre-existing LTCs. Consequently, participants said they felt abandoned and took it upon themselves to begin their own recovery.

The expectations most participants had on their follow-up care were not met, they felt let down and abandoned by the NHS. This is a contradictory finding as some other participants felt they had received great hospital care but were aware of the *postcode lottery* of support. The *postcode lottery* of care suggests someone's access to adequate care provision is dictated by their geographical location (McKenzie, 2019). Although this has been evidenced in cancer (Bungay, 2005) and surgery (Stevens et al., 2015), it has only recently been identified as a problem for people with neurological conditions, including stroke (Sue Ryder, 2019). As recently as 2019, Sue Ryder conducted a series of information of freedom requests from Local Authorities in England with social care responsibility. Of the 146 responses received, they found that people in the UK with neurological conditions are receiving different levels of services purely based on where they live. Not only can this result in poorer outcomes for people, but it also has the potential to exacerbate existing health inequalities. Most participants in this study described feeling disappointed with the follow-up stroke care they received, supporting Sue Ryder’s (2019) report suggesting a reduced prioritisation for people with neurological conditions.

Furthermore, these findings could be explained by the Covid-19 pandemic. Unfortunately, the time this study was conducted, healthcare was significantly affected due to the increased infection rates. Stroke recovery was considerably impacted, and patients did not receive the care they would have ordinarily received (Bersano et al., 2020).

Whilst considering the context of the pandemic through the interpretation of findings, at the time of stroke, some participants reported not receiving the follow-up care they were expecting, offering evidence of unmet needs. Supporting previous research, stroke survivors found they still had unmet needs in relation to their health beyond the rehabilitation needs, for example secondary prevention (Zawawi et al., 2020). Stroke survivors in this study took it upon themselves to look after their own health due to the absence of support.

Another interesting finding is that there was also a sense of abandonment of their other conditions (Breckner et al., 2021). The stroke took priority over the care of the other conditions, with existing long-term conditions consigned to receiving less focus than before their stroke event. Recent research has investigated the extent of multimorbidity in relation to annual reviews whereby the single-disease approach to condition management leaves individuals with multimorbidity with a multitude of annual follow-up appointments with GPs (Pedersen et al., 2019). Pederson and colleagues (2019) suggest the complexity of multimorbidity could form reason as to why primary care guidance is not sufficiently adhered to. Guidelines are developed for single conditions only, which makes them overwhelming and unmanageable for GPs to follow for patients with multimorbidity (Paderson et al., 2019). Individuals with multimorbidity are subjected to managing their symptoms in addition to living their lives, which is problematic with the current NHS system being illness-specific focused (Slightam et al., 2018).

4.1.3a Subtheme 3.1: Discussion of "It's self-responsibility of every part of me" - Self-Management after stroke

Due to the sense of abandonment, participants decided to take responsibility for their own health and therefore took steps to self-manage. This study found that most participants had either already changed their behaviours post-stroke or intended to do so. Contrastingly, literature suggests that stroke survivors do not have high intentions to change health-related behaviour after stroke (Brouwer-Goossensen, den Hertog et al., 2021). However, this mix of findings could be explained by the possible the lack of clarity of who is responsible, potentially being a barrier to fully engaging in health behaviours (Lawn et al., 2011). This study was also conducted in the context of multimorbidity, with participants perhaps more aware of the potential of self-management and behaviour change due to their past experiences. This suggests the presence of multimorbidity, and individuals' perceptions appear to be a key consideration for understanding health behaviour after stroke. Furthermore, differences in definition of what self-management is provides a lack of clarity on the roles of the healthcare professionals and stroke survivors. This could impact on being able to measure whether someone is self-managing successfully (Rodham, 2020).

Given the complexity of multimorbidity, it is not surprising that participants in this study were unclear as to where the responsibility for their health and care resides. If healthcare professionals find it challenging to support patients with multimorbidity, patients are likely to feel unsupported. In addition, self-management can be challenging without effective support and information to start that journey within the context of the patients' lifestyle, family, and culture. Whilst Health Psychologists agree that considering the patient's context in the wider system would be advantageous to self-management (Rodham, 2020), collaborative partnerships are not always achieved (Lewis et al., 2022). This is often because healthcare professionals and patients have disjuncture between logistics and outcomes of self-management (Lewis et al., 2022).

The mismatch of expectations and responsibilities between patients and healthcare professionals has been recently researched in the context of self-management. Research indicates that the interactional style used by healthcare professionals is essential in providing opportunities for collaborative self-management (Franklin et al., 2019), thus providing support that the lack of support from healthcare professionals resulted in a lack of clarity of the meaning of self-management. Franklin et al. (2021) recently explored the perceptions of roles in self-management support in healthcare professionals and found that there is a clear incongruence between participants' characterisation of their role as person-centred and the reality of engaging in more traditional practices.

Furthermore, this study found that the concept of self-management was not always clear to participants and definitions of self-management was extremely variable amongst stroke survivors (Parke et al., 2015; Boger et al., 2015). Similarly, the concept of self-management was not explicitly linked with stroke recovery (Sadler et al., 2017). This is finding is extremely problematic considering all participants had conditions that required self-management skills prior to their stroke.

Parappilly et al. (2020) explored the changes in perceived barriers and facilitators associated with stroke survivors participating in health behaviours aimed at preventing a secondary stroke. They interviewed 19 stroke survivors and 9 caregivers at two time-points (2-weeks and 6-months). The findings suggest that stroke survivors were motivated to change their lifestyle to a healthier one, despite encountering some barriers in their journey (Parappilly et al., 2020). This study supports their findings; however, the current study offers evidence of these motivations as far as 12-months post-stroke. Similarly, anxiety was a key motivator to change behaviour which was also found in this study through fear of having another stroke. However, Parapilly and colleagues (2020) overlooked the impact of other health conditions and how this may have impacted motivation and rationale to change behaviour. Rutherford et al. (2018) also explored the challenges to self-management 6-months after stroke. They interviewed 56 stroke survivors with 26 significant others and found that recovery in the context of multimorbidity was considered a challenge to self-management as participants faced competing daily demands (Rutherford et al., 2018), further outlining the importance of the context the stroke survivor is recovering in.

Medication adherence was a key behaviour discussed in this study, especially when referring to self-management. It has been found that stroke survivors' perceptions of seeking treatment and being medically adherent was more important that changing lifestyle behaviours (Lin et al., 2022). This is not a concept apparent in this study, however it may explain why participants focused on medication adherence when discussing self-management. Moreover, within this study, there was a lack of knowledge about what condition the medication was for and how helpful it was to the pre-existing condition, which also contributed to participants' motivations to take it. Participants discussed being more inclined to take medication when they had knowledge it would reduce the risk of further health issues. This could be explained by the Necessity-Concerns Framework (Horne et al., 2013). The framework proposes that medication adherence is influenced by two implicit judgements: *necessity beliefs* and *concern beliefs*. *Necessity beliefs* are concerned with individuals' perceived need for the medication and *concerns beliefs* are associated with the concerns individuals have about their medication. This has been found to predict medication adherence in people with multimorbidity (Schüz et al., 2011), thus providing support in this study's findings.

The findings from this study and supporting literature suggest that self-management is too heavily relied upon as a panacea for people with multimorbidity, without a common understanding between healthcare professionals and individuals with complex health needs. Taking a whole person approach has been recommended in the literature however, the UK health system still fails to deliver and consider care for those with complex health needs such as multimorbidity. Furthermore, the context in which people are trying to manage is often overlooked (Rutherford et al., 2018; Rodham, 2020). There is a plethora of evidence to suggest that taking patient concerns into consideration when offering self-management support is essential to successful self-management, as well as providing reassurance to patients that they are being listened to (O'Connell et al., 2021).

The findings of this study add to the evidence of complex self-management in stroke survivors with pre-existing conditions. It would be useful for healthcare professionals to be given opportunities to truly understand what self-management means to each individual and as such a tailored collaborative plan could be developed. These findings suggest that self-management is nuanced by individual definitions. As such, self-management responsibilities of the patient and support offered by healthcare professionals should be clearly communicated for patients to feel supported (Freilich et al., 2020). Care and support for stroke survivors with multimorbidity to self-manage is complex and although this study provides a gateway to the complexities experienced, more in-depth understanding is needed to support self-management in individuals with stroke and additional long-term conditions.

4.1.4 Theme 4: Discussion of "Nothing is going to be the same again" – Acceptance and hope

This theme focused on the participants' acceptance of the situation they were in as a consequence of their stroke, yet still being able to have hope for a better future. Returning to normal was a common goal across most participants. Normality was presented as being able to engage in the activities they once could. Therefore, supporting previous evidence where normality was identified as returning to premorbid levels of functioning (Graven et al., 2013). Most participants in this study discussed having returned closely to their premorbid level of functioning even if that functioning had already been compromised by their pre-existing conditions. However, for those that had not returned to their premorbid levels of functioning, they emitted a sense of optimism that it will be something that they could achieve in the future. Acceptance of the consequences of stroke was nuanced by the perceived severity of the stroke and the lack of disabling symptoms participants experienced.

Many concepts discussed in this study are supported by previous work conducted by Crowe et al. (2016), such as fear of stroke and lack of acceptance. However, in contrast to Crowe et al. (2016), this current study found acceptance was a key concept in helping participants move forward and take their health more seriously. Acceptance was also presented in the form of optimism for the future, for example although participants expressed an uncertainty of what might happen, it enabled them to refocus how they wanted to live their life. Participants' attitudes shifted to accepting the situation they were in and as such, shifted the mind-set that the stroke was not going to impact on how they were going to live their life. Acceptance is a dynamic process and perhaps a concept that could change over time, thus providing reason for the difference in findings.

Despite accepting their situation, asking for help was common for participants. It was a significant behavioural response towards acceptance. Acceptance was seen by some participants as an obligatory factor in being able to move forward in life. There was a sense that participants would not be able to recover without accepting what had happened and the consequences of that, such as asking for help and relying on other people (Graven et al., 2013). The literature exploring help-seeking behaviour predominantly focuses on seeking help at the time of the medical emergency (Iversen et al., 2020; Moloczij et al., 2008) rather than after the event had occurred. Help-seeking behaviour beyond the stroke event has been scarcely researched. These findings contribute some coherence about how responses to stroke adjustment and acceptance can influence behaviour.

Acceptance and hope are not mutually exclusive; however, a reasonable assumption is that hope is not necessarily needed when an individual has accepted their situation. In this study, the majority of participants described a sense of hopefulness for further recovery. Bright et al.'s (2011) systematic review concluded that hope functioned as a motivator and source of strength through recovery as well as a being linked to positive outcomes. Additionally, Cross and Schneider (2010) also found hope to be an integral factor for positive functional outcomes beyond 6-months post-stroke in women. In line with previous research, this study found that having hope in the acute and subacute phases of stroke may also be expected in patients even where pre-existing long terms conditions are present and could be harnessed to drive recovery.

Interestingly, the acceptance of circumstances did not subject participants to losing hope for the future. The acceptance shown in the findings of this study came in parallel with hope and optimism for the future. This can be explained by the ‘working model of adjustment to chronic illness’ (Moss-Morris, 2013) whereby it is argued that successful adjustment, including acceptance of illness can lead to good psychological, physical, and social adjustment. Caution must be taken as the model suggests it is a combination of contributing factors that can lead to positive adjustment. However, as seen across the earlier themes, engagement in good health behaviours, which participants described they were engaging in, also contribute to this. Therefore, the acceptance of the stroke and subsequent decline in health, as depicted by the participants’ health identity could lead to good physical adjustment. Further research into this acceptance post-stroke and changes over time would be useful for clinicians to apply in their work with stroke survivors.

4.2 Implications and Recommendations

Four key recommendations are informed by the study findings:

1. Individuals who are considered high risk for stroke should be assessed to explore what health means to that individual and the level of acceptance of illness labels and diagnoses. Exploring individuals’ perceptions of health in line with their pre-existing long-term conditions could offer opportunity for intervention and support in order to prevent a stroke from happening. This study’s findings suggest that

having a positive health identity reduces the perception of risk of stroke. Considering health perceptions in assessment for intervention has not yet been considered in line with policy and guidance to date.

2. Every stroke survivor should be given the opportunity to discuss their recovery and health in the first year after stroke (NICE, 2013), as well as at initial diagnosis of any long-term condition or cardiovascular risk factor that requires daily management. If self-management is going to be as relied upon as it seems to be in long-term condition management; understanding what self-management means to that person is needed, before recommending the use of self-management in patients. Consistently, healthcare professionals involved in self-management of conditions need to reflect on the meaning of self-management for the person and be clear about responsibilities. Clinicians should understand the context of the adjustment to stroke and multimorbidity. Understanding the illness perceptions of the stroke survivor in relation to their stroke and other conditions could provide useful insight when offering self-management support for stroke recovery, lifestyle behaviours and prevention for secondary stroke. The findings from this study and corresponding recommendation echoes those of the NICE guidelines targeting individual behaviour change, by specifying the need to ensure the interventions meet individual needs (NICE, 2014). However, the guidance appears to lack consideration of the individuals' beliefs of health and illness and how these could impact the engagement of health behaviours, which this study recommends.
3. Establishing a level of acceptance of the stroke seemed to direct participants to a more fulfilling recovery. Interventions aimed at guiding towards acceptance should be offered to those less accepting or hopeful. Acceptance and commitment therapy has been recommended by NICE for people diagnosed with Chronic Pain (NICE, 2021). However, this is yet to be recommended for stroke.

4. Multimorbidity is becoming more prevalent. It is clear this has a deleterious impact on the individual, however the impact on the wider societal context needs to be considered, as outlined in these findings. Depending on the LTC, different challenges are apparent. Integrated care systems could identify target populations using a ‘Population Health Management’ approach (NHS, 2021) and make it fit for purpose for them rather than one service per condition. This recommendation fits very well with new national approaches to integration of services.

4.2a Considerations for future research

This research is the first to explore stroke in the context of pre-existing long-term conditions. The phenomenon of multimorbidity has begun to gain traction in the literature in recent years, however, the evidence is still scarce (Skou et al., 2022). Deeper insight into these uncomfortable and unknowing concepts and phenomena of health is warranted. Due to the aging population, the number of people experiencing multimorbidity is going to rise (King et al., 2020). By honing on specific conditions with this context, we will be able to apply our knowledge and develop key clinical interventions for this population. Having a stroke is a unique experience and one that cannot be compared to other long-term conditions, due to the disparity in characterisation (Kirkevold, 2002). The components associated with stroke such as the likelihood of being diagnosed with additional conditions such as hypertension or high cholesterol, and the elevated risk of having a stroke in the context of an existing long-term condition, renders this a ripe area for future research building on the present study.

Interestingly throughout this study, individuals did not consider some of their ailments as long-term conditions. Comparing self-reported conditions with patient medical records to identify what is salient and important for individuals, may offer deeper insight into influences on behaviours, with some participants suggesting some LTCs are more important than others. As this study lacks distinction of LTCs across participants. Further in-depth qualitative research approaches could offer more specific explorations regarding how and why different LTCs impact on stroke recovery.

4.3 Strengths and Limitations

This study has several strengths and limitations. This study explored patient experiences of stroke in the context of multimorbidity which has not yet been researched. I chose this area of research as I have clinical experience of working with stroke survivors with pre-existing long-term conditions. This offers both strengths and limitations. A specific example of where this may have had the most impact is during the analysis phase of the research. Due to my experience with this patient group, there is a risk that this influenced my coding and theme development during analysis, as I had preconceived expectations of what might be found. However, Braun and Clarke (2022b) propose that the researcher’s subjectivity is a valued contribution to the analysis due to the interpretive reflexive process when using reflexive thematic analysis. Reflecting on the way researchers conduct research and how their beliefs, values and assumptions influence outcomes is integral to good quality research (Corlett & Malvin, 2018). Therefore, I completed a reflexive diary throughout the process. The reflexive diary offered an opportunity for me to be aware of and reflect on my biases. To ensure good quality analysis, reflexivity allows the researcher to reflect upon their experiences and how it contributes to the analytical process and interpretation of findings.

Although qualitative research has been argued to contribute enormous amounts to the fields of health and medicine, qualitative and quantitative research have often been pitted against each other in terms of trustworthiness (Meyrick, 2006), with qualitative approaches critiqued as less rigorous and findings less transferable than in quantitative research (Anderson, 2010). Tracy (2010) developed the Eight "Big-Tent" Criteria for Excellent Qualitative Research framework for researchers to apply to their research to allow other readers to be assured of the quality of the work. Therefore, to strengthen my research, I used the quality framework provided by Tracy (2010) to offer reassurance in the quality of my work (see table 4).

This study focused on self-reported pre-existing conditions and stroke diagnosis. This could be problematic as accuracy of self-reported stroke is variable dependent on the characteristics of the population (Woodfield et al., 2015). Participants were asked during eligibility screening what LTCs they had previously been diagnosed with. There is a risk that participants may miss or forget conditions they have been diagnosed with alternatively, there is also a chance that participants report self-diagnosed conditions. This could be due to poor patient-clinician communication (Smith et al., 2008). However, as this study was an exploration in the impact of conditions, it was important to understand what was important for participants daily lives in managing conditions. Therefore, it was assumed that participants would report diagnoses important to them on a day-to-day basis.

