Managing after stroke

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Abstract

Self-management of chronic conditions is a set of approaches, comprised of mostly group programme interventions. These interventions aim to teach participants to take an active role in managing their health condition(s) and to provide them with the skills required to manage and live well. The structure and content of programme interventions are based on medical understandings of long-term conditions and have largely retained the same format since first designed. Despite decades of research and application, the benefits of conventional self-management programmes remain modest and of short duration. Alternative models, such as capability theory, which take into account the societal conditions which make it difficult to implement management strategies may offer a new approach.

This doctoral study aimed to construct new knowledge that would assist clinicians to support and enable people to manage after stroke. This was achieved by asking the question – what can be learnt about self-management after stroke, from talking to stroke survivors and significant others? Nested within a larger qualitative longitudinal study which interviewed people (and their significant others) following a stroke at four timepoints over three years, this doctoral work utilised qualitative descriptive and interpretive description methodologies to understand how people manage and the societal conditions with impact on how people manage.

Three layers of analysis were completed to address the research question. In the first phase the foundations for managing were explored by a targeted analysis of data co-constructed at 6 months after stroke of 52 people and 26 significant others. It was found that participants needed to manage biographical disruption and formulate a cause for their stroke, in order to know what to do. These findings prompted the second study which re-explored the 6 month data to reveal the resources participants had to draw on to address disruption and develop a foundation upon which to manage. Participants mostly managed alone, drawing on whatever resources were available to them. Those with many resources managed better than those with few resources.

The third study was a longitudinal qualitative analysis of data co-constructed with 12 participants purposively selected from the parent study, at 6-, 12-, 24- and 36-months after stroke. This study explored how ways of managing were used and developed through time. To move forward and manage, participants needed to construct new understandings of stroke and of themselves. Finding ways to resume, develop and balance active and reflective activities, created a sense of wellbeing. Also connecting with others and reciprocating support from important people was essential to managing.

This doctoral study demonstrated that managing stroke was a continuous process of trial and error over the three years after stroke. No one managed all aspects of life after stroke, and no participants failed to manage any of the consequences of stroke. This research moves beyond describing the experience of stroke to creating new knowledge about what participants did to manage stroke. A rich and detailed understanding of managing after stroke was produced which illuminates the need for person centred, contextual and political approaches. Also, findings highlight the need for interventions to identify, increase, and utilise social, economic, and cultural capital. The findings point to interventions that increase health literacy, and equity and integrate health and social services, as being necessary to support people to manage after stroke. Rethinking stroke self-management to be ongoing support, interventions embedded into usual care and innovations to reduce systemic and societal barriers to managing over time, rather than being the responsibility of individuals that is only relevant in the acute phase post-stroke, produced contemporary understandings of what it is to manage after stroke.

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Attestation of authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Sandy Rutherford
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Co-authored works

This thesis contains two jointly authored published articles in peer-reviewed journals (chapters two and five).

The principal author (SJR) drafted all first complete manuscripts with a contribution of at least 80%.

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2. Rutherford, S. J., Hocking, C., Theadom, A., & McPherson, K. M. (2018). Exploring challenges at six months after stroke: what is important to patients for self-management? *International Journal of Therapy and Rehabilitation, 25*(11), 565-575.

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Chapter five Rutherford, S. J., Hocking, C., Theadom, A., & McPherson, K. M. (2018). Exploring challenges at six months after stroke: what is important to patients for self-management? *International Journal of Therapy and Rehabilitation, 25*(11), 565-575.	Rutherford 80% Hocking 6% Theadom 6% McPherson 8%

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Ethical approval (appendix A) was obtained from:

- Multi-Region Regional Ethics Committee of New Zealand (NTX/11/07/058) and the Auckland University of Technology Ethics Committee (11/295) on 2nd August 2011
- AUT University Ethics Committee on 1st November 2011

Overview of Thesis

My thesis presents a series of studies exploring data collected from one longitudinal study of people who experienced a stroke and their significant others. The parent study aimed to explore the recovery journey following stroke and what helped or hindered recovery. For my PhD, I originally set out to focus on the specific practical strategies that people used to self-manage. My dataset included the perspectives of people who had experienced a stroke (N=52) and their nominated significant others (N=26). However, the findings from my analysis of the initial interviews conducted at 6 months post-stroke revealed that, despite my questioning, people did not want to discuss strategies, rather what was most important to them was finding a way to deal with the biographical disruption that they were experiencing. This meant I needed to shift the focus of this thesis. Consequently, I relooked at the data from 6 months post-stroke, by applying Capability Theory to explore how people understood and responded to the biographical disruption. This analysis described how people experienced the disruption, how their feelings informed their thinking and their actions and responses to it. Given the complexity of the large dataset with different participant responders (e.g., those with personal experiences and the perspective of their significant others) and the complexities of managing such a large dataset over different timepoints for the longitudinal analysis, I purposively selected twelve participants to enable me to conduct a detailed analysis of how their experience changed or remained the same over time. This necessitated a change in methodology from qualitative descriptive to interpretive description to enable the exploration of how knowledge of strategies can help clinicians to support and empower people with stroke to manage and flourish. The methodologies and research questions for each layer of this thesis are indicated in Figure 1 below.

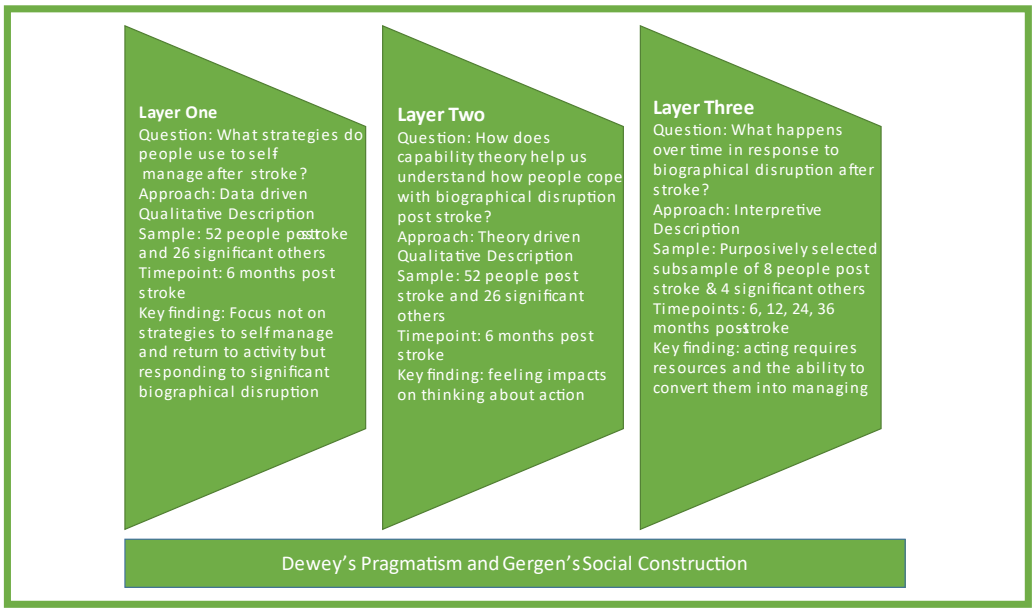

Figure 1 *Three phases of analysis presented as separate layers in this thesis*

Chapter One: Introduction

This research explored how people manage after stroke via the stories they tell about reconstructing a meaningful and satisfying life. Whilst the lived experience of stroke and the problems that can get in the way of managing are well established, how people with stroke self-manage over time is less understood. Accordingly, the underpinning assumption of the study was that the expertise and knowledge stroke survivors have of their own lives, their strategies, and ways of coping, is a rich and somewhat untapped resource that could expand and enhance current self-management models. From that perspective, the important components of managing needed to be identified, to inform healthcare professionals about how best to support people with stroke and suggest ways services need to be structured for clinicians to be able to provide that support. The primary consideration within this research was thus to present new knowledge about how people manage over the first three years after stroke in a format that could be directly applied to practice.

This chapter provides the groundwork for the thesis: the concepts of self-management and stroke self-management are introduced and the context in which the study took place outlined. I then position myself as a researcher, as influenced and constructed by my experience as an occupational therapist and clinical researcher in previous roles. Based on this background, the research aims are stated. The chapter concludes by explaining the structure of this thesis.

Stroke Management

The impairments and impact of stroke are highly diverse and are unique to each stroke survivor (Sarre et al., 2014), therefore recovery is an individual experience (Ahuja et al., 2013). It was not that long ago that stroke was considered to be an acute medical event, which people either survived or not. However, it is now realised that on-going and long-term management is needed as many difficulties persist and new problems

can arise even following a mild stroke (Kirkevold, 2002). Recovery takes time; is rarely complete and has many ups and downs rather than linear experience (Sarre et al., 2014). The approach increasingly taken to assisting people to manage the after-effects of having a stroke is termed ‘self-management’.

Two approaches to self-management have been identified. Firstly a narrow approach, which is about a person managing their health condition well, in which the clinician and their expert knowledge dominates (Morgan et al., 2017). The healthcare professional ‘trusts’ the person to monitor themselves. This trust is justified when biomarkers are within an acceptable range and are seen as proof of compliance (Sarre et al., 2014). In contrast, a broader approach in which the person-professional relationship is more egalitarian is where a person with a chronic condition is seen to manage well within their own context focussing on what is important to them, their wellbeing and they are supported to be autonomous (Morgan et al., 2017). This thesis focused on the broader approach as this is in alignment with my occupational therapy practice model which positions the person, the environment and the occupation always interacting on the others.

New Zealand healthcare system

The study was conducted in New Zealand, where the healthcare system is a complex mix of public and private services regulated by the minister of health, who also provides leadership and policy (Ministry of Health, 2022b) District Health Boards were established in 2000 and are responsible for delivering most of the health and disability services to people in their area (Ashton, 2005). Services include primary care, mental health services, hospital service, public health, services for older people and non-governmental organisations (Ashton, 2005; Ministry of Health, 2022a). All services are fully funded by the government except for General Practitioners, who are able to charge for their services, with the government fully funding visits for children aged 13

and under (Ashton, 2005). Services for people who have had an accident are funded by the Accident Compensation Corporation from levies (Ministry of Health, 2022b).

Rehabilitation best practice involves comprehensive discharge planning, tailored to the person. It is also considered helpful to include what the person and their family feel they need such as physical, emotional, social, recreational and community support from the multidisciplinary team. The Australian and New Zealand stroke guidelines direct clinicians and services to address the long-term management of risk factors such as adherence to medication, to lower cholesterol and blood pressure and manage diabetes. The provision of secondary prevention is largely seen as the responsibility of General Practitioners, with support from allied health clinicians. Support for lifestyle modification for recognised risk factors, such as smoking cessation, managing diet, exercising, and addressing alcohol consumption, is also recommended (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010). A causal relationship where implementation will lead to better outcomes is implied (Menon et al., 2010).

According to the guidelines, self-management should address risk factors and include strategies for improving and managing physical and cognitive functioning, relationships, the home environment, and participation in the community (Mahawish et al., 2018; Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010; Watkins, 2017). Self-management is thought to be best overseen by General Practitioners but ultimately the responsibility to follow recommendations is assigned to the person with stroke and their supporters. Structural barriers and practitioner skill are thought to prevent widespread uptake of best practice guidelines, so they remain aspirational and what the experts say, rather than what clinicians are routinely able to do (Bayley et al., 2012; Menon et al., 2010). The goal of this research was to close this gap between aspiration and practice by constructing recommendations which make sense to clinicians and can be directly applied to practice.

Background to the research: positioning the researcher.

Since I first started working as a new graduate occupational therapist in 1994, I noticed a difference in the way myself and other occupational therapists talked about what we do and the way in which we do it. I remember that for many years I spoke the language of impairment in the medical notes and in team meetings, while I worked on meaningful occupations and participation in life and community within therapy sessions. I was not alone in this experience, Fleming and Mattingly (1994, p. 296) wrote about the "unease at the heart of practice" where there is a difference between the knowledge which occupational therapists use to underpin practice decisions and the type of knowledge which is valued in the setting in which they work. So, using a top-down approach with clients to focus on roles and goals which were meaningful and important to them as means and ends, rather than a bottom-up focus on the remediation of impairments.

For much of my career as a practising occupational therapist I worked in neurology – in acute services, rehabilitation, outpatient, and community roles, with people with a range of neurological conditions including stroke. During my time working on acute stroke wards, I worried about people who had a 'mild' stroke from a medical point of view and who were discharged home from acute services. They were not 'impaired enough' to require or qualify for inpatient rehabilitation, despite very limited opportunities for therapy in the community. While they were independent in basic activities of daily living, these sorts of tasks did not reflect the complexity of the work which goes into reconstructing a meaningful life after stroke and managing long-term.

Others were referred to an inpatient rehabilitation unit, directly from the acute wards and this was their only opportunity for inpatient rehabilitation. Following their inpatient stay, they were discharged home to wait sometimes several months for community therapy to commence, which was often only once a week for a limited duration. Or they were sent home to manage alone, following an inpatient rehabilitation programme;

the length of which appeared to be determined by resources rather than need. The focus of their rehabilitation was independence with mobility, transfers, and personal care. I experienced great frustration at the lack of follow up; often there was no service to refer people to, or the rules and structure of the system made it impossible to help them find support. I was also dissatisfied with the biomedical model alone being used as an underlying model for occupational therapy in these settings and the focus of rehabilitation being only on the physical aspects at the cost of emotional and spiritual needs.

Observing, thinking, and asking about how it is to be a recipient of occupational therapy services or rehabilitation is fundamental to evidence based, client centred practice (Thorne, 2011). I was aware that sometimes the experience of services can be far removed from the intentions of those who deliver them, and that the contexts in which this occurs can be complex, with many barriers and facilitators (Bright et al., 2012; Thorne, 2011). One way of progressing or improving this experience is via qualitative research utilising methodologies which have arisen in response to the challenge of improving experiences for both clients and clinicians (Thorne, 2011).

One of my first research roles was as a clinical researcher on a large randomised controlled trial investigating goal setting after traumatic brain injury. Key learnings from this experience were that recovery occurs over a period of many years and that participants appeared to benefit from a client centred approach focussing on goals that were meaningful, particularly when based on the person's values and identity. As I tried to apply what I learnt from the goals study into my practice, I discovered that outside of the randomised controlled trial, in the 'real' world, it was not as easy as I thought it might be. In the 'real world' there are many structural barriers and competing agendas.

The other part of my role when I commenced work at the Auckland University of Technology was to develop the occupational therapy service in Akoranga Integrated Health Clinic, our interdisciplinary, student run campus clinic, providing clinical

placements as well as a service to the local community. Alongside this work I was completing postgraduate papers in occupational science and became interested in teaching my clients about the relationship between their everyday occupations and wellbeing, both individually and in a group format (Hocking & Wright-St Clair, 2011). Such an approach supports clients to take control and redesign their life to include occupations, habits, routines, and ways of thinking which support and enhance their wellbeing and quality of life (Clark et al., 1997).

I collaborated with the counselling psychology supervisor to provide a generic self-management group in the clinic that would both meet the needs of people who may wish to attend as well as providing an interprofessional placement for occupational therapy students and counselling psychology interns. We constructed a programme, the content of which was based on clinical interviews conducted prior to the course beginning. Themes from the initial clinical interviews revealed that our participants wanted to have better control over their chronic condition. But of equal or greater importance was the need to feel better. Existential concerns regarding identity and purpose seemed to be unrelated to specific diagnosis and was a dominant theme in the interviews. The process of developing the programme and reflecting on its efficacy and acceptability afterwards, led me to re-examine the self-management literature and wonder whether the underpinning models; in use for more than 30 years and not originally designed for stroke, were still relevant.

Soon after running our group programme, I was employed as a clinical researcher on the qualitative part of the Auckland Regional Community Stroke Programme (ARCOS) IV, which was a population-based study which aimed to identify the incidence and burden of stroke and TIA in New Zealand (Krishnamurthi, Jones, et al., 2014). The Stroke Experience Study formed one component of this programme and was a longitudinal qualitative study designed to complement the quantitative data from the incidence study, to uncover the richer detail of life as a stroke survivor. The aims of the

Stroke Experience Study were to explore recovery from stroke over time and to identify what helps and hinders recovery, to inform service provision. As I completed the first few interviews, I began to wonder what the participants' experience could tell us about self-management after stroke. I came to this research from a place of 'knowing' that the focus of practice can and should be different; that change in self-management of stroke is needed. That awareness was the starting point for my doctoral studies. Consequently, I embedded some questions specifically focusing on self-management into the qualitative interviews completed as part of this study to form the basis for this doctoral work. Completing this work as part of the larger programme offered distinct advantages such as purposeful sampling (to capture diversity of experience) at specific timepoints post-stroke that would not otherwise be possible. The data were analysed separately from the main study.

Development of theoretical thinking over time

Having laid out the starting point of the study, its guiding research question, and key terms, I now outline how I have structured my thesis to reflect the layered process I went through in completing my study (Weatherall, 2019). I simultaneously read theory, developed methodology and methods, and co-constructed and analysed data for the different parts of this work. My theoretical scaffolding was not 'finished' prior to commencing the data co-construction but developed alongside, informed by the data, tested on the data and was a continuous journey of discovery as previously hidden parts of the literature and ways of thinking came into view. I moved back and forth between chapters, working on multiple chapters simultaneously. I also moved back and forth between data and theory, testing out theories both in analysis of transcripts and with participants as interview questions (Weatherall, 2019). Each layer acted as a stage in my research, and I acknowledge are just some of the ways the layers could have been integrated or woven together, given the partial views available to me. As the process unfolded, I reviewed my "principles and practices" and changed them in light of

new information and evidence: a process Dewey called reconstruction (Kadlec, 2006, p. 523).

Defining key terms

Self-management

Self-management is a set of tasks and skills that people with one or more long-term conditions are thought to need to live well with their illness or injury, along with the confidence to deal with medical professionals (Taylor et al., 2014). The person with the long-term condition taking an active role in their management is seen as a key component (Lorig & Holman, 2003). Programmes which aim to teach these skills are usually comprised of education and techniques to encourage behaviour change. Self-management refers to education programmes, some of which are reported to be underpinned by behaviour change theories which aim to change patient attitudes and responses to chronic illness and limit healthcare costs. Self-management programmes aim to help people feel more able to cope with their long term condition, more independent doing so, and more motivated (Joice, 2012). There is widespread agreement that self-management is comprised of three key components based on Corbin and Strauss' three lines of work: medical management including health promotion activities and symptom management; role management; and emotional management and adjustment (Audulv, 2013; Audulv et al., 2012).

Self-care

Self-care is the preventative work completed at home by healthy individuals (Furler et al., 2008).

Strategies

Strategies are the things that people do to find and use resources to minimise the impact of illness or injury on their daily lives (Bury, 1991).

Coping

Coping is the mental processes that people engage in, to maintain or develop a sense of value and meaning in their lives despite the presence of a long-term condition (Bury, 1991).

Peer led, lay led, lay health worker

Peer led, lay led, lay health worker are the names given to the trained volunteers, who sometimes lead self-management programmes (Punna et al., 2019). Lay health workers have lived experience of managing a chronic condition which may or may not be the same condition or illness as all of the participants in a programme (Punna et al., 2019). It could be that they are the same or similar to programme participants in terms of socioeconomic status, level of education and culture (Punna et al., 2019), which may be especially helpful with tailoring the content to participants' beliefs and causal model (Foster et al., 2007). Peer or lay leaders work as support workers, teach programme content and are role models (Punna et al., 2019). Peer support can be less formal than a standardised self-management programme, which may encourage more discussion than programmes led by healthcare clinicians where the presentation style may be didactic (Foster et al., 2007). Lay leaders are sometimes referred to as tutors to denote the delivery of an education programme (Foster et al., 2007) rather than the peer support model used in diabetes management, where the peers are one to one coaches (Funnell, 2010).

Professionally led or professionally instructed

Professionally led or professionally instructed self-management programmes position the clinician as expert and may answer questions but not necessarily facilitate a group process (Cohen et al., 1986).

Chronic condition, long-term condition and chronic disease

Chronic condition, long-term condition and chronic disease are related but different terms which are used somewhat interchangeably in healthcare literature and have now expanded to include disabilities which persist through time. The New Zealand Ministry of Health defines long-term conditions as any condition which has “ongoing, long-term of recurring effects on a person’s life” (Ministry of Health, 2022a) and for which there is treatment to manage the condition, but no cure. The term more often used by international organisations such as the World Health Organization is non-communicable disease (WHO). Some non-communicable diseases are long lasting but not all long-term conditions are transmitted between people such as hepatitis and HIV/AIDS. Many chronic conditions have lifestyle risk factors in common such as tobacco use, inadequate diet and exercise, and alcohol/drug abuse (Ministry of Health, 2022a). The most common long-term conditions are cardiovascular such as heart disease and stroke, chronic lung diseases, diabetes, and cancer (World Health Organization, 2022). Also included are dementia, renal diseases, mental illness, arthritis, and chronic pain (Ministry of Health, 2022a).

Stroke severity

The Modified Rankin Scale for measuring neurological disability was developed for stroke in 1988 (Banks & Marotta, 2007) and was used in ARCOS IV to determine *stoke severity*. A score of 1 indicates a person is able to carry out all of their roles and occupations as before, despite symptoms. Mild disability (2) is slight disability when the individual is unable to carry out all previous activities but able to manage their own affairs without assistance. Moderate disability (3) is when the person needs some help with tasks such as shopping and managing their affairs and can walk without assistance. Moderately severe disability (4) means the person needs assistance to walk and manage their bodily needs. Severe disability (5) is described as being

bedridden, incontinent and needing 24-hour nursing care. A score of 6 is given when a person has died as a result of their stroke.

There is some variation in the literature as to what proportion of strokes are mild-moderate and severe, however it has been reported that 60-80% of stroke survivors in Canada experience a mild to moderate stroke and only 10-15% of all those affected receive rehabilitation services (Jones et al., 2000; Mayo et al., 1999; Rochette et al., 2007). Motor function and the ability to carry out activities of daily living is not affected to a significant degree, however those with mild-moderate stroke report that their quality of life is impacted by impairments which are not always visible such as fatigue, and impaired cognitive and affective functioning (Carlsson et al., 2009; Rochette et al., 2007). People with mild stroke can have ongoing difficulties with coping with loss and returning to participation (Carlsson et al., 2009; Taule & Råheim, 2014). Although mild to moderate stroke survivors do not require much physical assistance, many need to draw on support from their social networks in order to cope with the disruption and move forward (Hodson et al., 2019). For professionals working in stroke rehabilitation, these findings challenge the assumption that people with mild to moderate stroke achieve a near full recovery with minimal support (Edwards et al., 2006).

People with severe stroke take longer to recover, have greater difficulties completing daily self-care tasks, with mobility, speech and fine motor control, and typically receive inpatient rehabilitation and longer hospital stays (Pereira et al., 2012). Resources are currently focused on providing rehabilitation for this subgroup of people who experience stroke (about 10-20% of stroke survivors) as they have least likelihood of significant return of function (Pereira et al., 2014). There is a higher chance of being discharged home (Pereira et al., 2012) when there is a caregiver present (Pereira et al., 2014). This leaves most people following stroke with unmet needs. Perhaps then, rehabilitation should focus less on the remediation of impairments and more on

education, social support and managing long-term consequences for all people effected by stroke (Pereira et al., 2012).

Thesis aims

My doctoral study initially aimed to identify and develop an in-depth knowledge of how people self-manage in terms of the strategies they develop or use in order to successfully reconstruct a meaningful life following stroke. This focus was taken to move away from previous evidence which focused on the problems people experience after stroke. I aspired to uncover how strategies and ways of coping were developed and why these ways of coping worked or were important. However, following initial results that self-management in its conventional format was not of primary importance or relevance to my sample, my thesis research question shifted to understanding how people make sense and manage the biographical disruption experienced post-stroke over time.

In this chapter I have introduced the concept of self-management and its application to stroke. Chapter two details the methodology of the parent study from which I drew my participants, and my study was nested within. Chapter two provides the background to my doctoral work.

Reporting the study

Researchers are urged to draw on published reporting guidelines to ensure all essential elements of studies are addressed when reporting the nature and topic of their research, its significance and key elements, including the objectives, the guiding research paradigm, methods, and ethical considerations. The researcher must be adequately introduced, along with the context of the study and the participants. The Reporting Checklist for Qualitative Study developed by O'Brien et al. (2014) was selected for that purpose for this study. The completed checklist is presented in Appendix B.

Structure of thesis

My thesis presents a series of analyses conducted using data gathered for the longitudinal Stroke Experience Study. Due to the need to change my approach over the course of the PhD, the thesis has been organised into three layers each reflecting a different stage and approach used to analyse and make sense of the data and people's experiences as outlined in Table 1.

Table 1 *Structure of this thesis: Managing after stroke*

Chapter	Content
1	**Introduction**: Provides an overview of stroke management, the NZ Health Care System, Researcher Positioning and development of theoretical thinking and defines key terms used within the thesis.
2	Presents the published **methodology** paper of the parent study to provide context for my PhD and to outline how my PhD analyses were distinct from the main study.
Layer One: Conventional self-management: Feeling the disruption	
3	**Literature review on self-management:** a brief overview of the self-management literature which has influenced the development of stroke self-management.
4	**Ontology, epistemology and methodology** the theoretical underpinnings of my PhD.
5	**Published paper for layer one:** foundations for managing.
Layer Two: A sociological & contextual approach: Feeling informing thinking	
6	**Literature review on sociological understandings of self-management.** A brief overview of the sociological literature that influenced my understandings of the contextual factors influencing managing.
7	**Methods and findings for layer two**: Feeling impacting on thinking and managing at 6 months after stroke.
Layer Three: A whole system approach: Thinking informing action	
8	**Literature review: a whole system approach to self-management.**
9	**Methodology and Methods for layer three:** an introduction to the Interpretive Description methodology and methods for the longitudinal study.
10	**Findings layer three**: part 1 Thinking about how to manage after stroke.
11	**Findings layer three**: part 2 Acting to manage after stroke.
12	**Discussion:** Learnings from all three layers are brought together, strengths and limitations of the whole study are discussed, implications for practice and future research directions are recommended.

Chapter 1 provides an introduction to the context in which the study was conducted and to the researcher. Chapter 2 further contextualises the study. It comprises a published paper describing the methodology of the parent study.

Layer one (see Figure 2) presents the starting point for this thesis. This layer encompasses chapters 3-5. In chapter 3, I briefly review some of the self-management

literature which had influenced the development of the approach in stroke. The overview of literature presented in chapter 3 was written at the beginning of my PhD research. It represents my knowledge and thinking at the time layer one of this research was being designed, thus providing insights to the rehabilitation and research context within which the data collection and analysis methods occurred. Relevant literature is updated in the discussion chapter, chapter 12, ensuring the findings are considered in the context of subsequent knowledge developments. In chapter 4, I present the ontological and epistemological underpinning of this layer of the research. This positioning was carried forward to the entire study. In the following chapter the qualitative description methodology and methods used in the Stroke Experience Study and underpinning my first findings section are outlined.

Layer two contains a targeted literature review of the sociological understandings of self-management (chapter 6). Again, the literature in this chapter outlines what I was reading and thinking during layer two of this doctoral work. The findings and sensitising concepts used in layer one caused me to look for literature that could shed light on the different ways participants seemed able to manage or not, related to their environment and circumstances. I looked at the data collected using the methodology from layer one, with new eyes and focused on an aspect of the data that seemed pivotal to managing, which was access to resources. Findings two – chapter 7 – contains the findings from this targeted analysis. New “lines of thought” are introduced throughout the parts that are different to where I began and what is found in layer one.

Layer three begins with a review of literature that supports a whole system approach to self-management (chapter 8). It is followed by an introduction to the interpretive description methodology and methods used to guide my longitudinal study (chapter 9). The findings of this study are reported in chapters 10 and 11. Finally, chapter 12 the discussion, bringing together the three layers of this work.

Chapter Two

What helps or hinders recovery from stroke (Stroke Experience Study)?

Prelude to manuscript one: this chapter is an adaptation of the manuscript entitled "Capturing the stories behind the numbers: The Auckland Regional Community Stroke Study (ARCOS IV), a qualitative study." Published in the *International Journal of Stroke*, 9(1), 64-70, in 2014, the version inserted here is the final version accepted for publication, prior to copy editing, with the exception of some minor modifications of the text to ensure consistency and relevance to the current chapter and thesis. The methods section has been expanded and updated to reflect what we did rather than an outline of what was planned. Whilst this study is not included specifically as part of my PhD, it provides important context to my PhD analyses, shows how the analyses I completed as part of my PhD was distinct from the parent study and was work that I led whilst conducting my PhD.