Contrastingly, not all participants remembered all their long-term conditions at the screening stage. Other conditions came to light throughout the interview that perhaps participants had not thought of as long-term conditions or even consider them important enough to mention. Research investigating the correlation between medical records and individual self-reporting of long-term conditions could help add to our understanding of the patient experience and what conditions are perceived as more important.

Additionally, data regarding the type of stroke was not collected. Ischaemic strokes are caused by a blockage to blood supply to the brain, whereas a haemorrhagic stroke is cause by a bleed in or around the brain (NHS, 2019). Ischaemic is the most common with approximately 85% of stroke being attributed to this (Lincoln et al., 2012). However, evidence suggests there are little differences in the outcomes between the two types of strokes (Perna & Temple, 2015) although they do require different treatments (Lincoln et al., 2012).

Severity of stroke was not measured in this study. The Modified Rankin Scale is often used to measure disability and stroke in both clinical practice and research (Carmo et al., 2015). It is a functional assessment scale that measures dependence or a degree of disability. Severity of stroke is subjective, and these findings suggest that perceived severity was determined through comparisons to other people. Stroke severity has been shown to be an important predictor of health outcomes (Kogan et al., 2020). Therefore, authors conducting future research may want to consider including a self-reported stroke measure to understand how this might drive perceptions and health behaviours in the context of stroke and multimorbidity.

As this is a qualitative study, a strength of this research is that this study gave a platform for a wider range of stroke patients than in previous research. Stroke research has often excluded participants with aphasia after stroke, which affects the transferability of findings (Franklin et al., 2018). I decided to include participants with mild to moderate aphasia as I wanted to ensure the inclusion criteria was as inclusive as possible for any stroke survivor who wished to participate. To facilitate this, I worked with stroke specialist healthcare professionals to develop aphasia-friendly resources for this study. Although only one participant with moderate aphasia participated in this study, the opportunity to participate was offered to this often-neglected population.

This study included participants from a range of groups and populations. The range of ages across participants reflects an array of experiences. The mean age of people experiencing stroke has reduced in recent times, with more working aged individuals having a stroke now than ever before (British Heart Foundation, 2018; Feigin et al., 2021). Therefore, by including participants with a mean age of 55 years in this study increases the transferability of these findings. Additionally, women have often dominated participation in qualitative research, and as a result it has been reported that women are over-presented, and men are under-represented in qualitative research (Plowman & Smith, 2011). This creates problems in the transferability of findings. To overcome this barrier in my research, I recruited a relatively even split of men and women.

The participants in this study included people who identified as Black African and British Pakistani. Nevertheless, the participants were predominantly from a white background and identified as British. Health inequalities is a complex phenomenon and was not directly addressed in this study. It is evident that the wider social determinants of health influence behaviour (Short & Mollborn, 2015), thus suggesting the importance of understanding the experiences of different populations in order to utilise these findings further (Bray et al., 2018). The differences in experiences across participants could not be explored within this study.

Patient and public involvement (PPI) was utilised in the design phase of the research. Including healthcare professionals in the development of the resources such as the lay summary and aphasia friendly resources played a vital role in helping me assess the appropriateness, wording and timing of the resources including the topic guide. The first two interviews were also used as pilots, and I took that opportunity to discuss the topic guide development and the aims of the research to see if there was anything missing from a patient perspective. Nevertheless, incorporating in-depth PPI was constrained by resources within the project. There were also the added difficulties of the Covid-19 pandemic which hampered efforts to attend support groups or events which were cancelled. To strengthen this in future studies co-production must be utilised to ensure inclusive research practices (National Institute for Health and Care Research, 2021). It is vital that stroke survivors are involved in throughout whole the research process and in a meaningful way.

As recruitment was through social media, it is likely that the participants were more likely to already be seeking support and therefore may be more interested in and more likely to be involved in the management of their condition. Although this could have impacted the results of the study and reduce the transferability of findings, recruitment through social media is considered the most effective recruitment method for those considered *hard-to-reach* (Topolovec-Vranic & Natarajan, 2016). Nevertheless, researchers must consider that by only recruiting through social media, there is a possibility that a large group of people who do not use these platforms could be missed.

5. Conclusion

Stroke is complex disease that has been linked to poor outcomes and reduced quality of life in survivors. The majority of stroke survivors recover from their stroke in the context of pre-existing long-term conditions. However, the literature and evidence to date has not explored stroke recovery in this context. This study explored the impact of having a stroke on the management of pre-existing long-term conditions.

The participants in this study held a positive health identity prior to their stroke, despite having pre-existing LTCs. Having a stroke challenged these perceptions whereby participants re-evaluated their health and shifted their health identity from well to unwell. Participants described experiencing a *teachable moment*, which was a significant point where self-management began. The shifting perceptions of health that participants discussed also resulted in a change in health behaviours. However, the actions needing to be taken surrounding the self-management and change in behaviours were uncertain, and participants were unclear as to where the responsibility lay terms of recovery and rehabilitation. Participants expressed disappointment in their care due to the unmet expectations surrounding their stroke. However, despite this, participants described taking responsibility and taking steps to improve their health. These actions appeared to be influenced by participants value of their health, the support they received, what self-management meant, acceptance of their situation and their hope for recovery in the future.

Exploring health identity, illness perceptions and locus of control in individuals with LTCs may strength and help guide facilitated self-management. Furthermore, the diagnosis of stroke is underused as a teachable moment for changing health behaviours. The expectations of self-management need to be communicated and managed between healthcare professionals and individuals with LTCs.

The mechanisms involved in understanding why participants perceived themselves as well prior to their stroke despite having LTCs, warrants further attention. However, several recommendations applying to the system and clinical practice were observed. These include clinical recommendations such as healthcare professionals exploring the individual’s health perceptions to aid stroke prevention, supporting stroke survivors in their self-management of stroke and pre-existing LTCs and engaging in interventions aimed at guiding acceptance. Furthermore, a recommendation regarding integration of services could improve services to support individuals with multimorbidity. The findings of this research offer significant opportunities for clinicians to develop effective interventions to aid the management of multimorbidity whilst supporting the recovery from stroke.

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Appendix A – Systematic Review

What Psychosocial Interventions Work for Stroke Survivors Well-Being in the First 6 Months? A Systematic Review

Abstract

Background: Stroke is the fourth biggest killer in the United Kingdom and is the leading cause of adult disability. Approximately 33% of all stroke survivors experience depression which has been shown to impact negatively on survivors and healthcare services. Studies have found that there is a peak of post-stroke depression and anxiety between 3-6 months post-stroke. Early psychosocial interventions have been shown to increase psychological well-being.

Objective: To examine the effectiveness of psychosocial interventions administered in the sub-acute phase of stroke (<6 months) on stroke survivors' psychological wellbeing.

Method: Five databases were searched MEDLINE, CINAHL plus, PsychARTICLES, PsychINFO and AMED as well as hand searching the references of relevant articles. A strict inclusion criteria was used to determine eligibility. Full texts were screened by two reviewers. Two independent researchers assessed the quality of the studies included using the EPHPP.

Results: Nine studies met the inclusion criteria. Studies were grouped by intervention approach and synthesised in relation to methodological quality. The heterogeneity of studies meant statistical comparisons were not feasible. There were inconsistent findings of psychosocial interventions on psychological well-being in stroke survivors.

Conclusions: There is not enough strong evidence to advise on psychosocial interventions in first time stroke survivors. The most common methodological flaws were blinding,

confounders, section bias and withdrawals. More robust RCTs and longitudinal prospective studies need to be conducted in this area.

Introduction

Stroke is the fourth biggest killer in the United Kingdom[1] and the second biggest killer globally[2]. Stroke can cause a vast array of long term negative effects in survivors; including cognitive impairment; functional and mobility impairment; and emotional problems[3]. It is the leading cause of adult disability[1] and has been shown to have a negative impact on longer-term functioning and quality of life (QOL) in stroke survivors[4,5]. The presence of an acute stroke has shown to have a negative impact on an individual's mental health; for example, post stroke depression (PSD) and anxiety, post-traumatic stress disorder, personality changes, and emotional regulation[6,7]. Approximately 33% of all stroke survivors experience depression[6] which has been shown to increase mortality[8], reduce engagement in rehabilitation[9], increase hospital readmissions[10], and reduce QoL[11].

Prevalence of Psychological Distress Post-Stroke

The majority of research in the psychological well-being of stroke has focussed on PSD[6]. Ayerbe et al[14] found that most episodes of depression in stroke survivors started within the first year of stroke, with 33% experiencing PSD within 3 months. This is consistent with a systematic review looking at the frequency of depression in stroke survivors[15]. PSD and anxiety have been examined at 3 and 6 months post-stroke[16,17]. De Wit et al[17] found that prevalence of PST was found in 28%, 30% and 24% of stroke survivors at two, four and six months respectively; suggesting a slight reduction in post-stroke depression within the first 6 months. Whyte and Mulsant[18] argue that there is a peak in PSD between 3–6 months from onset however, depression can develop hours to days after stroke and this has been found to be likely associated with spontaneous hospital readmissions[10]. This highlights the need to reduce the incidence of PSD.

Barker-Collo et al[16] found moderate to severe depression and anxiety was present in 22.8% and 21.1% of participants respectively at 3 months post-stroke. If mild depression and anxiety were included, then these percentages increased to 45.6% for depression and 38.6% for anxiety. De Wit et al[17] found that anxiety was prevalent in 22% of their participants at 2 months, this increased to 25% at four and six months post-stroke, suggesting a consistent rate of anxiety. Thus, supporting previous findings that anxiety was consistent over time for the first 3 years after stroke[19]. It seems that post-stroke anxiety does not improve without treatment, suggesting treatment or prevention interventions are necessary. Additionally, it has been postulated that anxiety is a predictor of post-stroke depression later in the stroke journey[14], strengthening this argument.

Impact and Treatment of Poor Psychological Well-Being

The ways in which patients react and adapt to their stroke unfolds over time[20]. Increased psychological distress can create problems for later recovery such as increased mortality[8], disengagement from rehabilitation[9], increased hospital readmissions[10], and reduced QoL[11]. Therefore, insight into interventions effective in this early phase are important.

Research has shown that poor QoL is determined by several factors including anxiety, depression, and physical impairment in first-time stroke survivors[11,12]. West et al[4] found that ongoing psychological symptoms at 6 months post-stroke was associated with reduced physical functioning at 1 year, even after adjusting for age, sex and initial disability[4]. These findings highlight a vicious cycle of depression and functional recovery and outline the significant complexity of stroke and psychosocial well-being associated with it[15]. Such findings have stemmed research into the emotional consequences of stroke[5,7,13,20].

Stroke rehabilitation should start as early as possible in order to ensure stroke survivors get the best possible recovery[21]; this typically includes physiotherapy, occupational therapy and speech and language therapy[21]. The recommendations that psychological support is imperative in stroke rehabilitation has been well documented[22,23]. However, the timing of implementing psychosocial interventions has scarcely been researched. Hackett et al[24] found limited but moderate evidence that psychotherapy reduced psychological distress in the acute stage of stroke. This systematic review only included four trials and therefore highlights a need for further research into psychosocial interventions post-stroke. Mehta et al[25] found moderate effectiveness of psychological interventions for improving stroke survivors' well-being at the chronic stage of stroke (>6 months).

Brandstater and Shutter[21] have commented that the adjustment and psychological well-being of stroke survivors is not a focus until the later phases of rehab. They suggest that the initial concern is survival which then leads onto fear about the uncertainty of the future for the patient and their families. It is not until these issues have been addressed that adjustment and psychological well-being is considered.

There is limited research related to preventing psychological distress in stroke survivors. Nevertheless, a systematic review has found that psychotherapy has a small yet significant effect on reducing PSD[23]. Additionally, research regarding the treatment of psychological distress have found inconsistent findings due to poor methodology of studies[24], inclusion of different stroke types[26] and implementing interventions at different times[24,25]. Emotional support is important now more than ever before and crucial in the early phase of rehabilitation, when the stroke survivor attempts to make sense of what has happened and may experience fear and uncertainty[27]. Patients need opportunity to explore their feelings in a safe environment and learn to understand that the emotions they are experiencing are normal reactions to a stroke[27]. Previous research in the early after stroke onset has discovered a significant benefit of Motivational Interviewing in improving mood from baseline to 3 months after stroke[13]. Moreover, further research has also found that information provision is beneficial to stroke survivors by reducing depression scores[28].

Current UK recommendations

There are many current UK guidelines from key organisations supporting the need for psychological support after stroke. The Sentinal Stroke National Audit Programme recommends that psychological support should be available to all stroke survivors[22,29,30]. The specificity regarding timelines is not clear in their report but they do make a number of important key recommendations supporting the current literature. For example, they state that psychological interventions such as motivational interviewing or problem-solving therapy should ideally be offered before considering antidepressant medication[22].

NHS improvement documented a recommendation that a minimum of 40% of all patients within stroke services should receive psychological support within 6 months, as the psychological care for this group is essential[23]. In comparison, the National Institute of Clinical Excellence[31] also recommends that if anxiety and depression is present in stroke survivors (albeit without cognitive impairment), it should be treated in line with the recommendations outlined in “Depression in adults with a chronic physical health problem”[32] and “Generalised anxiety disorder”[33]. Similarly, to the SSNAP guidelines, the timeframes are not clear[22,29,30].

Due to the vast differences in service provision and delivery[22] and the limited evidence only first-time stroke survivors were included, therefore minimising the possibility of having previously been exposed to psychosocial interventions related to a previous stroke. Additionally, it could be argued that people who are experiencing a recurrent stroke respond differently to those experiencing stroke for the first time; although research in this area is scarce.

Why is it important to do this review?

In summary, the consistent reporting of post-stroke depression and anxiety within the first six months of stroke emphasises the need for interventions to treat and prevent these issues. Due to the effects that psychological distress can have on the stroke survivor in the long-term with the current push for psychological support, there is a need to review the literature. The current UK guidelines support the need for psychological support within stroke in general. However, the lack of detail specified in these reports and the small amount of evidence recommending the best timeframe to intervene forms the basis for this systematic review. Therefore, the aim of this systematic review is to investigate the effectiveness of psychosocial interventions administered in the subacute phase of stroke (<6 months) to help improve psychological wellbeing of stroke survivors.

Methodology

Protocol and registration

This systematic review was submitted for registration and accepted by PROSPERO in July 2018 (ID: CRD42018099790). No protocol is available however, authors can be contacted for more details.

Eligibility Criteria

Studies were included in this review if participants were ≥18 years old (if a study included participants whom were ≥16 years, authors were contacted to confirm if any participants under the age of 18 had participated. If not, this study would meet the inclusion criteria for age). Participants had to have a clear diagnosis of a first-time ischemic or haemorrhagic stroke and had to be within the subacute phase of stroke (0-6 months) at recruitment. Studies were excluded if they included participants who had experienced a Transient Ischemic Attacks (TIAs) and/or a Subarachnoid Haemorrhage (SAH). TIAs typically lasts up to 24 hours and should therefore not have any ongoing symptoms[34]. Some researchers do not consider SAH a stroke due to the location of the bleed in the brain[35].

Interventions had to be psychosocial based on the following definition from the BPS[36]: "A 'psychosocial intervention' is a broad term used to describe different ways to support people to overcome challenges and maintain good mental health. Psychosocial interventions do not involve the use of medication" (p.2). Outcome measures used to determine any psychological well-being such as mood, emotionalism, stress, quality of life were included in this review.

Although randomised control trials (RCTs) have been considered the 'gold standard' of research studies as the risk of bias is minimalised, and the methodology is robust; it has been argued that RCTs may not necessarily be the most influential in the application of intervention into practice[37]. Jackson and Waters[38] recommend the inclusion of all study designs, particularly where RCT evidence is lacking. The length of follow-up nor publication status was a restriction in this review. Therefore, non-randomised control trials were included. Details of all the eligibility criteria are listed in table 1.

Information Sources/Literature Search Strategy

Five databases were searched (last search date 23.07.2018); MEDLINE, CINHAL Plus, PsychINFO, PsychARTICLES and AMED.

Grey Literature Searching

References of similar systematic reviews[25,39,40] were searched as well as the included studies[41-49]. N=11 additional studies were found through hand searching however, none were included as they did not meet the inclusion criteria.

Table 1: Inclusion and Exclusion criteria.

	Inclusion	Exclusion
Population	Stroke survivors >18 years old In sub-acute phase of stroke (0-6 months) First time stroke	TIA Subarachnoid Hem Paediatrics <18 years old Caregivers of SS In chronic phase of stroke (>6 months) at time of recruitment Recurrent stroke
Intervention	Psychosocial interventions directly aimed at improving psychological well-being in SS including but not limited to: MBIs; Acceptance and Commitment Therapy; Cognitive therapy; Behavioural therapy; Peer support; Self-management; Psychotherapy; Psychoeducation; Motivational interviewing; Counselling; Therapy focussed on coping skills / management of symptoms skills	Interventions focussed on rehabilitation not focussed on psychological well-being i.e. Physiotherapy/ physical therapy/ exercise; Occupational therapy; Family interventions/therapy/support; Care management interventions; Yoga/Tai Chi Couple-based interventions
Outcomes	Psychological well-being including but not limited to: Quality of life; Depression; Anxiety; Psychological distress; Psychological adjustment; Stress management; Coping	Caregiver well-being Functional ability such as limb function Outcomes not related to psychological well-being
Other	English	Non-English studies or no translation available Conference abstracts
Study Design	Quantitative Studies only including stroke survivors	Qualitative Protocol Studies including illness groups other than stroke

Search

Three concepts were used to guide the search strategy: 1) stroke; 2) psychosocial interventions; and 3) psychological wellbeing (appendix 1). Refer to appendix 2 for a full example of a search within EBSCO. Limiters included human only and English language only.