Key words: stroke, longitudinal, qualitative, strategies, adaptive, mixed methods

Conflicts of interest: None declared.

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Abstract

Background: Qualitative data can add value and understanding to more traditional epidemiological studies. This study was designed to complement the quantitative data from the incidence study ARCOS-IV by using qualitative methods to uncover the richer detail of life as a stroke survivor, thereby extending our understanding of the impact of stroke.

Aims: The aim of this paper is to describe the methodology and the challenges and advantages of embedding qualitative research into a large epidemiological study.

Methods: Longitudinal study utilising a qualitative description design in a subset of those taking part in the incidence study. Participants were interviewed at 6, 12, 24 and 36-months post stroke. Semi structured interviews explored three key areas: (1) Issues of importance to people following a stroke and their whānau/family; (2) The perceived impact on people's sense of recovery, adaptation and hopes; (3) Key strategies that people with stroke and their whānau/family use and find most helpful in living life after stroke. A qualitative description analysis was conducted using iterative constant comparison methods.

Summary: This methodology paper demonstrates the application of mixed methods in epidemiology. It also considers some of the practical and methodological issues that have emerged and may provide a useful framework for other qualitative projects in population-based studies.

Introduction

Despite the valuable data provided by standardised quantitative assessments, many experiences of health and ill-health remain untapped by current measures (Demain et al., 2006; Kayes & McPherson, 2010; McPherson, 2006). Whilst major advances have

been made in the field of patient reported outcomes such as quality of life, (de Haan, Aaronson, et al., 1993; de Haan, Horn, et al., 1993; McPherson et al., 2004) aspects of importance to stroke survivors regarding their recovery and adaptation remain unexplored (Horgan et al., 2009; Ironside et al., 2003; Kirkevold, 2002). An understanding of what it is to 'live a life after stroke' is important (Burton, 2000b; Eilertsen et al., 2010; Ellis-Hill et al., 2008), not just because highlighting this perspective is morally justifiable, but because such views can inform future healthcare innovation (Hart, 2001; Wilson et al., 2007).

A further issue with stroke research is that it has focused largely on the *problems* of stroke, with the barriers to recovery well described (Carlsson et al., 2009; Pound et al., 1999; Reed et al., 2010). To date, there has been little attention to *positive strategies* individuals and their whānau/family use to cope with life after stroke (Faircloth et al., 2004; Pound et al., 1999) or positive life changes following stroke (Dyall et al., 2008). 'Strengths based' approaches are increasingly identified as a theoretically sound approach to working with people within the mental health sector but as yet have not been well explored in rehabilitation (Evans, 2011; Siegert et al., 2007). This study aimed to identify the active and adaptive ways in which people respond to stroke, utilising such a strengths-based framework (Grohn et al., 2012; Siegert et al., 2007; Worrall et al., 2010) to generate and refine interview questions and to aid data analysis. The current study is the first we are aware of that examined recovery and adaptation over the first 3 years post-stroke.

Objectives of this paper

While it is increasingly common to publish protocols for randomised controlled trials, it is not typical to do this in qualitative research as methods evolve in response to the data with sampling, analysis and interview questions developed concurrently. We considered it would be most valuable and appropriate to focus our report on the challenges to date of conducting a large longitudinal qualitative study which informed,

and was informed by, an epidemiological study as well as detail our response to those challenges. Thus, in this paper we aim to:

1. Give background to the study and describe our methodology and the contributions that qualitative research can make to epidemiological studies.

2. Outline the factors and issues that arose in implementing our design, how we addressed them and what we learnt.

3. Illustrate how quantitative and qualitative components of a linked study can bring value not only during analysis of results but also while the research is being conducted.

Methods

This study used a qualitative description methodology (Sandelowski, 2000b) informed by Grounded Theory (Charmaz, 1990, 2004). A specific application for ethical approval for this study was granted by the Northern X Regional Ethics Committee (NTX/11/07/058) (see appendix A).

Recruitment

Participants recruited into the ARCOS IV incidence study (Krishnamurthi, Jones, et al., 2014) were asked if they would be interested in receiving information about this study at 28 days post stroke where possible, or 6-months following their stroke where ARCOS researchers considered it too burdensome or were not able to ask earlier. Those who were interested in taking part in this study were asked for their consent to share the demographic and medical information collected as part of the incidence study with the qualitative study team to reduce repetition and burden. Additional to the incidence study, consent was obtained for participating in this qualitative study. Stroke survivors, significant others if nominated, and proxy participants were provided with

verbal and written information about the qualitative study prior to completing consent forms (appendix B) participant information and consent forms).

Eligibility

Participant eligibility was based on the following criteria:

Inclusion criteria: (a) people ≥16 years of age who experienced a stroke as defined according to the World Health Organization (WHO) criteria, between 1st March 2011 to 29th February 2012, (b) a resident of the Auckland region; (c) a registered participant of the parent incidence study. All participants who agreed to hear more about this study were contacted by the qualitative team. **Exclusion criteria:** (a) unable to provide informed consent; (b) unable to engage with an interviewer despite support (e.g. even with support from an interpreter or speech and language therapist), (c) participating in the Motivational Interviewing in Stroke trial (MIST) (Krishnamurthi, Witt, et al., 2014).

Sampling

This study aimed to recruit a sample of 40 participants with stroke and a nominated whānau/family member where possible. Whānau is a Māori language word commonly used in New Zealand English and is used here to mean extended family. In practical terms, that meant an adult of importance to the participant, who supported them in their recovery. Given the nature of people with stroke, and prior research, it was anticipated that n=40 would enable data saturation (Morse, 2000) (i.e., no new data emerging) in relation to key questions and allow for 25% attrition over time. Moderate sample sizes of 20-50 are usual for qualitative descriptive studies (Sullivan-Bolyai et al., 2005), where maximum variation of experience is sought rather than recruitment of a representative sample. Accordingly, people with communication and cognitive impairments were eligible to participate in the study to ensure a range of perspectives and experiences were captured. Their interviews are shorter, and participants often chose to be interviewed with their nominated family member for support with word

finding and recall of events. Questions were more directed than open ended to reduce anxiety.

Data collection

Each participant and their nominated whānau/family member (if identified and consenting) were interviewed at 6, 12, 24 and 36-months using minimally structured open-ended questions (appendix C) (Sandelowski, 2000a). Interviews were conducted individually or as a dyad, according to the participants' preference, and audio taped and transcribed verbatim. Emotional expression such as laughter, tearfulness and emphasis were indicated in the transcript (Robison et al., 2009). Field notes were also completed during and after the interviews (Ellis-Hill et al., 2009).

The research officer who carried out the interviews (SJR) is an occupational therapist and has previously worked in stroke services. While this experience provided background, context, and some shared experience with participants, it could have influenced interview questions, interactions, and analysis. This was managed through written reflections and journaling, supervision, and a team approach to coding.

Analysis

Overview of the approach

The qualitative description approach aims to produce a nuanced summary and description of an experience. Whilst it is less common to articulate the theoretical basis of methods used in epidemiological research, such transparency is crucial in qualitative research as it allows others to understand the frame of reference, or context for interpretation. The longitudinal design of this qualitative description study (Sandelowski, 2000b) assumes that life after stroke is socially constructed or, that the experience results from an interaction of many factors involving the person, and their social context and relationships (Charmaz, 1990). Thus, social constructionism informed our design, with the data explored in relation to predefined areas identified in

the study aims. Because qualitative descriptive research does not have a specific methodology, researchers often make use of methods or techniques from other traditions (Sandelowski, 2000b). To ensure a rigorous approach, our methods drew on the principles of grounded theory (Charmaz, 1983, 1999). Grounded theory methods can be used flexibly to inform the ongoing direction of a study and provide additional tools for data analysis. For example, comparisons during each stage of analysis included comparing data with other data within interviews, early interviews with later ones, and between participants (Charmaz, 2006).

Analysis was conducted concurrently with ongoing interviews, using iterative constant comparison methods (Mays & Pope, 2000). Hence, data from the first five participants were analysed prior to completing the subsequent interviews. Simultaneous interviewing, analysis and literature review, refined data collection at the 12-, 24- and 36-month data collection points and ensured richer extraction of data from the following interviews (Wilson et al., 2011). Sensitising concepts of 'The Good Lives Model' (Siegert et al., 2007; Ward & Brown, 2004), strengths based approaches (Grohn et al., 2012) and active adaptation to stroke (Pound et al., 1999) were used to inform early interview questions and analysis. The aim of analysis was to identify key themes that characterised people's experiences of recovery and adaptation and key issues for people in relation to important life roles and their strategies. This was achieved by staying close to the data and language of the participants. It involved some interpretation but did not aim to generate theory or concepts (Neergaard et al., 2009). The intention was not simply to generate a list of strategies or describe coping approaches but shed light on the process by which people reconstruct a life after stroke.

Coding

Preparation for coding involved reading and rereading printed transcripts, underlining and writing notes in a wide margin (Sandelowski, 1995). Each transcript was read,

considered, re-read and attempts made to understand it as a whole before moving on to other time points and other participants (Sandelowski, 1995). The interviews were coded on paper initially. Codes were developed from the data itself, using participants' words, with the process influenced by new data and emerging insights (Sandelowski, 2000b). Contextual and demographic information, whether the data came from the participant, carer/significant other, whānau, friend, or proxy, was indicated in the coding. As analysis progressed initial patterns were identified and tentative codes and categories were developed and defined, NVivo software, version 10 (NVivo qualitative data analysis software, 2012) was used to manage the data set, produce code books and enable the generation of reports both within and across participants and to facilitate observations over time. We then went back and recoded earlier transcripts to ensure all instances and examples were captured.

The core team for the study (SJR, AT, KM) met regularly to discuss analysis and areas for further exploration in subsequent interviews. Team discussion was utilised to view the stories from different perspectives (occupational therapy, nursing and health psychology) (Dierckx de Casterlé et al., 2012). Alongside the reading of each transcript, sensitising concepts from relevant literature were applied to assist with seeing beyond the surface (Charmaz, 2006). Memos and ideas from team discussions were also included in the early analysis (Sandelowski, 1995) and were used to keep a record of what and why coding decisions were made.

Once all of the transcripts were coded, a tentative theme map depicting the process of adjustment over time (Theadom et al., 2018), was developed. Transcripts were re-read with the framework in mind to determine if anything of importance was not included or had been overlooked and to test the fit of our model to the data (Dierckx de Casterlé et al., 2012). Our suggested process was presented to the community reference group for their feedback and was refined in response to that feedback. Feedback called for more

constant comparison to identify negative cases and further conceptual development of the themes. The process framework was again tested against transcripts for fit.

Methodological and ethical considerations and actions

The key issues that arose are specified below and the actions we took to deal with them delineated and summarised in **Table** *2* below.

Table 2 Summary of challenges and strategies for resolution

Challenges	Strategies for resolution
Researcher perspectives of participant burden impacting on recruitment	Education and discussion of ethical and methodological consequences in approaching research participants and enabling them to make a choice (Dresser, 2003; Juritzen et al., 2011). Regular communication between researchers on both teams. Sharing of emerging findings and potential impact on practice. Sensitive issues training (Dickson-Swift et al., 2007; Logie et al., 2012; Richman et al., 2012; Wassink et al., 2004).
Reducing participant burden and maximising benefit	Increase comfort by efforts to create rapport, trust, empathy and understanding. Responsible questioning (Clarke, 2006), monitoring for distress, onward referral when appropriate, attention to sound methodology and thoughtful dissemination (Emanuel et al., 2000). Use of a community reference group to inform translation of findings.
Ensuring diversity of experience	Regular review of sample demographics. Concurrent recruitment and analysis (Sandelowski, 2000b). Ethical amendment to recruit proxy participants nominated to represent participants with significant communication and/or cognitive impairment.
Facilitating participant retention	Regular study updates, recording of comprehensive contact information (Graziotti et al., 2012) and emphasis of the importance of the study and participant contribution.

i) Researcher perspectives of participant burden

While vulnerable people need to be protected from unnecessary and distressing effects of research, benevolence needs to be balanced with paternalistic power (Dresser, 2003; Juritzen et al., 2011). Gate keeping, inaccurate interpretation of eligibility, judgements about participants' ability to understand the research, and assumptions regarding the burden on participants, can have a significant effect on recruitment into research (Ewing et al., 2004; Steinhauser et al., 2006). However, if the frail, complex, and difficult to engage are always excluded from research, guidelines for best practice can never be developed with any certainty that they are appropriate and acceptable,

and services cannot be developed or improved (Nordentoft & Kappel, 2011). Researching sensitive issues with vulnerable people has in fact rarely been found to cause distress for participants (Legerski & Bunnell, 2010). In the small percentage of people for whom this has occurred, the distress is not thought to be long lasting or harmful (Ahern, 2012) and does not prevent them from feeling that they have benefited from the experience (Campbell et al., 2010; Jorm et al., 2007).

Perceptions of harm and burden were identified as affecting recruitment to this study. There were a number of studies involving extensive assessments that were linked to ARCOS IV and the clinical researchers on the parent incidence study were the main point of contact for recruitment. Some of these researchers expressed that they initially experienced some guilt when asking people if they would also like to volunteer for the qualitative study because of the substantial time commitment required for participation in the parent incidence study. These concerns were explored and addressed in a number of ways. A key component was regular attendance of the qualitative researcher at team meetings. This enabled updates and initial findings to be shared alongside education and discussion regarding the ethical issue of *deciding for participants* instead of giving them the opportunity to *choose for themselves*.

Other discussions highlighted the benefits of giving people the opportunity to have their story recorded to improve services in the future. This was seen as valuable because it provided a space for recording information that is not possible to give, given the highly structured questionnaires and measures used in the parent incidence study (Derrett & Colhoun, 2011; Wassink et al., 2004). Further, as a result of these discussions, sensitive issues training was put in place to assist researchers to manage their own emotions when listening to troublesome stories (Dickson-Swift et al., 2007; Logie et al., 2012; Richman et al., 2012; Wray et al., 2007).

ii) Reducing burden on participants and maximising benefits

Taking part in research should arguably be a valuable or beneficial experience for participants and steps should be taken to reduce any burden (Richards & Schwartz, 2002). Interviews were therefore conducted at times and locations that suited the participant to reduce inconvenience as much as possible (Richards & Schwartz, 2002). The key researchers on this study had backgrounds and experience in community and rehabilitation settings, which enabled them to be sensitive and responsive to distress and fatigue for example and onward referral was arranged if required. Participants were asked about what had gone well and interviews were concluded, whenever possible on a positive note such as reflecting on improvements to date, support received or valued activities (Sim, 2010). Training for the researchers was given, where required, to ensure appropriate levels of experience and expertise, and supervision occurred regularly (Richards & Schwartz, 2002). The building of rapport was balanced with responsible questioning using professional skill and discretion, knowing when to invite further detail and when to listen in silence so that participants could tell the parts of their story that they wanted to and did not feel pressured to reveal too much (Clarke, 2006).

Participants frequently stated that one of their motivations for participating in the study was to ensure better services and experiences for others. This emphasised researcher responsibility to ensure a methodologically robust study that addressed the identified gap in knowledge and contributed to improving services and experiences of those that follow (Emanuel et al., 2000). This sort of methodology is thought to be particularly appropriate for the development and critique of clinical interventions (Thorne, 2008). In part, this is due to data collection and analysis methods seeking information about how to best manage specific health issues *directly from participants* and describing this in language that people with the condition, and clinicians who translate this knowledge into practice, will understand (Sullivan-Bolyai et al., 2005).

iii) Ensuring diversity of experience

Despite the efforts of recruitment noted above, initially those taking part had experienced relatively mild stroke and were predominately NZ European as compared to the more variable population recruited to the parent incidence study. Some participants with stroke who were registered for the parent incidence study were initially too unwell or had significant communication difficulties, that precluded their ability to take part in the assessments. On these occasions a proxy was nominated to take part on their behalf, necessarily precluding participation in our study with the original inclusion criteria. Once the lack of diversity with regards to residual disability and ethnicity within the qualitative study sample were noted, two steps were taken. Firstly, further participants were recruited from the parent study targeting ethnicity and stroke severity. The second step was to seek ethical approval to invite proxy whānau/family members to take part in interviews to ensure findings reflected this important group's experience. Interviews involving whānau/family members and proxies sought information about what it was like to support a person with stroke, acknowledging that stroke affects both the individual and the people close to them. The sample recruited were regularly reviewed in light of early findings in order to identify whether further steps were required to ensure appropriate heterogeneity (Mays & Pope, 2000).

iv) Facilitating participant retention

Retaining participants over the course of a longitudinal study has been identified as problematic (Ejiogu et al., 2011; Gibbons et al., 2010). Learning what makes participation 'worth it' is important. Participants in our study reported a number of benefits to participating in this, and the parent incidence study, particularly valuing being followed up and monitored and that important aspects of their recovery were recorded, given the paucity of community services for people with stroke. Participants also requested information, took opportunities to ask questions about their stroke and recovery, and discussed concerns and issues. Conscious attention was given to the

building of relationships (Graziotti et al., 2012). On commencement of the interview, time was allowed for participants to sense the interviewer was truly hearing them rather than being there to complete ‘a task’. On completion of the interview, steps were taken to ensure interviewees were not distressed and had the researcher’s contact details. We also used other approaches to maintain contact, including multiple tracking techniques, 6 monthly study updates and flexibility around appointment times, and by being willing (and able) to travel long distances in order to complete interviews (Graziotti et al., 2012). The aims and importance of the study were explained at every contact point, and the participants’ contribution to these acknowledged. Attrition rates were low: 48 interviews were completed at six months, 52 at 12-months, 47 at 24-months, and 37 at 36-months (Theadom et al., 2018).

Remaining grounded – use of a community reference group (CRG)

A community reference group was formed to inform, enrich and support the study. This is comprised of a small group representing people with stroke support organisations and providers who met quarterly with the operational working group. The primary aims of the community reference group were to consider the translation of research from the beginning of the study, to advise the team how to better connect the study with the community and ensure that the study reflected and addressed the needs of people with stroke and their whānau/family and developed with appropriate consultation. This group also commented on design, methods, analysis, study progress, findings, and dissemination. The potential to involve this group in the planning of future studies was explored. Indeed, our emphasis on truly ‘being present’ during interviews was highlighted in the CRG as being fundamental if we wished participants to tell us their stories.

Added value of the qualitative component to ARCOS IV

Whilst quantitative research necessarily involves some qualitative interpretation and judgment of data and analyses (McPherson & Kayes, 2012), it is becoming much more common for clinical research to include a 'formal' qualitative component (thereby introducing mixed methods) (McPherson & Kayes, 2012; Plano Clark & Creswell, 2008; Shaw et al., 2010). The wide range of approaches to mixed methods has been well summarised elsewhere (Giddings & Grant, 2006), with the most common approach being to combine structured interviews and questionnaires within a cross-sectional design (Bryman, 2006). Our study contributed to the advancement of mixed methods research in stroke, being longitudinal and having a larger and more diverse sample than many other qualitative studies in stroke. By explicitly linking to the longitudinal population based quantitative study, our intention was to enable a richer understanding of the 'experience' of recovery and adaptation; address factors that are not amenable to the standardised measurement; promote new questions of importance to people with stroke for further research; and augment consideration of surprising or unexpected findings in the quantitative study.

There are certainly a number of problematic issues that arise in mixed methods (most commonly that one or other approach is an afterthought or 'weak' add-on) (Creswell et al., 2004; Devers, 1999; Fisher & Stenner, 2011; Giddings & Grant, 2006; Hancock et al., 2012; Howe, 2011; Leech et al., 2011; Mingers, 2001). To counter these risks, our approach was to ensure clear communication within and between the two study teams, and having shared core staff and joint meetings, enabled us to provide novel findings and methodological advances of how other epidemiological research might utilise qualitative methods.

Summary

This study offers two specific benefits to what we know about stroke. Firstly, it is one of few qualitative investigations in stroke to benefit from sampling from a representative population of stroke survivors. In addition, longitudinal qualitative studies have rarely been conducted in stroke and the information on changing perspectives post stroke will increase knowledge of the natural course of recovery and provide information on access to and satisfaction with stroke services, especially for Māori and Pacifica people who are at high risk of stroke and face inequities in accessing health care. The study also identified service gaps/unmet needs to ensuring evidence-based policy, resource allocation, prevention planning, management services, and evaluation of service performance.

There are also some specific benefits to running quantitative and qualitative studies concurrently. Communication and discussions between the two teams assisted with addressing some of the methodological challenges that arose over the duration of the studies.

Limitations of the research

Our sample was not representative of Māori and Pacifica people, who are overrepresented in conditions like stroke. Also stroke survivors participating in the Motivational Interviewing in Stroke trial (MIST) were not eligible for the Stroke Experience study, so those who were more motivated to change health behaviours after their stroke may have been less likely to take part in this study. Additionally, the MIST study recruited participants after their first ever stroke, therefore our sample may have been more likely to have already had a stroke.

Conclusion

This study aimed to identify the key barriers and facilitators to recovery and adaptation as perceived by stroke survivors over the first 3 years following stroke to inform support

interventions for New Zealand stroke survivors and their whānau/families. We experienced a number of challenges as we attempted to achieve the study aims. However, what we learned as we developed strategies to address these difficulties is potentially useful for other teams attempting to respond to the increasing interest in combining qualitative research with population-based studies. We would highlight the importance of communication between research teams working on linked studies, the sharing of early findings, ongoing and responsive researcher training, and consultation with a community reference group.

Acknowledgements

The authors wish to acknowledge the contribution of the study participants, the ARCOS IV research assistants, the medical staff at all the Auckland public hospitals and the members of our community reference group.

Layer One: Conventional self-management

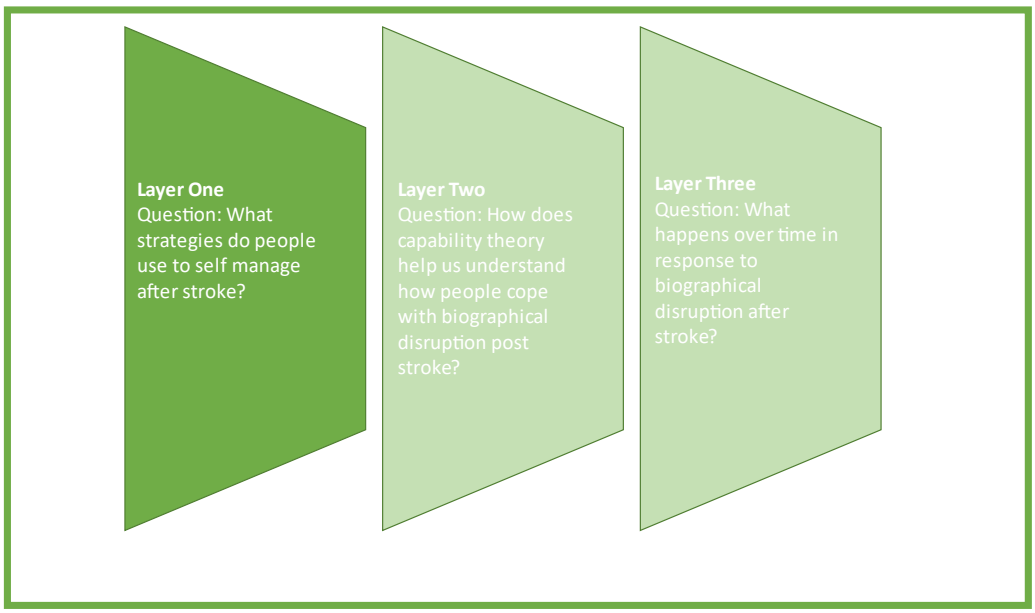

Figure 2 *Layer one research question*

Chapter Three: Literature review conventional self-management

This brief literature review gives an overview of the history of self-management and the mainstream or conventional models used to structure and underpin programmes reported in the rehabilitation and biomedical literature. These programmes influenced the development of self-management programmes for stroke survivors and provided the initial knowledge base for the development of interview questions at the beginning of my doctoral study. At the time I wondered if existing self-management programmes could be modified to contain the right content to be helpful to New Zealand stroke survivors. Therefore, my research question for layer one was what strategies and ways of coping do people use to manage after stroke and how might knowledge of these strategies inform a self-management programme (as shown in Figure 2, on the previous page)? Literature that influenced my thinking as the study progressed is reported in subsequent chapters.

Self-management a brief history

Thomas Creer is credited with providing the first description of self-management, stemming from his involvement in the development of a paediatric asthma programme in the 1960's (Creer et al., 1976; Lorig & Holman, 2003). He acknowledged Bandura's work and believed that the patient should be an active participant in their treatment.

During the 1980's Kate Lorig and colleagues at Stanford University developed a self-management programme for people with arthritis (Lorig et al., 1985; O'Leary et al., 1988) and in the 1990's a generic programme was developed (Lorig, 1993; Newbould et al., 2006) for people with conditions such as cardiac disease, lung disease, stroke and arthritis (Lorig et al., 1985; Lorig et al., 1999). The Stanford model as it came to be known (Lorig et al., 1985) was premised on the idea that education resulted in behaviour change which in turn improved health outcomes (Lorig et al., 1989). However, that idea was challenged by an unexpected finding that self-efficacy was the

factor most significantly associated with positive outcomes such as reduced pain and use of medical services (Lorig et al., 1989). Since this time, programmes have primarily been underpinned by this component of Bandura's social cognition theory (Lorig, 1993; Lorig & Holman, 2003). However, theoretically grounding self-management approaches in the notion of self-efficacy could result in blaming the participant if their efforts do not translate into improvement in function, in part because the notion of self-efficacy does not account for context. Having confidence could mean that people are more likely to attempt a task, but this does not ensure success or competence (Clark & Gong, 2000) and the long-term benefits of such actions have not been established.

Self-management programmes were given new life when in the late 1990s, government white papers were published in the United Kingdom outlining the reorganisation of the National Health Service. Part of this was the development of the 'Expert Patients Programme' or self-management for people with chronic disease and disability. The programme is based on the generic Stanford chronic disease self-management programme (Griffiths et al., 2007). In taking up the concept of self-management, the NHS was envisaged as a resource for people to access to enable them to manage better (Newbould et al., 2006). Early on the programme was critiqued for failing to account for the impact both health professionals and societal understandings of long-term conditions have on the way people respond to their health condition (Wilson, 2001). Nonetheless, by 2003 the programme had been picked up by over 100 services in the United Kingdom, with many more planned, and was thought it would result in a significant shift in thinking and acting for clinicians and patients (Donaldson, 2003). However, not all health professionals believed it would be helpful and some disliked the name, preferring something less confronting to medicine but indicating more patient involvement in care (Shaw & Baker, 2004). Others recognised that collaboration between service providers and service users would require a different mindset for some clinicians and patients, to avoid perpetuation of the biomedical model, which places power and expertise with professionals (Tattersall, 2002; Wilson,

2001). That is, a biomedical approach needed to make room for self-management so that they could complement rather than contradict and undermine each other (Tattersall, 2002).

Initially the expert patient self-management programmes in the United Kingdom were thought to be part of the answer to health inequalities. The aims were perceived to be similar to supporting patient autonomy and empowerment and appeared to have the potential to reach participants from lower socioeconomic status and ethnic groups (Vadiee, 2012). However, the participants and lay leaders recruited were those similar to the Stanford model in the United States of America, who were likely to do well anyway (Vadiee, 2012). Some trials did show benefits such as increasing self-efficacy and health behaviours whilst lowering cost, especially for diabetes and COPD, but effects were typically small and faded over time (Vadiee, 2012). The difficulty some participants might have with self-management, given low rates of health literacy amongst minority groups, had not been acknowledged (Wilson et al., 2007). However later versions of the programme were developed to be more inclusive of those who might struggle to attend in person, such as those caring for others, including children with long-term conditions, and those for whom English is an additional language (Wilson & Mayor, 2006).

Implementation of self-management

While self-management programmes came to be applied across a range of diagnostic groups, there are important differences that might account for lower efficacy than anticipated. For example, unlike arthritis, conditions such as diabetes, asthma, and epilepsy require ongoing monitoring of symptoms, biomedical markers, diet, and lifestyle (Barlow et al., 2002). Self-management programmes for asthma, on the other hand, often emphasise adherence to professional instructions, such as taking medications and avoiding triggers, and the leadership from professionals has been described as authoritarian and prescriptive (Koch et al., 2004). Arthritis self-

management programmes are said to have a more ‘holistic approach’ (Barlow et al., 2002). For conditions such as asthma an action plan may be recognising when an acute attack is a medical emergency. For stroke survivors and people with arthritis, goals and action plans may be about increasing participation despite the presence of ongoing pain and disability (Parke et al., 2015). Therefore, programmes such as the Stanford model may require extensive modification to benefit stroke survivors.

Accordingly, the expectation that self-management will result in reduced costs and healthcare use may be “too simplistic”. Early indicators were that an increased focus on health leads to increased engagement with health services, not less, and there is no evidence it reduces costs (Greenhalgh, 2009). A more appropriate and helpful approach may be to change the way in which people interact with services for example, fewer exacerbations and acute admissions and more interactions with G.P services or peer support (De Silva, 2011). Generic programmes have also proven problematic because, although there may be some very basic strategies that all people need, for the most part management may be unique to each person given their disease process, lifestyle and circumstances (Clark & Gong, 2000). There was also some evidence that self-management and compliance with professional directions via achieving a good relationship between the person and the professional had become a goal in and of itself (Chew-Graham et al., 2004; Clark & Gong, 2000). Other issues identified included a lack of training for health professionals in self-management and collaboration skills (De Silva, 2011; Norris & Kilbride, 2013).

Structure of programmes

In this section I present a representation of different self-management models to demonstrate their emergence and development over time. Examples have been chosen that demonstrate the diversity of programmes in terms of focusing on change within individual clients' capacity to manage their own health and models that placed

emphasis on change within the health service itself or in clinicians to support them to work differently. Issues with implementation of these models are also highlighted.

Stanford model

The underlying assumptions of Lorig's Stanford model include that people with arthritis can learn the principles needed for better management of their condition. Also, that people engaging in self-management activities will have better health outcomes than those who do not. It is also believed that self-management will increase accessibility to healthcare and reduce costs, in part because it is possible to train lay role models with the same or similar condition to lead programmes, which is viewed favourably by participants and health professionals (Lorig et al., 1985).

As mentioned earlier, underpinned by Bandura's social cognition theory, one of the initial steps needed for the behaviour change that self-management programmes seek to bring about is an increase in self-efficacy and outcome expectancy or confidence that a specific goal can be achieved (Griffiths et al., 2007). Programmes are typically composed of six or seven sessions delivered over several weeks in the community (Lorig et al., 1985). However, a group format may not suit all participants and the highly structured sessions may limit the time that can be spent on issues of importance for individual participants. Delivery as a one-off opportunity also may not work for those looking for ongoing support.

Managing a chronic condition requires the patient and the professional to collaborate to manage the person's health, including changes through time to reduce interactions with the healthcare system to a more 'appropriate' level (Lorig, 1996, p. 680). To support that outcome, the Lorig model is comprised of 5 core skills including learning to work collaboratively with professionals to establish priorities and being an active partner in their care. That includes being able to accurately report their symptoms to health professionals and make decisions based on sound knowledge, such making healthy choices about food and exercise. Practical problem-solving skills are also taught, such

as finding and using resources in the community. Being able to take action to address problems identified involves setting goals and making and acting on plans. A number of other behaviour change strategies are often included like identifying barriers and facilitators to change.

Multiple long-term conditions

For people with multiple long-term conditions, self-management is even more complex (Tran et al., 2015). Most healthcare systems are siloed into individual long-term conditions (Parekh et al., 2011). Stroke survivors, for example, are likely to have more than one long-term condition such as diabetes, heart disease, hypertension and hyperlipidaemia. Advice and education from health professionals about each condition can be confusing and contradictory (Lorig, 1996). The Stanford chronic disease self-management programme was developed in part to provide a self-management programme for the increasing numbers of people who have multiple long-term conditions (Lorig, 1996). It is taught by lay leaders who also have more than one long-term condition (Lorig, 1996).

Chronic Care Model

The chronic care coordination model grew out of earlier work that had identified that healthcare professionals do not follow best practice guidelines for chronic conditions due to structural issues, such as a lack of time and having no systems for identifying and organising patients with the same condition (Coleman et al., 2009). Rather, care is generally organised in the same way acute services are, which is to react to patients making an appointment to be seen for diagnosis and treatment (Wagner et al., 1996). It was acknowledged, however, that sometimes people with chronic conditions need support and education, proactive follow up to limit secondary complications, and their care to be planned and delivered by an expert team (Wagner, 2019; Wagner et al., 1996). The model therefore aimed to reorganise existing services and remove barriers to self-management in order to improve outcomes for people with long-term conditions

(Wagner et al., 1996). It outlined the responsibilities health professionals and services have in assisting patients to navigate a confusing and siloed system in order to self-manage and advocated that, in order to deliver planned care, clinicians adhere to a protocol, something that is difficult to achieve outside of a randomised controlled trial. The self-management tasks addressed in the model are almost identical to the Stanford model – engaging in health promoting activities, forming positive relationships with clinicians and following their recommendations, self-monitoring to underpin good decision making to meet needs and manage the impact of the long-term condition of roles, relationships, emotions, and self-esteem (Wagner et al., 1996). While restructuring primary care is an ambitious goal, it has resulted in improved quality of care for participants with long-term conditions when accomplished. However, health outcomes have been more difficult to shift and measure over the years, which would be required to achieve change (Coleman et al., 2009).

Flinders' Model

The Flinders' programme has its origins in Australia and started out as a reform of funding systems, recognising that care was disjointed and funded by multiple sources meaning that it did not efficiently or effectively deliver services to people with long-term conditions (Battersby et al., 2007). The intention was that appropriate services could be purchased according to patient need with a future focus on management via best practice guidelines. Research to address this problem funded by the Australian government began in 1997 (Battersby et al., 2007). It was reasoned that when healthcare is fee-for-service, reactive interventions favour a rapid journey through acute services, rather than an outcomes-based, proactive individual pathway (Battersby et al., 2007).

The Flinders' self-management support model was developed unexpectedly out of these trials. Some participants with multiple, complex and severe long-term conditions did not need much of the service coordinator's time as they were successfully

managing their condition. The approach was said to be successfully supporting people to change their behaviour and so self-management was integrated into the programme, in which clinicians are trained to deliver the support to individual participants (Battersby et al., 2007). The intervention was focused on identification of problems and goals, that participants were supported to identify (Battersby et al., 2001). Motivation and communication tools are utilised to co-construct a care plan that includes who is responsible for different aspects of care, the aims, interventions and review dates (Lawn & Schoo, 2010). At two years, 61% of participants were still in the first trial. Health and wellbeing were improved for some participants, but the intervention did not reduce admissions to hospital enough to cover the cost of the care plan (Battersby et al., 2007).

The programme was also piloted in South Australia with Aboriginal people with diabetes by trained Aboriginal health workers. It was modified to be more culturally appropriate, was found to be acceptable and seemed to increase self-management, although quality of life was unaffected (Battersby et al., 2008). HbA1c levels and blood pressure improved. The combination of tailored self-management support and resolution of a life problem – psychological or social in nature – resulted in increased self-management behaviours, which was identified as an ‘intermediate step’ to better health outcomes (Battersby et al., 2008). The Flinders’ programme has also been used in Canada, New Zealand and the United States (Lawn & Schoo, 2010).

The self-management principles that underpin the Flinders’ programme included brief, targeted assessment, collaborative decision making underpinned by evidence, and a non-judgemental approach. Also important were that providers, formats and interventions were diverse so that they could be tailored to the person, address self-efficacy and include active follow-up (Battersby et al., 2008). Development of the approach was influenced by the chronic care model which promoted change in both the clinician and the system (Lawn & Schoo, 2010). This model was based on the premise

that more than simply training staff was needed; organisational and structural changes were also required. Clinicians need the time and opportunity to practice the skills and tools, support to learn them, and must understand the need for change and underpinning philosophy (Lawn & Schoo, 2010).

WISE model

Similar to the Wagner's chronic care coordination model, described above, the WISE (Whole Systems Informing Self-Management Engagement) model was developed in the United Kingdom (Kennedy et al., 2010). The WISE model was based on the recognition that it can be difficult to recruit participants into the group programmes in which self-management skills are taught, and those that are recruited are better educated and have greater economic resources than most people with long-term conditions. It was therefore proposed that integrating it into usual care may mean more people could be reached (Kennedy et al., 2013). A key feature of programmes was that interactions are repeated over time, rather than being offered as a 6-week programme that people attend once, and the interactions should be with clinicians who have medical expertise rather than lay leaders (Kennedy et al., 2013). The outcomes of the programme, however, were not well supported. In a study with over five and a half thousand participants there was no significant effect on utilisation of services or other outcomes (Kennedy et al., 2013). The training was found to be acceptable to clinicians but there were significant barriers to implementing the programme. For example, GP practices would not free up staff for follow up reinforcement sessions and most would not allow treatment fidelity checks (Kennedy et al., 2013). It is not just the person with a long-term condition who needs be engaged in self-management, their professional and the service also need to be engaged and for this, a cultural shift is needed (Taylor et al., 2014).

Lay or professional led

Self-management interventions are most often delivered in group-based formats led by a facilitator. Lay led self-management programmes are thought to be more focused on participant needs and to have a more authentic voice of experience (Furler et al., 2008). The use of lay leaders has been found to be as successful as professional leaders in producing benefits for participants (Fu et al., 2003). Both have advantages and disadvantages, some programmes may have both (Cadilhac et al., 2011). The use of lay leaders may be problematic when group participants have questions regarding their medical treatment or disease process, but having professionals deliver such interventions may restrict discussion to topics the professional feels are within their professional boundaries (Kennedy et al., 2007). The benefits of lay led programmes are thought to be small in terms of health outcomes, poor attendance may indicate this format is not acceptable to potential participants, and leaders may not have the training to deal with the complexity associated with living with a long-term condition (Furler et al., 2008). Despite these shortfalls, the United Kingdom, Scandinavia, Australia and North America, in particular, have adopted the lay led approach to self-management (Griffiths et al., 2007).

Evidence for self-management

Evidence supporting the efficacy of self-management programmes has a number of short comings. When reported in single studies, the benefits of conventional self-management initially appeared promising, however, meta reviews demonstrated that while programmes increase self-efficacy, there was no impact on health outcomes (Greenhalgh, 2009). There was also no difference in outcomes for lay led and professionally led programmes (Greenhalgh, 2009). A Cochrane review of self-management programmes for people with chronic conditions completed in 2007 found that programmes can led to small gains, lasting a short period of time, and increase confidence and what people think about their health. However, there was no change in

interactions with primary health care, or quality of life (Foster et al., 2007). No one component of self-management has consistently been found to be more effective than another (Taylor et al., 2014).

Participants in self-management trials that report positive outcomes tend to be predominantly female, young, middle class and well educated, and likely to manage well anyway, with research designs and recruitment tending to exclude those with more severe physical and cognitive limitations (Jones, Riazi, et al., 2013; Lorig et al., 1989; Lorig et al., 1999). Those who do not volunteer are men, indigenous people and those with English as an additional language, and people juggling multiple roles and responsibilities (Foster et al., 2003). Cochrane reviews of self-management programmes for people with chronic diseases have found no change in psychological health, or symptoms (Foster et al., 2007). It is unclear whether participants prioritise changes in self-efficacy and outcome expectancy over other benefits such as reducing symptoms (Griffiths et al., 2007).

Evidence supporting the benefits of self-management programmes has been based on the assumption that if people change their behaviour their health will improve. This standpoint comes from epidemiological studies that link behaviours, such as poor diet and not exercising, to future health problems, but this may not be true for people already living with a chronic condition (Paterson, 2001). Behaviour change is not the only focus, self-management may need to change the way people think, feel and act (De Silva, 2011) in order to improve their health. If people with chronic conditions are not able to improve their health via self-management techniques, then it does not seem possible that costs can be reduced.

Stroke self-management

Stroke and the Stanford model

The Stanford model, with its focus on self-efficacy, dominates the research into self-management for stroke, with some programmes adapting the model to maximise fit. Programmes are often a mix of one to one and group work, sometimes with additional components like an exercise class (Rimmer et al., 2000) or telephone follow up (Allen et al., 2009). Some researchers have trialled a workbook that people use at home (Johnston et al., 2007), but the most common way of delivering content was via a group of participants with a range of long-term conditions. Some variability in duration and intensity is apparent: from two to three sessions to several times a week for up to 6 months. However, most programmes that are group-based are once a week for 6-8 weeks. One example was a pilot programme that focused on increasing self-efficacy and decreasing risk factors for US veteran stroke survivors (Damush et al., 2011). Another exploratory programme adapted the Stanford model by adding an extra seven sessions focusing on community integration, increasing self-efficacy for managing health and participation, but data on the 'actual changes' were inconclusive (Wolf et al., 2016). Others have applied the conventional six session version of the Stanford model to people directly after experiencing a mild stroke with no effect on the outcomes measured (Wolf et al., 2017).

The Bridges Programme

The Bridges programme, which was developed in 2006 in consultation with key stakeholders, also aimed to increase self-efficacy (Jones, 2006; Jones et al., 2009). At that time, there was sufficient evidence for interventions that target self-efficacy to be included in self-management programmes for stroke survivors, as education alone was seen as insufficient to change behaviour (Jones, 2006). However, the way in which programmes should be structured and the necessary components was unclear, because the impact of stroke is diverse, with attention needed to individual and

contextual factors (Jones & Riazi, 2011). The Bridges programme is based on the belief that self-management needs to come much earlier in a stroke survivor's interactions with healthcare professionals so that people can develop strategies, start to come to terms with what has happened, and be creative with finding supports and alternatives to clinician-led rehabilitation (Jones & Riazi, 2011). Early inclusion of self-management was also thought to help avoid stroke survivors becoming dependent on health professionals (Jones, Postgesb, et al., 2016).

The Bridges programme is delivered via a workbook, for an individualised approach (McKenna et al., 2015). The aims include guiding professionals to work at increasing participants' confidence and teach self-management skills and knowledge (Jones, Postgesb, et al., 2016), and helping them move away from a position of expertise and a directive approach (Jones, Postgesb, et al., 2016). By the early 2010's, it had become apparent that a focus on system structures and processes such as goal planning and finding ways to persuade clinicians to use self-management in their practice was needed (Jones, Postgesb, et al., 2016). The principles underpinning the Bridges programme therefore include goal planning, problem solving, using resources, self-discovery, reflection and action (Jones, Postgesb, et al., 2016). It makes sense that the principles of self-management be embedded into rehabilitation and other parts of the health service. However, most of the participants in this study had already been discharged from acute services directly to home. They either did not qualify for rehabilitation services as their stroke was 'mild', or there were no publicly funded, inpatient, outpatient or community rehabilitation services to refer them to for additional support. Many participants were told about the Stroke Foundation but decided not to take up offers of support from them.

Evidence for stroke self-management

The quantitative literature reporting on the efficacy of stroke self-management mirrors that for other chronic conditions; the results of individual RCTs are mixed, with mostly

very modest benefits (Cadilhac et al., 2011; Gillham & Endacott, 2010; Harwood et al., 2012; Johnston et al., 2007) perhaps providing preliminary support for continuing research investigating stroke self-management (Lennon et al., 2013). However, it is unclear whether the focus on the self-efficacy component of Bandura's model has been a fruitful direction (Korpershoek et al., 2011). Instead, it has been argued that self-management programmes for stroke survivors should focus on increasing function and participation, that are hypothesised as enabling people to manage their medical and emotional problems (Warner et al., 2015). A Cochrane review of programmes that target quality of life for people with stroke provided low quality evidence for benefits to quality of life and self-efficacy (Fryer et al., 2016). A systematic review of studies reporting on adherence to medication found some significant findings in some studies if the self-management intervention occurred often and continued long-term (Chapman & Bogle, 2014).

An increase in knowledge about stroke and managing risk factors was one of the reported benefits from studies that included a qualitative evaluation of their programme (Catalano et al., 2003; Taylor et al., 2009). Participants reported increased motivation, sense of coping and social support while the programmes were running (Huijbregts et al., 2009; Taylor et al., 2009). Exercise and goal planning were valued components as well as the sense of achievement that came with achieving goals (Catalano et al., 2003).

Participants reported it was difficult to maintain these benefits after the end of the programme, and once the support of the group was gone this impacted on motivation (Catalano et al., 2003). Some participants also had difficulty managing things like transport and costs and other medical conditions, which were complications that got in the way of maintaining any change (Catalano et al., 2003; Huijbregts et al., 2009).

Conclusion

This chapter has provided an overview of the self-management literature that informed the development of the first phase of the study. It reports the types and structure of programmes that are either aimed at the individual with a chronic condition and attempting to change their confidence, skills and behaviours to support managing, or aimed at professionals and the systems within which they work, to assist with embedding self- management techniques into usual care. The next chapter details the methodology used for layer one of this research.

Chapter Four: Ontology and epistemology

In this chapter I outline the ontology and epistemology underpinning my research thesis. I begin with an overview of the qualitative description approach, used for the first and second layers of my thesis. I then discuss the paradigm of pragmatism, that underpinned all of the layers of my thesis, followed by an underlying methodological approach of social construction. This is followed by discussion of the influence of my occupational therapy perspective and the research procedures for layer one.

The usual starting point in qualitative description studies is to construct a theoretical framework to study the phenomenon in question, in its 'natural state' (Colorafi & Evans, 2016). The aim is to uncover the ways that participants form understandings and meanings about what has happened to them (Lincoln, 2007). The framework is flexible, and researchers are able to move away from it should their experience of operationalising the principles, analysing the data or the findings take them in new directions (Kim et al., 2017). The theoretical scaffolding is thus considered to be a temporary initial structure (Thorne, 2008) rather than established and fixed beliefs and concepts. This flexibility is especially relevant for methods of sampling, data collection and analysis, and the presentation of findings (Kim et al., 2017; Sandelowski, 2000b). In this study I constructed my theoretical framework by layering Dewey's pragmatism, with Gergen's social construction through my disciplinary lens of occupational science and therapy.

Ontology and epistemology are concepts that are difficult to separate (Crotty, 1998) and are often presented as a dualism (Cutchin, 2007) rather than a continuum or as intertwined. Here I separate pragmatism as ontology and social construction as epistemology, partly to comply with convention and partly to signpost the type of knowledge I was seeking (Shaw et al., 2010), although there is some overlap that reflects the layered way in which my understandings developed. I discovered on embarking on my research journey that nesting my doctoral work within the wider

ARCOS IV programme and using different methodologies for the qualitative studies was a messy layering of theory rather than the clean, linear and sequential process I thought I saw in research texts. Writing and conducting all phases of this research were undertaken concurrently, however, they are separated here to illustrate how I developed each layer of the whole, as demonstrated in Figure 3.

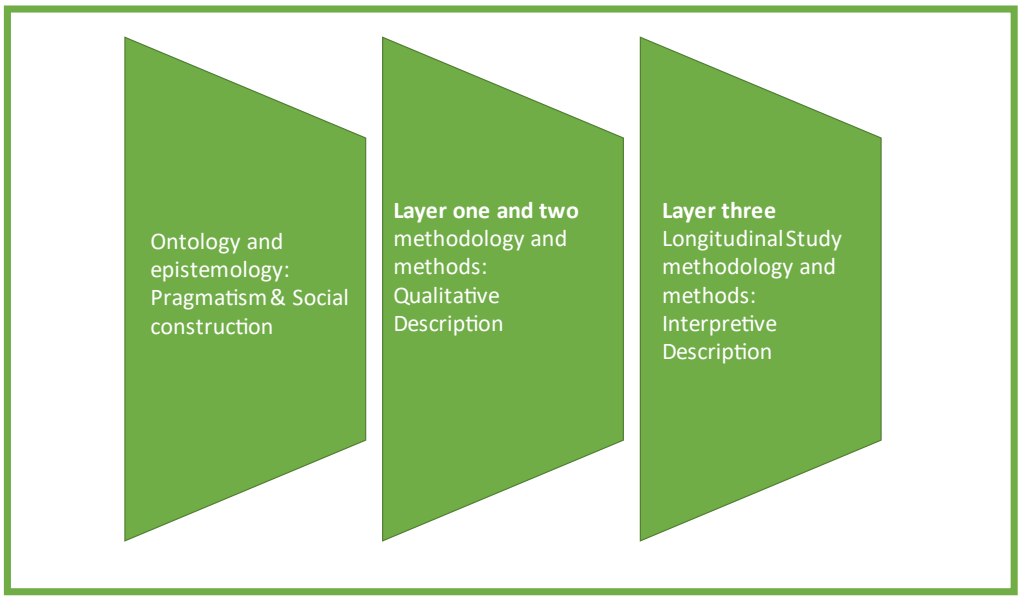

Figure 3 *Ontology and epistemology methodology and methods for each layer*

Overview of Qualitative Description

Qualitative Description aims to summarise the perspectives of participants, in a targeted and nuanced way (Sandelowski, 2000b). It is said to be an important early step in knowledge production, concept development, and intervention or service advancement and improvement (Artinian, 1988; Neergaard et al., 2009). Qualitative description has become a popular methodology in nursing and midwifery, being congruent with the aims of person-centred care including supporting people, their families and their views (Bradshaw et al., 2017). It is a methodology often used in mixed methods research and studies that aim to reduce health disparities (Sullivan-Bolyai et al., 2005). For example Dowswell et al (2000) as part of a programme of research investigating the effectiveness of community stroke specialist nurses, used

semi-structured interviews, with interview questions based on literature and outcomes from their randomised controlled trial.

The purpose or aim of qualitative description and interpretive description research is to develop action-oriented knowledge, that will take understandings one-step further in thoughtful ways. Professions such as occupational therapy tend to believe that all knowledge is potentially applicable. The aims of research are thus not necessarily to produce a new 'fact' that changes a field, but insights that will help improve practice. That is, clinicians have a different relationship to knowledge, seeing value in that which can be directly applied. This knowledge goes beyond description but is not considered to be the final answer. Rather, it is a continuous process of trying to understand things and how they work. As an occupational therapist and researcher, I see myself as a knowledge generating practitioner, knowledge that hopefully serves a need. My practice is underpinned by a valuing of the knowledge gained from the perspectives of clients and their significant others (Hooper & Wood, 2023). What the researcher believes about knowledge or what there is to know and how to acquire it are important to think about when designing research. One of the functions of theory in Qualitative Descriptive research is to provide the ontological and epistemological perspectives of the researcher's profession as the foundations of the research (Sandelowski, 1993). Occupational therapy is rooted in pragmatism, believing that people are intrinsically motivated to learn and grow, influenced by their context. Which makes pragmatism a natural choice (Hooper & Wood, 2002).

Pragmatism

Ontology or "the nature of being" (Thorne, 2008) is what there is to know, what is 'most real' to the researcher (Hooper & Wood, 2002). Pragmatism as ontology is concerned with the usefulness of discovered truths and how they operate, the truth being a solution to a problem (Shaw et al., 2010), and being of value when it can be used (Frankel Pratt, 2016). What there is to know is constructed by the interaction between

people and the environment (Miettinen, 2006). What is real is the world that we make as we interact with it and it with us (Frankel Pratt, 2016). The ontological propositions for this doctoral work are explicated below.

- Pragmatic knowledge is uncertain

For pragmatists, knowledge is uncertain (Hooper & Wood, 2002). Believing that it is not possible to know the truth, all that can be known or seen is the outcome of the application of theory, ideas, and practices within a social context (Ormerod, 2006).

- Pragmatic knowledge changes over time (Hooper & Wood, 2002).

We live in an unstable, unpredictable world and respond to this in dynamic and contextualised ways (Aldrich, 2008). Our response is based on both previous and immediate experiences (Schmieding, 1987) and influenced by our cultural, social, political and physical context (Dickie et al., 2006). Pragmatism, as ontology, understands people to be engaged in a constant state of acting, in and on the world, underpinned by reason, meaning and value (Goldkuhl, 2012).

- How pragmatic knowledge arises

Pragmatic knowledge arises from experience and habitual, culturally bound ways of thinking (Hooper & Wood, 2002). Pragmatism is a process of turning knowledge into action (Doane & Varcoe, 2005) and rather than only observing the world as it is and reporting this, the aim is to influence the world (Goldkuhl, 2012). Dewey suggested five layers of reflective thinking that are not chronological but rather continuous or 'fluid' (Farrell, 2012). A problem is perceived, and possible solutions are considered. The specific dimensions of the problem are clarified, and more focused solutions are used to observe the problem more closely. All possible solutions from the moment and memory are more fully thought about or reasoned to form a 'hypothesis' that is tested (Farrell, 2012). Dewey's reflective thought or inquiry, whether ontology or in everyday

life, means that some part of reality is examined so that the new knowledge produced by the inquiry results in positive change (Goldkuhl, 2012).

- Knowledge pragmatists value and seek

The knowledge that is sought and valued by pragmatists, is knowledge of how to do something (Kielhofner, 2005). Pragmatism is about investigating ideas, concepts, cultural practices, beliefs, and values by looking for and at their consequences (Crotty, 1998). For pragmatists, theory is always present in practice, and scholarship is about looking for the effect or consequences on action (Doane & Varcoe, 2005).

Pragmatism has been suggested as an appropriate underpinning philosophy for occupational therapy (Ikiugu & Schultz, 2006) because findings account for time, place and other aspects of context and are aimed at practice problems and decision making (Ormerod, 2006). Pragmatism is congruent with how occupational therapists think and work in practice as every person is viewed as unique, how they carry out occupations is also unique and context dependent. Knowing cannot be separated from doing and the doing or growth is both means and ends (Ormerod, 2006) just as occupation is both means and ends (Gray, 1998).

Social construction

Epistemology is the process by which knowledge is constructed between the “knower and what can be known” (Bradshaw et al., 2017, p. 2). We construct meaning by acting on and in the world. The real world is not something that exists as something to be discovered, it is socially constructed via the person who experiences it (Doane & Varcoe, 2005). Social constructionist researchers exist in, act on, and interpret the world, as participants and others do. Any generalisations made as a result of inquiry are temporary and incomplete social constructions heavily influenced by the perspectives, values, beliefs and context of the researcher, which may differ from participants. Dewey’s work, especially after 1915, has been used as epistemology

(Prawat, 2000) and for Dewey thinking and reflecting are ways of socially constructing and changing the world (Miettinen, 2006) although, as Cutchin (2007) reminds us, individuals do not form society, society forms individuals, in that collective ways of being and acting develop over time, present in everyday life as culture, and generate habits.

From a constructionist perspective, all understandings of the world are limited and mediated by culture, history and ideology (Chen et al., 2011). At a practical level, what we understand to be knowledge of the world comes from the relationships we have both with other people and the environment. This belief allows researchers to hear many different versions of reality and construct a new answer that has some meaning and truth within it, while acknowledging that it will not hold true for everyone or every context. For any 'thing' there is an unlimited number of ways to describe and explain it, one explanation is not better or more true than another, although our values lead us to construct things in a certain way (Gergen, 1999). It is possible to create alternatives, because people have the capacity to appreciate each other's discourses and construct new ones and in doing this create the future (Gergen, 1999). Consequently, it may be possible to create an enriched life for all people, including after stroke, but only if we constantly question and reflect on our constructions. For health practitioners working in self-management, we also need to question and reflect on societal constructions of stroke as lay cultural knowledge differs from healthcare knowledge (Bury, 2001; Rutherford et al., 2018).

For Dewey, society is created and perpetuated by the transaction of person, collective and environment, therefore the study of changes to places, spaces, habits of thought and doing, have an ethical component (Cutchin, 2007). In order to socially reconstruct an experience such as managing and coping after stroke, attention to social injustice is needed – a feature of qualitative description, interpretive description (Thorne, 2008),

Gergen's social construction (Gergen, 1999) and Dewey's pragmatism (Miettinen, 2006) and consequently fits well with my thesis research questions.

Researcher reflection: An occupational therapy lens to ontology, epistemology, and methodology

Although it is essential to recognise the core structures and understandings of the researcher's profession to make explicit the disciplinary logic that the researcher brings with them to the study in other qualitative approaches, it is not usually a feature in Qualitative Description (Thorne, 2008). However, the explicit use of theory to assist analysis, justify the starting point for a study and explain context, and for the researcher to understand the choices they make, is a feature (Sandelowski, 1993). As occupational therapy models, concepts and theory shape what I see as managing, the questions I asked of the participants and the data, and the way I structured the findings are influenced by these. Consequently, I include my disciplinary underpinnings here. Occupational therapy is the lens through which I look at and make sense of my practice world and therefore functions as my theoretical perspective (Crotty, 1998).