Study Selection

Upon completion of the search, all references were exported and managed through Refworks. Duplicates were then removed through Refworks and manually by hand. One reviewer screened through all the titles and citations twice; to ensure that no citations or articles were missed. All full text article references were exported to a software management tool called Covidence; two reviewers could access the full texts of the studies and complete their decisions on study eligibility. An eligibility form was used (see appendix 3) to determine inclusion. Once the studies had been identified another independent reviewer used the same eligibility form to standardise the process in assessing each of the included studies.

Data Extraction Process & Data items

One reviewer extracted data using a pre-written data extraction spreadsheet (see appendix 4). Data was extracted on participants, methodology of the study, interventions, outcomes, results and quality of the studies. This table was summarised further to provide the key characteristics of studies and are discussed in the results section of this paper (see table 2).

Synthesis of results

Due to the differences between studies use of outcome measures and intervention administered, it was not considered appropriate to conduct a meta-analysis in this instance. Therefore, a narrative synthesis summarising the included studies in relation to applicability and utility for implementation in real-world settings, in relation to methodologically quality was produced.

As each of the nine studies investigated a different psychosocial intervention, the ability to group them based on intervention type for this synthesis is limited however, the interventions will be divided by intervention approach.

Risk of bias

Two reviewers independently conducted a quality assessment using the Effective Public Health Practice Project (EPHPP) tool[50] for each of the included studies by two reviewers. This tool has been found to be adequate to assess the quality of health behaviour research, as it is robust with appropriate psychometric properties[51]. Two researchers resolved three discrepancies. The findings were used to discuss the strength of the evidence of the included studies.

Results

A brief description of studies will be provided highlighting the key characteristics. Then a narrative synthesis will be presented discussing the effectiveness of psychosocial interventions on the well-being of first-time stroke survivors in the first 6 months.

Study Selection

Upon searching the databases there was a total of N=4841 hits. N=13 studies were then screened by a second reviewer to ensure full eligibility. Upon discussion, the authors decided that N=5 of the studies had ambiguous data and therefore the authors were contacted for further clarification. If there was no response by the time data extraction started, then the study was excluded. One author replied, leaving N=9 articles included[41-49] (refer to figure 1).

Description of studies

Table 2 highlights the key characteristics of the interventions, study design, settings and the main results of each included study.

Participant Characteristics

A total of 840 stroke survivors completed their participation across all studies. The ages ranged from a mean age of 53.3 (SD=9.6) years to a mean age of 73 years old (SD not given); although three studies did not report the ages of their participants[41,42,46]. The type of stroke was not reported by four of the included studies; confirmation of studies fitting the eligibility criteria was given by all contacted authors[41,42,46,48]. Three studies included only ischemic strokes[45,47,49]. Two studies included a mixture of both haemorrhagic and ischaemic strokes[43,44.] The earliest time since stroke at recruitment was 48 hours post-stroke[47] and the longest was a mean of 5.5 months since stroke onset[48]. Three of the included studies conducted the interventions at home or remotely over the telephone[42,47,48]. The other remaining six studies all administered their interventions within a rehabilitation unit.

Intervention Types

Of the nine included studies, each study presented a different psychosocial intervention. Five studies were cognitive and behavioural studies[42,43,45,47,49]. The remaining studies included a Self-Management Workbook[48]; Emotional Support Group[46]; Art Therapy[41] and Life Review Therapy[44].

Risk of Bias in included studies

EPHPP[50] was used to assess the quality of each included study (see table 3). Overall, the study quality in this systematic review is weak to moderate with no studies being rated as strong. The results of the quality assessment will be discussed in line with the results in the next section.

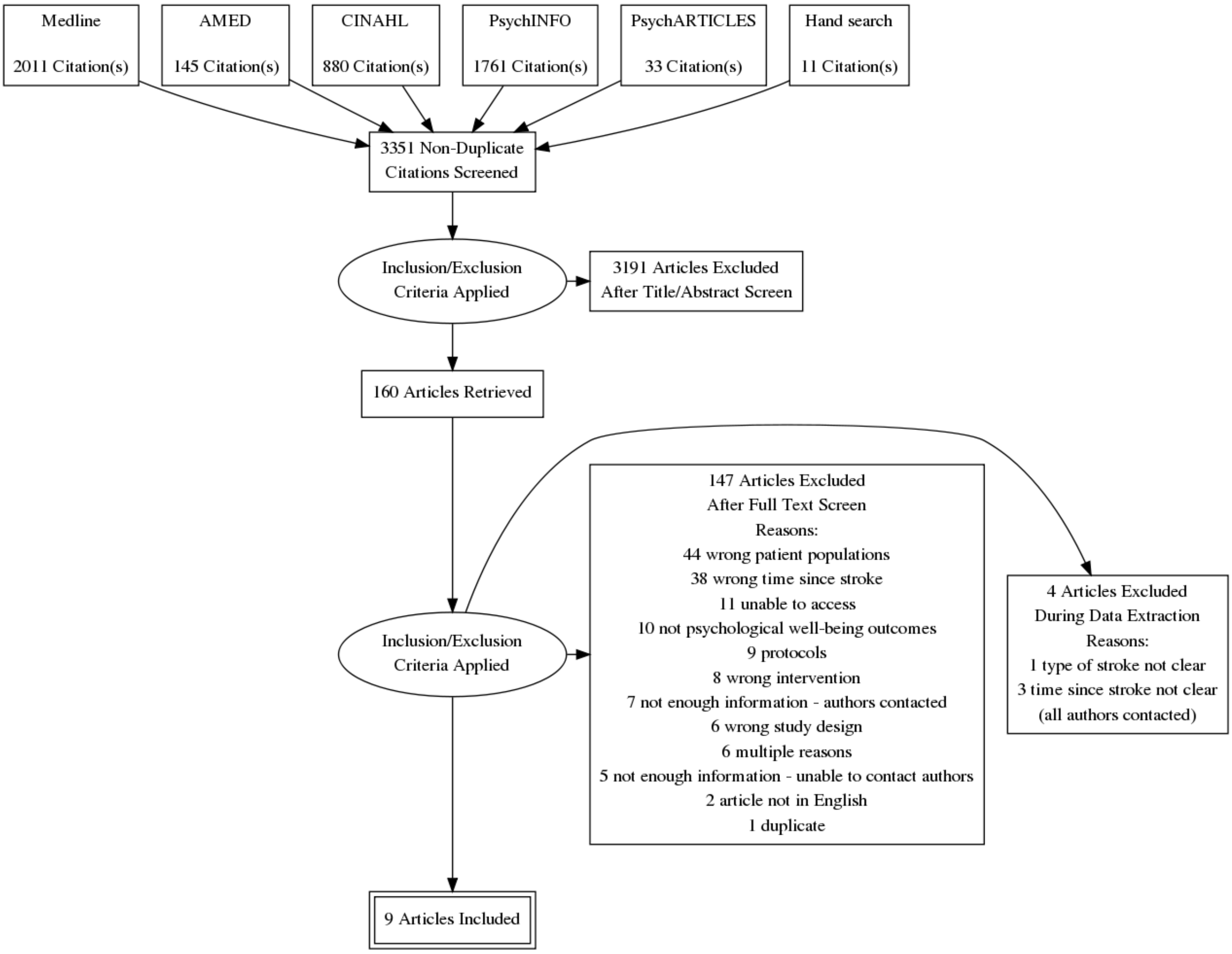

Figure 1: Prisma Flow Diagram for Study Selection

Effectiveness of Interventions

Effectiveness of cognitive and behavioural interventions on psychological outcomes

Five of the included studies investigated cognitive and/or behavioural interventions in stroke survivors. These results will be presented by grouping similar intervention approaches: problem solving therapies, cognitive therapies, and behavioural therapies.

Problem-Solving (PST)/Solution Focussed Therapies (SFT)

Two studies investigated the effectiveness of a form of PST in stroke survivors however, they differed in their delivery of the intervention[47,49]. One study delivered Solution-Focused Brief Therapy (SFBT) as a group within a hospital setting[49] and another delivered a PST to survivors in their homes on an individual basis[47]. These factors could be why both studies found contrasting evidence. Hadidi et al[47] found a trend towards reducing depression in the treatment group, from baseline to 10 weeks post-intervention. However, this is was not significantly different when comparing with the control group (p=0.08).

Table 2: Characteristics of included studies

Author Date Location	*Study Design; Setting*	*Primary Outcome(s) of study*	*Participants completing study*		*Stroke details*		*Intervention details (type of intervention; frequency; format)*		*Follow-up times*	*Outcomes and measures of interest*	*Results*
			Intervention	**Control**	**Type**	**TSS at recruitment**	**Psychosocial Intervention**	**Control**			
Ali et al[41] 2014 UK	Repeated measures experimental design; Rehabilitation unit	Mood; Therapy Outcomes	N = 6 Av. Age = 69 years 100% male	N = 21 No demographic information	All either ischemic or hemorrhagic **	<6 months**	AT Group 2 sessions per week Approx. 50 mins 6 weeks	UC	BL; PT	Mood (HADs)	No statistical analysis Reduced scores in the experimental group for HADs from pre to post intervention (anxiety mean score = 8 to 6, respectively; depression mean score = 10 to 4, respectively).
Barker-Collo et al[42] 2015 NZ	RCT; Community	Change in systolic blood pressure and low-density lipoprotein cholesterol levels	N = 169 NZE/Other =78.8%	N = 178 NZE/Other = 83.4%	All either ischemic or hemorrhagic **	<28 days	MI Individual 4 time points (28 days and 3, 6, 9 months PS) Approx.1.5 hrs	UC	PT (3, 6, 9 and 12 months)	QoL (SF-36) Mood (HADs)	The groups did not differ significantly at any time point for each of the QoL or mood scales (p>0.05). SF- 36 physical components – p=0.237, p=0.886, p=0.942, p=0.593 (3,6,9,12 months respectively) SF-36 mental components – p=0.691, p=0.241, p=0.842,

											p=0.538 (3,6,9,12 months respectively) HADs anxiety – p=0.505, p=0.759, p=0.743, p=0.539 (3,6,9,12 months respectively) HADs depression – p=0.745, p=0.913, p=0.637, p=0.286 (3,6,9,12 months respectively)
Chang et al[43] 2011 China	Repeated measures experimental design; Rehab unit	Anger; Anxiety; Depression; Physical Functioning; Activities of Daily Living	N = 34 Total sample: Males = 68.2% Av. age = 58.86 (SD = 10.4) years	N = 32	Ischemic = 65.2% Hemorrhagic = 34.8%	Mean = 136.29 days (approx. 4.4 months) (SD = 69.1)	K&BT (counselling) Individual 1 or 2 hrs x 1 month	RT	BL; PT (1 month)	Anger (STAXI); Mood (HAS and HDS) Physical functioning (SS-QoL)	There were significant differences between groups across time for state anger, anger-out, anger control, depressive symptoms, QoL (where all p values were p< 0.001) and anger-in (p<0.05), all with a medium to large effect (partial eta2 = 0.28; 0.28; 0.25; 0.3; 0.4 and 0.09, respectively). Independent t-tests were also conducted to compare the mean differences between groups. K&BT group showed significant improvements in state anger (d = -1.24); anger out (d=-1.25); anger control (d=1.17); depression (d=-1.34) and QoL (d=1.59) (p<0.05). Additionally, there was an unexpected significant large difference for anger in (d=0.61) indicating the control group reporting better improvements in anger-in compared to the experimental group).

Davis[44] 2004 USA	Post-test only design; Rehab unit	Depression; Life-Satisfaction (QoL)	N=7 Av. Age = 68.5 years Males = 57.1% 100% Caucasian	N=7 Av. Age = 67.5 years Males = 57.1% 100% Caucasian	CVA = 100%	<6 months	LRT Individual 1 hour sessions 3 consecutive days	ALT 1 hour sessions 3 consecutive days	PT	Mood (ZDS) Quality of Life/Life satisfaction (LSI-Z)	The treatment group scored significantly higher on the depression scale than the control group (p<0.01) indicating that LRT did have a significant effect. This result was the same for the life satisfaction scale, suggesting the LRT can increase life satisfaction in stroke survivors (p<0.01).
Gao et al[4] 2017 China	Interrupted time series; Rehab unit	Depression	Group C: N = 92 Av. age = 64.9 (SD=8.0) years Males = 52.2% N = 87 completed study	Group A: N = 91 Av. age = 67.2 (SD=9.6) years Males = 52.7% N = 86 completed study Group B: N = 91	Ischemic = 100%	Time-points: 1) during hospitalisation 2) between discharge and 3 months post stroke 3) between 3 and 6 months post stroke 4) between 6 and 9	Group C: CBT (& placebos) Individual 2 x 1 hr sessions per week >3 months	Group A: Non-psychological general discussions 2 x 1hr sessions per week for 3 months Group B: Citalopram 20mg/d and non-psychologic	BL; PT (3 months)	Mood (HAMD and MES)	No significant differences between groups on the HAMD measure when comparing all three groups (p=0.60), group A and B (p=0.79), and comparing group A and C (p=1.0). Significant differences between all groups on the MES (p=0.02) and when comparing group A and B (p=0.02). No significant differences found on the MES for comparisons of group A and C (p=0.51). Time analysis – Comparing grp A, B and C: No significant differences between all three groups in the HAMD and BRMS at time 1 (0-3 months; p=0.12, p=0.12 respectively), time 2 (3-6 months; p=0.55

				Av. age = 66.0 (SD=7.3) years Males = 50.5% N = 85 completed study		months post-stroke		al discussions 2 x 1hr sessions per week for 3 months			and p=0.62 respectively) or time 3 (3-6 months; p =0.06, p=0.05 respectively) Time 4 shows significant differences between all three groups for MES (p=0.03). Comparing group A and B: Significant differences HAMD and MES at time 3 (p=0.02, p =0.02). No significant differences found for time 1,2 or 4. Comparing group A and C: Significant differences on MES at time 4 (p=0.02). No significant differences found on HAMD at any time or the MES at time 1,2 or 3.
Gurr[46] 2009 UK	Repeated measures experimental design; Stroke Unit	Mood	N = 34 No other information given	N/A	All either ischemic or haemorrhagic**	<6 months**	ESG Group 1 sessions x 2 weeks Approx. 1.5hrs	N/A	BL; PT (immediate)	Mood (HADs)	HADs – No significant differences from pre to post intervention. Found a non-significant reduction in anxiety and depression (p>0.05) from pre to post intervention for N=34. A separate analysis of the first group (N=6; whom had been given the intervention for 3 weeks) showed a significant reduction in anxiety scores post intervention (p<0.05). **no p values were reported in this study paper but the ones reported in

											this review are based on the statistical basis that p<0.05 indicates clinical significance.
Hadidi et al[47] 2014 USA	CCT; Community	Mood; Functional Recovery	N = 11 Av. Age = 73 years Males = 18% White = 82% Black = 18%	N = 11 Av. age = 69 years Males = 45% White = 82% Black = 9%	Ischemic = 100%	48 hours	PST Individual Approx 1.5 hrs 10 consecutive weeks	UC	BL; 5 weeks; 10 weeks; 3 months	Mood (CES-D)	CES-D: scores were not significantly different from baseline to 10 weeks for either the control (p=0.08; d = 0.85) or the experimental group (p=0.09; d = 0.80). Additionally, there seemed to be a pattern of improvement for time x group however this was not significant (p=0.83).
Jones et al[48] 2009 UK	Single study design; Community	Self-efficacy; locus of control; mobility; daily living activities; physical and social outcomes; Mood	N = 10 Av. Age = 61.5 (SD=8.15) years Males = 70%	N/A	All either ischemic or haemorrhagic**	Mean = 24.2 weeks (approx. 5.5 months)	SM Individual Baseline differed for each ppt, started it between 5-11 weeks after randomisation Intervention lasted 4 weeks	N/A	BL and every week until each ppt was assessed 14 times. Assessed between >5 and <7 days apart	Self- Efficacy (SSEQ; GSEQ); LoC (RLOC) Mood (HADs)	Self-efficacy (SES) (<0.001) and recovery locus of control (RLOC) (p<0.005) were statistically significant for each of the tests. General self-efficacy (GSE) and mood (HADs) were not significant after the randomization test had occurred (p>0.05). Nine out of the ten participants depression scores had improved by the end of the study

Wichowicz et al[49] 2017 Poland	RCT; Rehab unit	Mood; Adjustment; Self-Efficacy	N = 30 Av. age = 53.3 (9.9) years	N = 32 Av. age = 54.2 (9.4) years	100% ischemic stroke	9±2 days	SFBT Group 10 x sessions Approx. 60 mins	UC	BL; 49 days; 84 days	Mood (HADs) Adjustment (Mini-MAC) Self-Efficacy (SES)	HADs – significantly different at baseline (depression p=0.047; anxiety p=0.001) and at 84 days after stroke (p<0.01 for anxiety and depression). Mini-MAC – significantly different at 84 days for all items (p<0.01) SES – significantly different at 84 days for all items (p<0.01) No significant differences found for any outcome at 49 days post-stroke (p>0.05) No effect sizes were reported

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TSS: Time Since Stroke; PS: Post Stroke; RCT: Randomised Controlled Trial; CCT: Controlled Clinical Trial; BL: baseline; PT: post-test

AT: Art Therapy; MI: Motivational Interviewing; K&BT: Knowledge and Behaviour Therapy; LRT: Life Review Therapy; CBT: Cognitive Behavioural Therapy; ESG: Emotional Support Group; PST: Problem-Solving Therapy; SM: Self-Management; SFBT: Solution Focussed Brief Therapy; UC: Usual Care; RT: Regular Therapy; ALT: Alternative Therapy

CES-D: Center for Epidemiologic Depression Scale; Mini-MAC: Mini-Mental Adjustment to Cancer scale; LoC: Locus of Control; SSEQ: Stroke Self Efficacy Questionnaire; GSEQ: General Self Efficacy Questionnaire; RLOC: Recovery Locus of Control Scale; HADS: Hospital Anxiety and Depression Scale; QoL: Quality of Life; Sf-36: Short Form 36 Scale; STAXI: State Trait Anger Expression Inventory; HAS: Hamilton Anxiety Scale; HDS: Hamilton Depression Scale; HAMD: Hamilton Depression Scale; SS-QoL: Stroke Specific Quality of Life Scale; ZDS: Zung Scale for Depression; LSI-Z: Life Satisfaction Index Form Z; MES: Bech-Rafaelsen Melancholia Scale; SES: Self-Efficacy Scale.

**as confirmed by author, exact details not available

***exact quantities not available

Individual = 1:1

Both groups had similar depression scores in the 3-month follow-up (experimental mean=5.6(4.2); control mean=4.6(3.7)). Contrastingly, Wichowicz et al[49] found significant differences in favour of the intervention between groups for mood ($p<0.01$), adjustment ($p<0.01$) and self-efficacy ($p<0.01$) at 84 days post stroke (no effect sizes reported). Interestingly, there were no initial effects of the intervention for any outcome at 49 days post-stroke ($p>0.05$)[49].

These findings must be taken with caution due both RCTs having significant methodological flaws that contributed to the final quality rating of the studies being weak. The outcomes in Wichowicz et al's[49] study were assessed by a blind researcher, thus minimising researcher bias, which was not discussed in Hadidi et al's study[47]. Participants in both studies were aware of the aims of the studies therefore contributing to possible response bias. The inconsistencies in findings may also be due to the small sample sizes across studies. However, Hadidi et al's[47] feasibility study did achieve what it aimed to achieve, whereby the intervention was possible and useful.

The attrition rates for both studies differed significantly. Wichowicz et al[49] found that less than 60% of their sample maintained their participation in the study. Contrastingly Hadidi et al[47] had an attrition rate of less than 20% thus reducing the impact of this methodological limitation. Both interventions were delivered over a similar timeframe, however dropouts could be due to the method of delivery or the setting. The convenience of Hadidi's et al[47] intervention being administered within the participants' homes not only gives us insight into the community stroke population but may have contributed to the maintenance of participation. Furthermore, Wichowicz et al[49] may have had difficulty maintaining participants as they may have been discharged from the unit before the end of the intervention. Therefore, the lack of methodological quality of both studies means we have limited evidence to suggest problem solving as an effective intervention for stroke survivors psychological well-being.

Cognitive Therapies

Gao et al[45] investigated the effectiveness of cognitive behavioural therapy (CBT) compared to general discussions on depression in stroke survivors. Chang et al[43] investigated the effectiveness of Knowledge and Behaviour Therapy (KBT) on stroke survivors' physical and emotional well-being. Chang et al[43] found a significant effect of treatment for depression (time x group; $p<0.001$) with a large effect size (partial $\text{eta}^2=0.3$) whereby the treatment group had significantly fewer depressive symptoms than the control group. Both groups had significantly reduced anxiety symptoms at post intervention ($p<0.01$), therefore suggesting that the reduction in anxiety may have been spontaneous or due to factors not controlled for in this study[43]. Significant differences between groups across time were found for depressive symptoms and QoL in favour of the intervention ($p<0.001$), all with a large effect (partial $\text{eta}^2=0.3$; 0.4 respectively); therefore, highlighting a significant effect of KBT[43].

In contrast, Gao et al[45] found no significant differences between groups when comparing the placebo group and the CBT group, when stratification of time was not taken into consideration (p>0.05). When time was considered, there were no significant differences found on the Hamilton Depression Scale(HAMD) when comparing groups (p>0.05)[45]. There was however, a significant difference in Bech-Rafaelsen Melancholia Scale(MES) scores when participants recruited were at 9 months whereby the CBT group scored significantly lower (mean=9.4, SD=1.7) than the placebo group (mean=11.3, SD=2.7)(p=0.01). This suggests that participants given CBT were more likely to have reduced depression scores than those in the control group when the intervention is delivered later than 6 months post-stroke. These results suggest that the sensitivity of detecting depression is higher in the MES than the HAMD. The difference in statistical findings between these two measures provide evidence that potentially one standardised outcome measure for post-stroke depression should be used across studies to provide consistency.

The differences in findings could be due to the participants already being depressed in Gao et al's[45] study and not in Chang et al's[43] study. The participants who were already depressed may have had a larger scope for improvement. Moreover, Chang et al[43] reviewed the effectiveness of a two-component intervention so it is difficult to determine whether the effect was due to both the behavioural and knowledge components or if one had a larger effect than the other. The statistical analysis conducted in this study meant that it is not feasible to determine which component, if any, was the most effective at reducing depression in stroke survivors.

Gao et al[45] provided moderate to strong quality ratings on all of the EPHPP[50] criteria except selection bias as less than 60% of eligible participants agreed to participate. This may have been due to the involvement of a pharmacological intervention as adverse effects are more likely to develop than low-risk psychological therapies. Furthermore, Chang et al[43] did not describe allocation concealment for either the outcome assessors nor the participants, therefore making it difficult to rule out social desirability or researcher bias. Both studies had a moderate quality rating and should be taken with some caution[43,45]. However, we can take some optimistic evidence for CBT based interventions.

Motivational Interviewing (MI)

Barker-Collo et al[42] investigated the effectiveness of MI to reduce the risk of a recurrent stroke. This was one of the largest included studies with N=234 participants completing the study and had one of the stronger bases of evidence as its quality rating was moderate. They seemed to have difficulty recruiting participants, as this component was rated the weakest on the EPHPP[50]; less than 60% of the eligible participants agreed to participate[42] therefore increasing the risk of selection bias. No baseline data was observed in this study and there was no data post-intervention so it is difficult to determine whether the first MI had any impact on the participants so early after their stroke[42]. Results showed that the intervention had no difference of effects between groups for QoL or mood ($p>0.05$)[42]. As these were secondary outcomes for this study, no intention to treat analysis was applied. However, confounders were adjusted for which offers strength to the statistical analysis used.

It must be noted that MI is a psychosocial technique aimed to change behaviour[52] and therefore the lack of statistically significant findings may be due to the intervention not specifically aiming to improve psychological well-being. Additionally, this lack of findings may also attribute to the gaps between each MI session; participants received three MIs over 9 months. This may have been too long to maintain the intervention effects[42].

Although Barker-Collo et al[42] had a large dropout rate which highlights the risk of attrition bias, the study had strength with its study design as a RCT and confirmation of allocation concealment for outcome assessors. The moderate methodological quality suggests that these findings do provide some evidence that motivational interviewing does not reduce depression or anxiety symptoms when aiming to reduce recurrent stroke[42].

Effectiveness of other psychosocial interventions on psychological outcomes

The four remaining studies included in this review investigated Art Therapy (AT)[41], Emotional Support Group (ESG)[46], Life Review Therapy (LRT)[44] and Self-Management (SM)[48]. These results will be presented by grouping art therapy and support group therapy as they had similar aims and Life Review Therapy and Self-management will be reviewed independently as the differences between such approaches make it difficult to compare.

Art Therapy and Emotional Support Therapy

Ali et al[41] investigated the effectiveness of AT on reducing depression and improving therapy outcomes in stroke survivors on a rehabilitation unit. Participants were provided with a safe space to engage in AT and offer indirect social support by using the time to talk about their stroke experience[41]. Similarly, Gurr's[46] ESG aimed to reduce depressive symptoms in stroke survivors in the community by also providing a safe space for participants to discuss their stroke journey.

The differences in baseline characteristics were not mentioned in one study[41], which means there may have been confounders affecting the effectiveness of the intervention. All participants were male, which Ali et al[41] argued could be positive for the group, as they may feel more comfortable to share their experiences to people of the same sex. This demonstrates possible bias within the study, as the findings are not representative of the population. Research shows that stroke is prevalent in women[53].

No statistical analysis was made when analysing the effectiveness of AT[41]. However, scores indicated a trend towards the improvement of depression and anxiety in the experimental group. The lack of statistical inference means the results should be taken with caution. This study had a control group however due to ethical considerations they did not complete the HADs outcome measure. Therefore, the trend seen in the experimental group may not necessarily be due to the intervention. In comparison, Gurr[46] also found a trend in improving anxiety and depression based in the ESG, however this was not statistically significant ($p>0.05$). This could be due to spontaneous recovery over time rather than the intervention itself, as they did not have a control group[46]. Each group was only run twice and although this is an extremely short intervention, it is consistent with the current discharge rates within acute stroke units[46].

Due to the very weak quality of the evidence provided, the findings are unable to be used to recommend either AT or ESG to improve psychological well-being in stroke survivors.

Life Review Therapy

Davis[44] studied the effectiveness of LRT on the depression and quality of life (QoL) of stroke survivors. Their intervention was administered rapidly over three consecutive days. They found significant differences between the experimental and the control group for depression ($p<0.01$) and life satisfaction ($p<0.01$), thereby suggesting that the experimental group scored lower on depression (mean=31.9; SD=3.24) and higher on QoL (mean = 24.3; SD=3.24) than the control group (depression mean=44.6; SD=5.68; QoL mean=20.3, SD=5.68). Intervention effects were not measured at follow-up and therefore the maintenance of effects cannot be assumed. This post-test only study design makes addressing the effectiveness of LRT difficult, as there is no group or timeframe to compare to.

Davis[44] had difficulty recruiting and therefore only managed to obtain N=18 participants in the study with N=14 completing the study. By only recruiting participants through referrals from a physician, a high level of selection bias was present. Additionally, it was not addressed as to whether the included participants were blinded to the studies aims, therefore putting the study at risk of social desirability. Moreover, the outcome assessor was the same person administering the intervention, thus increasing the risk of researcher bias. Although, the randomization procedure was strong in this study. Overall, the level of quality was weak for Davis[44] as there was a high risk of bias across the study.

Self-Management

Jones et al[48] investigated the feasibility of introducing a self-management workbook in first-time stroke survivors. Due to the preliminary nature of the study, the sample size was small with only N=10 participants of which 70% were male; therefore, not being representative of the population[53]. They found that stroke specific self-efficacy (<0.001) and recovery locus of control (p<0.005) were statistically significant for each of the tests[48]. General self-efficacy and mood were not significant after the randomization test had occurred. Although the author notes that nine out of the ten participants depression scores had improved by the end of the study therefore, suggesting a trend in favour of the intervention. There was no comparison group, which suggests that the changes could have occurred regardless of the intervention. Additionally, the lack of blinding of participants puts the study at risk of further bias. This pilot study gives scope for a larger trial as they managed to feasibly conduct the intervention[48]. Nevertheless, the poor methodological quality highlights a lack of reliable evidence and therefore an inability to provide recommendations.

Table 3: Quality Assessment table based on EPHPP

	A -Selection Bias	B- Study Design	C- Confounders	D - Blinding	E - Data Collection Method	F- Withdrawals and Dropouts	Global Ratings
Ali et al[41]	2	2	3	3	1	3	3
Barker-Collo et al[42]	3	1	1	2	1	2	2
Chang et al[43]	2	2	1	3	1	1	2
Davis[44]	3	1	3	3	2	2	3
Gao et al[45]	3	1	1	2	1	1	2
Gurr[46]	2	2	1	3	1	3	3
Hadidi et al[47]	3	1	1	3	1	1	3
Jones et al[48]	2	2	3	3	1	1	3
Wichowicz et al[49]	1	1	3	2	1	3	3

*1=strong (no weak ratings); 2=moderate (one weak rating); 3=weak (two or more weak ratings)

Discussion

This is the first systematic review to examine the evidence of the effect on well-being of psychosocial interventions on first time stroke survivors in the 6 months of stroke. General findings from the nine included studies of weak to moderate quality show inconsistent results of psychosocial interventions for the psychological well-being of stroke survivors. The lack of strong evidence suggests that more needs to be done in this field to truly determine the effectiveness of such interventions.

Summary of the Evidence

A large inconsistency of findings was found across the included studies. The evidence suggests that art therapy, an emotional support group and motivational interviewing (MI) did not provide any statistical evidence of improving psychological well-being in first-time stroke survivors. Although it has previously been found that emotional support can improve psychological well-being in stroke survivors[40]. Moreover, in contrast to Barker-Collo et al[42], Watkins et al[13] found that MI improved stroke survivors' mood. Watkins et al[13] did not subject their sample to first-time stroke survivors and the MIs were administered specifically to improve mood. Barker-Collo et al's[42] aim was to reduce recurrent stroke. These differences may contribute to the inconsistent results. However, this may also be because Watkins et al[13] delivered their intervention over a much shorter period than Barker-Collo et al[42].

PST also showed inconsistent findings[47,49]. The content of each intervention the studies administered may provide explanation to the differences in results. Previous research has found PST to be beneficial in preventing post-stroke anxiety in first time and recurrent stroke survivors[54]. Additionally, Life Review Therapy improved mood compared to a control group[44]. Self-management seemed to improve self-efficacy and recovery locus of control in stroke survivors[48]; which is consistent with previous research[55]. Cognitive behavioural interventions (CBI) provided moderate evidence for improving mood in first time stroke-survivors in the early phase of stroke[43,45]. However, earlier research has found that CBI for post-stroke depression did not find any significant treatment effects[56].

Other psychosocial interventions such as information provision has also been found to reduce depression scores in stroke survivors[28]. Although, no studies implementing psychoeducational interventions have been conducted in first time stroke survivors. This highlights a clear gap in this research area and further research could consider this as a potential avenue to explore. All the included studies differed in length of follow-up periods, study designs and delivery of interventions therefore limiting the conclusions that can be drawn from the studies. Moreover, methodological quality should also be considered when reviewing the evidence.

Methodological Quality and Implications for Future Research

There were some methodological strengths as study designs across the evidence was relatively strong, with none of the included studies being rated as weak. Additionally, the data collection method was also strong whereby common valid and reliable tools were used across studies although the diversity of outcome measures used provided difficulty when comparing. Gao et al's[45] study also highlighted the differences in sensitivity of outcome measures as they compared two depression outcome measures. It would be logical to have future studies using consistent outcome measures.

The most common methodological flaws across studies were blinding, unadjusted confounders, section bias and withdrawals. The difficulty of recruiting participants was a common theme. Only two studies managed to recruit between 80-100% of participants approached[43,46]. The remaining studies were either <60% or were not clear. This could be due to the complex and traumatic nature of stroke where participants do not feel ready to participate in a trial so early after onset. Poor psychological well-being can result in reduced motivation to engage in rehabilitation[9], which may also be apparent for research trials.

The reporting of confounders across studies was inadequate, which is consistent with similar systematic reviews[6]. None of the included studies were sufficiently powered and therefore the reliability of evidence is deficient. Not only this, but only one study managed full blinding of intervention deliverers and participants[45]. However, it is difficult to fully blind participants in health behaviour research[57] due to the nature of psychosocial interventions usually involving health care professionals such as a therapist or psychologist.

All interventions sought to improve psychological well-being either primarily or as a secondary outcome in stroke survivors however, most failed to incorporate a theory base into their intervention, in addition to differing durations of interventions from 3 days to 12 weeks. Only one study had a clear theoretical framework described in the study[44]. The variety and random nature of choices point to a lack of direction of clear aims across studies which is confirmed by the lack of theoretical framing. Jackson and Waters[38] state that reviewers should aim to investigate the impact of a theoretical framework on the effectiveness of the intervention.

Furthermore, all studies applied a restricted eligibility criteria which may decrease the generalisability of the findings, due to limiting the clinical representativeness of the sample. Most studies did not include people with aphasia, severe cognitive impairment or severe stroke. In addition, the average age of participants across studies were 53–73 years old however, a third of stroke survivors have a stroke under the age of 65[1]. Therefore, the evidence presented may not be representable of the population.

Implications for implementation of psychosocial interventions in the sub-acute phase of stroke arose such as the timing of interventions. The quickest timeframe for inclusion into the study was 48 hours[47] whereas other studies did not include participants if they were <2 weeks post-stroke due to the complex symptomology of stroke[43]. Moreover, the longest mean time since stroke was approximately 5.5 months since stroke which is a significantly longer time frame[48]. As Gao et al's[45] results highlight, it may be better for CBT to be implemented later in survivors experiencing post-stroke depression. These however, do not account for the participants whom are not necessarily depressed or anxious but may have difficulties coping or adjusting to stroke[27].