The most important knowledge that is most real to occupational therapy is knowledge about occupation, or 'doing' (Hooper & Wood, 2002, 2023; Drolet, 2014). The occupational therapy and science view that doing cannot be separated from the environment, and the environment and person are changed by occupation (Pentland, Kantartzis, Clausen & Witemyre, 2018) is congruent, and indeed underpinned by the position of Dewey. What people do has an impact on their health (Hammell & Iwama, 2012; Hooper & Wood, 2023; Wilcock, 1993) . Occupation can transform people and the environment, which can be the result of many seemingly minor changes over time (Wilcock & Hocking, 2015). Environments can facilitate or be a barrier to engagement in occupation and result in occupational performance that underpins health and wellbeing or ill-health (Law et al., 1996; Wong & Fisher, 2015, Hocking & Sutton, 2023) and as their context is constantly changing, so too is their doing (Law et al., 1996).

Occupational therapy started outside of the medical model and was initially focused on wellness rather than illness (Paterson et al., 2005). However nowadays practice most often happens in healthcare settings (Pentland, Kantartzis, Clausen & Witemyre, 2018). In occupational therapy, as it is for other health professions, the theory-practice gap has been seen to be an impediment to advancing knowledge and therefore the profession (Kielhofner, 2005). However, scholars of occupational science are partnering much more with clients and clinicians who can make use of and apply the new knowledge being produced (Hocking & Jones, 2023). Occupational Science is establishing and contributing to a knowledge base for occupational therapy. Knowledge that is relevant to and helpful for progressing and improving practice (Hocking & Jones, 2023). That issue makes pragmatism a natural fit as ontology for occupational therapy practice and research, as it is also concerned with knowledge that is useful and practical and addresses inequality. In occupational therapy rights are about the opportunity to 'do' occupation, and inequities have an impact on what people are able to do (Morrison, 2021). A focus on the individual without attention to environment will not ensure wellbeing, to which everyone is entitled (Hammell & Iwama, 2012). From an axiological perspective, the right action in occupational therapy reflects the values of the profession. One example might be collaborating with clients, who cannot be considered as separate from their context, where collaboration enables the achievement of wellbeing via meaningful participation in occupation (Hooper & Wood, 2023).

There is not always agreement within occupational therapy about an underlying philosophy for the profession, which has impacted on how occupational therapists and others perceive the profession, and understandings about what we do and how it works (Turner & Knight, 2015). Occupational therapy knowledge appears to stem from two ideologically incompatible views of the person (Hooper & Wood, 2023). The pragmatism of Dewey in particular, which views people as whole and inextricably a part of their context (Hooper & Wood, 2002), and structuralism, with its body as a machine

viewpoint (Hooper et al., 2014). Both pragmatism and structuralism have been present in occupational therapy thinking since at least the early 1900s, each has been dominant at different times, but both are always present (Hooper et al., 2014). My practice journey both theoretical and geographical as described in the introduction to this thesis is indicative of the duelling ontologies of pragmatism and structuralism in occupational therapy knowledge.

In order to learn to work alongside the medical model, rather than try to work within it, I needed to formulate a theoretical scaffolding for practice. An identity reflecting the kind of occupational therapist I wanted to be, would help me address the complexities of people, context and practice (Kielhofner, 2009). I needed to find my own strategies for addressing the theory practice gap while “learning to think with theory” (Kielhofner, 2009, p. 281). Thinking with theory has been a major part of my thinking, practice, and research since I learnt how to do it and to recognise when I was doing it. The theoretical foundations as understood via my disciplinary lens, informed the methodology and methods in an ongoing and dynamic way as I conducted participant interviews and sought to understand the theory in action.

Methodology

Methodology is the principles that guide the enactment of the theoretical framework via methods. It is how researchers go about acquiring the knowledge they believe to be valuable and able to be known (Bradshaw et al., 2017). The theoretical scaffolding of this research functions as a methodology and therefore the research plan was to consider how best the study objectives could be investigated and allow and acknowledge that ontological and epistemological issues arise together (Crotty, 1998). The fundamental principles of Dewey’s pragmatism, Gergen’s social construction and my disciplinary lens that informed my research are:

- Knowledge is uncertain and changes through time

- Knowledge arises from experience, interacting with others and the environment, and culturally learnt ways of thinking
- Habitual ways of feeling, thinking, and acting are repeated through time
- Theories are useful if they solve practice problems

Data analysis

In qualitative description, commonly agreed meanings of words and phrases and the perspectives of participants are maintained rather than transformed into new and abstracted meanings (Sandelowski, 2010). Analysis is focused on the narratives of participants' lives, to which context is essential to understandings and interpretations (Vaismoradi et al., 2013). The specific process of data analysis for this study is described in chapter two and the next chapter, chapter five which is a publication presenting the first findings of this doctoral study.

Presentation of findings

Findings are presented in the language and words of participants so they can be usefully applied by participants and clinicians (Neergaard et al., 2009). Findings should reflect the purpose of the research, in this case to describe what participants view as important to adaptation after stroke (Sandelowski, 1998). Findings are presented in a flexible way which makes sense given the data generated (Colorafi & Evans, 2016). This includes extensive use of 'direct' quotes to demonstrate credibility (Milne & Oberle, 2005).

Conclusion

This doctoral study was inspired and informed by experiences and literature describing the positive ways people can respond to stroke. It followed an approach that moved beyond the negative experiences already explored in depth in the qualitative literature, to action informed by those who know – the stroke survivor participants and their significant others. Qualitative and interpretive description were appropriate methodological choices to address these aims.

This chapter has outlined the philosophical and theoretical framework of the design for layers one and two of this study. In the next chapter the application of this framework as methodology and methods are outlined in the first findings publication for this study. Chapter nine in layer three presents the longitudinal Interpretive Description methodology, which informed the design of a more focused analysis of changes through time.

Chapter Five: Feeling the disruption 6 months after stroke

"I don't know what caused it, I don't know how to get it better".

Prelude to manuscript two: this chapter is an adaptation of the manuscript entitled "*Exploring challenges at 6 months after stroke: What is important to patients for self-management after stroke?*" Published in the *International Journal of Therapy and Rehabilitation* 25, (11), 565-575, in 2018, and is inserted as submitted for publication prior to editing, with the exception of modifications to the text to ensure consistency and relevance to the current chapter. In addition, a paragraph outlining the relevance of these ideas to self-management after stroke has been inserted.

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Abstract

Background/Aims: Self-management models have recently been applied to stroke, but the most effective components are yet to be determined. To inform the ongoing refinement of stroke self-management programs, this study explored challenges at 6 months after stroke.

Methods: 52 people and 26 significant others were interviewed 6 months after stroke. Results were analysed qualitatively using qualitative descriptive methods which are data driven, whereby codes are generated from the data.

Findings: Stroke was experienced as a shocking and frightening event regardless of severity and participants struggled to manage the consequences of their stroke. The stroke experience occurred within the context of more than one chronic condition and with competing demands of everyday life. Participants struggled to formulate a model of causation for their stroke, yet this appeared a necessary basis for action.

Conclusions: The findings suggest that healthcare targeted at enhancing self-management, including self-management programs, may benefit from encompassing a specific focus on participants' beliefs as an important foundation for recovery after stroke.

Key words: Stroke, qualitative research, self-management, public awareness of impact of stroke

Key points:

- This qualitative study carried out interviews with stroke survivors and significant others to explore how they were managing 6-months after stroke.

- The beliefs that stroke survivors form about the cause of their stroke appeared to influence the ability to move forward and manage the consequences. Professional explanations need to be individualized and start with the person's understandings in order to be useful.

- Recognition of the psychosocial impact of stroke is important to stroke survivors who struggle to deal with shock and grief beyond the acute phase.

Introduction

Stroke is a common cause of death and disability worldwide and the incidence is expected to rise (Feigin et al., 2015; World Health Organization, 2002), with more people surviving their stroke and approximately 70% living with on-going impairment (Tobias et al., 2007). This increase, combined with a shortage of health care workers, poses new challenges for the management of stroke, which can impact on all areas of a person's life in complex ways (Burton, 2000b; Clarke, 2009). There is significant evidence of ongoing psychological and emotional needs (Pearce et al., 2015) and long-term negative impact (Jones, 2006). Stroke survivors also report feeling inadequately prepared for discharge from hospital and a lack of support later in their recovery (Burton, 2000a; Cadilhac et al., 2011; Ellis-Hill et al., 2009)

Stroke is experienced as a sudden and shocking event and many survivors worry about the possibility of subsequent, more disabling strokes (Lawrence, 2010). They often struggle to understand the cause of their stroke and may, as a result, form their own theories when medical explanations are not individualised (Lawrence, 2010). How people interpret their experiences has been shown to influence how they recover (Leventhal et al., 1998), although there has been limited investigation of this in stroke (Twiddy et al., 2012).

Self–management programs after stroke

One proposal to address these issues is self-management. Kate Lorig completed early and important work in the field of self-management and defines it as “learning and practicing the skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition” (Lorig, 1993, p. 11). Different purposes of self-management programs for people living with chronic conditions have been identified, ranging from clinician directed control of the condition and the relevant biomedical markers to a broader and potentially more collaborative and individualised approach to living well with a condition (Morgan et al., 2017). How clinicians’ move from a traditional rehabilitation or acute model to a more collaborative working relationship has not been fully addressed, and there is emerging evidence indicating that this may not be an easy transition (Jones, Postgesb, et al., 2016; Mudge et al., 2015).

Although self-management programs have been reported in the literature since the 1980s, this way of working has only relatively recently been applied to stroke (Jones, Livingstone, et al., 2013). With only modest benefits reported to date (Fryer et al., 2016; Lennon et al., 2013), evidence of self-management’s effectiveness after stroke cannot be considered definitive (Sadler et al., 2014). The apparently low efficacy of self-management programs after stroke may be attributable to the wide range of outcomes measures used to evaluate efficacy, some of which are not validated for use in stroke (Boger et al., 2013). Alternatively, the lack of evidence may relate to program content or delivery. Stroke differs from other chronic illnesses in that the onset is sudden, therefore generic programs may not be relevant to this experience (Norris & Kilbride, 2013). Additionally, there may be other stroke specific differences such as communication and cognitive challenges that require a different approach to program development and delivery (Jones, Riazi, et al., 2013).

Programs for stroke survivors have utilised individual workbooks (Jones et al., 2009; Jones, Riazi, et al., 2013) or group-based formats (Kendall et al., 2007), been led by

lay and/or professional facilitators (Cadilhac et al., 2011) and included participants with other neurological conditions (Jones, Postgesb, et al., 2016). Although there is some variation in underpinning theory and approach (Ellis-Hill et al., 2009; Lennon et al., 2013) there appears to be two core principles: the use of behaviour change techniques (De Silva, 2011) and collaboration between clinicians and patients to construct a plan (Jones & Brimicombe, 2014). Decisions about the content of self-management programs after stroke is similarly unclear. Education may increase a person's knowledge, yet increased knowledge alone rarely leads to changes in how people manage their condition (Johnston et al., 2007). Consequently, self-management programs must be underpinned by specific behaviour change techniques that influence patient attitudes and responses to chronic illness. Such programs are designed to increase skill, confidence and motivation to enable people to more effectively and independently manage their condition (Jones, Riazi, et al., 2013).

This focus on managing the health condition has given rise to critique of self-management as being based on the medical model, with the primary aim of increasing patient compliance with professional advice and instruction (Wilson, 2011). It has also been critiqued for failing to consider the context in which people are trying to manage (Jones, Postgesb, et al., 2016; Kendall & Rogers, 2007; Sadler et al., 2014), which may be one reason for the lack of patient engagement in self-management programs (Sadler et al., 2014). Although there are problems with the application of self-management programs in stroke, it is clear that something is needed. People with stroke indicate that they would like more help with managing consequences such as fear, loneliness, and role and identity loss (Satink et al., 2013). These impacts require time and work to adjust to (Stone, 2005) and may be ongoing for several years post stroke (Pallesen, 2014). For instance, Hanger et al. (1998) followed stroke survivors for 2 years and found participants continued to have questions regarding cause and risk factors, with questions about the psychological impact of stroke increasing over time. More recent reviews confirm that educational needs remain unmet (Hafsteinsdóttir et

al., 2011). Most self-management programmes, however, are offered as a one off opportunity, usually without adaptation to stroke severity or phase of recovery (Jones, Riazi, et al., 2013). The study presented here aimed to explore participants' concerns and their influence on managing 6 months after stroke.

Methods

The Stroke Experience Study was initiated to inform the ongoing development of effective supports for people after stroke, including how better to inform clinicians and stroke survivors on successful strategies to support self-management. It is a longitudinal qualitative study nested within The Auckland Regional Community Stroke Study (ARCOS) IV, an epidemiological study being carried out in New Zealand (Krishnamurthi, Jones, et al., 2014). The study utilises a qualitative descriptive methodology and aims to produce a "comprehensive summary" (Sandelowski, 2000b) of how people manage on a day-to-day basis and reasons they may be struggling. Factors influencing what they do to manage the challenges experienced after stroke and whether that changes over time are being explored. The design is underpinned by social constructionism, which asserts that people's knowledge of the world comes from relationships with others and the environment and is influenced by culture and history (Gergen, 1999). As part of the stroke experiences study, participants were interviewed four times over the first three years after stroke at 6-, 12-, 24- and 36-months. A total of 78 participants and significant others were recruited. This article addresses one aspect of the 6-month findings that was present in almost every transcript and felt too important to be diluted or lost in an overview of the full study findings (Theadom et al., 2018).

Study design

Recruitment

Of the 2096 participants in the ARCOS study, 424 were not eligible for the Stroke Experience Study as they had been recruited to a nested clinical trial investigating motivational interviewing for secondary stroke prevention (MIST) (Krishnamurthi, Witt, et al., 2014). A further 983 were followed up but were unable to be contacted or declined further contact by the research team. An additional person was unable to give informed consent due to a combination of hearing loss and cognitive impairment and was thus ineligible, and one was not recruited due to family reluctance. From the 687 remaining cases, 52 (plus 26 significant others) were purposively sampled at the first time point, to ensure diversity with regards to age, gender, severity of stroke and ethnicity.

The participants were aged 16 years or older, experienced a stroke between 1st March 2011 and 29th February 2012 and lived in the Auckland region. The study focused on adults as context, experience and services are different for children. Participants with cognitive or communication difficulties were offered support such as extra time, the presence of a support person, and visual aids to participate in an interview. One person was represented by her proxy (son) due to cognitive impairment as a result of dementia. Another was represented by her proxy (daughter) due to cognitive impairment as a result of her stroke. A further two participants had proxies due to a significant level of aphasia but were present during the interviews at the proxy's request and participated as able with the support of their proxy and the interviewer.

Data collection

The 6-month interviews occurred between December 2011 and November 2012 and used minimally structured open-ended questions (Cadilhac et al., 2011; Sandelowski, 2000b). Interviews were conducted individually or as a dyad, according to the

participants' preference. Interview duration ranged between 10-90 minutes, with an average of 49 minutes. Full details of the interview schedule have been published elsewhere (Rutherford et al., 2013). In brief, questions and prompts focused on what had gone well, or not so well, for participants and their significant others since their stroke and their strategies and ways of coping. For example, "*Can you tell me about things that have been difficult?*" and "*Are there things you are doing to stay well and active since your stroke?*"

Data analysis

Audio recordings were transcribed intelligent verbatim, and transcripts managed using NVivo software. All versions of the code books created in NVivo were dated and saved. All decisions regarding codes names, retiring codes, and condensing data into themes were recorded in the codebooks. Initial coding, in which data-driven codes were produced, was completed across all of the 6-month transcripts, with complete coding initially and then a constant comparative approach (Charmaz, 2006). The codes were then examined for themes, which were organised into a map to identify the relationships between them. The map was then re-applied to some transcripts to check for fit and representation (Tobin & Begley, 2004).

Prior to commencing the interviews, which were conducted by SJR, reflections were written detailing thoughts and expectations of the study, relationship to participants, stroke recovery and the data, both as an occupational therapist and a researcher (Tobin & Begley, 2004). A journal was also kept to record responses to the interviews, information about context that might aid interpretation, and potential biases and professional and/or personal 'knowledge' to be explored and reflected on with the rest of the team (Morrow, 2005).

The initial coding was completed by SJR and then discussed in analysis meetings (Morrow, 2005) with all the authors. Code names and definitions were developed through successive discussions amongst the team and returning to the data for

clarification. Although there was no disagreement regarding identification of the key themes, we did experience some difficulty in ensuring the theme and code names accurately captured the diversity of experience. In these instances, we returned to the data to identify all types of experience and refined the code names and descriptions accordingly. Whilst two of the authors had some input to the wider ARCOS program of studies, data analysis for this study was led by the first author.

Saturation of findings has become a somewhat fluid and contentious concept (Caelli et al., 2003) with some arguing that it is not possible to capture every example of limitless experience (Thorne, 2008). However, we attempted to achieve as much variation as possible through demographic and theoretical sampling based on the stroke literature. We also asked questions of the data based on actual and theorised outliers (Thorne, 2008), such as participants with a wealth of, or extremely few, coping strategies. While there was variability in individual stories, these were consistent with patterns already discerned and no new codes were formed (Guest et al., 2006) after approximately 35 participants.

Sensitising concepts (Charmaz, 2006) of self-regulatory theory (Bandura, 1991) and Corbin and Strauss' Illness Trajectory model (Corbin & Strauss, 1985) were used to facilitate interpretation of participants' stories and for the ongoing refinement of interview questions alongside analysis (Charmaz, 2006) (appendix E). These concepts were a starting point only for ways to look at the data and facilitators for making explicit prior and disciplinary assumptions. Other areas of the literature were explored alongside analysis to aid interpretation. We also used memoing to reflect on the analytic process and identify patterns and perceptions from the different disciplinary perspectives of the research team (Ellingson, 2008). Preliminary findings were presented to our community reference group (which included service providers and people with personal experience of stroke and their feedback incorporated. Their views supported the theme presented in this paper and directed the analysis to look for

negative cases and further theoretical development (de Casterle et al., 2012). The sensitising concepts and relevant literature are woven through the findings in the interests of transparency and sincerity, and to accurately represent the analytic process (Tracy, 2010).

Ethical approval

Ethical approval was obtained from the Multi-Region Regional Ethics Committee of New Zealand (NTX/11/07/058) and the Auckland University of Technology Ethics Committee (11/295).

Findings

Fifty-two people with stroke were consented into the study at the first 6-month time point (Rutherford et al., 2013). Participants were invited to nominate a significant other, for example a spouse, to take part (n=26). This was in recognition of their role in assisting people to manage after stroke, their perspective was considered valuable to this research (Kendall et al., 2007) and that self-management programmes often include carers (Johnston et al., 2007).

Participants were aged 38-94 years at the beginning of the study, and all had pre-existing medical conditions such as hyperlipidaemia, diabetes, heart disease, COPD, depression, arthritis and cancer. Barthel scores at 6-months post stroke ranged from 1-20 with a median of 19 (interquartile range=6) indicating minimal ongoing dependence on others for activities for daily living (data missing from one participant). The participants with stroke at the first time point were 26 men and 27 women, with a first or subsequent stroke (seven with at least one prior stroke and 13 a reported TIA). Length of stay in acute hospital or inpatient rehabilitation varied from 0 to 113 days with a mean of 23 days (data missing from one participant). Participants were 56% New Zealand European, 6% each of Māori, Pacific Island and Indian/Asian, and 26% Other European.

Pseudonyms are used to protect participants' identity, with age at the time the stroke occurred included to assist interpretation. Four themes relating to how self-management is experienced, and maybe facilitated, were elicited relating to their perceived need for:

1. Acknowledgement
2. Person centred services
3. A causal model
4. Ongoing services.

Participants reported insufficient explanations of why their stroke occurred. At a time when they were feeling overwhelmed and vulnerable, they experienced services as impersonal, brief and inadequate as preparation for managing alone. Without an understanding of what happened to them and why, participants struggled to develop strategies and skills for managing.

"There is no such thing as a small stroke and a big stroke": The need to be acknowledged.

As has been previously described (Ellis-Hill et al., 2008; Lamb et al., 2008; Pearce et al., 2015), participants experienced their stroke as a devastating event that came without any warning. At the time of the 6-month interviews, they described ongoing feelings of shock, disruption, disbelief and distress. Participants were not able to think about the skills they needed to manage their health and recovery, or what to do next. Instead, their thoughts were focused on dealing with the shock and finding a cause, partly to prevent a subsequent more severe stroke, being fearful of more significant impairment (Townend et al., 2006).

> *"But you see, you don't feel ill. You feel ill afterwards when you know the damage that's been done, you know, to your brain, affects the different parts of your body…People are scared of the unknown …and whether they show it or not they do panic underneath. I did, at first, I thought my God, am I gonna die? How am I gonna cope?"* Barbara, 66 years.

Many participants felt that although they may have experienced a mild stroke compared to others, any neurological condition, irrespective of the severity of presenting symptoms, is cause for concern and attention.

> *"They look at you and they go 'Oh she's alright,' you know? 'She looks alright.' … they don't realize that you're sick, that you've had a brain injury…it may have been a minor one and the clot medication may have just cleared it. But there's still some sort of damage there because I still couldn't do things properly. I couldn't remember anything."* Lisa, 48 years.

The negative impact was not mitigated by a medical classification of mild or moderate stroke. The realisation that an event, which may not cause symptoms such as pain or nausea, could result in significant and permanent impairment, challenged cultural understandings of stroke and contributed to participants' sense of disruption.

"I'm not typical": The need for person centred services

Many participants stated that they were 'not typical' of a stroke survivor given the common understanding in society and amongst health professionals and the participants that stroke causes hemiplegia; this is reflected and reinforced by the main focus of rehabilitation that is often physical impairment (Desrosiers et al., 2006; Murray et al., 2003; Peoples et al., 2011). Making sense of what had happened was at times complicated by services and information which did not map onto the difficulties people were in fact experiencing. Leaflets, explanations, and other information focused predominantly on physical impairments, and to that end, only addressed one component of the consequences people experienced. Participants, therefore, queried the relevance of the information for them personally.

> *"And the material I was given, I sort of thought 'Oh ok, well this doesn't apply to me because I've had no loss of a single side of the body.'"* Debra, 47 years.

Although not referred to professional services, perhaps due to the assumption of minimal impact, some participants actively sought out services that might provide them with information. However, the available programs often did not feel like a good fit

because they appeared to be designed for stroke survivors with significant motor impairments.

> *"A lot of people were more severely injured by their stroke. I think if they looked at me they'd think what's she doing here?"* Linda, 60 years.

Life is complex for most stroke survivors, as they are often trying to manage more than one chronic condition such as diabetes or heart disease. Participants worked hard to accommodate the consequences of an unexpected stroke in addition to their other needs, for themselves and their significant others (Corbin & Strauss, 1985). Recovery was effortful and time consuming and a balancing act of competing demands and priorities. For each condition, they received different and sometimes conflicting information. When combined with the very common experience of fatigue, this left little time and energy to act on the advice received.

> *"It's just an ongoing battle…. because even when I go to the hospital, you know you've got three appointments split up in one day…So you are just trying to juggle your appointments then you go one day after day after day, but you have to go because I'm only trying to improve my health."* Robert, 75 years.

"I don't know what caused it; I don't know how to get it better": The need for a causal model

A person's usual ways of solving problems, their experience and knowledge may not apply to this new problem of stroke (Ellis-Hill et al., 2008; Herrmann et al., 2000). Although aware of risk factors such as elevated blood pressure and cholesterol, diabetes and heart conditions, the participants in this study sought a direct cause in their own situation (Bendz, 2003). Like others who experience serious illness they considered the possible causes (Walter & Emery, 2006), in part by attributing causation to their biological makeup and medical history to piece together what happened and why.

> *"It may be that I've inherited a genetic condition and that my arteries aren't as strong as my brothers and sisters. I'm one of six … and I'm the only one something like this has happened to. So I must be genetically structured differently."* Linda, 60 years.

Participants also theorised that perhaps there was something about their past or present lifestyle that was impacting on both the cause of their stroke and their recovery. Physical and emotional stresses were felt to play a major role in tipping the balance to cause stroke, and participants worried about what they could do to prevent another. Explanations from acute medical teams, General Practitioners, and information drawn from prior health knowledge, felt inadequate and unacceptable, and appeared to be contradictory and limited (Bury, 2001). As researchers have previously noted, information focusing on risk factors does not make sense because it does not start with the person's prior experience, knowledge, beliefs and fears (Townend et al., 2006).

> *"I would have liked to have understood more about what I was like before the stroke and possibly if stress was a big part of me having a stroke. Because I never smoked cigarettes and I didn't exercise, I was a bit overweight but not extremely overweight. I'd never been on cholesterol medication because my GP didn't think it was bad enough. The hospital immediately put me on cholesterol medication, and they couldn't figure out what had caused the stroke."* Mary, 53 years

A few participants did appear to have formed a tentative causal model or found a way to tolerate the ambiguity and move on.

> *"I've just made up my mind it was cholesterol. Yeah, I just more or less decided it was that and cutting lavender [laughs], working very hard…. a combination of two things that really was a bit too much I suppose".* Betty, 84 years.

One participant had greater knowledge and understanding of risk factors than most stroke survivors and followed all professional lifestyle recommendations, prior to his stroke. This knowledge felt incomplete, however, and he struggled to find a way to respond.

> *"I understand I had a thrombus yeah, why I should have a thrombus at that time I don't know… I had a history of ischemic heart disease. I used to get ischemic pain when I ran sometimes, but I'd had two stents so it seemed to me quite clear that if you had the potential to have a clot on your heart equally you had the potential to have a clot on your brain …when I thought about it afterwards, I thought, 'Well this can't come as such a huge surprise', although it did".* James, 67 years.

Participants appeared to need a causal model that made sense to them, against which to determine the fit and potential benefits of health professionals' advice,

recommendations or information. Such advice will not be understood or followed if it does not take account of the person's current and previous social reality and ways of understanding (Ellis-Hill et al., 2008), thus leaving them unsure how to self-manage the consequences.

> *"Should I do exercises? Is there tablets to take? Should I exercise more? Should I diet? Why? No one's told me why I had a stroke (laughs). They told me … the areas of how people get given hypertension, smoking, no exercise, diabetes, overweight etc. I was an active, I'm just retired right? So I'm just on the pension and … no one can tell me what to do."* Allan, 65 years.

"Then they went – 'see ya'": The need for ongoing services

Data from our study extended that of others (Burton, 2000a; Cadilhac et al., 2011; Ellis-Hill et al., 2009; Gustafsson & Bootle, 2013), highlighting that participants felt that once the acute stage was over they were left to fend for themselves. Discovering that there are not the services and support they thought there might be after discharge added to the shock they experienced.

> *"But then there was no 'Now what we suggest is you should look at this website or go to this group or we have aftercare' or anything. It was just 'We've analysed it. We've done what we had to do. We've ticked all the boxes. See ya'."* Allan, 65 years.

The participants and their significant others knew about the role of neuroplasticity in recovery, and that early, intense intervention is recommended. However, they were not eligible or faced long waits for community rehabilitation, which may only have been an hour a week (Demain et al., 2013). The perceived delay or limited community input appeared to intensify feelings of abandonment and disillusion with rehabilitation. Some participants wondered if their recovery had been curbed as a result.

> *"And those first 6 to 8 weeks she really needed that help from the people that were supposed to help her after the stroke. And that's what I was concerned with. Is that we didn't get that. You know. And so as a result I don't think Mum proceeded as she should have."* Helen's (94 years) daughter

Discussion

Our findings support previous research and show that even at 6-months' post stroke, participants reported shock and disbelief at experiencing a stroke (Lawrence, 2010), the lack of information relevant to their particular medical situation (Hafsteinsdóttir et al., 2011), and at having to manage its consequences with limited or no input from rehabilitation services (Ellis-Hill et al., 2009). There are two contrasting models that underpin community rehabilitation and self-management services. Some tend to focus on a specific health condition (Allen et al., 2009; Cadilhac et al., 2011; Jones, Gage, et al., 2016; Nuñez et al., 2009; Roy et al., 2011; Weaver et al., 2014), while others take a more generic approach (Hirsche et al., 2011; Lorig, 1996). Including the skills and knowledge needed to manage multiple conditions within an individual maybe an essential component for stroke survivors. Structural changes to siloed healthcare systems may also be required in order for a multiple chronic condition approach to be effective (Parekh et al., 2011).