Quality of Current Review

Although a comprehensive search following a rigorous process was conducted, it is possible that some studies were not identified. Another researcher involved in the screening process would have limited the likelihood of missing studies. Additionally, due to the time constraints of the current systematic review, qualitative data evidencing the utility and applicability of stroke survivors were not reviewed. It is recommended that another systematic review including both the qualitative and quantitative data in the synthesis, to gain a more enriched picture of the psychological impact and pragmatic nature of the intervention being measured[38]. The subjective nature of psychosocial interventions must be taken into consideration however a definition was provided[36] to try and limit the subjectivity

First-time stroke survivors were included, this is because individuals may respond differently to a recurrent illness[58]. However, previous research has suggested that no significant differences in anxiety and depression from first or recurrent stroke have been found[59]. Therefore, it may be worth considering reviewing the evidence across all stroke survivors. Therefore, further research into exploring the differences between first time and recurrent stroke survivors' psychological well-being and adjustment to stroke is recommended.

Conclusions:

Stroke survivors are at risk of developing psychological problems. The general current nature of the studies highlights the growing interest in the psychological impact of stroke. This is a new and growing area of evidence and one that needs to be explored in much greater depth. The lack of quality evidence investigating psychosocial interventions in the 6 months of stoke is prevalent. However, all studies have subsequently added to the awareness of the need for further high quality research. Methodological flaws should be considered when designing future studies as well as the acceptability of interventions in this patient population. Additionally, the clear lack of a theoretical basis for each of the interventions also highlights a growing need for an increase in the integrity of the interventions, both shown in this review and for future psychosocial intervention studies[38].

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Appendix B – Reflective Chapter

My position as a researcher has changed throughout the process. I began my research design with the position of a Stroke Recovery Co-ordinator working for the Stroke Association. My position as a practitioner at the time of developing the research question and aims played a significant contribution towards the rationale for the study. I was working as a stroke recovery co-ordinator in the community which led to me basing some of my initial project ideas on the experience of working with this population. Assessing all initial needs such as physical, cognitive, psychological, communication and support networks, I became acutely aware of some of the challenges this population faced. What was particularly notable was the perceptions and attitudes towards the self-management of their other long-term conditions. One particular experience struck me, whereby I visited a stroke survivor in her home. During the visit I noticed a pile of pre-made Dossett boxes all filled with medication. I was there to assess the individual's needs as she had just been discharged from hospital after experiencing her fifth stroke. I began to wonder why she did not take her medication. What were her beliefs about her medication that prevented her from taking them? It also struck me that if I was to see this individual in hospital, I would not have made that observation, I may never have known that she was not taking her medication. I observed this behaviour more and more during my work, and although this was anecdotal evidence, my interest in self-management, multimorbidity and stroke developed.

Personal Experience

A significant challenge I faced throughout my research at the time I was preparing for data collection, was that my father experienced a stroke. It was a shock for my family at the time and was challenging. It was during the midst of the Covid-19 pandemic, a time when we were unable to visit him. We relied on technology to communicate while he was there. It occurred to me that the people I would be interviewing will have had a similar experience, but they would have been the ones in the hospital, disconnected from their support networks. My research suddenly felt very close to home, and I knew this would influence the direction of my research. I found this was significant during the interviews and data analysis. For example, I found that during the interview I wanted to share my experiences. Sharing experiences can show the person that you empathise or understand where they are coming from. However, I was focussed and mindful that my role was as the researcher. I tried to provide as relaxed environment as I could during the interviews, I felt I was able to achieve this without sharing my own personal story, which was so raw. A useful strategy I used to aid me in this was writing a reflective journal after each interview. This helped shape my thinking throughout the process, which also helped me during the analysis phase of my research.

My Researcher Journey

I began my Health Psychology and research journey during my A-Levels in 2007. At the time of choosing my A-Level options at secondary school, I had no idea my budding interests would become my career. I was excited at the prospect of understanding human behaviour and investigating how and why people behave in certain ways. One of the modules I had to complete during my A-Level was Health Psychology. This was the start of my understanding of the importance of promoting good health and the challenges associated with managing long-term conditions.

It was during my Psychology A-Level that I began to understand the importance of research as I was subjected to learning about classic psychological studies. Part of my studies involved learning about research methods. This was the first time I had to conduct a practical investigation and when I first considered psychology as a science. I learned about key debates and issues such as ethical considerations, practical issues in the design of research and concepts such as reductionism vs holism.

My interest grew deeper during my undergraduate Psychology degree. However, unlike my A-Level, I found research, particularly the writing up of reports, challenging and I struggled with understanding it, especially during the first two years. I resented conducting research as I knew I was going to have to write it up and could not see myself as a researcher in the future. In my final year, I was relieved that I was finally able to study Health Psychology again. My thirst for the topic grew even further and it was at this point that I decided to do my MSc in Health Psychology.

It was not until during my MSc that I experienced a ‘click’ for research. I was reassured that I suddenly understood it. I particularly enjoyed the research seminars as it gave us opportunities to build our critical and analytical thinking skills. I understood how research questions contributed to the design of the research study. As a result, my research interest further deepened when I discovered an interest in recovery and rehabilitation during my MSc. Coupled with my newfound understanding of research and the research process with my interest in rehabilitation and recovery, I sought to find a job as a Research Assistant. I was extremely fortunate to be offered a role at the National Institute of Stroke and Applied Neurosciences (NISAN) at the Auckland University of Technology. My intrigue of research heightened as well as my curiosity for Health Psychology, which is when I decided to undertake the Professional Doctorate in Health Psychology.

Development of the research

I began thinking about the research question before I had started the professional doctorate. I was working as a Stroke Recovery Coordinator for a charity in London. My role consisted of assessing stroke survivors needs at point of discharge and at 6-months post-stroke. It was during my time in this role that I began to gain an understanding of the complexity of stroke and the behaviours associated with a perceived positive stroke recovery. I worked closely with NHS colleagues as well as the stroke survivors and their families/carers. During my time as a SRC, I made lots of observations. However, two observations stood out to me; 1) the lack psychological support for stroke survivors and 2) the context in which the stroke survivor was recovering such as taking into account needing to make lifestyle changes, engage in rehabilitation and manage their other long-term conditions. It struck me just how difficult that must be. Often stroke survivors would only be focussing on recovering from the stroke such as overcoming physical, communication or cognitive effects and often considerations for lifestyle changes were not at the forefront of their mind.

A core responsibility of mine as a SRC was to ask stroke survivors to complete a depression and anxiety self-reported screening tool. I noticed that many of the stroke survivors I was working with scored higher on the scale, indicating that they were experiencing mood issues. As my role was to offer information and signpost them to services for further support, I became privy to the IAPT referral process. Although I felt the referral process was relatively straight forward for me, I was working in a very deprived area of London where many stroke survivors did not have the physical or psychological capabilities to refer themselves to the service. There were many occasions I became frustrated as I would refer and individuals on my caseload to IAPT, and the referral was often rejected due to their complexity. I could not understand why. It was at this point that I started to design the systematic review for the professional doctorate looking at psychosocial interventions for stroke survivors.

As I was working with a community team, I often visited patients jointly with the therapists. There was one time when I visited a patient with a physiotherapist. I was observing the session and it was clear that the therapists and the patient had different goal ideas, which resulted in the patient getting quite frustrated. It was at this point along with the experience described earlier with the patient’s medication adherence, that my curiosity grew further around the concept of goal setting, rehabilitation, and self-management.

Once I had started on the professional doctorate and it was time to design my research, I met with both my supervisors to discuss the ideas I had around stroke and self-management. It was during these discussions that I had opportunity to explain my observations about stroke survivors managing more than just their recovery and self-management. I was thrilled and relieved that my supervisors found this an interesting and novel perspective for a research study. Consequently, I began writing my literature review and protocol for the research and I was both pleased and frustrated that it appeared that my anecdotal observations and experiences did highlight a gap in the literature. With so many stroke survivors recovering in the context of multimorbidity, and with the current systems being single disease-focused (Stou et al., 2022), it seems this area had very little research conducted, and the system did not consider the wider context the stroke survivor was recovering in.

Recruitment

The recruitment process was extremely challenging. I specifically decided not to go through NHS ethics as I had gone through that experience during my MSc. It was a long process that added a lot of additional stress due to timeframes. I was aware of the timeframe for the doctorate and subsequently decided that recruiting through charities would fit the logistics. Upon reflection, I'm pleased I decided to recruit through social media and charities. I believed there was a possibility I would recruit individuals who I may not have reached through the NHS. Moreover, I'm pleased it seemed to be the right decision for me as a lot of the participants were not receiving NHS care at the point I interviewed them. Nevertheless, what I found most challenging was that I ended up recruiting in the midst of the Covid-19 pandemic, which meant that most charities were unable to assist me with recruitment due to unprecedented pressures and limited resource. Positively, I received support from the Stroke Association. They invited me to talk at two of their support groups to promote my study and potentially recruit some participants. Unfortunately, it seemed that most of the stroke survivors did not meet my inclusion criteria. I received great support from the stroke survivors I did get to talk to, which provided me with reassurance that it was a worthy topic. As a result, I ended up recruiting all participants from social media such as Facebook and Twitter.

As mentioned, I was due to begin recruiting at the beginning of the Covid-19 pandemic. It was a time of uncertainty for everyone, especially for individuals considered ‘at-risk’ such as stroke survivors. After deliberation with my supervisor, I decided to take a break and suspended my studies. It was also at this point that my father had his stroke, so it enabled me to focus my family, at an already difficult time. I believed this the right decision for me as when I began recruiting for the study, I felt like personally I was in a better position mentally but also it was a more appropriate time, given the wider context, than the previous six months had been. Although the COVID-19 was still on-going, it had been a year since the pandemic began. Life was not ‘back to normal’ but we had almost become accustomed to this temporary new way of living.

Data collection

Conducting interviews has always been my strong point. I have had extensive experience of interviewing participants which have included, service users, caregivers, and health care professionals either during my studies at undergraduate and post-graduate level, as well as during my academic roles. However, for some reason, knowing these interviews were for my doctoral thesis seemed to release an already familiar feeling of self-doubt, imposter syndrome and apprehension. I did not overcome this per se, however I became increasingly comfortable and confident with the more interviews I conducted.

I prepared for the first interview thoroughly however, I was always mindful that I was conducting a semi-structured interview, so I did not want to focus on learning my topic guide but rather becoming familiar with my research question again. During the first few interviews I felt anxious immediately afterwards as I knew I had not probed as much as I had wanted. Upon reflection, I could see how I stuck to the topic guide too rigidly which perhaps led to the interviews being shorter than the subsequent interviews.

I learned from the process. After each interview, I listened back to it, sometimes more than once. I questioned what I did well, was there anything I wish I went into more depth about? I was consistently mindful of the experience the participants were going through. They had all gone through a significant experience within the last twelve months and although I could have kept the interviews going for far longer than they had, I was respectful of their needs.

However, what I do find challenging in a research context is the boundaries. When the interview ended that essentially would end the researcher-participant rapport. My stroke practitioner role enabled me to see how participants improved over time, yet I am aware that in this scenario that is not appropriate. Nevertheless, a truly fulfilling aspect of the interview process was when a few of the participants shared that they appreciated participating in the study. They were grateful for the opportunity to talk about their struggles and challenges as well as reflecting on their experience. It was clear that some participants had felt extremely isolated up to the point they were interviewed and had not had a chance to share their story.

Analysis

Before I started the analytical process, I understood the concept of 'researcher bias'. This encompasses how the researcher's values and assumptions may influence the analytical process. Therefore, throughout the analysis, I ensured I interpreted the data from a multitude of perspectives. I interpreted the data from a researcher, practitioner and person with lived experience of stroke perspectives. However, I saw this as a strength as I not only analysed the data with consideration of the context, but I also analysed the data from a theoretical standpoint. Being a practitioner health psychologist trainee and having already completed a MSc in Health Psychology, I was aware that I bring understanding and knowledge of concepts that someone without my specific educational experience would.

I was mindful that my biases and views of the world would have impacted my analytical interpretation. Although there is guidance on how to conduct a thematic analysis, fundamentally there is no official right or wrong way to do it. This is one of the reasons I found analysis the most challenging yet rewarding element. There were times I felt extremely overwhelmed by the amount of data as I have not experienced this volume of qualitative data at this level before. Due to my perfectionism, I wanted to make sure I conducted the analysis as thoroughly as I possibly could. This almost came at my detriment as during the coding phases, I truly struggled to focus at times. I wanted to be certain that I did not skip any step and wanted to be fully present and focused at each stage of the analytical process. As someone who struggles with severe anxiety, I could feel myself becoming increasingly overwhelmed. Overcoming this challenge was extremely difficult however I sought support from my family and my supervisors. Talking through my thought processes and feelings enabled me to make sense of what I was thinking.

Going through my findings at pivotal points with my supervisors helped me articulate my findings in a way that helped me solidify connections and meanings across the data. When I first presented my initial themes, I was aware that I had too many. However, taking the opportunity to reflect and talk it through helped me make sense of it. Qualitative analysis is an immersive experience. I found myself getting lost in my thinking and at times I had to take a step away and stop the analysis temporarily. By taking some time away I was able to make sense of my thoughts, which helped me move from 'topic summaries' to more conceptual themes.

Once I had written up the initial full narrative, I realised that I was being too descriptive. I needed to be more conceptual and be more analytical. I became frustrated and struggled to see the difference between topic summaries and themes. However, after immersing myself into creating thematic maps, I was able to build on concepts. This was such a relieving revelation and it felt like my findings suddenly made sense.

Writing the thesis

Both conducting the analysis and writing the thesis took significantly longer than I had anticipated. I find writing a challenge and always have done. It is something that I have worked on since my undergraduate degree. I particularly struggled when it came to the writing of the discussion. I noticed I was keen to share all the findings and explain every point I found. I realised I was so enthusiastic about my findings that I wanted to keep writing. I also found myself getting extremely anxious that I was not writing it correctly. As a result, I structured and re-structured the discussion multiple times before I was satisfied with the messages. I felt I was writing too much and therefore, I ensured I brought the focus back to the research questions and aims throughout my writing. Due to my educational background and interest in models of health behaviour, I found I was relating my findings back to multiple models and theories in order to apply the findings to the wider health psychological context. Consequently, my discussion chapter became very long and was not as succinct as I had wanted it to be.

Supervision

Throughout the degree I have experienced some difficulties with two of my Director of Studies leaving. I have had a second supervisor during the whole process which gave me consistency throughout. During the analysis and write up phases, my own mental health deteriorated. I realised I needed to find a way of managing my mental health while maintaining momentum. It was very difficult to find a balance between looking after myself and getting the thesis finished. I was extremely grateful for both my supervisors at this point. I was able to share my concerns with them and we came up with a realistic plan by setting smaller, more achievable deadlines in order to reach the bigger goal. I was reminded that I am not accountable to anyone but myself, which really helped ground my thinking. I sought reassurance from my supervisors and my colleagues throughout this very challenging time, so I am extremely grateful of the support I had around me.

Appendix C – Recruitment Advert

The Impact of Stroke on the Management of Pre-Existing Conditions

Vickie Rowland is recruiting participants to complete an interview as part of a Professional Doctorate in Health Psychology. The virtual interviews will **explore individual's views and experiences of having a stroke** and how they manage their recovery and any additional conditions. The aim of this study is to explore how having a stroke may change the way a person manages other long-term health illnesses they have previously been diagnosed with.

There is opportunity to **win a £50** online shopping voucher of your choice!

For further information and to register your interest, please click here!

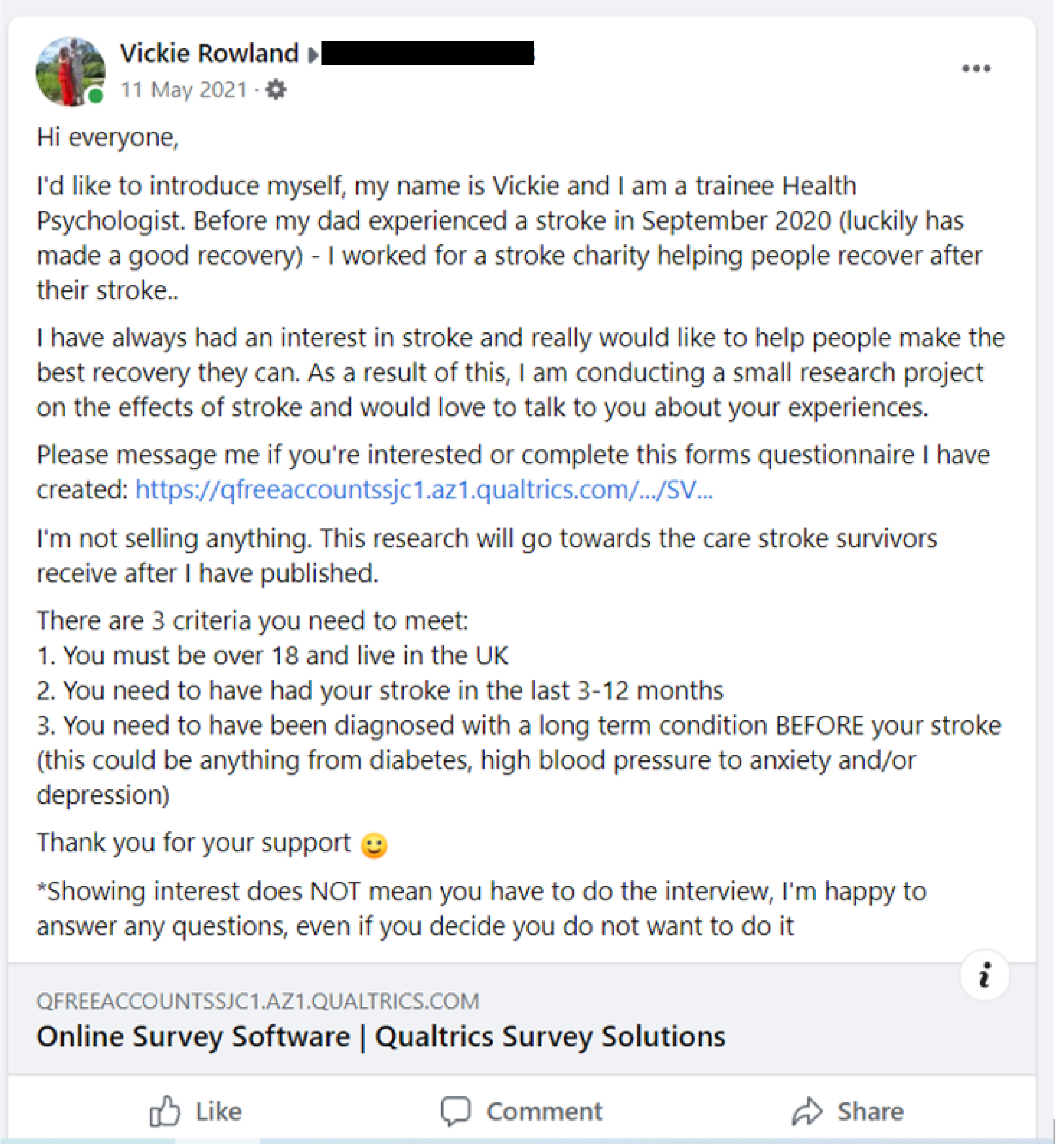
Your participation is much appreciated.

If you have any questions, feel free to email me: victoria2.rowland@live.uwe.ac.uk

Participants Needed

Please note: *Speaking to us about the research does not commit you to anything, we will be happy to answer questions and help you to decide if getting involved in this interview is right for you.*

Appendix D – Example recruitment social media post



Hi everyone,

I'd like to introduce myself, my name is Vickie and I am a trainee Health Psychologist. Before my dad experienced a stroke in September 2020 (luckily has made a good recovery) - I worked for a stroke charity helping people recover after their stroke..

I have always had an interest in stroke and really would like to help people make the best recovery they can. As a result of this, I am conducting a small research project on the effects of stroke and would love to talk to you about your experiences.

Please message me if you're interested or complete this forms questionnaire I have created: https://qfreeaccountssjc1.az1.qualtrics.com/.../SV...

I'm not selling anything. This research will go towards the care stroke survivors receive after I have published.

There are 3 criteria you need to meet:
1. You must be over 18 and live in the UK
2. You need to have had your stroke in the last 3-12 months
3. You need to have been diagnosed with a long term condition BEFORE your stroke (this could be anything from diabetes, high blood pressure to anxiety and/or depression)

Thank you for your support 🙂

*Showing interest does NOT mean you have to do the interview, I'm happy to answer any questions, even if you decide you do not want to do it

QFREEACCOUNTSSJC1.AZ1.QUALTRICS.COM
Online Survey Software | Qualtrics Survey Solutions

Appendix E – Recruitment letter to Stroke Association

To Whom It May Concern,

My name is Vickie Rowland and I am a Health Psychology Professional Doctorate student at the University of West England. I have a deep interest in stroke and multimorbidity due to my experience of working with individuals from these groups both therapeutically and in a research environment. I truly understand how important it is to improve the quality of life of these individuals and therefore I am focussing my doctorate dissertation on answering ‘how can having a stroke impact an individual with multiple long-term conditions?’

With the Stroke Association’s drive to support people rebuild their lives after stroke. I recognise the work you provide in information provision for stroke survivors and their families is evidence-based. In addition to this, I understand the great dedication the Stroke Association has towards continually conducting up-to-date research has a profound effect on the services you offer. I feel we share a common vision to improve the lives of stroke survivors for them to live the best life they can after stroke. Therefore, as a highly respected leading UK organisation I am asking you for the Stroke Association’s support for the recruitment of participants in this study.

Research title: The Impact of Stroke on the Management of Pre-Existing Long-Term Health Conditions

Aim: The aim of this study is to explore the impact of having a stroke on management of and required adjustment to pre-existing chronic conditions in the first 3-12 months after stroke.

Why I am doing this: Stroke is a complex disease. Many stroke survivors leave hospital feeling lost about how to manage the effects of their stroke. Additionally, 75% of stroke survivors have at least one pre-existing chronic condition that they still have to manage. Previous research on the management of chronic conditions has often focussed on a single-disease approach and may not be easy to apply to those with multimorbidity. The Shifting Perspective Model provides a wealth of theoretical underpinning of how people shift their focus from illness to wellness and while applicable to this population, requires further examination in multimorbidity.

What the research will entail: I will be interviewing stroke survivors who have been diagnosed with at least one other co-morbidity/long-term condition prior to their stroke.

A bit about me: I am currently undertaking my Professional Doctorate in Health Psychology. I have a special interest in stroke due to my previous work with stroke survivors in the voluntary sector as a Support Coordinator and conducting research in acquired and traumatic brain injury at the Auckland University of Technology. I currently work for a Public Health team in London, whereby I am interested in disease prevention and long-term condition management.

Please see the attached participant information sheet and lay research summary for more information. I have also attached the letter of approval from the ethics committee at the University of West England.

I have the support if three well-established researchers:

- Dr Catrin Griffiths (Registered Health Psychologist and Senior Research Fellow at the University of West England)

- Dr Kait Clark (Lecturer in Cognitive Neuroscience at the University of West England)
- Dr Julian Bath (Programme Manager for the Professional Doctorate in Health Psychology at the University of West England)

I appreciate your consideration and welcome an opportunity to discuss this further with you.

Yours sincerely,

Vickie Rowland
Health Psychologist in Training
University of West England

Appendix F.1 – Consent form (standard)

Consent Form

This consent form will have been given to you with the Participant Information Sheet. Please ensure that you have read and understood the information contained in the Participant Information Sheet and have asked any questions before you sign this form. If you have any questions please contact a member of the research team, whose details are set out on the Participant Information Sheet.

If you are happy to take part in "The Exploration of the Impact of Stroke on Pre-Existing Long-Term Conditions" by being interviewed, please sign and date the form. You will be given a copy to keep for your records.

- I have read and understood the information in the Participant Information Sheet (v3.1 dated February 2021) which I have been given to read before asked to sign this form;
- I have been given the opportunity to ask questions about the study;
- I have had my questions answered satisfactorily by the research team;
- I agree that anonymised quotes may be used in the final Report of this study;
- I understand that my participation is voluntary and that I am free to withdraw at any time until the data has been anonymised, without giving a reason;
- I agree to take part in the research

Name (Printed) ………………………………………………………………………

Signature ………………………………………………………………………

Date ………………………………………………………………………

Researcher Name (Printed) ………………………………………………………………

Researcher Signature ………………………………………………………………

Date ………………………………………………………………

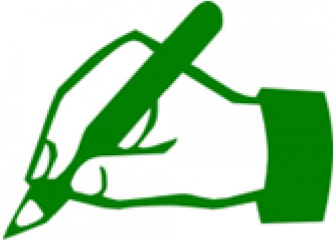
Appendix F.2 – Consent form (aphasia-friendly)

Consent Form

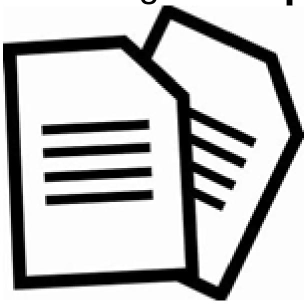
You have been given the **Participant Information Sheet**.
Read the Participant Information Sheet.

Ask any questions.

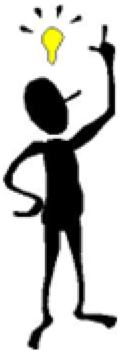
If you would like to be in the study, **sign** this form.



You will get a **copy** to keep.



I **understand** the information in the Participant Information Sheet



I have **asked questions** about the study.

I have had my **questions answered** by the research team.

I agree that what I say may be used in the final Report of this study. My name will not be in the Report.

I chose to be in the study.

I can **stop** being in the study at any time. I do not have to say why.

I **agree** to take part in the research.

Name (Printed) ……………………………………………………

Signature ……………………………………………………

Date ……………………………………………………

Researcher Name (Printed) ………………………………….

Researcher Signature ………………………………….

Date ………………………………….

Appendix F.3 – Proxy Consent Form

Consent Form - Proxy

This consent form will have been given to you with the Participant Information Sheet. Please ensure that you have read and understood the information contained in the Participant Information Sheet and asked any questions before you sign this form. If you have any questions please contact a member of the research team, whose details are set out on the Participant Information Sheet.

If you are happy to take part in "The Exploration of the Impact of Stroke on Pre-Existing Long-Term Conditions" by being interviewed, please sign and date the form. You will be given a copy to keep for your records.

- I have read and understood the information in the Participant Information Sheet (v3.1 dated February 2021) which I have been given to read before asked to sign this form;
- I have been given the opportunity to ask questions about the study;
- I have had my questions answered satisfactorily by the research team;
- I agree that anonymised quotes may be used in the final Report of this study;
- I understand that my participation is voluntary and that I am free to withdraw at any time until the data has been anonymised, without giving a reason;
- I agree to take part in the research

Name (Printed) ………………………………………………………………………

On behalf of ………………………………………………………………………

Signature ………………………………………………………………………

Date ………………………………………………………………………

Researcher Name (Printed) ……………………………………………………………

Researcher Signature ……………………………………………………………

Date ……………………………………………………………

Appendix G – Eligibility Form

Have you had a stroke in the last 3 – 12 months?	Yes	
	No	

If yes, when was the stroke? (for example; DD-MMM-YY or MMM-YY)

	What conditions had you been diagnosed with before the stroke? Please state when you were diagnosed with each condition.		
Hypertension	Yes		Diagnosis date
	No		____________________
Chronic Obstructive Pulmonary Disease	Yes		Diagnosis date
	No		____________________
Diabetes – Type 1	Yes		Diagnosis date
	No		____________________
Diabetes – Type 2	Yes		Diagnosis date
	No		____________________
Diabetes – Type not known	Yes		Diagnosis date
	No		____________________
Asthma	Yes		Diagnosis
	No		____________________
Chronic Pain (including Migraine)	Yes		Diagnosis
	No		____________________
Cancer (including in remission or undergoing treatment)	Yes		Diagnosis
	No		____________________
Atrial Fibrillation	Yes		Diagnosis
	No		____________________
Chronic Heart Disease	Yes		Diagnosis
	No		____________________
Chronic Kidney Disease	Yes		Diagnosis
	No		____________________
Myocardial Infarction (Heart Attack)	Yes		Diagnosis
	No		____________________
Arthritis	Yes		Diagnosis

	No		________________
Epilepsy	Yes		Diagnosis
	No		________________
Stroke	Yes		Diagnosis
	No		________________
Dementia	Yes		Diagnosis
	No		________________
Liver Disease	Yes		Diagnosis
	No		________________
AIDs/HIV	Yes		Diagnosis
	No		________________
Anxiety/Depression	Yes		Diagnosis
	No		________________
Post Traumatic Stress Disorder	Yes		Diagnosis
	No		________________
Inflammatory Bowel Disease (IBD)	Yes		Diagnosis
	No		________________
Irritable Bowel Syndrome (IBS)	Yes		Diagnosis
	No		________________
Epilepsy	Yes		Diagnosis
	No		________________
Serious Mental Illness	Yes		Diagnosis
	No		________________
Multiple Sclerosis	Yes		Diagnosis
	No		________________
Parkinson’s Disease	Yes		Diagnosis
	No		________________
Diverticulitis	Yes		Diagnosis
	No		________________
Other			Please State: ________________ ________________ ________________ ________________

Appendix H.1 – Information sheet (standard)

Participant Information Sheet

You are invited to take part in research taking place at the University of the West of England, Bristol. Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve. Please read the following information carefully and if you have any queries or would like more information please contact Vickie Rowland, Faculty of Health and Applied Sciences, University of the West of England, Bristol victoria2.rowland@live.uwe.ac.uk.

The project lead is Vickie Rowland. Dr Catrin Griffiths is the Director of Studies, Dr Kait Clark is a secondary supervisor and Dr Julian Bath is third supervisor. The team's bios and details of their work are available at the University of West England website: www.uwe.ac.uk.

What is the aim of the research?

The research is looking at trying **to understand how having a stroke can impact an individual's management of previous long term health conditions.** Our research questions are hoping to answer how the experience of having a stroke can influence the self-management of previous long-term ('chronic') health conditions.

To help us answer these questions we will be **conducting interviews**. The aim of the interviews will be to collect information that will be made anonymous.

The results of our study will be analysed and written in a report made available on the University of the West of England's open-access repository. The anonymised results may also be used in conference papers and peer-reviewed academic papers.

Why have I been invited to take part?

We are interested in gaining information about your experiences and views so the interview will ask you about how the experience of having a stroke can influence the self-management of previous long-term ('chronic') health conditions.

What questions will I be asked?

The interview will focus on different aspects your health, healthcare, and experiences of having a Stroke and living with multiple pre-existing conditions. Questions will be focused on how you cope and manage your health conditions as well as your thoughts about how you adhere (or comply) with treatment and medication recommendations.
For example:

1. Could you tell me about your life before stroke?
2. Can you tell me about your other long-term conditions?
3. Can you tell me about the management of your conditions?

4. Is there any type of additional support that you would like that you think might help you to adhere to your treatment recommendations?

Do I have to take part?

You do not have to take part in this research. It is up to you to decide whether you would like to be involved. If you do decide to take part, you will be given a copy of this information sheet to keep and will be asked to sign a consent form.

If you do decide to take part, you are able to withdraw from the research without giving a reason. At the analysis stage of the study, your data will be fully anonymised and can therefore no longer be traced back to you. This point will take place approximately 6 months from the date you signed your consent form.

If you want to withdraw from the study within this period, please write to Vickie Rowland, victoria2.rowland@live.uwe.ac.uk. Deciding not to take part or to withdrawal from the study will not impact the standard of care you will receive.

What will happen to me if I take part and what do I have to do?

If you agree to take part, you will be asked to take part in an interview via telephonic or online methods (for example Zoom, MS Teams or Skype). This will be conducted by Vickie Rowland. The team members are all experienced in the subject matter and are sensitive to issues it may raise. Please note that you are not obliged to answer any question you do not want to answer.
The interview will take approximately 45-60 minutes.

The subject and focus of the discussion will be experiences and self-management of illnesses. Your answers will be fully anonymised.

Your interview will be recorded on a voice recorder, but the recording will not contain your name. A unique identifier will be used to re-identify you if you choose to withdraw from the study within the period specified above. At the point of transcription (i.e. when the recording is typed up, verbatim), your voice recording will be deleted. Your data will be anonymised at this point and will be analysed with interview data from other anonymised participants.

What personal information will be collected?

All personal information will be obtained by the researcher through the participant. No third parties will be contacted to gain access to any medical records or personal information.
The type of information that will be collected will be given by the discretion of the participant. We will be asking for the following information:

- Demographic information such as sex/gender, ethnicity, age
- Medical information such as details of any other long-term medical conditions, date of stroke, type of stroke
- Your own experiences/views about your health, wellness and illness.

What are the benefits of taking part?

If you take part, you will be helping us to gain a better understanding of the facilitators and barriers to self-management when you experience a stroke and will be used to inform future research within the management of stroke and pre-existing health conditions.

What are the possible risks of taking part?

We do not foresee or anticipate any significant risk to you in taking part in this study. If, however, you feel uncomfortable at any time you can ask for the interview to stop.

If you need any support during or after the interview, then the researchers will be able to put you in touch with suitable support agencies. The research team are experienced in conducting research interviews and are sensitive to the subject area. The interviews have been designed with these considerations in mind.

What will happen to your information (data retention)?

All the information we receive from you will be treated in the strictest confidence. All the information that you give will be kept confidential and anonymised at approximately 6 months after the interview has taken place.

The only circumstance where we may not be able to keep your information confidential is if the participant indicates a risk of harm to either themselves or others. Hard copy research material will be kept in a locked and secure setting to which only the researchers will have access in accordance with the University's and the Data Protection Act 2018 and General Data Protection Regulation requirements.

Voice recordings will be destroyed securely immediately after anonymised transcription. Your anonymised data will be analysed together with other interview and file data, and we will ensure that there is no possibility of identification or re-identification from this point. Anonymised data will be stored for up to 5 years.

Where will the results of the research study be published?

A postgraduate thesis will be written containing our research findings. This Report will be available on the University of the West of England's open-access Research Repository. You will not be able to be identified in any way within this report.

A hard copy of the Report will be made available to all research participants if you would like to see it. Key findings will also be shared both within and outside the University of the West of England such as, within medical journals and at conferences. Anonymous and non-identifying direct quotes may be used for publication and presentation purposes.

Who has ethically approved this research?