The new finding that emerged in this study was that without a causative model of their stroke that fitted, participants were unsure as to the appropriate course of action. A causal model was needed for people to comprehend why they may need to make the lifestyle changes recommended to them and how to cope most effectively. Without a causal model they were also unsure how to reduce the risk of a further stroke, which created uncertainty about engaging in physical activity or participating in community activities.

In forming a personal causal model, participants were drawing on culturally determined representations of stroke, including beliefs about the causes and how it affects the person in their context. These beliefs, and therefore a person's response, is often a synthesis of medical and lay ideas (Bury, 2001). Given that risk factors such as diabetes, smoking, hypertension, and inflammation do not fully explain the cause and incidence of stroke (Lindsberg & Grau, 2003), those understandings may be more

complete than the bio-medical and health promotion messages, of reducing risks and personal responsibility for one's health, as they account for factors such as family history, socioeconomic status and the environment. Some participants were able to come to a place where they were able to tolerate the uncertainty. Perhaps support and guidance through this process could and should be part of self-management after stroke, rather than talking about risk factors as though they are direct causes of stroke, as this mismatch between lay understandings of cause and medical constructions is problematic to assisting survivors to move forward.

Supporting the need to develop a personal causative model, stroke survivors and their significant others have expressed the need for education and information that is specific to their situation (Donnellan et al., 2013) and explains the cause and course of their stroke (Wachters-Kaufmann et al., 2005). There is some evidence that greater benefits may be achieved if information is individualised (Hafsteinsdóttir et al., 2011). Individualising information may mean it takes different forms at different stages in recovery and may need to be repeated due to distress and cognitive or communication difficulties (Hanger et al., 1998). Evidence suggests that education about recovery after stroke promotes understanding, knowledge of secondary prevention and contributes to decision making, which are important components of self-management programs (Hafsteinsdóttir et al., 2011). A Cochrane review of the provision of information to stroke survivors and their caregivers as a 'process of care' to enhance recovery, found small but statistically significant benefits (Smith et al., 2009). Information about stroke and its causes, prevention, symptoms and treatments also appear to reduce anxiety and depression, especially when there are opportunities for clarification (Hafsteinsdóttir et al., 2011). What this study makes clear is the paralysing impact of not having information upon which to form a causative model; 6-months after discharge, many participants remained uncertain about what action to take to manage their ongoing recovery. All of this supports the need for clinicians to have the skills and knowledge to underpin their work with best practice guidelines and evidence to improve treatment

and rehabilitation (Bonita et al., 2004; Wilson et al., 2007). They also need to be aware that known risk factors are only part of the picture because participants looked to professionals for information about causation and the implications and impact on their life going forward. Acknowledging that medicine cannot provide all the answers suggests both the need for public health campaigns to challenge current perceptions of stroke (Wakefield et al., 2010) and that self-management will involve drawing on people's own resources to resume their life.

In bringing together stroke survivors' own explanations of the cause of their condition and current medical understandings, clinicians are advised to avoid 'correcting' the person's understandings (Kleinman & Kleinman, 1991). Rather they could elicit, value, and take both views into account when negotiating a self-management plan. For example, making efforts to discover and understand a person's (and their significant others') model of their illness, including the extent and nature of their suffering, and base health interventions on that model as a starting point (Kleinman & Kleinman, 1991). While education alone is a weak behaviour change technique (Gibson et al., 2002), specific education to underpin a helpful causal model, which is formulated in a collaborative way, may be a necessary precursor to self-management. This sort of approach could strengthen or create the sort of relationships and partnerships that people with chronic conditions feel are necessary for self-management (Sadler et al., 2014).

The common-sense self-regulation model assumes that people are able to act to solve problems, review their efforts and change mental representations when prior ways of coping are ineffective (Leventhal et al., 1998), however, this may not always be possible after stroke. Stroke survivors may initially use active problem-solving skills less than people with other neurological conditions (Herrmann et al., 2000) as the early stages may be characterised by shock and loss, and it may be difficult to assume the responsibility required for managing their own recovery. Current programs may also be

missing an important starting point, which is that some people need to resolve what happened to them and why in order to begin the process of learning how to self-manage. They may require health professionals' assistance to do this and therefore be able to move forward sooner.

For example, one of the ways stroke survivors try to address their risk is by reducing stress and exertion, however some lack confidence in their ability to prevent another from occurring (Townend et al., 2006). If people are fearful about having another stroke as a result of physical activity, then this could impact on their willingness to engage with some self-management principles that may increase the likelihood of long-term secondary complications such as depression (Morrison et al., 2005) Just as there is socially constructed knowledge regarding the causes of stroke, there are also lay beliefs around the role of the clinician, who may be expected by people with stroke to possess the knowledge required to manage and improve their situation (Sadler et al., 2014) Given that the burden of stroke is increasing and funding for prevention and management has not been in proportion to this burden, there is a need to increase awareness for health professionals and the general public about the impact of stroke on individuals and society (Bonita et al., 2004). The public need to know how to reduce risk, recognise warning signs and get to hospital quickly (Bonita et al., 2004). Media campaigns have improved this knowledge, (Wall et al., 2008) and some have had a significant but perhaps small impact on behaviour (Noar, 2006). However, information about risk factors was not sufficient for our participants to understand why they had a stroke and what to do to decrease the risk of having another because they did not fit the stereotypical presentation of a hemiplegia and other physical impairments.

Designing effective public health campaigns requires initial exploratory research with the target audience in order to understand and address attitudes and behaviours (Lecouturier et al., 2010; Noar, 2006). It is also recommended that theory be used, for example social cognition theory, social norms theory and behaviour change theories

(Noar, 2006) to increase effectiveness. Stroke shares some of the same risk factors as coronary heart disease and some cancers, so funding such a program makes sense (Bonita et al., 2004)

Limitations of the research: This chapter presents only one aspect of the ongoing data analysis of the study. Causal attributions might change over time and this possibility will be explored in the longitudinal analysis of data from the other interview time points (12-, 24- and 36-months). As with any small-scale study, our sample may not be representative of all stroke experience. We also cannot discount the possibility that in Auckland, New Zealand, education for people after stroke is not provided to the same degree as in other settings. However, participants were recruited from across Auckland from three different hospitals/catchment areas and were seen by a range of practitioners trained both in New Zealand and overseas.

Conclusions

The understandings that stroke survivors formulated about the cause of their stroke impacted on their confidence to act on the credibility of other's advice and about what to do in response to their stroke. These findings emphasise the need for a truly person-centred approach, requiring professionals to listen to learn rather than recasting experience and perspective into a model that fits medical understandings and services. As part of this approach, clinicians need to ask patients about what they think or believe so that interventions, advice and terminology used can be tailored to fit their understanding. Causal models that survivors have hypothesised might be gently challenged if they are potentially harmful, or the mental health sequelae of excessive self-blame discussed, or perhaps the benefits of becoming physically active highlighted sooner by reducing the fear of the relationship between activity and a repeat stroke. Assisting stroke survivors to form an acceptable causal model of stroke may be crucial for enabling them to feel supported, perceive information provided to be personally meaningful and to actively engage in a process that encompasses drawing on their

own knowledge and resources. Understanding patients' causative models could also provide a foundation for acknowledging the extent and nature of the emotional and cognitive impact of stroke and should form a part of self-management programmes. To support clinicians' efforts to individualise advice about risk factors, the various cognitive, physical and emotional impacts of stroke, and the value of personal resources to recovery, greater public awareness is needed.

Learnings from layer one

I originally asked participants if they had any theories about the cause of their stroke because I expected to hear strategies to support a change in lifestyle such as diet and exercise. However, to my dismay I realised that I had been thinking about risk factors as causes rather than factors contributing to risk. I discovered part of the literature that explained much remains unknown about the cause of stroke (Lindsberg & Grau, 2003). I never considered that it was part of my job as an occupational therapist to explain to patients what had happened to them. I assumed that patients felt confident enough to ask, that the stroke team doctors did this and that answering questions on one occasion was sufficient. However, it became clearer during analysis of the early interviews, and reading literature that participants with long-term conditions and apparent low socioeconomic status did not feel comfortable or able to collaborate and make decisions with clinicians (Kennedy et al., 2013). Also, that lifestyle changes were often not possible given their reduced resources and did not fit into their everyday lives (Kennedy et al., 2013). How well services appear to match a person's needs is important. Stroke survivors need to feel able to access, use and navigate services. Research that focuses on behaviour change is a narrow view of the work that people with long-term conditions must do, there are other ways people can manage (Jones, Riazi, et al., 2013).

It would be very difficult to integrate a new model into existing services and systems, and that it may be that financial incentives are required (Kennedy et al., 2013).

Researchers also need to understand the context in which clinicians work as it may not be a lack of willingness to incorporate self-management into existing services but rather being constrained by usual practice and a lack of structures for doing things differently (Jones, Riazi, et al., 2013).

Initially I had expected participants to talk about practical strategies they had been taught during rehabilitation, researched in books, online or discovered for themselves. I also expected to elicit stories about strategies to support a return to valued occupations in the first interviews, 6-months after stroke. Instead, participants talked about the ongoing and significant biographical disruption to their life story and conveyed an urgent need to formulate a causal model for their stroke in order to reduce their distress and find a way forward. These early findings influenced the questions I asked participants in subsequent interviews and the theoretical literature I was reading as sensitising concepts.

I was surprised to find that the problems participants talked about needing to manage mostly did not arise from a poor fit with the physical environment. Going forward I changed my questioning approach in subsequent interviews and of the data, about the problems they did need to manage, and the assistance and support from others they found helpful or would have liked to have. I wanted to know about the sort of strategies participants used and/or developed. How did they emerge over time? In what contexts, and in what circumstances did they arise? While participants did develop or use existing practical strategies in new ways after stroke, those ways of doing things did not appear to substantially underpin managing at the 6-month or subsequent time points.

This chapter has reported the findings for layer one, which focused on a foundational aspect of managing at 6-months after stroke. Following this analysis, I needed to adapt my thinking about managing after stroke. The next chapter introduces underpinning theories and developments in my thinking, and my new focus on the data in layer two.

Layer Two: A sociological and contextual approach

Feeling informing thinking

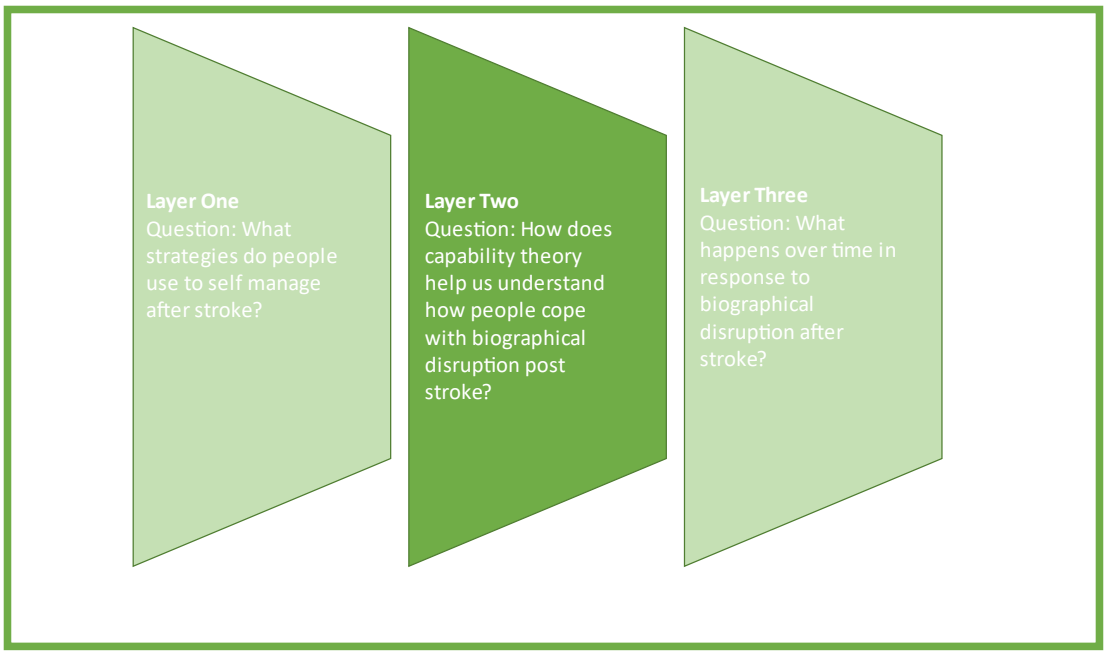


Figure 4 *Layer two research question*

Chapter Six: Literature review sociological understandings of managing

As I tried to match the theory, I saw in the self-management research with the needs and ways of managing that participants were telling me about, I could see the gaps and inadequacies in the literature. This layer of my research involved developing my thinking in relation to different theories (Figure 4, on the previous page) (Morse, 1994). In this overview of the concepts in the sociology of illness literature relating to self-management of long-term conditions, I outline the main influences on my thinking at this stage of my research. This layer differs from my reading for layer one, when I focused on the effectiveness of self-management and understanding the concept of self-efficacy, which was often the main target of self-management programmes. The revised perspective presented in this chapter arose from analysis of the 6-month data, when I noticed that biographical disruption and forming a causal model dominated the stories. Confidence in one's ability to carry out specific tasks (i.e., efficacy) was present as a theme, but it was only part of the complexity of reconstructing a meaningful and acceptable life after stroke. As I had a closer look at the literature I was reading, I realised that I had missed aspects that were underpinned by sociological understandings of chronic illness and the context in which people manage, and how this perspective carried through to self-management programmes.

My reading of the sociology of illness applied to chronic conditions revealed how difficult the work of 'managing' is. Understanding a person's context and the impact it has on how people feel and think about their long-term condition revealed another layer of the complexity of managing. A person's position in society, their culture, education, income and social ties all influence their health and ability to manage. Below I give an overview of context as facilitator or barrier to managing and important components to self-management of chronic illness. The components are wide ranging and include social support, trusting relationships, time, energy and psychosocial intervention. How these factors fit together in self-management programmes is not yet known, and the

sociological literature highlights that people with long-term illnesses manage differently at different times and go through repeating cycles in which they must cope with the impact on their identity, roles and the opportunities available to them to manage.

Capability Theory

A key influential strand in my new learnings was the capability approach. Originally developed by Amartya Sen to describe how economics can best facilitate development in impoverished nations (Siegert & Ward, 2010) it has subsequently been applied to the area of disability (Baylies, 2002; Biggeri et al., 2011), healthcare (Anand, 2005) and rehabilitation (Sharma, 2005; Siegert et al., 2010) It has been suggested as an alternative to the biomedical model with its 'negative' viewpoint and focus on the individual's impairments (Dubois & Trani, 2009). The capability approach looks not only at what a person does but also the range of alternative choices available to them (Dubois & Trani, 2009). Capability can be defined as the freedoms we have "to live as we would like to" (Sen, 1999). Our actual and practical freedoms include the freedom to move around, to have a job of our liking, to have friends and be a part of society (Sharma, 2005).

The capability approach emphasises a person's opportunities to make use of the resources that may be required in achieving wellbeing (Sharma, 2005). It can be linked directly to dignity and human rights. As rehabilitation professionals we may be morally obligated to assist people in developing the freedoms they need in order to live a dignified life that they are able to shape themselves (Siegert & Ward, 2010). Each person has the right to claim access, or have the opportunity, to do the things that matter to them, even though they may not choose to engage in them (Siegert & Ward, 2010).

Audulv (2013) described some of the barriers and facilitators to self-management that can be explained by this theory. For example, high social position and support have been linked to a higher frequency and range of self-management behaviours, while co-

morbidities, belonging to an ethnic minority, and less ‘resources’, are associated with less self-management. From a capabilities perspective, facilitators of self-management might be framed as being part of a social network and being able to get around the community, which contribute to the wellbeing of older New Zealanders, even when living with a long-term condition (Yeung & Breheny, 2016).

Capability theory has been critiqued for its focus on the individual and being in line with neoliberal thinking that people should be autonomous, free individuals capable of managing themselves and making rational choices. It has also been noted that it pays insufficient attention to national and worldwide injustice (Tanner et al., 2018). In Sen’s work at least, desirable capabilities are not specified as being locally and culturally specific, however, this makes it difficult to research and measure, and to redesign and fund services which will increase capability. Sen has indicated that capability theory is a framework and other theories can fill in the gaps but working out which ones are suitable requires more research and theorising. Martha Nussbaum’s list (Nussbaum, 2011) provides some guidance but has been critiqued for having a white western orientation (Jaycox, 2020). However, it may be that the capability approach, when viewed as a theoretical scaffold within which other midrange, context relevant theories are used, has the potential to bridge the gap between targeting social constructions, the good of communities and populations such as stroke survivors, and the individual clients’ clinicians work with in rehabilitation (Gopinath, 2018). However, these ideas are speculative, as I was unable to find any examples of capability theory applied to stroke self-management.

Sociological self-management: A brief history

Around about the same time that Kate Lorig was embarking on her programme of research, Juliet Corbin, Anslem Strauss and Michael Bury were applying sociological theory to self-management of chronic conditions such as emphysema and arthritis (Bury, 1982, 1991), Corbin and Strauss (1985) argued for a contextual approach that

acknowledges self-managing requires careful balancing and complex compromising, with much thinking dedicated to ways of maintaining roles and relationships. In particular, Corbin and Strauss's (1985) illness trajectory framework, which tracks the progression of the chronic condition, acknowledges the dynamic course of a chronic illness, all the related work involved in its management, and the impact on relationships, the person and significant others. They described this 'work' as difficult and complex, which appeared to be a common experience for participants who were often managing more than one chronic condition, increasing the complexity further. Corbin and Strauss divided this work into three main areas: illness related work, everyday life work and biographical work. There is a great deal of variation in terms of required timing, flexibility and effort for completing these tasks (Corbin & Strauss, 1985). Bury describes the process of adaptation to chronic illness: first there is the disruption of the illness, then people search for explanations about "why me?" in order to establish an acceptable and legitimate place for the condition within their life and understanding from others about the consequences. Then people search for treatment that makes sense given their circumstances (Bury, 1982, 1991).

Although the Stanford model of self-management focusses primarily on the self-efficacy component of Bandura's Social Cognitive Theory, when considered as a whole, it is an ecological theory that accounts for the impact a person's context has on how they think about what they are able to do. His theory acknowledges three interacting factors of agency: components and capacities of the person, behaviour, and the external environment (Bandura, 1997). Components of the person include biology, knowledge, expectations, and attitudes. Beliefs and cognitive competencies are developed and modified by social influences. Personal standards are social constructions that guide, motivate and regulate behaviour (Bandura, 2001). People have an impact on the environment, and it has an impact on action and behaviour. Social norms, for example, are part of the environment (Bandura, 1991). Maintaining social connectedness is important to self-management (Bandura, 1997). Friends and

family model ways of coping, provide motivation for getting out of the house and being active, and show that challenges can be overcome. However, Bandura acknowledges that the broader problems of society are difficult to address due to the individualist nature of western society (Bandura, 1997), which is the dominant culture in New Zealand.

As Corbin and Strauss were introducing the idea of an illness trajectory, Kathy Charmaz began to publish a substantial body of work on the suffering experienced by people with a wide range of chronic illnesses and disabilities. She described four types of suffering that result in a loss of self. These are: becoming socially isolated, having a restricted lifestyle, being a burden to friends and family, and being discredited by others seeing the illness or disability and not the person they felt they were (Charmaz, 1983). The view Charmaz (Charmaz, 1999) espoused was that, early on, talking about their suffering was justified, however, as time passes and the long-term condition remains, perhaps worsens, the person is seen as less. Charmaz (1995) described how adaptation to managing a chronic illness is a process involving gaining experience of the impairment and developing an ability to assess the body and live with the visible changes, which demands revising identity goals and ceasing the fight against the changes brought about by their condition. Furthermore, people with chronic conditions might experience this cycle multiple times (Charmaz, 1995). In a later elaboration of this proposal, Charmaz (2002) drew on Dewey's (1922) conceptualisation of habits as the things we do, feel, and think that are more or less automatic and do not require reflection. Habitual ways of thinking about the self and body take time to form and, once negative, can be difficult to change. However, habitual ways of doing, when managing a chronic condition, may no longer work and the person needs to develop new ones (Charmaz, 2002). Dewey's conceptualisation of habit may be insufficient on its own to be helpful to thinking about self-management as he did not consider how important a person's social position, and therefore the power available to them; is to the creation of habits and actions (Cutchin et al., 2008).

In the late 1990s, Hunt and colleagues also began to explore the differences in perspectives between people living in South Texas trying to manage their diabetes and the health professionals providing services. Clinicians talked about the problem of getting patients to follow recommendations, which they attributed to a lack of motivation. Biomarkers were evidence of compliance or deviance, and education was viewed as necessary to address non-compliance (Hunt et al., 1998). However, it was acknowledged that low income significantly reduced the resources that participants could draw on, and that cultural norms about diet, exercise and body weight were not always consistent with medical recommendations (Hunt et al., 1998). Problems with compliance seemed to be compounded by the fact that clinicians and patients are often different in terms of ethnicity, level of education and backgrounds. Accordingly, providers viewed success as control of glucose and behaviour, whereas participants were concerned with how they felt and how much their long-term condition impacted on their life (Hunt & Arar, 2001).

In similar research, a Canadian study explored the impact of social ties and support on the self-management of diabetes, utilising capability theory as a theoretical framework to investigate factors impacting on a person's ability to follow dietary recommendations (Weaver et al., 2014). People from the medium and high resource groups had broader social networks to draw on for information and support. They received more support at home, which maintained and increased their health capability, with little or no concern about the cost. People with low income could not afford to engage in social or physical activities outside of their home apart from walking, were less confident about their self-management knowledge, and tended to seek information from their doctor and not from other places (Weaver et al., 2014). In other research participants living in deprived areas reported feeling that it is their doctor's job to manage their long-term condition, whereas participants from more affluent areas were more likely to view it as the responsibility of the individual (Coventry et al., 2014). The key recommendation arising from Weaver's study was that health professionals should understand a person's social

position and health capability prior to making recommendations about behaviour change for self-management.

Considerations for the delivery of self-management programmes

The ability to manage one or more long-term conditions is not a tangible, linear end goal that people arrive at once they have had enough experience living with a condition and have learnt sufficient skills from healthcare professionals (Paterson, 2001). Rather, in chronic disease, illness is sometimes in the foreground when people are experiencing symptoms, grieving, and feeling overwhelmed; at other times wellness is at the forefront, when the person lives well, despite their long-term condition (Paterson, 2001). Self-management then tries to help people keep wellness in the foreground by addressing Corbin and Strauss' three lines of work. Ironically, to receive medical attention, illness needs to be in the foreground as evidence of the need for intervention (Paterson, 2001).

Delivery of self-management interventions are complicated by a lack of clarity about how these multiple components fit together and a best practice model has not been established that clearly maps onto what people with chronic conditions want in terms of goals and assistance (Morgan et al., 2017). In addition, most programmes are underpinned by the self-efficacy component of Bandura's theory, with a lack of attention on emotional, psychosocial, and socioeconomic, factors people face (Furler et al., 2008; Morgan et al., 2017).

To have an impact on how people manage, programmes need to be comprised of a wide range of components that can be individualised to the person, their views, beliefs, health condition and stage or severity (Taylor et al., 2014). For example, research in diabetes reports that people create their own foundations for self-management from emotional support and strategies and culturally based goals (Furler et al., 2008). Taken together, these insights frame expectations regarding the role of healthcare

professionals. Professional support for self-management needs to be in line with the person's expectations and it may be important to attend to their social, emotional and cultural background. The professional must balance supporting the person where they are and assisting them to reconfigure emotional strategies and ways of coping. However, there is some concern that healthcare professionals may "devalue and disrupt important social supports" (Furler et al., 2008, p. p. 215). Irrespective of these insights, people with chronic illness may be resistant to participation in self-management programmes. For example, an Australian group of researchers had to close their study early due to poor uptake, difficulty recruiting participants and poor attendance (Ackerman et al., 2012), despite having planned for difficulty recruiting based on literature reporting on the Stanford model. A range of weekday, weekend, and times of the day were offered, and the researchers had considered factors such as traffic and parking. The early refusers, when recruiting from populations of people who were using the public health system, were mostly older people who had been on the waiting list for surgery for a long time. Others were unable to attend all six sessions because of pain, decreased mobility, difficulty with transport, or work and family commitments. However, most people who refused did not want to participate because they were not interested (Ackerman et al., 2012; Rimmer et al., 2000).

Some small changes in lifestyle behaviours can be attributed to self-management skills when carefully designed and underpinned by theory but whether or not they influence health outcomes is not known (Glass & McAtee, 2006). This is thought to be due to a lack of attention to the influence of the social environment on behaviour, because when unhealthy behaviours such as smoking, poor diet and a lack of exercise are controlled for, low socioeconomic status remains a factor (Glass & McAtee, 2006). How unhealthy behaviours come to be socially constructed and the impact of shared ways of thinking and doing on a person's inherited biology is poorly understood and inadequately researched (Glass & McAtee, 2006).

Culturally tailored models

Within the self-management literature, some consideration has been given to the specific needs of minority groups. While studies of self-management programmes generally report high dropout rates, Rimmer et al.'s (2000) study of African American stroke survivors achieved an attendance rate of 93% with no drops outs. Eliminating barriers such as cost and transport appeared to increase adherence, while support from clinicians and other participants was also thought to be key. Participants took part in an individually designed programme, which involved reviewing eating habits; cooking instruction for low-fat; low cholesterol; budget meals; information about causes and risk factors for stroke; goal setting; stress; coping styles; and communication.

More recently, a new model of self-management education for minority ethnic groups in the United Kingdom has been developed via an action research framework consisting of facilitated peer to peer storytelling in a language in which they were fluent (Greenhalgh et al., 2005). Although a trial of the programme with people with diabetes achieved 79% attendance in the intervention group, compared to 35% in the control group, a third of those approached declined to participate. The only significant outcome was an increase in perceived knowledge of participants illness and ability to cope with it (Greenhalgh et al., 2011). However, these researchers recognised that for poor and disadvantaged minorities, self-management is probably as much about increasing social capital and overcoming structural barriers as it is about self-management skills. While not all people with chronic conditions experience disruption, it may be a luxury people with lower socioeconomic status and position in society do not have because they are often managing multiple medical conditions, of which stroke is only one (Faircloth et al., 2004) along with more pressing problems such as housing or finances (Pound et al., 1998).

Multiple long-term conditions

As mentioned earlier, multimorbidity is common in people with long-term conditions and is more common in deprived and rural areas, occurring 10-15 years earlier in life than in more privileged groups (Coventry et al., 2015; Mercer et al., 2012; Smith et al., 2012). Determinants of health include the availability of medical advances, level of income and social status (Hall & Lamont, 2009). The lower people are in a social hierarchy the poorer their health (Hall & Lamont, 2009). Health inequality reduces quality of life and economic capital, increases service use and the occurrence of mental as well as physical conditions and social problems (Coventry et al., 2015; Mercer et al., 2012; Mujica-Mota et al., 2015). People with multiple long-term conditions need to develop multiple strategies for managing (Townsend et al., 2006) and work hard to keep all aspects of their lives in balance, often needing to prioritise other roles above managing their illness (Townsend, 2012; Townsend et al., 2006). A further complication in stroke is that different conditions dominate at different times, increasing uncertainty (Coventry et al., 2015) and the number of appointments, medications and instructions to comply with (Bratzke et al., 2015; O'Brien et al., 2014). Accessing multiple services that are not integrated is difficult and clinicians can feel overwhelmed trying to help people negotiate a confusing and inadequate system (Coventry et al., 2015). Availability of services is often dependent on the size and age of the population, which can mean the neediest communities are the least well served (Mercer et al., 2012).

Amongst people with multimorbidity, it has been found that attending support groups and taking lots of medications can be avoided as they do not fit with their self-identities, nor do they help with keeping up the appearance of being the same as everyone else of their age and other cultural norms (Townsend, 2012; Townsend et al., 2006). Accepting help might also be avoided, while the need to be busy at something, keeping a clean and tidy home for example, can be prioritised (O'Brien et al., 2014).