The project has been reviewed and approved by Health and Applied Sciences University of the West of England University Research Ethics Committee. Any comments, questions or complaints about the ethical conduct of this study can

be addressed to the Research Ethics Committee at the University of the West of England at:
Researchethics@uwe.ac.uk

What if something goes wrong?

We do not foresee or anticipate any significant risk to you in taking part in this study. If, however, you feel uncomfortable at any time you can ask for the interview to stop.

Any concerns, queries and/or complaints will be handled by the researcher upon discussion with Dr Rachel Gillibrand, Director of Studies in the first instance. If necessary, the research ethics committee will also be approached.

What if I have more questions or do not understand something?

If you would like any further information about the research, please contact in the first instance:

Vickie Rowland
victoria2.rowland@live.uwe.ac.uk

Thank you for agreeing to take part in this study.

You will be given a copy of this Participant Information Sheet and your signed Consent Form to keep.

Appendix H.2 – Information sheet (aphasia-friendly)

Participant Information Sheet

I am inviting you to be in research taking place at the University of the West of England, Bristol.

Please read this information sheet.

Do not worry if you do not understand.

You do not need to decide now.

Please ask any questions.

My name is Vickie Rowland. I am the researcher and project lead. You can contact me on victoria2.rowland@live.uwe.ac.uk

I have three supervisors.

Dr Catrin Griffiths is the Director of Studies.

Dr Kait Clark is a supervisor.

Dr Julian Bath is a supervisor.

Their details are on the University of West England website: **www.uwe.ac.uk**

What is the aim of the research?

We would like to know how your stroke effects you.

We would like to know how you having a stroke effects your other illnesses.

You will be asked questions.

The questions may be sensitive.

You do not have to answer any of these questions.

The interviews will be analysed.

The results will be written in a report.

The report will be on the University of the West of England’s website.

The results may be used in conferences and papers.

Why have I been invited to take part?

We want to know about your stroke.

The interview questions are on a separate sheet.

Do I have to take part?

You do not have to take part in this research.

You choose if you would like to be interviewed.

We will ask you to sign a form. This form means you are happy to be interviewed.

You are able to stop the interview without giving a reason.

The data will not have your name on it.

You can take your information away from the study.

Write to Vickie Rowland, victoria2.rowland@live.uwe.ac.uk.

What will happen to me if I take part and what do I have to do?

The interview will take 45-60 minutes.

The interview will be done by either video call (for example, Zoom or Skype) or by telephone.

Vickie will ask you the questions.

The interview will be about your stroke and other illnesses.

The interview will be recorded. Your name will not be on the recording.

The recording will be typed up.

The audio recording will be deleted.

What personal information will be collected?

Vickie will ask you for your personal information.

Vickie will not contact anyone else for your personal data.

You do not have to answer, if you do not want to.

Vickie will collect information about how old you are.

Vickie will collect information about where you come from.

Vickie will collect information about your illnesses.

What are the benefits of taking part?

You will be helping us understand stroke.

The interviews will help us with research in the future.

What are the possible risks of taking part?

The researchers do not think there is any risk.

You can STOP the interview at any time.

Ask for support.

What will happen to your information (data retention)?

Your information will be kept locked away.

Only the research team will access your interview.

The interview will not be linked with your name.

If you are at risk, we will speak to a doctor.

The research material will be kept in a locked and secure place.

The interview recordings will be destroyed.

Data will be stored for up to 5 years.

The research will abide by the University's policies and requirements, the Data Protection Act 2018 and General Data Protection Regulation requirements.

Where will the results of the research study be published?

A report will be written.

You can read the report.

Key findings will also be shared.

What you say may be in the report.

Your name will not be in the report.

Who has ethically approved this research?

The project has been approved by Health and Applied Sciences University of the West of England University Research Ethics Committee.

If you are not happy, you can speak to the research group:

Researchethics@uwe.ac.uk

What if something goes wrong?

We do not think anything will go wrong.

You can STOP the interview at any time.

Vickie will answer all questions. She will be supported by Dr Catrin Griffiths.

What if I have more questions or do not understand something?

If you have questions, speak to Vickie.

Vickie Rowland victoria2.rowland@live.uwe.ac.uk

Thank you.

You will get a copy of this Participant Information Sheet.

You will get a copy of the Consent Form.

Appendix I – Demographic information form

Age ____________________

Gender (please state what gender you identify as) ____________________

Marital Status

Single
Married
Divorced
Widowed
Co-habiting

Living Status

Lives alone
Lives with spouse/partner
Lives with adult family member(s)
Lives with spouse/partner and children

Employment Status

Working – full time
Working – part time
Retired
Unemployed

Ethnicity:

White

English / Welsh / Scottish / Northern Irish / British ☐
Irish ☐
Gypsy or Irish Traveler ☐
Any other White background ☐

Mixed / Multiple ethnic groups

White and Black Caribbean ☐
White and Black African ☐
White and Asian ☐
Any other Mixed / Multiple ethnic background ☐

Asian / Asian British

Indian ☐
Pakistani ☐
Bangladeshi ☐
Chinese ☐
Any other Asian background ☐

Other ethnic group

Arab ☐
Any other ethnic group ☐

If other, please state: ____________________

Black / African / Caribbean / Black British

African	☐
Caribbean	☐
Any other Black / African / Caribbean background	☐

Appendix J.1 – Topic guide for interview (standard)

Topic Guide

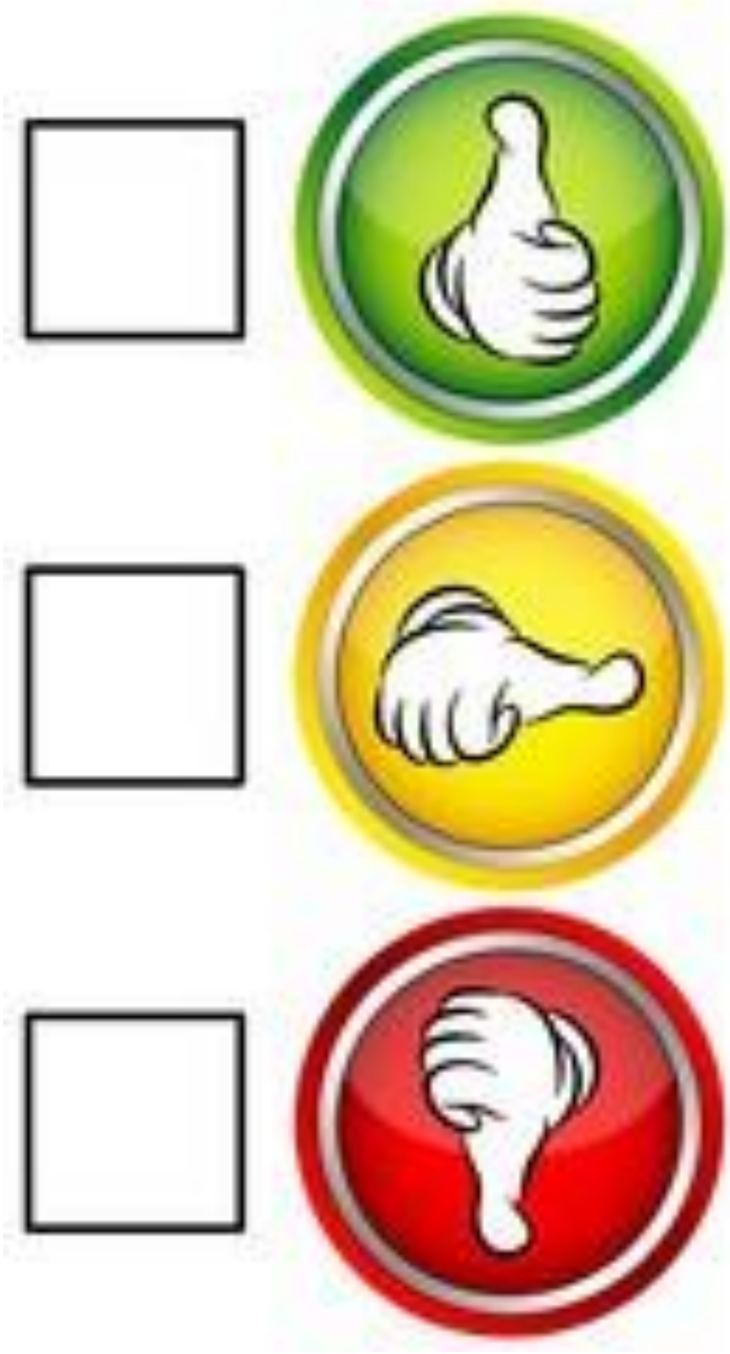
Topic	Question	Prompts
General health	Tell me about your health	
	Give me a snapshot before you had the stroke	
Stroke	Now we're going to focus on your most recent stroke. Could you tell me about your life before stroke?	*Could you describe an average day?* *What kinds of activities and events were important to you?* *What do you think caused your stroke?*
	Could you tell me about the day you had your stroke?	*Could you describe the stroke?* *How did the stroke affect you?* *What was your experience of being in hospital?* *What was your experience of returning home?* *Could you describe what an average day was like when you returned home (good days/bad days)?* *What are the ongoing effects of your stroke and how do you feel about these?* *Do you feel you have adapted to the effects of your stroke?* *Could you describe how you have recovered since your stroke?* *What do you feel has helped or hindered your recovery?*
	Could you tell me about your life following your stroke?	*Has anything changed since you experienced the stroke?* *Could you describe what an average day is like for you now?* *How has this changed over time?* *Journey, rehabilitation, recovery* *How long do you think your recovery will take?*
Multimorbidity / Pre-existing conditions	I can see from the eligibility form that you have been diagnosed with XXX number of conditions.	*Do you consider any of the illnesses that you have been diagnosed with to be more*

	Can you tell me about these?	*important to be managed than the others?* *What impact did this have on your life? How did you view your illnesses before you had your stroke?*
	Can you tell me about your other long-term conditions?	*How long do you think these conditions will continue?* *How well do you feel your treatment helps your conditions?* *How often do you experience symptoms from your conditions?* *What do you think caused your conditions?*
	Has there been any impact on your life after being diagnosed with these conditions?	*Personal values* *Mental and/or physical well-being?*
Coping/management of conditions	What does self-management mean to you?	*Are you clear about what actions you need to take to self-manage?* *Do any of these actions conflict with the treatment of other conditions?*
	Can you tell me about the management of your conditions?	*Do you think having a stroke has changed anything in relation to managing your health?*
	Did you use health care services before your stroke?	*Do you use health care services more or less than before your stroke?* *Do you use health care services regarding your other long-term conditions?*
	How can you see your recovery in the future?	*What are your future plans?* *Do these plans differ to those you had prior to your stroke?*
Treatment Adherence	What treatment are you currently receiving for X and Y conditions?	**could focus on both/all conditions?*
	What have health professionals recommended that you do to manage your condition(s)?	

	To what extent are you able to adhere to these?	*How easy do you find it to complete these? What things are easy/difficult?* *Have you experienced any obstacles that have got in the way of adhering to your treatment?* *Is there any type of additional support that you would like that you think might help you to adhere to your treatment recommendations?*

Appendix J.2 – Aphasia-friendly pictorial aids

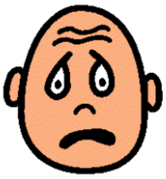
Topic Guide Pictorial Aids (Aphasia)



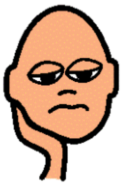
Feelings

afraid

afraid

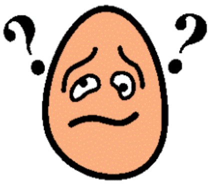


bored

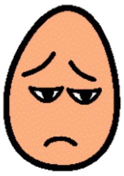


cold

confused



disappointed



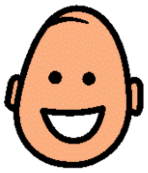
dizzy

embarrassed

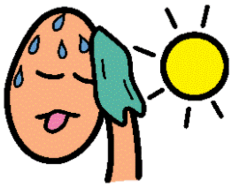
excited

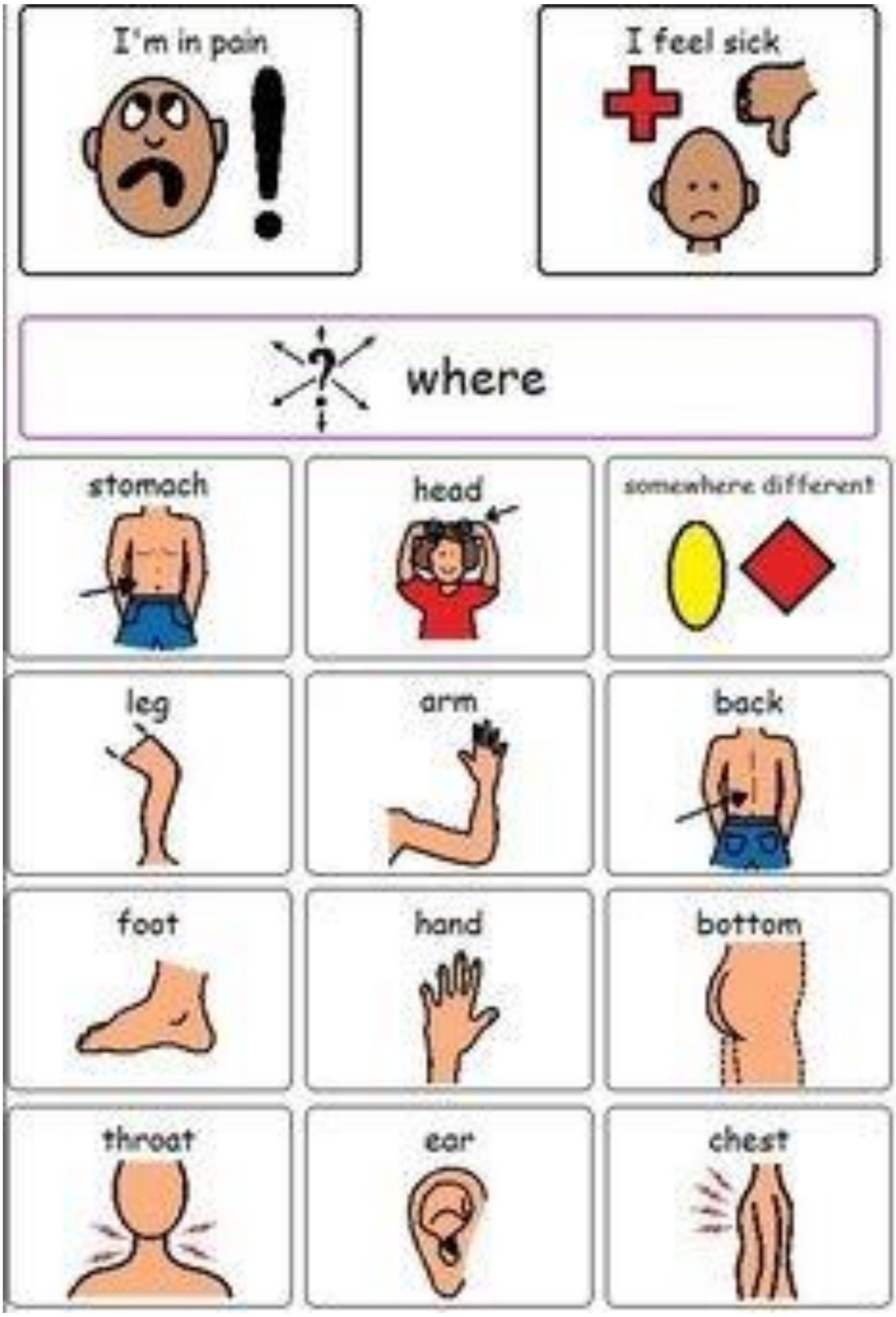
frustrated

happy



hot



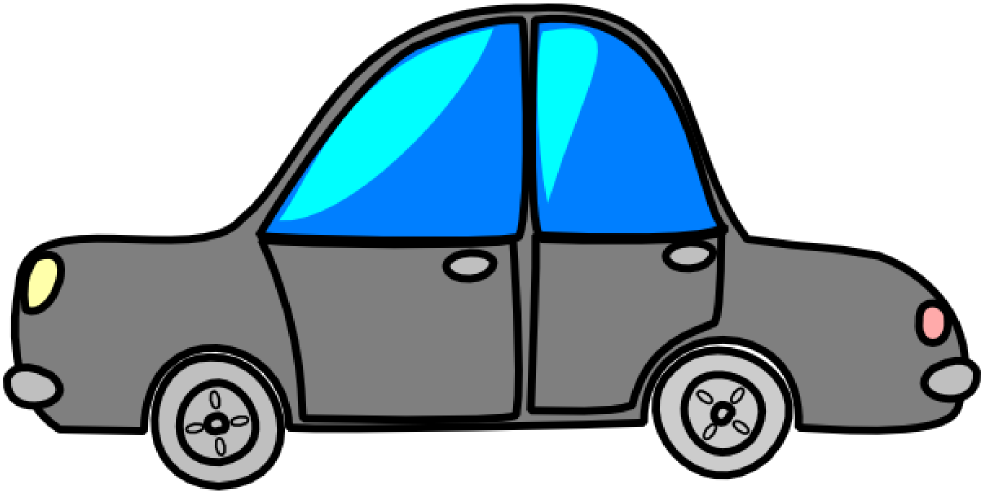

I'm in pain
I feel sick
where
stomach
head
somewhere different
leg
arm
back
foot
hand
bottom
throat
ear
chest

House

Family

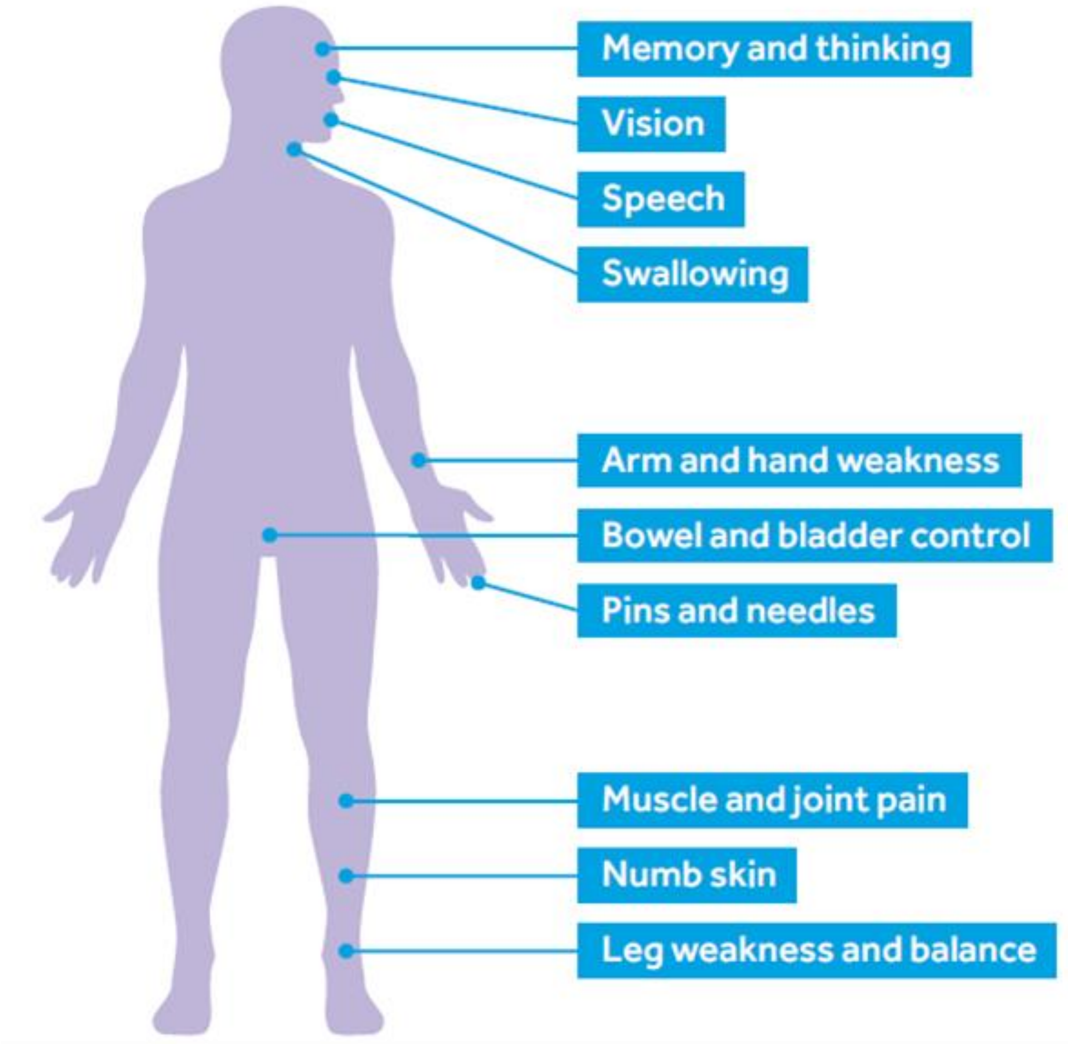
Health

Transport



Money

Friendship / Socialising


Memory and thinking
Vision
Speech
Swallowing
Arm and hand weakness
Bowel and bladder control
Pins and needles
Muscle and joint pain
Numb skin
Leg weakness and balance

Page Break

Page Break

YES

NO

Appendix K.1 – Debrief/thank you letter (standard)

Thank you / Debrief

Thank you for participating in this study. You have helped us to understand more about stroke and your experiences of it. If you have any queries or worries or would like more support please inform the researcher.

Your interview will now be typed up and deleted. If you wish to withdraw from the study, you will have six months to contact the researcher.

Vickie Rowland – victoria2.rowland@live.uwe.ac.uk

Appendix K.2 – Debrief/thank you letter (aphasia-friendly)

Thank you / Debrief

Thank you for being in the study. You have **helped** us a lot.

Your answers will be **typed up**.

If you wish to **stop** being in the study, speak to Vickie.

Do you have a **question?** Speak to Vickie.

Vickie Rowland – victoria2.rowland@live.uwe.ac.uk

Appendix L - Lay summary

Lay Research Summary

Brief background/context

As we are now living longer, many of us are now being diagnosed with an increasing number of long term (‘chronic’) health conditions. We know from earlier research looking at long-term conditions on their own, that quality of life, mood, well-being and self-management are all impacted.

Self-management refers to an individual’s ability to manage symptoms and be responsible for taking their medication to reduce how often they use health care services. Mood refers to anxiety and depression.

A stroke is a bleed or a blockage in the brain that cuts off the blood supply. This can cause effects such as, limited ability to move one side of your body whether that be the arm or leg or both. It may cause someone difficulty to speaking or ‘finding the right words’. It may even lead to other effects such as extreme tiredness.
We understand that having a stroke can be a difficult experience to come to terms with, without other long-term conditions to manage. Which is why we are interested in finding out how having a stroke can affect the management of other long-term conditions.

Aim of study

The aim of this study is to explore how having a stroke may change the way a person manages other long-term health illnesses they have previously been diagnosed with.

How we will go about the research

We are asking people who have recently (3-12 months previously) had a stroke to join our study to be interviewed.

We would like to know what their experiences are of managing the long-term health conditions they had previously been diagnosed with, now that they have had a stroke. We would also like to know how these experiences impact different areas of their life such as; mood, physical health, family/relationships, socialising, work and so on.

The interview will be conducted remotely, audio recorded and then analysed. The interview will be anonymised; that’s to say that we will not know who’s interview it is.

All the data and information will be kept locked away and secure so that only the research team can have access to it.

The information the research will provide

We are hoping that we will understand how people manage multiple long-term health conditions. This is so, in the future, we can try to reduce the amount of healthcare resources that are used, improve quality of life and reduce negative mood (i.e. anxiety, stress) in these individuals.

Appendix M – Privacy Notice

Privacy Notice

Purpose of the Privacy Notice

This privacy notice explains how the University of the West of England, Bristol (UWE) collects, manages and uses your personal data before, during and after you participate in the **Exploration of the Impact of Stroke on Pre-Existing Long-Term Conditions**. 'Personal data' means any information relating to an identified or identifiable natural person (the data subject). An 'identifiable natural person' is one who can be identified, directly or indirectly, including by reference to an identifier such as a name, an identification number, location data, an online identifier, or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.

This privacy notice adheres to the General Data Protection Regulation (GDPR) principle of transparency. This means it gives information about:

- How and why your data will be used for the research;
- What your rights are under GDPR; and
- How to contact UWE Bristol and the project lead in relation to questions, concerns or exercising your rights regarding the use of your personal data.

This Privacy Notice should be read in conjunction with the Participant Information Sheet and Consent Form provided to you before you agree to take part in the research.

Why are we processing your personal data?

UWE Bristol undertakes research under its public function to provide research for the benefit of society. As a data controller we are committed to protecting the privacy and security of your personal data in accordance with the (EU) 2016/679 the General Data Protection Regulation (GDPR), the Data Protection Act 2018 (or any successor legislation) and any other legislation directly relating to privacy laws that apply (together "the Data Protection Legislation"). General information on Data Protection law is available from the Information Commissioner's Office (https://ico.org.uk/).

How do we use your personal data?

We use your personal data for research with appropriate safeguards in place on the lawful bases of fulfilling tasks in the public interest, and for archiving purposes in the public interest, for scientific or historical research purposes.

We will always tell you about the information we wish to collect from you and how we will use it. We will not use your personal data for automated decision making about you or for profiling purposes.

Our research is governed by robust policies and procedures and, where human participants are involved, is subject to ethical approval from either UWE Bristol's Faculty or University Research Ethics Committees. This research has been approved by the Health and Applied Sciences University of the West of England University Research Ethics Committee.

Ethics application reference number: HAS.19.07.235
The email of the research ethics committee is Researchethics@uwe.ac.uk for any queries, comments or complaints.

The research team adhere to the **Ethical guidelines of the British Educational Research Association (and/or the principles of the Declaration of Helsinki, 2013) and the principles of the General Data Protection Regulation (GDPR).**

For more information about UWE Bristol's research ethics approval process please see our Research Ethics webpages at: www1.uwe.ac.uk/research/researchethics

What data do we collect?

The data we collect will vary from project to project. Researchers will only collect data that is essential for their project. The specific categories of personal data processed are described in the Participant Information Sheet provided to you with this Privacy Notice.

All data collected will be by the researcher from the participant. It will be up to the discretion of the participant to share as much or as little information as they choose.

Who do we share your data with?

We will only share your personal data in accordance with the attached Participant Information Sheet and your Consent. No personal information will be shared with any third party organisations.

How do we keep your data secure?

We take a robust approach to protecting your information with secure electronic and physical storage areas for research data with controlled access. If you are participating in a particularly sensitive project UWE Bristol puts into place additional layers of security. UWE Bristol has Cyber Essentials information security certification.

Alongside these technical measures there are comprehensive and effective policies and processes in place to ensure that users and administrators of information are aware of their obligations and responsibilities for the data they have access to. By default, people are only granted access to the information they require to perform their duties. Mandatory data protection and information security training is provided to staff and expert advice available if needed.

How long do we keep your data for?

Your personal data will only be retained for as long as is necessary to fulfil the cited purpose of the research. The length of time we keep your personal data will depend on several factors including the significance of the data, funder requirements, and the nature of the study. Specific details are provided in the attached Participant Information Sheet. Anonymised data that falls outside the scope of data protection legislation as it contains no identifying or identifiable information may be stored in UWE Bristol's research data archive or another carefully selected appropriate data archive.

Your Rights and how to exercise them

Under the Data Protection legislation you have the following **qualified** rights:

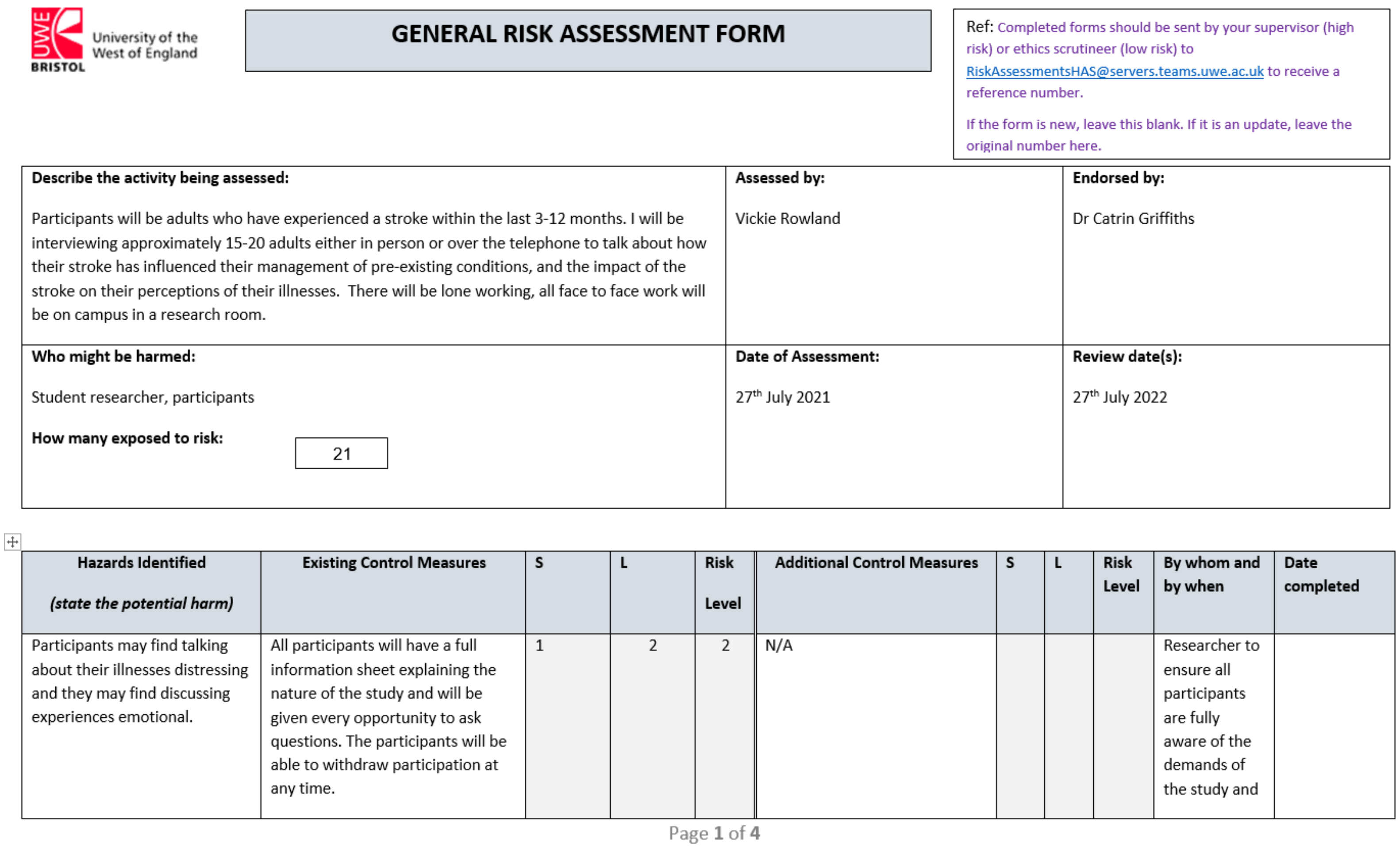
1. The right to access your personal data held by or on behalf of the University;
2. The right to rectification if the information is inaccurate or incomplete;
3. The right to restrict processing and/or erasure of your personal data;
4. The right to data portability;
5. The right to object to processing;
6. The right to object to automated decision making and profiling;
7. The right to complain to the Information Commissioner's Office (ICO).

Please note, however, that some of these rights do not apply when the data is being used for research purposes if appropriate safeguards have been put in place.

We will always respond to concerns or queries you may have. If you wish to exercise your rights or have any other general data protection queries, please contact UWE Bristol's Data Protection Officer (dataprotection@uwe.ac.uk).

If you have any complaints or queries relating to the research in which you are taking part please contact either the research project lead, whose details are in the attached Participant Information Sheet, UWE Bristol's Research Ethics Committees (research.ethics@uwe.ac.uk) or UWE Bristol's research governance manager (Ros.Rouse@uwe.ac.uk)

Appendix N - General Risk Assessment Form



UWE BRISTOL University of the West of England

GENERAL RISK ASSESSMENT FORM

Ref: Completed forms should be sent by your supervisor (high risk) or ethics scrutineer (low risk) to RiskAssessmentsHAS@servers.teams.uwe.ac.uk to receive a reference number.

If the form is new, leave this blank. If it is an update, leave the original number here.

Describe the activity being assessed: Participants will be adults who have experienced a stroke within the last 3-12 months. I will be interviewing approximately 15-20 adults either in person or over the telephone to talk about how their stroke has influenced their management of pre-existing conditions, and the impact of the stroke on their perceptions of their illnesses. There will be lone working, all face to face work will be on campus in a research room.	**Assessed by:** Vickie Rowland	**Endorsed by:** Dr Catrin Griffiths
Who might be harmed: Student researcher, participants **How many exposed to risk:** 21	**Date of Assessment:** 27th July 2021	**Review date(s):** 27th July 2022

Hazards Identified *(state the potential harm)*	**Existing Control Measures**	**S**	**L**	**Risk Level**	**Additional Control Measures**	**S**	**L**	**Risk Level**	**By whom and by when**	**Date completed**
Participants may find talking about their illnesses distressing and they may find discussing experiences emotional.	All participants will have a full information sheet explaining the nature of the study and will be given every opportunity to ask questions. The participants will be able to withdraw participation at any time.	1	2	2	N/A				Researcher to ensure all participants are fully aware of the demands of the study and	

Page 1 of 4

									the opportunities to withdraw from the study at any time and up to six months after the interviews had been completed.	
The post-graduate researcher will be working alone in the community for the interviews. The PGR will have to travel to participant's homes and conduct the interviews.	The PGR currently works within research under a lone worker policy. A lone working assessment will be carried out and all necessary safety strategies implemented, such as a 'buddy system'. A buddy system will be developed with the PGR and the two supervisors to ensure the safety when conducting interview in the community. For example, a calendar invite will be sent to either Dr Rachel Gillibrand or Dr Kait Clarke to indicate what my whereabouts will be and for how long. This will include details of any travel arrangements. A text message will be sent to the buddy supervisor upon entry and exit of the interview. In addition, a safety strategy will be put in place if the researcher is at risk of any harm.	1	2	2	N/A				Researcher to be responsible for her own safety and to be vigilant when conducting interviews when on her own.	