Several other factors have been found to influence engagement in self-management, including the increased likelihood that people with multiple chronic conditions will have family members and friends who also have multiple chronic conditions (Pound et al., 1998). In communities where a shorter lifespan is an expectation, it has been found to impact on aspirations for the future (Coventry et al., 2014). Early life experiences influence how people respond to stress and challenges (Hall & Lamont, 2009). In addition, in areas of low socioeconomic status with high rates of unemployment and homelessness, life is already difficult and a condition such as stroke is just another problem rather than a catastrophic event (Pound et al., 1998). Thus, it is important to understand the life chances that participants perceive to be available to them, because a person must feel that they have a future in order to work towards self-management (Coventry et al., 2015). Their feeling and thinking influences expectations about the future and how feasible strategies of action are. Cultural frameworks should be foundational for policies to promote health behaviour (Hall & Lamont, 2009).

Putting self-management in context

The focus on lifestyle factors as controllable by the individual and as reducible risk may over emphasise health behaviours, such as physical activity, at the cost of other important aspects of life such as connecting with others and socialising with friends (Silva & Howe, 2012). It is via the social environment that people mainly acquire resources, most of the social capital people have is used to help navigate their day to day lives (Wellman & Wortley, 1990).

Research that demonstrates that people are nourished by other people and meaningful social contact is necessary for wellbeing could be applied to self-management (Silva & Howe, 2012). Size and content of networks makes a difference, and social expectations can prevent or enable changes in lifestyle (Vassilev et al., 2011). Larger networks, and networks made up of family and friends, are thought to create more favourable outcomes (Vassilev et al., 2011). Environmental factors can be major

barriers to managing and have a significant influence on behaviour. For instance, the western obsession with independence, autonomy, and freedom of choice could be at the expense of social connection and interdependence (Rimke, 2000). Could mainstream self-management be promoting social isolation? It has been argued that efforts in research and practice should be aimed at social self-management, to have a significant impact on managing (Kendall et al., 2011).

Current conceptualisations of self-management focus on an individual managing treatment and the psychosocial consequences of chronic illness independently (Thirsk & Clark, 2014). However, people are not 'free' to make choices; they are shaped, constrained and enabled by family, community, and societal conditions (Thirsk & Clark, 2014). Choosing is a complex process. Patterns of eating, shopping, and exercising, for example, stem from childhood, become habit and routine and are fairly fixed (Thirsk & Clark, 2014). A person's knowledge of illness is shaped by people around them via discussion of things like symptoms and is influenced by gender, ethnicity, and family experience (Vassilev et al., 2011). These cultural knowings define what is normal and what is deviant – whether the person is to blame or external factors (Vassilev et al., 2011). The work of managing is mostly done at home with family (Vassilev et al., 2011).

The cultural aspects of social networks are important as they provide support for managing illness, such as information about how to do it, how to get help from others and emotional support that decreases isolation (Hall & Lamont, 2009). Participants in self-management groups learn what they should do from health professionals and programme lay leaders, however, how it is done is learnt from their social networks (Greenhalgh et al., 2011). A person's membership to a social network can provide not only practical support but also influence how valued a person feels. Membership provides information about who belongs, who should be protected, respected, or kept at the margins (Hall & Lamont, 2009). Networks guide behaviours, such as the appropriate response to illness and influences abilities such as how to get help from

others and how people see themselves, their confidence and self-image (Hall & Lamont, 2009). If people were able to choose to follow the advice of clinicians or change their lifestyle then education could work, however, groups of people behave and act in similar ways because they are developed and shared by their social position just as much as their biology (Glass & McAtee, 2006).

Stroke self-management in context

Stroke significantly impacts on a person's identity and can result in loss and grieving (Sarre et al., 2014). This bereavement model can be used by health professionals when patients attempt to set goals thought to be unrealistic (Alszewski et al., 2004). The impact of stroke could be more to do with a person's perception, shaped by their context (Alszewski et al., 2004), circumstances and social support (Kouwenhoven et al., 2011). Clinicians may expect older people in particular to be unable to overcome the problems they face after stroke, but stroke survivors draw on different underpinning cultural knowledge that if they work hard enough recovery is possible (Becker & Kaufman, 1995).

Stroke survivors with a lot of social support recover more quickly and more completely than those with less support, who have an increased chance of recurrent stroke, myocardial infarction or death (Dhand et al., 2019). Quality of life is impacted by social connections just as much, if not more than physical function (Haslam et al., 2008). Mapping stroke survivor's social support as an intervention in rehabilitation would identify those with small networks who could be facilitated to increase their supports by linking with community resources, peer mentorship and support groups (Dhand et al., 2019). Stroke reduces and intensifies relationships that can impact negatively on stroke survivors and their families who are often providing care and support (Dhand et al., 2016, 2019). Addressing the three lines of work for individuals and their supporters to maintain networks could also be routine in stroke rehabilitation and management.

Knowledge of networks could assist in identifying key relationships and habits that help people manage their risk factors (Dhand et al., 2016).

Key insights from sociology

A contextual approach involves appreciating and looking for the continuity of patients' identity and biography as well as the disruptions (Newbould et al., 2006). Although there are some common problems most people with chronic conditions need to manage, the actual managing that people do is down to their individual social and material circumstances. It seems unlikely that a generic list or set of instructions and skills will be sufficient (Newbould et al., 2006). Sociological theory contributes to understanding how cultural, social, and economic resources impact on the illness experience and managing (Townsend, 2012). Some of the barriers to self-management are multiple chronic conditions, complex health systems and cultural norms around roles (Boehmer et al., 2016). Self-management programmes then should not focus solely on accessing or increasing capacity but also asking how a person's context impacts on their ability to manage and whether the self-management plan reflects the person's values, roles, and important activities (Boehmer et al., 2016).

A good life, one in which people flourish, is not just about what people do but the range of choices available to them: the things people would choose to do, given the opportunity and a conducive environment, and consider as reflective of a dignified life (Silva & Howe, 2012). Everyone should be able to make plans for the future, choose courses of action, and pursue goals based on their needs and values. However, stroke may disrupt a person's ability to choose and figure things out. This literature highlights the moral obligation of healthcare professionals to assist people to develop the freedoms they need in order to live a dignified life which they are able to shape themselves (Siegert & Ward, 2010). This new paradigm of ethical and moral intervention seeks to increase people's capacity to live a life they have reason to value, rather than impose specific activities, and also work to reduce inequality (Edwards et

al., 2011). It is a holistic approach that includes increased opportunity, medical treatment when needed, and social justice (Sylvester, 2011).

Conclusion

In this brief review of the sociology of illness literature I have highlighted concepts that have been helpfully applied to the challenges of managing a chronic condition. I have suggested that capability theory might provide some of the theoretical framework for transforming stroke self-management. Insights drawn from capability theory are not very evident in literature addressing delivery of self-management or culturally tailored models, or discussions of putting self-management in context. The emphasis the capabilities approach gives to the resources people have access to and whether they can convert them into outcomes they value is vital to understanding and supporting managing. In the next chapter I present my analysis of the dataset used in layer one but focusing on exploring the factors that influenced how people managed after stroke based on my new way of thinking.

Chapter Seven: Layer two findings

Feelings impacting on thinking and acting post-stroke

"Because according to society this is supposed to be our golden years"

This chapter presents the findings from my analysis of the factors that influenced how people manage after stroke and how they influence each other. The analysis focused only on the 6-month interview data due to complexity of the research question and likely nuances that would be elicited from analysing the data in this way. The research question sought to understand how capability theory might shed light on how people cope with biographical disruption after stroke. As I listened to stories about how people adjusted over time during the interviews, I noticed that circumstances, people, and neighbourhoods appeared to be functioning as resources for some participants, underpinning coping and strategies. Participants with few strategies appeared to have fewer resources. Participants with effective strategies appeared to have more to draw on as they went about trying to manage after their stroke. I was informed by my reading of capability theory and the health capability approach during these interviews and analysis (see methodology chapters three and nine for an overview of my sensitising concepts) and I started to wonder what participants were really able to do to manage, and what they might choose to do if their circumstances were different. I started to see for the first time, how strong the press of the environment could be in terms of how well participants were able to live, adapt and manage (Wiles et al., 2011).

Using NVivo (NVivo qualitative data analysis software, 2012) allowed me to export all excerpts from the transcripts which appeared to indicate the presence or use of resources which I could then analyse in-depth whilst retaining the participant information and time point (6-months), so that I was not tied to an inflexible structure and could envisage the person's contributing context including demographic information (Thorne, 2008). On commencing my focused analysis of a subsample of participants in chapter 10 and 11, I returned to this folder of excerpts, which formed the starting point for this next phase of analysis and new questions to ask of the data.

My sensitising concepts for initiating this analysis (Charmaz, 2006), as in the previous chapter were self-regulatory theory (Bandura, 1991) and Corbin and Strauss' illness trajectory model (Corbin & Strauss, 1985) with additional readings of the capability approach (Entwistle & Watt, 2013; Mitra, 2006; Sylvester, 2011) and Michael Bury's biographical disruption (Bury, 1982, 1991). I completed the coding, which was then discussed in supervision (Neergaard et al., 2009) Data analysis involved constructing codes via asking questions of the data based on patterns discerned from multiple readings and my sensitising concepts.

Key themes

Four themes were identified as being as 'data near' (Sandelowski, 2000b) as my epistemological lens allowed and enabled. As explored in chapter four and applied in chapter five, I drew on Dewey's pragmatism and the assumption that the interaction of personal, contextual and relationship factors influence and determine the experience of stroke (Charmaz, 1990). Four themes relating to how participants were feeling at six months post stroke are explored in this chapter with links to ways they affected how the person perceived their stroke and actions that they took.

1. Feeling disrupted and vulnerable
2. Feeling let down and stuck
3. Feeling connected and prepared
4. Feeling effective, useful and that I matter

In summary, participants reported feeling shocked as a result of the significant biographical disruption they were experiencing at this time. They felt vulnerable both in hospital and after discharge to further disruption. Participants felt let down by health professionals and services when seeking support, reassurances and comfort, and could feel stuck when trying to move around this disappointment. Some of the negative feelings were somewhat mitigated for some by feeling well connected socially, feeling that they had prepared for their retirement and future as best as they could foresee, and that their material resources provided some comfort post stroke. Feeling

that they mattered and were deserving of support and assistance went some way to enable participants to feel that they could draw on this support and that their efforts would be successful. Feeling that they could be of some use to others also allowed participants to feel able to draw on these resources.

Feeling

Dewey's theory of emotions, and further development of it by others, unifies emotion, thought and action; they are inseparable and thinking and acting cannot be understood without an appreciation of emotion (Garrison, 2003). This analysis of the feeling's participants described in the 6-months interviews following their stroke, is not suggesting that they are separate. Rather the thinking work for participants at this stage was focused on trying to make sense of what had happened, in part to feel better and that it was possible to manage. This emotional-cognitive work dominated the interviews at the 6-month time point and thus helps to explain the influences on participants' action or inaction (Garrison, 2003).

Participants' contexts determined how they felt about stroke as context could constrain or create choices, opportunities, possibilities and resources (Entwistle & Watt, 2013). What participants felt able to do and be after stroke, the sense of how much autonomy they had (Ruger, 2010), influenced how the disruption of stroke was felt. Creating choices and opportunities meant participants were able to form and choose the strategies and ways of coping which reflected their values and resembles a life of dignity and meaning to them. Rehabilitation and self-management services were often not available or a poor fit, however participants who were well resourced felt able to piece together aspects of mainstream activities in creative and innovative ways.

Feeling constrained, disrupted and vulnerable

Feeling disrupted

During the initial disruption of stroke, experienced as shock and trauma (Rutherford et al., 2018), participants described feeling the disruption of stroke and searched for

explanations about ‘why me?’ in order to establish an acceptable and understandable place for stroke within their lives, as well as understanding from others about the consequences (Bury, 1991).

> *He thinks because I’m recovered quite a bit, I can do things that I used to do….’ And he’s like ‘you’ve had enough time now.’ And I’m like ‘No you can’t say that.’ I’m not back to normal.* Lisa, 50 years

Stroke disrupted participants’ biographies. They described a loss of confidence in their body and health, which led to a loss of confidence in occupational performance (Bury, 1991).

> *Dorothy: what stops me… frightened of having a fall.*
>
> *Edward: we used to do line dancing every Monday morning for an hour.*
>
> *Dorothy: yes, miss that too.*
>
> *Edward: and she won’t… don’t feel confident doing it now so she sits while I do, carry on with it so that’s a bit sad, but she says she doesn’t feel, kind of like she’ll bump into somebody ’cause of one eye you know.* Dorothy, 84 years & husband Edward,

When a stroke occurs, people must cope with the loss of the life they had planned for themselves and face an uncertain future in which their usual ways of doing, knowing and problem solving do not always map onto their situation. The disruption is practical as well as biographical (Corbin & Strauss, 1985). Suddenly there are symptoms to manage, exercises to do, occupations that are difficult that once were easy and required no thought or planning. The things that define who they are as a person can be changed, the retirement they had envisaged, their control and independence can be lost.

> *I think it was a shock to them because they suddenly realized we were both older and we were vulnerable you know? And our third son has almost taken over the head of the family position you know? And he makes sure everyone keeps in contact.* William, 82 years

Stroke disrupted the usual routines and everydayness and the knowledge base that was their foundation (Bury, 1982). The things that usually happen to other people, such

as grief, sadness and the prospect of death, which were previously in the distance, suddenly became close.

> *And you sort of think… that you're invincible, that you're going to keep going for ever. And unfortunately we're flesh and bone. We don't keep going for ever.* Lisa, 50 years

Participants' experience of stroke did not match their prior cultural knowledge or understandings of stroke and added to the biographical disruption, becoming another problem to manage. For example, prior 'knowing' that stroke causes severe physical impairment, necessitating placement in institutional care. Stroke has a meaning within society, it is something that happens to old people and results in significant and visible physical impairment, and an image is called to mind (Bury, 1982). The image or cultural 'knowings' about illness influences how people respond (Bury, 1991).

> *I thought a stroke would really, would be a cut-off point and you'd be bedridden and just a question of time before you died. I suppose I knew about degrees of strokes but it didn't cross my mind. And when the ambulance driver or paramedic said 'you've had a minor stroke' I didn't listen to the word minor, I heard the word stroke and I wasn't very happy that day.* William, 82 years

As outlined in the previous findings chapter, medical explanations including predictions about recovery were not always available or sufficient and participants felt an urgent need for hope, and that better days were to come. Some participants were able to seek out a stroke mentor to observe and ask questions of about what the future might hold. For those able to find one, a stroke mentor could also be a source of comfort.

> *I think the GP has said I should eat more fish and to ease up on the salt. So that's what I've done. And my next-door neighbour, he's a long-term stroke patient… he's eased up on the salt too … he looks alright to me so I sort of eased up on the salt as well. he has been understanding because he's been through it worse than I have and I listen to him when he says things to me you know...I observe him and realize there is a chance that I can…get better. He has a slight slurred speech and he… drags his left foot a little bit. But he's quite cheerful. So I suppose I've got that to look forward to.* William, 82 years

Participants' previous knowledge did not fit but new explanations were not available or did not reveal themselves in this early phase following stroke, despite much thinking and attempting to process their experiences. Thoughts, values and behaviours stem

from social structures and are unconsciously learnt and absorbed (Cutchin et al., 2008). For example, the health knowledge that people 'should' actively respond to their stroke in order to recover. They 'should' be motivated to exercise, and it is their personal responsibility to do so (Becker & Kaufman, 1995). Knowledge that medical professionals have the answers and services, which if available and engaged with, lead to improvement, is disrupted. Recovery rather than managing is the dominant discourse. This is a cultural, habitual way of thinking about the 'right' way to respond to a health condition, which reflects the influence of the Puritan work ethic, and a western cultural bias to action and rapid improvement.

> *But I really think I would tell [other patients] to really work hard. Couple of ladies in the hospital that moaned a lot, that's being kind probably… but I felt that they could do more, if they wanted to. Make the effort… I really think that I would tell anybody to be stubborn and really try hard.* Betty, 83 years.

However, coping with feelings of biographical and cultural disruption left little time and energy for physical activity.

Feeling vulnerable

Participants described a *feeling of vulnerability* after their stroke. Some were fearful of having another stroke and thus of leaving hospital and being away from expert help and surveillance. Their world was no longer predictable and under their control. They could not rely on their body or brain.

> *[In hospital] you didn't have to worry. You didn't have to think was something going to happen. They hooked you up to a machine and it would tell them if anything was going wrong. You just had to lie there, and you could go off to sleep and it was peaceful and there's nothing to worry about.* Karen, 54 years

There was also the fear that if the stroke survivor was not able to work as a team with their significant other to address the shock and immediate consequences of stroke, they may not be able to live in the environment of their choosing. This they had in common with participants who did not have the prior resources in life to create a healthy and proactive lifestyle. They did not have the place in the social hierarchy to

have these opportunities and/or feel deserving of this sort of support. For these people, their presence in the community felt tentative and temporary; that they were at risk of having to move somewhere with fewer choices and less autonomy.

> *I shouldn't be here, but I like to be here because I can do what I like. That's all I want. [If they] put you in a home, you've got to do what they tell you, I don't want that, not yet. Well, I'll be 85 next week and … I just want to stay here".* Richard, 84 years

Participants in rental accommodation were limited in terms of the equipment they could have; even minor alterations to government housing are limited. Heating was not as good; repairs were not done.

> *Housing New Zealand house, we rent the house and they won't let us take the bath tub out so I can have a walk-in shower.* Cynthia, 58 years

Sometimes home does not feel like home. Participants felt unable to cope with busy, noisy areas where there is nowhere pleasant and safe to walk and be outside.

> *It was the smells. It was the diesel and the screaming saws and all those things that really are very difficult to cope with and I found that extremely frustrating. I couldn't get away from it. You can't. You know? Where do you go?* Helen, 86 years

Those participants who were still working described feeling in a vulnerable financial position, meaning that they felt unable to take time off to recover or have a graded return to work. Doing too much too soon increased their sense of vulnerability as mistakes were made and being on time was difficult due to fatigue and impaired executive functions. There was a lack of understanding from employers and colleagues.

> *I got a disciplinary for being late all the time and then people would say things to me, and it would…take me ages to understand what they had said. I heard what they said but I was trying to figure it out in my head. And they would go 'Are you going to answer me?' … and people would go 'Oh she's stupid' and that impacted on me too because then I got labelled as stupid and numbskull? I couldn't think and all that. So that put a lot more stress on me as well.* Lisa, 50 years

There is a sense of being taken advantage of or discriminated against especially in the early stages of recovery when participants struggled with cognitive deficits.

> *If I'd have been making decisions myself which at that particular time I was not…I would have rung for an ambulance and gotten myself to hospital. And if I'd have been thinking straight, I would have faced up to the old bitch who runs the place, and not moved out.* Joseph, 80 years

Worrying about paying the rent or mortgage also impacted on wellbeing. Working fulltime while worrying also meant there was little time for self-care activities such as physical activity, eating well and resting. There did not seem to be time for working, running a home and managing recovery. Working in casual, insecure positions meant that participants who were still working were not able to take breaks during the day, further impacting on their health. They felt at risk of being demoted to less responsible and satisfying positions or having their hours reduced.

> *But she started a new job… and she needed to get straight into it. So she got her license back. The doctor didn't want to give her license back at that point, and she didn't want you to go back to work. But you've got a pretty good case towards financial arrangements.* Elizabeth, mother to Debra, 46 years

Even for participants who were not working it was difficult to compete all the tasks they felt they should or needed to get done in a day.

Feeling let down and stuck

Feeling let down

For some participants being alone in hospital was a foreign and frightening experience of not being taken seriously, which stayed with the person. Rehabilitation and support were limited in duration and not available to many, participants were surprised they needed to manage navigating a confusing and contradictory system of services alone. Participants felt an urgent need to reduce the negative emotional and psychological impact of stroke (Bury, 2001). There was an expectation of comfort, assistance and services from professionals which was not always realised and added to the shock of the event (Bury, 1991) and contributed to feeling that they did not matter. The visibility and severity of their symptoms was important to legitimising their experience of loss (Bury, 1991).

> *So that was quite frustrating to…not only have had the stroke, but also to actually pretty much be on your own in terms of recovery from that. It was quite hard, and I don't know whether that's something that people that have perhaps a more damaging stroke might not have the same…* Debra, 46 years

There is a cost involved in having a stroke, such as more visits to the GP, and seeking conventional and alternative therapies and treatments. Some participants who did not have prior cultural knowledge about how the system works and about stroke, sought out therapies and treatments they could ill afford.

> *So I went to the physio, see because I didn't really understand the system and I needed help I had to pay money to go see a physio. It's the GP's recommendation …and when I got there I was told you had to pay $45… Isn't there any compensation or injury subsidy somewhere that I don't know? But I just paid because I needed help… I went to so many massages I was trying to find out and then I went to a chiropractor..., this is just me going around but all of that didn't help.* Pamela, 59 years

The length of rehabilitation appeared to participants to be determined by the needs of the service rather than the needs of the person with stroke. Participants felt they should have access to services funded by often many years of paying into the system. Outrage consumed energy which was already in short supply.

> *It was too long to wait. That was before anyone ever contacted me was a month. And then I waited another month for them to actually come out so altogether two months, that was before anyone ever saw me. That's too long for anyone to wait. You think when they're released from the hospital; somebody would contact them within the week, but no.* Julie, 49 years

Feeling stuck

Some participants developed strategies or used existing ones to start managing and had realised by 6-months post stroke that they would need to manage alone. However, some appeared stuck even when acknowledging potential opportunities. Some participants were offered services but felt unable to take them up and could not explain why. It could be that services were aimed at addressing impairments rather than the emotional support and comfort that they felt needed to come first. Some participants described feeling so traumatised by the model of care they encountered they are unable or reluctant to engage with the system they feel let down by.

> *…it just felt like they were not taking any of it seriously. And it was scary…each time they made me feel like I was in the way, and I shouldn't really be there. So it's another reason why I discharged myself. Because…they patronized me and they made me feel stupid.*
> Jennifer, 41 years

Participants were unsure what to do in the absence of expected services and resented having to search for alternatives at this difficult time**.** Information about services such as green prescription, half price taxis and alternative means of transport such as the RSA, how to find an affordable driving assessment, were some of the services participants were trying to find. The stroke foundation was a source of information and support for some participants, but those who felt stuck did not consider the organisation to be a good fit to their circumstances. Sometimes information was given at a time when the person and their family were in shock about the stroke and could not make sense of it. Both the right time and mind-set seemed to be needed for participants to feel they could actively seek information about how to move forward alone.

Feeling creative, connected, and prepared

Feeling connected

For the participants who felt connected to services, family, friends and their community there was a sense of belonging, stability, purpose and opportunities to make and sustain friendships (Sylvester, 2011). Managing after stroke can be underpinned by maintaining and where necessary adapting habits, skills, and preferences from childhood (Bury, 1991).

> *We have a card game here on Thursday nights and I really like playing... My mother was great on games. We always played games.*
> Helen, 86 years

With this history and societal position comes the knowledge that it is good for wellbeing to seek out the company of others. They possess the skills and confidence for forming and maintaining friendships. Habits of doing, thinking, and feeling are passed on from older members of the family and community to the younger members. Having an accessible and wide social circle gives a sense of security and not being alone. Having

a '*coordinated and loving family'* is a resource both practically and emotionally. Adult children take turns providing supervision, support and assistance, monitoring with a daily phone call. Support from family and friends provided social interaction and cognitive stimulation, as well as practical assistance with tasks like gardening. Neighbours pitched in bringing meals, providing transport, putting out the rubbish, and paying social visits.

> *…wonderful support from everybody, neighbours, friends, community… from people coming and doing gardening bees, dropping meals in regularly organising a meal roster, people coming to read to James, friends coming from overseas to see us, so that has been huge …* Anne, wife of James, 67 years

For those who can afford to live in retirement villages, organised activities, outings, and exercise classes were available. Residents can pick and choose which activities they find meaningful and enjoyable and what they can physically cope with at this early stage. Extra energy does not have to go into finding transport, someone to go with, organisation and planning. Energy was a resource which needed to be rationed. Social physical activity was valued and sought out by participants who felt connected and prepared. There was a quality to their social connections that suggested close ties and regular contact. Having something to draw on was underpinned by a feeling of belonging. It appears possible that the negative influence of lower socioeconomic status on health and wellbeing was mitigated sometimes by close family ties (Macintyre, 1997).

> *…and my daughter [I go] around to see her and have a cup of tea. And I usually have tea with them on a Friday night. So that gets me out… My son lives [close by]. I usually go and catch up with him, his kids on the Sunday…4 o'clock. Go for a drive out there, catch up with them.* Betty, 83

Having a partner at home meant that stroke was a challenge that is faced together. The fitness and ability of a significant other was also a resource as they could act as a coach and project manager of recovery and rehabilitation. There was much work to be done in finding and arranging services, support, and experiences to facilitate a good quality of life. A significant other can also navigate through this world for the participant,

freeing time and energy for recovery. Participants felt supported and that they mattered when they had a significant other who took charge of and or helped to find activities that are rehabilitative and/or serve as a proxy for services from the hospital.

Feeling prepared

Forethought is the thought processes that allow a person to be anticipatory and proactive. It is motivating and guides actions (Bandura, 1991). Some participants were able to use foresight to plan for their future (Bandura, 1991) and prepared somewhat for their 'old age' if they have had the reserves. As reflective thinkers with resources, they were able to set things up in advance (Dewey, 1997). Some participants had well-paying jobs that enabled them to pursue a healthy lifestyle, they lived in safe neighbourhoods with parks and pleasant spaces to walk, and could afford gym memberships, good food, and had a choice over their living situations. The cultural knowledge that going outside, engaging in meaningful occupations out of the house and with others was good for their wellbeing and recovery, required prior preparedness in order to be enacted. Exercise was not only 'known' to be a good thing to do, it was also possible.

> *George: so yes I was fairly fit*
>
> *Shirley: oh he was very fit*
>
> *George: yeah, before the stroke um*
>
> *Shirley: I mean that he was 66 when he did the West Island way*
>
> *George: it was um twice a week going to the gym when things got settled and 2 days of the week at least*
>
> *Shirley: playing golf yeah, and then he walked the other days*
>
> *George: so I wasn't a marathon runner or a half marathon runner but I just keep myself fit*
>
> *Shirley: the cardiologist said if he hadn't lived the lifestyle he's led um the coronary artery disease would have hit him in his 30's.* George, 77 years & his wife Shirley

Being a homeowner meant that some people were able to downsize to a single level house or a retirement village which was warm and dry, with medical help, transport and other services close by. Having medical services in close proximity to home gave a sense of security and as a result people felt safer and less vulnerable. Not just from having another stroke or medical event, but that someone will find them, they would not be lying on the floor for days, which they linked to a poorer outcome and more significant disability. Feeling prepared seems to be a buffer or provide a better platform to start to manage after stroke. Perhaps it is easier to come home from hospital to somewhere on one level, which is familiar, in a neighbourhood participants felt comfortable in, and which is low maintenance. There was room for walkers and wheelchairs, or they had the financial resources to adapt their home, so it was suitable.

> *Warmer. Where we lived, we were up in the bush and it was very cold and …we were past that. It's good when we're young but as you get older you need warmth. Especially in winter but ah there's no firewood to chop and all this sort of thing. It's gas heating. That's made things easier. We have got heated floors in the toilet which makes it very nice to get up.* Sharon, 71 years

Having an ongoing relationship with a G.P and the financial resources to visit regularly was a way of having questions answered and concerns allayed as they occurred for some participants. These resources reduced feelings of disruption and vulnerability. The situations and problems that needed to be managed could be reduced by having a GP who found and referred the prepared participants to services and acted as a navigator through health systems.

> *… a really good GP is important when you're recovering from a stroke…Because you need to be able to talk to your GP at times when you don't go to the clinic…... Make you feel comfortable with what it is, that's worrying you. Because when you have a stroke, there are lots of little things that worry people.* Sharon, 71 years

Although some participants do not live in close proximity to services and were not able to drive and attend outpatient clinics, because they knew that they mattered, found a way to be of use to others, were able to advocate for themselves and access services and support in other ways.

> *when they said they'd like me to be an outpatient and I said 'no, it's impossible'……And then I went to these physio tests and everything. That's where I've been going most of the time, and she's given me all these exercises to do. In fact, the last time, I just spent a week in hospital.* Lois, 84 years

Feeling effective, useful and that I matter

Feeling effective

As participants struggled to create a new identity or modify the old one some participants felt what they do to help themselves would be effective. In their life before stroke, they had confidence that their actions would lead to positive outcomes. They formed beliefs about what could be done and anticipated the consequences of their actions (Bandura, 1991). While stroke was a shock from out of the blue, they were able to take some action in response to it and were able to gain confirmation that their actions and occupations could, once again positively influence their wellbeing and situation.

> *My left eye I still know is not quite right… I've taken to playing cards on the computer which I hope will help me to co-ordinate my eyesight. I used to play snooker a lot… and I've gone back to that now…playing snooker makes me concentrate on the precision of balls in the game you know? I think it must be helping my eyesight.* William, 82 years

Feeling that I matter

Some participants could make decisions to use strategies to save energy and to comfort themselves, because they had the financial resources to do so, and the social connections to draw on for this cultural knowledge. For example, accessing convenience meals which are fresh and good quality versus frozen and cheap. But they also felt that they mattered, that their quality of life was important and a priority. This feeling that they mattered enabled them to save energy for pleasurable and enjoyable occupations. They drew on feeling that they were deserving and had the resources and the right to pursue a life of meaning and purpose.

> *Can't do a lot like I used to. One of my sons came over… last weekend and he brought a bag of compost and…strawberry plants and he put them in that for me…He sorted wires out behind the TV…and he did*

> *quite a lot of work. It was really lovely. That made me feel good.* Ruth, 95 years

Some participants living in retirement villages and serviced apartments could have a social life which was as busy and varied as they liked it to be. Activities such as coffee mornings and card clubs are just along the hallway, the mobile library comes to the village and right to their door if required. It is experienced as a personalised service and was further evidence that they mattered. For example, a librarian who brought books to their door, kept a list of preferences and did not repeat any books. Participants felt that someone else cared about their quality of life. They were able to continue with enjoyable and valued occupations. Doctors and nurses visited who knew the value of social connections and encouraged residents to get out and about. Receiving encouragement from others to be active and connect socially helped make it a possibility.

> *that is something that is positive…what's made a big difference I think is you are encouraged a lot to do things and that is a good thing. Set yourself goals and try to achieve them.* Shirley wife to George, 77 years

People with financial resources seemed able to prioritise exercise and saw it as important to stroke recovery and general health and wellbeing. They could afford to go to a gym and were able to make efforts to keep themselves fit. The financially well-resourced also appeared to have a history of pleasant and enjoyable leisure activities and hobbies such as hiking and painting and also brought with them to stroke already formed habits of social physical activity. Being physically active was seen as a preventative buffer against ill-health and is sometimes believed to delay the onset of serious illness until later in life.

Feeling useful

Significant others of participants both at home and in care worked very hard to find ways to for the person with stroke meaningfully and productively spend their time. They created opportunities for the person with stroke to feel as though they were still

making a contribution and being of use to others and adapt previous favourite occupations.

> *I've been offered a little job, which I used to do beforehand…I used to go over to the local old folks' home and my neighbour across the road was there and she just wanted company…and you were glad to give her company.* David*,* 75 years

Conclusions

The way participants responded to stroke, depended on their cultural repertoires and social practices (Bury, 1991). Managing at 6-months after stroke was often related to ways of coping and sets of strategies that had been proven to be effective in the past. These strategies were enabled by higher social position and better paying work prior to retirement and stroke. Prior privilege enabled a healthy lifestyle, a value of physical activity and active leisure pursuits, a wide social circle, and a place of residence of their choosing. Participants' position in society allowed the creation of a lifestyle which was anticipatory and proactive (Bandura, 2001). Lifelong habits, routines and problem-solving skills were sometimes able to be applied to this new problem of stroke. Well-resourced participants had experiences prior to stroke that those with few resources did not. Experience could enable people to acquire practical knowledge which could guide actions and help them choose and made available to them strategies and ways of coping which were successful (Hébert, 2015).

As human beings we strive for and are motivated to maintain a coordinated state between feeling, thinking and action, when disrupted this could be due to a failure of habitual or unconscious ways of managing, becoming a problematic situation to resolve in order to return to equilibrium. Emotions then, arose when habitual ways of thinking and doing were found to be insufficient in dealing with the situation in which participants found themselves (Oatley & Johnson-Laird, 1987). Solving problems required "emotional clarity and cognitive conciseness" (Garrison, 2003, p. 419) both of which may be affected by stroke.

The person and their environment are inseparable, the environment being the origin of sociocultural understandings and practices, emotions being at least partly socially constructed and ways of responding habitual dispositions to think and act in certain ways based on those sociocultural understandings (Garrison, 2003). How a person responds to stroke appears to be heavily influenced by how they view the world and their usual style of managing, coping, and solving problems (Bury, 1991). Participants, of course, brought with them to stroke their socio-cultural, physical, and societal context. For some participants, their contexts provided them with resources, that is, social, economic and cultural capital. Well-resourced participants possessed the ability to convert capital into ways of managing and moving forward.

The number and type of choices people have after stroke is in part determined by the resources available to them. How effective their resources are, how amenable to being converted into health is influenced by the person's context and ability to apply the capital to their situation. The stroke survivor's social position shaped their preferences and habitual ways of thinking and doing, it influenced what they saw as appropriate and acceptable for 'someone like me' in this situation of trying to manage after stroke. Following this analysis, I wanted to explore in more depth how the participants' resources, contexts and feelings influenced their thinking about how and what their engagement in occupation and strategies would be as they worked to manage after stroke. I wondered what could be learnt from the managing stories to assist those who appeared to be stuck and struggling. Also, to think about how to assist those without resources to manage, as well as looking beyond managing to flourishing after stroke.

Learnings from layer 2

The 6-month analysis led me to wonder how occupational therapy, rehabilitation and self-management could influence the social, cultural, and economic circumstances of people after stroke. I learnt that choice is not a simple thing, people are constrained by normative pressures, and do not necessarily see opportunities as such. Participants

did not appear to be limited by reduced motivation or poor choices, instead ‘social structures’ (Kandt, 2018) limited or enhanced what was possible and seen to be possible and imagined.

As an occupational therapist I am interested in the doing, but what I have observed in my practice as well as our research participants, is that how people think about their ‘doing’ may need to come first. Ways of thinking as well as doing, can be habitual. If people use the environment in habitual ways and the environment triggers habitual thinking and acting or ways to respond to tensions (Garrison, 2003) then could the environment and therefore habits be changed?

When these ideas are applied to inquiry, seeing how the interaction of people and places can impact on health outcomes, starts to be possible (Cutchin, 2007). For example, communities with safe parks and green spaces with adequate footpaths do not alone lead to better health. Beliefs, attitudes and ways of thinking about exercise probably need to be present also, stimulated by the environment for habits of acting (Cutchin, 2007).

In this chapter I have reported the findings of a targeted analysis of data collected at 6-months after stroke, focusing on the resources participants did or did not have to draw on when trying to manage after stroke. In the next layer I will first outline the methodology and methods for my longitudinal analysis as a different approach was needed to encompass exploration of changes over time.

Layer Three: An alternative way of thinking about managing stroke

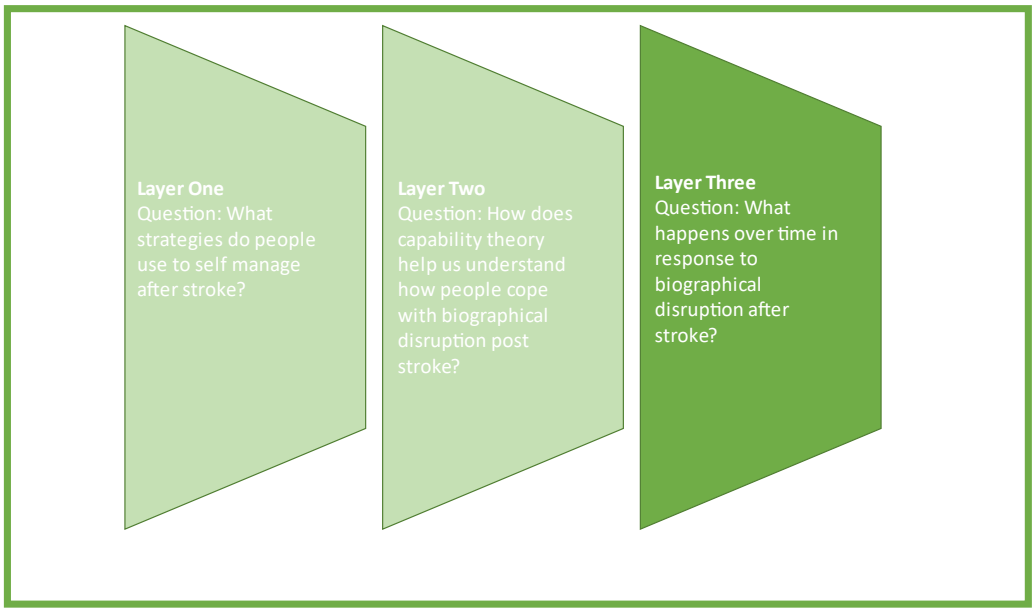


Figure 5 *Layer three research question*

Chapter Eight: Thinking impacting on acting and flourishing

By this layer of my study, I was wondering if there was anything that rehabilitation could offer stroke survivors in New Zealand, when many of the problems participants were talking about were social, economic and cultural in their origins. I started to think about health promotion and prevention, and interventions that were political in nature and societal in their focus, addressing social justice and human rights, and wondered what a single clinician or rehabilitation team could do within our current healthcare system. I therefore turned back to the literature to seek evidence of practitioners and researchers thinking beyond individually focused rehabilitation and the theory they were drawing on to guide and explain what they were doing and what they learned. It was around this time that the Auckland of University of Technology's Department of Occupational Science and Therapy hosted Dr. Ana Malfitano, a visiting scholar and occupational therapist from Brazil who critiqued rehabilitation for trying to fix the person and not asking the question – "*how did you get so disadvantaged?"* Thus challenged, I questioned whether, researchers and practitioners would need to: identify the stakeholders who influence policy and understand the ideologies required to create change at this level? I wondered what this sort of intervention would look like and how those considerations might relate to self-management.

Against the calls for a radical re-focusing of health to address the social determinants of health, some shifts in thinking are e/vident in the self-management literature. It took me time to travel through self-management, rehabilitation, and sociology of illness literature, to the capability approach and wellbeing and perhaps even the idea of flourishing to draw together the layers of my thesis. At the fringes of my reading and analysis I found a springboard to a place where I appreciated the extent of the radical system change, I think is required to move from modest or no benefits of current approaches to a real-world positive impact. In some ways I have circled back to the beginning of my analysis in layer one, in my search for explanations and possibilities in

academic literature. As I read more, I started to become much more aware of the influence of neoliberalism on self-management and rehabilitation. I saw the possibility that rehabilitation and managing could be about social change.

I started this layer of the analysis with the notion that self-management after stroke was about supporting individuals to do differently and do more by changing the environment and considering context. I then thought about changing what clinicians do within healthcare systems that also need to be changed to allow them to practice in different ways. Some of this change is about the client-clinician relationship and the way in which support occurs at a time of disruption. This also seemed inadequate, and I wondered about change at the level of society via research and rehabilitation with a political agenda. However much the long game needs to be about a structural and political approach to health promotion, people are still going to have strokes in increasing numbers and require rehabilitation. Rehabilitation is still going to need to know how to respond to stroke self-management and expand and redesign what we do, leaving behind independence and embracing interdependence. Moving to a place where we find methods to map a person's social capital, the relationships and closeness of their ties. To look for opportunities for stroke survivors to contribute to their communities and reciprocate the support they are going to need at home. To establish and add to the economic and cultural resources they will also need to reconstruct life after stroke. Interventions focusing on increasing social, economic, and cultural capital may take time. Perhaps longer than a typical inpatient admission, especially for those with mild stroke who may only have access to interventions like this for a few days. Therefore, stroke survivors currently need to self-manage and it is not known how this changes over time, hence the research question for this layer of my thesis as indicated in Figure 5.

I explore these lines of thought below, beginning with an exploration of the impact of health literacy on self-management, followed by the impact of neoliberal thinking on the

western emphasis on the individual versus the collective notion of interdependence. The influence of the responsibility an individual must assume when cultural knowledge of the self-help is underpinned by neoliberalism is also outlined. When wellbeing is understood from a western, neoliberal perspective, it is the privileged who are seen, and minority groups are left behind. Understanding more about the capability tradition illuminated the resources needed for converting capabilities into managing, let alone flourishing for people with less, such as the indigenous people of New Zealand.

Self-management and health literacy

Medical understandings of health literacy are that it is the ability to read, understand and make use of health information (Greenhalgh, 2015). However, the World Health Organization has broadened this definition from characteristics of the person, such as reading level, to include their social resources, and those of the community to which they belong, also their ability to access services (Dodson et al., 2015). Health literacy is known to impact on self-management, health status, and use of acute services and low health literacy is more common in disadvantaged groups (Greenhalgh, 2015).

A person's health status is determined by complex interacting layers of factors such as health literacy, social circumstances, behaviours and the design and delivery of services (Allin et al., 2018; Greenhalgh, 2015). One approach is to analyse the cause of poor outcomes for groups of people who have limited health literacy, choices and chances and analyse the causes of their poor outcomes (Greenhalgh, 2015) such as the World Health Organization's work on the 'causes of the causes' (Dodson et al., 2015).

The beginnings of interventions that address health literacy, and the causes of the causes can be seen in an Australian project that sought to increase health literacy and accessibility of services via co-design for location unique applicability. The process involved a needs assessment to establish levels of health literacy, the need for self-management, developing interventions such as the recruitment of volunteer health

mentors, increasing skills in clinicians, increasing close social ties in older people and increasing the flexibility of services to better meet community needs (Beauchamp et al., 2017). However, the interventions were co-designed with staff rather than also including community members and were focused on changing behaviour at the level of the individual. Results followed the same pattern as rehabilitation and sociological self-management research into self-management in that quantitative measures showed some small effects on a limited range of outcomes, and qualitative evaluations revealed that the programme was helpful for some (Beauchamp et al., 2017) who were likely those who would have more or less managed anyway.

An alternative approach using participatory action research was designed by Ravesloot and colleagues to develop the Living Well with a disability programme (Ravesloot et al., 2007). The process involved end user input at every stage, such as identifying issues requiring self-management, measurement development and the content of the programme (Ravesloot et al., 2007; Seekins et al., 1990). The theoretical underpinnings of Ravesloot and colleagues project was the Independent Living philosophy, with its focus on removing environmental barriers to participation in all levels of society. In this case, that meant removing barriers to health promotion opportunities. A sense of community was a by-product of the programme and participants continued to meet after the completion of the programme, supporting each other's efforts towards wellbeing and advocating for themselves (Ravesloot et al., 2007). Benefits of the programme were a reduction of the impact of secondary conditions such as depression, adjustment, and a lack of access (Ravesloot et al., 1998). Increased quality of life and reduction in costs, symptoms and health service use were also reported, although the effect was small when participants were followed up at two months (Ravesloot et al., 2005).

One of the drivers of participatory methodologies in health promotion is to overcome the lack of acceptability, relevance and efficacy of programmes when dominated by

clinician and researcher agendas and not tailored to the populations it is intended for (Neuhauser, 2017). Despite decades of participatory design in health promotion, “intensive participation” is an exception rather than the rule (Neuhauser, 2017, p. 161). Outcomes remain modest and inconsistent; however, success is seen when a contextual approach is taken which accounts for the beliefs, values, habits, emotions and preferences of end users (Neuhauser, 2017). A person-centred approach aimed at individuals, organisations, systems of services and communities is recommended (Allin et al., 2018). Additionally, a change in focus is needed from short to long-term, from the continued application of the same models to asking what could and should be (Neuhauser, 2017)?

Interdependence

It is via our interactions with others that humans come to know themselves. We need other people (Knabb et al., 2012) to feel that we belong (Malfitano, Whiteford, et al., 2019). The collective notion of interdependence acknowledges that life outside of the collective is not possible. Many of life’s activities requires the cooperation of groups of people and we have a responsibility to each other (Malfitano, Whiteford, et al., 2019). In many cultures, people live within a network of relationships, where groups can support one another and act together, this means that capabilities are created by individual efforts as well as interacting with others (Dubois & Trani, 2009). In education, for example, curricula that encourage students to help each other succeed and increase interdependence are thought to increase civic responsibility and their efforts towards goals that are good for all, as well as their own wellbeing and psychological health (Johnson Listwan et al., 2010). When times are bad, people turn to others and consider their interdependence with others (Orehek & Kruglanski, 2018).

The environment and closeness of friends and family can have a key influence on how people manage. Indeed, a person’s place of residence has been linked to their health, influencing both chances and choices (Bernard et al., 2007). People live where they

can afford to live and where others like them also live. Trust and the number of social interactions are also linked to health (Bernard et al., 2007). In some areas, a person's neighbours may not have the capacity to help and support them (Woolf & Braveman, 2011). Additionally, people with less are not as able to organise themselves to protest a lack of services or advocate for change (Woolf & Braveman, 2011).

Systemic barriers to managing

While individual healthcare professionals are identified as important to helping people manage after stroke, it has also been acknowledged that it can be difficult to do when healthcare structures do not support or promote collaboration and integration of services (Parke et al., 2015). Healthcare systems require modification for self-management to become an embedded part of usual practice (Lorig & Holman, 2003). Structures need to be in place, such as appropriately trained staff. A move away from an acute care model to episodic self-referral as needed seems to be required. Contextual and social processes and approaches are indicated, as the biomedical model alone has not been sufficient (Malfitano et al., 2014).

An alternative way of thinking, rather than attributing poor outcomes to a lack of compliance with clinical instructions, is attributing positive outcomes to partnership between active and engaged individuals with a long-term condition and society (Wilson, 2001). According to this line of reasoning, the person is able to influence their health and the state contributes empowering practices and resources (Wilson, 2001). However, a critical examination of the concepts of enablement and empowerment reveal them to be problematic and representative of the hierarchy of power held by health professionals (Hammell, 2016). Despite the realities of contemporary practice, with its neoliberal valuing of independence and self-responsibility, health agency and the associated resources to achieve it, could be aspirational to best practice in self-management and rehabilitation (Hammell, 2016). Capability theory may provide the necessary underpinning for practice that addresses what a person would choose to do

based on their values, as well as what they are able to do, that is their abilities and opportunities (Hammell, 2016). Such practice would align with a human rights perspective and shift the narrow interest on impairments to a more strengths-based position (Hammell, 2016) and provide an alternative to neoliberal thinking that attributes rights only when accompanied by self-regulation and self-management (Ericson et al., 2000). Context, cultural norms, and health literacy are often not considered in the development of self-management programmes, nor do they aim to impact the social and political environment (Greenhalgh, 2009).

Community level action

Resources and services are not evenly distributed in all geographical areas, the quality of housing is also variable (Glass & McAtee, 2006). Access to public transport differs, further increasing the distance to services, which impacts on unwell, disabled and older persons (Bernard et al., 2007). The proximity and quality of parks, footpaths, cycle ways, leisure centres, museums and art galleries decided at the level of local government are also resources that people could convert into health and wellbeing (Bernard et al., 2007). Those who decide the distribution of resources such as programmes to increase educational outcomes, employment, and economic stability and recovery are located outside of health and may be unaware of the links to health (Woolf & Braveman, 2011). Public health policy such as those directed at reducing smoking by increasing the price of cigarettes and banning indoor use, have been much more effective than medical recommendations (Woolf & Braveman, 2011). Collaboration with town planners, local and national government, schools, health and others seems logical and desirable.

This is a form of interdisciplinary working not commonly seen in rehabilitation, where collaborators are usually closer together, in terms of the type of knowledge they have, rather than further apart from different disciplines and paradigms (Choi & Pak, 2008). Helping policy makers to understand the connection between improving social

circumstances and the increase in income and therefore available tax dollars and reduction of spending on health would benefit everyone (Woolf & Braveman, 2011). Now is the time to increase funding in these areas rather than reduce it to cut costs following global recession. A further consideration is that preventing, addressing and researching interventions for long-term conditions is a long-term endeavour and does not match the three-year political cycle in New Zealand.

Traditionally, measuring the health of a nation is done via the economic indicator; gross domestic product, what is of value to white, western, capitalist societies. This method has been critiqued as failing to account for the fact that although some societies have grown wealthy, wellbeing and satisfaction with life has reduced and mental health conditions and distrust have increased (Diener & Seligman, 2004). In fact, negative outcomes increase with increasing prosperity (Huppert et al., 2009). Measuring health outcomes does not account for how unevenly they may be spread over a population (Mitchell, 2015).

There have been efforts over decades to develop subjective measures of wellbeing, components of which are thought to include “personal growth, positive relationships, purpose in life and self-acceptance” (Huppert et al., 2009, p. 304) the things that people consider to be of value (Diener & Oishi, 2018). Also important is social capital, so incorporating components that are collective rather than entirely individualistic in their orientation (Huppert et al., 2009). Subjective wellbeing is comprised of a complex range of elements including appraisals of how well individuals think their lives are going and enacting personal values about how life should be lived (Huppert et al., 2009). There appear to be two approaches to the measurement of wellbeing in the western tradition. One prioritises pleasure, enjoyment and satisfaction with life or feeling, having and being; the other fulfilling potential and having a sense of purpose or functioning and doing (Huppert et al., 2009; Ruggeri et al., 2020).

Unlike traditional self-management, which places emphasis on behaviour, the capability approach focusses on people having the capability and freedom to choose and engage with activities that they value (Coast et al., 2015; Mitchell, 2015). Measures have been developed of values via participatory methodologies such as the ICECAP-O (ICEpop CAPability measure for Older people) which is comprised of dimensions such as love and friendship, security, roles of value, enjoyment, and control (Coast et al., 2015). As I completed the analysis of my longitudinal data, I wondered what participants had to say about what was of value to them as they managed their stroke over time.

Much progress has been made since Diener and Seligman's seminal work published in 2004, which critiqued the use of only economic indicators to measure the state or success of a nation (Diener & Seligman, 2004). It is now known that societies with high levels of wellbeing tend to be wealthy, have well developed laws based on human rights, and social welfare systems that provide adequate income support for all, have low levels of corruption, high levels of employment, and healthier greener natural environments (Diener et al., 2015). What is good for the collective appears to be good for individuals. Individuals also value wellbeing and the state could do more to assist people construct and maintain a life of value and meaning and these efforts may reduce the economic burden on the healthcare system as people who report high wellbeing live longer, happier and healthier and more social lives (Diener & Oishi; Diener et al., 2015).

Based on the cultural knowledge that independence is essential to being a good citizen, the aims of rehabilitation currently seem to be to return a person to being a productive, independent member of society. However, it could perhaps be a site for social change (Fadyl et al., 2019) if there was acknowledgement of the structural and systemic influences on how people can be supported to manage within the collective (Malfitano, Whiteford, et al., 2019). That is, if interventions, treatments, services,

policies, advocacy and supports for managing could aim for goals like increasing quality of life and participation (Fadyl et al., 2019) and on being and becoming as a person, as well as being busy and productive with the doing (Wilcock, 1999).

One approach going forward could be to focus research efforts on population level determinants of health such as how social structures impact health or the built environment, rather than individual attributes (Glass & McAtee, 2006). One justification for the proposed refocusing is that interventions that aim to change individual behaviours are usually unsuccessful, as behaviours often occur in clusters or patterns that influence each other (Short & Mollborn, 2015). Patterns of behaviour are shared in families, communities and cultures and are shaped by all levels of society and the environment (Short & Mollborn, 2015). Intergenerational patterns have been shown to influence genetic activity and so addictions, trauma or unhealthy lifestyles may be passed on (Short & Mollborn, 2015) in the absence of mitigating factors. Additionally, it is important to consider a person's age when worldwide events occur, such as a global recession or pandemic, the cumulative effects of events, stressors and illnesses, and the number and frequency of occurrence of positive or negative factors (Glass & McAtee, 2006).

The self-help movement influencing cultural knowledge

Health promotion is currently aimed at those who are assumed to be lacking the right knowledge to choose correctly and require education or are in risky circumstances and therefore require protection (Abel & Frohlich, 2012). However, according to Sen's capability approach, if people are to have access to a range of options for self-managing, then their lack of capital, their ability to convert capital into health, and the societal forces that create their preferences must all be addressed (Abel & Frohlich, 2012). Moderating that claim, the capability approach has been critiqued for not considering how individuals are able to resist the pressure from their cultural collective to conform to acceptable ways of acting, leading to the conclusion that the focus of

intervention should be on creating capital and not personal factors (Abel & Frohlich, 2012).

Irrespective of these perspectives, mainstream self-help movement is underpinned by western psychological thinking focusing on the self-improvement of the person rather than seeing people as the product of social and cultural influences (Rimke, 2000) and connected to a collective with the associated sense of belonging (Knabb et al., 2012). The self-help movement is based on the belief that the application of psychological theory and self-help techniques results in feeling happy, well and normal (Rimke, 2000). The individual is viewed as responsible for success or failure in the pursuit of achievable happiness (Rimke, 2000) which is underpinned by autonomy (Knabb et al., 2012). Independence is highly valued, while interdependence is seen as shameful and weak (Knabb et al., 2012). Good citizens then, are responsible for themselves and this responsibility is rewarded (Malfitano, Whiteford, et al., 2019). It is the person who is perceived as the problem (Rimke, 2000) rather than isolation from the connectedness and community from others (Knabb et al., 2012) or an unaccommodating system (Kendall et al., 2011).

The continuation of these mainstream perspectives of self-help is supported by ideas taken up in the 1980s, when a lot of health promotion policy was developed. The ideas promulgated about healthy lifestyles were picked up by the media, with benefits promoted for the individual but also for society (Ayo, 2012). People were swamped with guidelines, recommendations, diets, ‘health’ foods, exercise regimes, sports equipment, and supplements from self-proclaimed experts for citizens to ‘choose’ from and purchase (Ayo, 2012). So the individual, their body and “good” or “bad” choices they freely made without state interference became the target, rather than social determinants of health as recommended by the Ottawa and Bangkok Charters (Ayo, 2012; Potvin & Jones, 2011). Not only were people with long-term conditions viewed as having made poor choices, but there was and perhaps still is, the expectation that they

should follow these recommendations regardless of the limitations placed on them by their health condition and social position.

The assumption that good choices result in health and wellbeing and societal monetary savings is mirrored in the self-management literature (Kendall et al., 2011). This sort of thinking positions the person with the condition as a drain on healthcare (Kendall et al., 2011). Noncompliance is deviant and problematic and reduces a person's right to services (Kendall et al., 2011). People have choices, but if their way of managing is different to professional views of self-management then it is discouraged. This sort of approach has been said to further increase inequalities rather than address them (Kendall et al., 2011), an irony not acknowledged by many in the mainstream self-management literature.

Inequalities in New Zealand

Some health disparities are not explained only by socioeconomic status but independently by ethnicity. New Zealand is a colonised nation with a history of institutional racism, including within health institutions (Came & Griffith, 2018). Indeed, despite the existence of Te Tiriti o Waitangi, which established a legal obligation to protect Māori health, Māori are worse off, on almost all indicators measured, than first nation peoples of the USA (Bramley et al., 2005).

Like other countries, New Zealand politics has been greatly influenced by neoliberal thinking (Ericson et al., 2000), which places responsibility with individuals and has one white system or approach that is applied to all people. Increased funding to the top of society is assumed to trickle down to those below (Came & Griffith, 2018). Good citizens are able to regulate their behaviour, share resources with others, take responsibility for educating themselves, and take well considered risks with minimal state intervention (Ericson et al., 2000). Any inequalities are seen as personal choice not to self-govern in the 'correct' way (Ericson et al., 2000). Although there was some governmental softening of the neoliberal approach from the mid-1990s, when District

Health Boards were required to address and reduce health disparities, this form of thinking is still pervasive in self-management (Tobias et al., 2009). A number of strategy documents were published around this time, the New Zealand Public Health and Disability Act, the New Zealand Health Strategy and He Korowai Oranga (Maori health strategy) (Tobias et al., 2009) which should provide clear legal and moral obligations to address health inequities. It could be that the healthcare system is to blame for a lack of adherence to the instructions of professionals rather than the individual person (WHO, 2002).

Conclusion

Healthcare professionals and scholars could more actively examine the form and impact of neoliberal ideologies on everyday life, access to health and healthcare and as an underpinning philosophy for rehabilitation and self-management (Malfitano, Whiteford, et al., 2019). A focus on individuals and their bodies, where people live and the people they interact with daily, and the structures, ideologies and inequalities of the system requires a flexible and broad vision. Interventions would be required for all levels; changing what individual people do, what clinicians do within a system that also requires change and changing, and what the collective does, values and believes. Managing requires a range of programmes, assistance and advocacy when navigating services and systems. It also requires thinking about how the layers of society interact with each other and through time influencing what people do, and full circle back to the clinician-stroke survivor relationship and how influential the way in which support is enacted, could be at a time of disruption (Fadyl et al., 2019). Such changes are imperative, especially if support to manage was aimed at supporting individuals and societies to flourish. Interventions going forward need to be designed in partnership with stroke survivors. A sense of control and empowerment seems necessary alongside a response to stroke which is in alignment with values, beliefs and priorities of stroke survivors.

The next chapter outlines the methodology by which I examined my longitudinal data. It was based on the 6-month analysis and my reading of sensitising concepts, and the perspectives examined in this literature review chapter. Participants were purposively selected based on these understandings.

Chapter Nine: Layer 3 methodology and methods longitudinal study

The aims of the longitudinal analysis were to identify and extend the strategies and ways of coping that the participants developed in order to reconstruct a meaningful life. Interpretation focused on how people coped following stroke and developed strategies for managing on a day-to-day basis to continue or facilitate recovery. Analysis aimed to produce interpretations that pointed to ways forward for clinicians to support stroke survivors to manage. Therefore, the research question for layer 3 was – what happens over time in response to biographical disruption after stroke. I begin this chapter by discussing interpretive description as methodology, then I provide the reasons for changing my analysis approach and outline the methods used for this part of the thesis.

Overview of Interpretive Description

For analysis of the longitudinal data, I applied Sally Thorne's interpretive description. Interpretive description is based on the same social construction paradigm located within a pragmatist view of the nature of reality (Morse & Stern, 2009, p. 536) that underpins my thesis. Both qualitative description and interpretive description are concerned with creating knowledge that can be immediately used in a practice setting. Qualitative description is about discovering what is happening, the "dimensions of the concept" being investigated and its variations, asking who, what and where questions of the data and experience (Sandelowski, 2000). Interpretive description focuses more on the 'so what?' (Thorne, 2008) and aims to discover how the concepts relate to each other, the patterns and how they work.

Interpretive description was developed by Sally Thorne to answer complex practice questions about experiences of using, delivering, and thinking about nursing services, which is "interpretive or explanatory" (Thorne, Kirkham, & O'Flynn-Magee, 2004, p. 2). Research questions focus on ways of addressing participant problems versus understanding more about their experience (Thorne, Paterson, et al., 2002). For

example, Henderson and Jackson (2004) used an interpretive description methodology to understand the health needs of young women who had experienced childhood trauma and deprivation, rather than the experience of trauma itself. Like other 'non-categorical' methodologies, interpretive description arose out of research where the usefulness and applicability of the findings to real world practice was limited when traditional methodologies were used (Thorne et al., 2004). Like qualitative description the roots for interpretive description can be found in nursing research (Morse, 1989), and it has also been used in diverse fields such as sport (Clark, Spence, & Holt, 2011) tourism education (Buissink-Smith & McIntosh, 2001) and public health (Burnett & Corlett, 2017).

Interpretive description is a flexible methodology that allows the researcher to draw critically from other methodological and analytical traditions. This is done with the understanding that the purpose of the research is to directly impact on practice and answer practice questions such as how can health professionals best support people to manage after stroke? Traditional, or what some would consider 'pure', methodologies are also contextual and emerged from certain times and beliefs about knowledge. Strict adherence to traditional methodologies can place value on the methods rather than the clinical problem that prompted the question (Chamberlain, 2000; Thorne, 2008). The interpretive description approach frees the researcher from rigidity regarding methods but retains quality to construct an approach that will answer a question within the context from which it has emerged (Crotty, 1998).

The development of interpretive description methodology gave a name, structure and alternative to the ideological dilemmas and confusion Sally Thorne and colleagues found in a methodological review of social science literature (Thorne et al., 2002). Researchers with an applied science background used their discipline specific theoretical literature as sensitising concepts and ways of thinking about data and phenomena, rather than as underpinning methodology (Thorne et al., 2002). Thorne

talks about the need for the findings of interpretive description research to pass the 'thoughtful clinician test' (Thorne, 2008) where the interpretations and insights make intuitive sense to those experienced in the relevant field, and confirm, clarify, and shed new light on practice problems (Thorne, 2004). As interpretive description is a methodology designed to increase knowledge of complex clinical issues, produce potential solutions and useful interventions, raise new questions and is flexible in light of emerging data, I considered it to be the most appropriate to address the aims of my longitudinal study (Morse, 2010; Thorne, 2008).

Interpretive description can be oriented within the qualitative description category with interpretation being further developed to ensure practice insights are achieved (Hunt, 2009). In the analysis for this longitudinal study, I aimed for a deeper level of interpretation, which transformed selected transcripts into narratives, and I hope exposed some of the strategies and ways of coping people use or develop to manage after stroke and get on with or back to living their lives. Interpretive description also differs from qualitative description in terms of the increased relevance and emphasis of disciplinary grounding, that is, the philosophical history, influences and stance which influences research questions and design (Thorne, 2008). Interpretive description involves synthesizing findings with literature and current knowledge, and re-contextualising findings to the relevant practice setting (Neergaard et al., 2009, p. 53).

Although I have talked about qualitative description and interpretive description as separate and distinct methodologies, research in the real world does not map onto clear and clean classifications. In 'reality' the overlap and lines are blurred, and probably qualitative description and interpretive description are more similar than different (Sandelowski, 2010).

An Interpretive Description Methodology

An interpretive description study is underpinned by seven principles as outlined in Thorne's (2008) text.

1. A respectful space for participants

   The research took place in a place of participants' choosing, using a conversational style of interviewing to create a safe, comfortable, and respectful space for participants to share their stories.

2. Participants' stories are valued

   In order to shed light on the clinical question I sought and valued participants' perspectives and stories about their experience.

3. Retaining idiosyncrasies

   My research aimed to identify and construct stories that were common to many participants as well as outliers. Data and findings were constructed that reflected important themes common to managing after stroke but also retained the idiosyncrasies and complexities of the individual participant's circumstances.

4. Stories for the clinical mind

   Stories were constructed that can be applied by the 'clinical mind' in practice going forward, which also reflects participants' context and the moment in time in their journey.

5. Socially constructed experience

   All experience is socially constructed and viewed through the lens of experience; all views are partial with the whole illusive to all.

6. Contradiction and change

Contradiction and change were a feature of participants' stories. The construction of their experience is multi-layered, and not all understandings and meanings are stable over time. My longitudinal qualitative study allowed for the examination of the layered and changing nature of experience and the re-storying over time.

7. Co-constructing data

   The researcher influences and co-constructs data with participants. The participants and their stories are inextricably linked. The interpretive description researcher examines the practicalities and strategies of everyday life that may shift after a significant event and over time.

Justification of a longitudinal approach

Dewey's position that knowledge is uncertain and changes over time supports a longitudinal study in which participants are interviewed at different timepoints after a stroke. People have habitual ways of feeling, thinking, and acting that are repeated through time. Qualitative longitudinal work enables examination of 'transitions' and their meanings from the perspective of the person experiencing them, the identification of 'turning points', and 'epiphanies' (Millar, 2007). It may reveal the thinking behind decisions to act or respond to events, and choices made (Millar, 2007). Not all transitions are significant, and they can be viewed differently after the passage of time. Talking to people over long periods of time "helps us to understand how people cope, manage and adapt to their situation, which may also be relevant to understanding the longer-term trajectories that are experienced by individuals and social groups" (Millar, 2007, p. 536). It is a design for revealing how participants talk about how they 'choose' to act and how their circumstances create or constrain their thinking and acting.

Methods longitudinal analysis

Interview questions for this longitudinal analysis were developed based on my experiences working in stroke services as an occupational therapist, the literature, sensitising concepts, and early analysis. For this part of the analysis I drew on multiple theories, such as capability approach, health capability model, Bandura's social cognitive theory and Wilcock's occupational perspective of health, and texts to "think with theory" as a way of examining the complexity and contribution of context and social relationships to managing (Jackson & Mazzei, 2013, p. 261). Texts were the data co-constructed during interviews, memos about different aspects of the analysis, qualitative literature, reviewer comments, my memories of the interviews and past clients, my personal and professional knowledge of the field, and discussions with colleagues (Jackson & Mazzei, 2013). I looked for connections, alignment, and difference, tested organising frameworks, and tried out theory informed questioning during data construction (Jackson & Mazzei, 2013).

Using theory enabled me to think beyond and deeper than practical everyday strategies of doing, which were not central to managing after stroke and could have distracted me from co-constructing knowledge valuable to practice. Rather than listing and organising strategies by type or utility, I also asked questions of the data about why some participants managed and some did not. I thought about what underpinned the type and use of strategies, the type of voice participants used and how that came to be. Although questions about socioeconomic status, for example, were not on the interview guide, through thinking and analysing with theory, contextual influences became more visible to me (Jackson & Mazzei, 2013). These concepts also helped to explain and added to my lens. I alternated multiple readings of interview transcripts and theory (Jackson & Mazzei, 2013). It felt important to try and move beyond what is already 'known' in terms of the challenges people face in the aftermath of stroke, to how rehabilitation and self-management can support people to meet challenges

(Pearce et al., 2015). Data, theory, and method together helped me to know what I think, to think differently and move beyond static usual practice when needed (Jackson & Mazzei, 2013).

Rationale for focusing on a sub-sample of participants for the longitudinal analysis

Given the large number of participants used for layers one and two, I was faced with many storylines and themes that I could have pursued for the longitudinal analysis. This was initially a distraction as I tried to hold all possibilities in my head, after coding the multiple interviews for the first few participants. I realised that it would not be possible to analyse the data for all participants in a meaningful way over time. In order to select a subset of participants I identified the key threads that were relevant to my research question and sensitising concepts (St. Pierre & Jackson, 2014) I then decided to purposively select participants who were articulate about converting economic, social, and cultural capital into managing. I drew on my sensitising concepts to think about which participants experiences were good differential examples of managing after stroke based on what participants had described at 6-months that they yearned for, what they felt was missing and prevented them from managing. I looked for the presence or absence of capabilities, experiences, enjoyment, and pleasure in life or when this was missing from stories. I also looked for a sense of purpose to participants' doing and managing, as well as unfulfilled potential and contribution. As I was attempting to create clinically applicable ideas from the analysis of the challenges of managing through time, I selected a methodology that would help me rethink everything I thought I knew about managing after stroke.

Selecting a sub-sample of participants helped me to identify and explore managing after stroke in greater depth. Theory helped me see which data could go towards shedding light on my research questions (St. Pierre & Jackson, 2014). Using theory to think, construct interview questions and data, and during analysis is not one particular method but involves repeated and careful reading of data and theory before creating a

theoretical scaffolding. Methods then, consist of a number of analytical techniques (St. Pierre & Jackson, 2014) to use in conjunction with, and guided by, the methodological scaffolding.

Sampling

Interpretive description is a methodology that can be conducted on any sample size; however 5-30 participants is usual (Thorne, 2008). Twelve participants for this longitudinal study were selected from the main study using purposeful (Bradshaw et al., 2017) and theoretical methods, in keeping with the methodology. Participants were those who spoke particularly insightfully and articulately about important aspects of managing after stroke (Hunt, 2009; Thorne, 2004). These participants were able to tell rich stories detailing much information about managing after stroke (Malterud et al., 2016). A smaller sample size is used in interpretive description to enable sufficient exploration of implicit concepts and ideas, so that patterns can be identified, and knowledge be created that contributes to clinical understandings (Thorne, 2004).

As I had co-constructed much of the data and played a key part in early analysis, I had an idea of potential patterns and characteristics that may be helpful for answering my question. I created a table of all the participants in the main study, detailing some demographic information, how many times they were interviewed, who coded their transcripts, if they had nominated a significant other, if interviews were conducted as a dyad or separately and some preliminary analytical notes pertaining to my research questions (appendix F). I selected purposively from this list for my longitudinal study.

Data construction: gathering with participants

The data used for the longitudinal analysis included transcripts of semi structured interviews ranging between 30-90 mins. The interviews had been conducted at 6-, 12-, 24- and 36-months post-stroke. Interviews were conducted at a location chosen by participants, most often their home. Verbal consent was re-sought at the beginning of every follow up interview, in the phone call to arrange the interview and in person prior

to turning on the recorder and taking notes. If nominated, a significant other was sometimes present for support and to also participate in the interview, if consenting. Participant dyads were interviewed together or separately, according to the stroke survivor's preference. I kept a record of all analytical decisions and processes in order to create a transparent and full audit trail (Heaton, 2008). Interviews involved asking participants to look back and reflect on changes since the stroke and the previous interview, as well as look forward, goals for the future, and think about what the future may hold Walker and Leisering, 1998 in (Millar, 2007).

Whilst the 6-month interviews had been analysed for layers one and two, the data were coded afresh and used to inform the longitudinal analysis to determine how the person's experience in the later interviewers mirrored or changed from their 6-month interview. Analytical memos assisted this process (appendix G). To be able to look at the data with fresh eyes, I utilised a range of analysis tools to gain enough distance to move from summary and description to interpretation and application (Richards, 1998). The distance was significantly more difficult to achieve than the closeness, and distance was required for abstraction and moving to a level of awareness that is not possible for participants, who could not do the analysis for me via theoretically driven questioning (Richards, 1998). Closeness was required initially in order to take account of the participants' context which was so essential to working out what underpinned managing or not managing and was not necessarily overtly recorded in the transcripts (Richards, 1998).

I returned to my sensitising concepts to think about them more deeply and looked for recent publications in the self-management literature. I also looked for different analysis tools to assist me to see the stories through new ideas. Coding can involve both separating themes from transcripts into separate categories (Maxwell, 2008) as well as examining the whole story. Looking for connections, relationships and sequences within the whole can be helpful for illuminating the influence of events, ideas, and

actions, on one another (Maxwell, 2008). Both types of coding are particularly useful when trying to understand the things that people respond to and how they respond (Elliott, 2005).

The first of these analysis tools was to create a “longitudinal qualitative data summary matrix” so that I could separate themes from the transcripts and create separate categories (Saldana, 2013, p. 235). Data from the four interview time points were arranged into a matrix for each participant (see appendix I for an example) to determine how self-management strategies changed over time to identify any patterns, whether some are abandoned or added later (Audulv et al., 2012; Saldana, 2013) and organised by time points, type of strategy, or the tasks being managed (Audulv, 2013). Coding involved looking for storylines, turning points, how and when strategies and ways of coping emerged and the context from which they appeared to arise (Saldana, 2013). Analysis identified patterns of self-management behaviours – some being consistent, others being when needed, episodic, or transitional.

The matrices were compared and contrasted with other participants and synthesized (Audulv et al., 2012). Analysis was cross-sectional to capture what is happening at each time point between participants and longitudinal to account for time and change within each narrative (Calman et al., 2013). I also used analytic memos (Ayres et al., 2003) to ask questions such as - what stories are re-told and what does the re-telling do?

The next analysis tool I employed was used to create the distance needed to examine whole stories. A narrative approach can be both method and methodology. The story itself can be studied but also it can be a method for studying experiences (Moen, 2006). As a method it can be underpinned by social construction as we tell ourselves stories as a way of making sense of the world that we learn about through social interactions with others (Moen, 2006). The past and present can be made sense of via narratives and reflect our values and feelings about experiences (Moen, 2006).

“Deriving narrative from transcripts” for this stage of my analysis involved identifying and highlighting all of the text relating to the storyline or theme (Caelli et al., 2003, p. 278) identified from the matrices. To do this I converted each transcript into a story (see appendix H for an example) by arranging events into an approximate chronological order that allowed me to view both the sections of transcript and the whole story as units of analysis (Daiute & Lightfoot, 2004).

Using the participants’ words, as far as possible the story was condensed by removing repetition, correcting grammatical errors, and finishing or deleting incomplete sentences. I removed any rapport building conversation and small talk or interruptions such as the telephone ringing, which were not directly connected to the interview, allowing me to start to view the transcript and story as a whole. I then removed my voice from the transcript, occasionally adding a few words to what remained so that the sections of text made sense. Creating a chronology of stories from the transcripts made a deeper reading more possible and assisted in identifying changes across the time points. Each time point was coded separately and in sequential order initially and then compared to reveal changes.

I also wrote memos and reflections in my field notes about what I was reading at the time, to keep track of how sensitising concepts, stroke self-management literature and theoretical testing impacted on how I co-constructed the interviews and data. Microsoft excel was used to help organise and manage the data and code books from the stories see appendix J. I was finding NVivo constricting and constraining during this longitudinal analysis, with codes created in the early part of the analysis for the Stroke Experience Study distracting me from developing new codes. I needed to move away from NVivo (to excel) so that I could see the data as something more or different (Richards, 1998).

Presentation of findings

Interpretive description findings are located within relevant literature, acknowledging that interpretations and conclusions are filtered through existing understandings but with the hope of contributing something new (Thille & Russell, 2010). Therefore, concepts and theory that are congruent with ideas generated during analysis are threaded through as appropriate. Once I had constructed four themes and had begun the process of selecting quotes as examples and evidence to support my analysis, I became frustrated that the short quotes did not reflect the complexity of the process of managing and my participants' context. I returned to the narrative as method literature. Each participant had two or three dominant themes or story lines that characterised and reflected their story and I recorded these on my analysis matrices. I chose one participant for each theme or category (Polkinghorne, 1995) and condensed the data relating to that theme, into one short narrative to support understanding of the theme.

Rigour: Quality Considerations for Interpretive Description Research

Thorne (2016) takes a 'grounded approach' to rigour and does not see checklists and guidelines as sufficient for guaranteeing excellence, instead it is important to establish whether a study has demonstrated the hallmarks of credibility and coherence. For Thorne, a great qualitative description study inspires the clinical imagination. I can now see new possibilities in how stroke services could conceptualize helping people to manage. This doctoral work offers in-depth understandings and enriches knowledge about managing that enhances what is known. I set out the logic from my research question through to the conclusions, and addressed whether it has added an original and meaningful contribution to what is already thought to be known.

Moral defensibility

In health research there is a risk of something finding its way into practice which is not beneficial to clients and the collective to which they belong (Thorne, 2016). There is a special kind of moral obligation to consider how findings might be interpreted and used.

I initially thought I was going to be adding stroke specific knowledge to existing self-management programmes, but quite quickly realised that it would not be helpful to do so, in fact it could mean further disadvantage to the disadvantaged and those without adequate resources. Continuing to work in the same way, with the people who more or less manage anyway and are able to convert their resources into health and wellbeing, was not helpful for finding ways to enable stroke survivors to flourish. So, I had a moral obligation to try to really see the barriers participants faced. I considered the possible uses of my findings, who and how they will benefit. This concern led me to parts of the literature which enabled me to take a more critical view of managing and ask my data what the conditions are that underpin managing?

Pragmatic obligation

To commence, interpretive description research agreement about what is seen to be real and valid is needed. The axiological, ontological and epistemology for this research was developed prior to starting the study, which is outlined in this chapter and chapter 9. These philosophical positions and how they reveal what is true enough and what is worth knowing, are made explicit. There is an assumption that knowledge generated by Interpretive Description studies will be applied in a practice setting. Therefore, findings that will improve services and outcomes for potential recipients of practices changed or enhanced by these findings must do good, or at least do no harm. Scholars working in the field of managing chronic illness, disability, and other disadvantages emphasise that this work is at least partly about rights and are calling for social change, which is addressed in this thesis with the explicit intention to illuminate that change is needed (Henderson & Jackson, 2004; Ruger, 2010).

Epistemological integrity

A transparent, logical line of reasoning is required from the assumptions made about the nature of knowledge to the methodology which influences decisions about how the study will be operationalised (Thorne, 2016). This can be found in chapters 2, 4 and 9,

which outline the ontology, epistemology, and how they informed the methodology and methods, for each layer of this research.

Credibility

I used crystallisation as a framework for ensuring *credibility*. Crystallisation is a process, starting with understanding your own worldview, and an openness to seeing the world from other perspectives (Sandelowski, 1995; Stewart et al., 2017). The first step then, as a novice researcher, was to attempt to understand myself, my occupational therapy disciplinary lens, and experience of working with people after stroke (Stewart et al., 2017) which I explored in supervision and through writing memos. A crystal, as a metaphor for acknowledging shifting, evolving and unstable subjectivity, which is constructed via language, does not have well defined, visible set boundaries (Richardson & St. Pierre, 2000). My research then did not attempt to uncover the truth; rather it aimed to illuminate complexity, and achieve a deeper, although incomplete, understanding (Richardson & St. Pierre, 2000).

Crystallisation involves the researcher engaging with multiple forms of data, analysis, and representation of findings (Ellingson, 2014). Therefore, I analysed data co-constructed between myself and multiple participants at multiple time points. I completed concurrent data collection and analysis, using multiple analysis tools. Data are represented in different formats in the three findings chapters, with literature and theory woven through (Ellingson, 2014) to form the layers of this thesis.

Data collection and analysis occurred together, and I wrote memos and used writing as a form of data collection and analysis (Richardson & St. Pierre, 2000). These additional tools captured that which was not in transcripts or field notes, the thinking and ideas in the researcher's mind, which are collected via writing (Richardson & St. Pierre, 2000). Writing is thinking and a process which is integral to analysis rather than something that happens later in the research process, and I engaged in this practice from the beginning of the study (Richardson & St. Pierre, 2000; Sandelowski & Leeman, 2012).

I was aware that I needed to provide thick descriptions of my analysis and quotes as practical examples of that analysis. In addition, for the longitudinal analysis, I condensed whole transcripts (cutting out interviewer questions) to focus on the participants' stories.

Analytic logic

Analytic logic was achieved by careful and honest documentation of my methods and the challenges encountered over the course of this research, such as those detailed in chapter four. All research decisions were recorded and documented throughout my research process to ensure transparency. Justifications for decisions were articulated, such as the need to move from NVivo to excel during the third layer of this research, as detailed in chapter 4.

Interpretive authority

I constructed sufficient information from the data before developing metaphors, and the names of codes, themes, and chapters. If the theory I was testing did not fit what I was reading and coding, then I discarded it. I consulted with the community reference group set up for the main study, in the course of which I especially worked with a member who has lived experience of stroke. I had many long conversations with them about what I thought I was seeing in the data and what they could see as a member of a different profession.

Professions such as occupational therapy tend to believe that all knowledge is potentially applicable, especially when it is about doing or engaging in occupation. I hope that from my descriptions of the ordinary and everyday thinking, feeling and doing of participants it may be possible for the reader to see the ordinary, habitual and routine as transformative. The findings of my study revealed the everyday strategies and ways of thinking that enabled managing stemming from and embedded into the context in which participants were trying to manage.

Coherence is demonstrated by the philosophical congruence of my theoretical framework, methodology and methods. My literature reviews set the scene for my research question and each layer of this doctoral work and underpin interpretation of the findings. Also, the study's conclusions and recommendations address problems, omissions, and debate in the self-management literature.

What the researcher believes about knowledge or what there is to know and how to acquire it are important to think about when designing research. I aligned my study design with my disciplinary lens and way of thinking to illuminate and give confidence of the reasoning behind it, and relevance of the recommendations (Thorne et al., 2016). One of the functions of theory in Qualitative Descriptive research is to provide the ontological and epistemological perspectives of the researchers' profession as the foundations of the research (Sandelowski, 1993) and this is outlined earlier in this chapter.

Disciplinary relevance

As Thorne emphasises, it was not enough to follow methodology and methods correctly. Rather, the knowledge sought must in some way contribute to ongoing developments in stroke rehabilitation. Accordingly, I did not ask participants about their experiences of stroke. I asked them about how they were responding to stroke, and what did they did to manage stroke. The findings have potential to make a novel contribution to the field of managing after stroke. Caveats to that claim include acknowledging that new knowledge is always located within society which constructed it. The findings were generated from thinking and memos written from my own perspective, my experience, as well as my occupational therapy and occupational science lenses. Thus, the findings need to be viewed as contextualised in the socially constructed reality of knowledge and practices in early 21st century New Zealand. Thorne (2016) also urges researchers to recognise that while there is not an absolute truth, we do search for and report probable truths. Interpretive description methodology

can only create meaning rather than truth. The “truth” revealed in this study is what it means to try and manage stroke in New Zealand’s largest city.

Conclusion

Interpretive description is a qualitative methodology that aims to produce practical solutions to problems encountered in real work practice. It is appropriate for the research aim of understanding how people manage following stroke over time to enable clinicians to work with people post-stroke more effectively. This longitudinal study seeks to understand how people layer and construct their managing, and how clinicians might best support their efforts. Several methods and analysis tools were employed to enable analysis of data between participants and across multiple time points providing alternative ways of viewing managing after stroke.

In this chapter I have outlined the methodology and methods for the longitudinal study within this thesis. The methodology and methods were different to the first two phases, being longitudinal and aiming to create practice ready insights via deeper interpretation. The next chapter reports on the findings produced as a result of this interpretive study.

Chapter ten: Layer three findings: Part A

Thinking about how to manage after stroke

"I wish I didn't have a stroke, but I am good"

The 6-month stories outlined in the previous findings' chapters (chapters 5 and 7) were dominated by feelings, by 12-months and onwards participant's thoughts and ways of acting played a more important role. Two key overarching themes emerged from the longitudinal analysis:

A) Thinking about how to manage after stroke

B) Acting to manage stroke and flourish

To enable the nuances of each of them to be explored in sufficient detail and to advance our understanding of managing post stroke, each is explored within its own findings chapter. This chapter integrates data from all four time points from the participants in this study to illustrate what happened over time in their thinking about how to manage after stroke. The time points at which the data collection occurred were chosen to enable sufficient time to have passed between each timepoint to enable differences to be identified. However, this should not give a false sense of structure to the development of strategies and ways of coping. The actual changes participants went through were an ongoing forward and back, complex journey of responding to feelings of disruption by rethinking how they managed their everyday lives and actions that they took in response.

The disruption of stroke, which combined with the person's circumstances, occupational history, and resources, resulted in the situations that needed to be managed, which were ongoing over the three years I followed participants. Feelings arose, then came the thinking work where some of the disruption started to be processed, mitigated, and managed. Actions and practical strategies flowed from the thinking work done by participants and will be explored in the next findings chapter (chapter 11). The cognitive processing or ways of thinking were also strategies, in and

of themselves, both conscious and unconscious. Feeling, thinking, and acting occurred within the participants' context that both created and constrained managing after stroke. Themes from layers one and two are threaded through these findings to illustrate changes through time and are indicated by the use of italics.

Participants: Longitudinal study part A

Seven stroke survivors and five significant others were purposively sampled from the larger dataset including, five men and seven women for the whole longitudinal study. Participant characteristics for this findings chapter part A are detailed in Table 3 below.

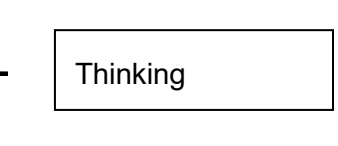
Table 3 *Participant characteristics Findings: Part A longitudinal study*

Participant, Age	Interviews	Theoretical and purposive sampling	Storyline
Michael 48 years and wife Jenny	Interviewed separately at 6-months, together at 12-, 24-, 36-months	Limited resources	No causal model
Linda 60 years	Interviewed at 6-,12-, 24- and 36-months	Cognitive strategies Set goals and steps to achievement (Bandura, 1991)	Causal model re-storied through time
John 59 years	Interviewed at 12-, 24-, 36-months	Mild cognitive impairment Being (Wilcock, 1999)	Acceptance and hope can co-exist

Key themes: Thinking about how to manage after stroke

There were two sub-themes in relation to the role of people's thought processes on how people managed after stroke.

1. Managing by forming a causal model
2. Managing ambiguity and becoming attuned



Participants described formulating an individualised *causal model* for their stroke which was a necessary basis for becoming *attuned* to their bodies and needs. Once they thought differently about how they were going to move forward, the ability to tolerate uncertainty and *ambiguity* grew. See Figure 6.

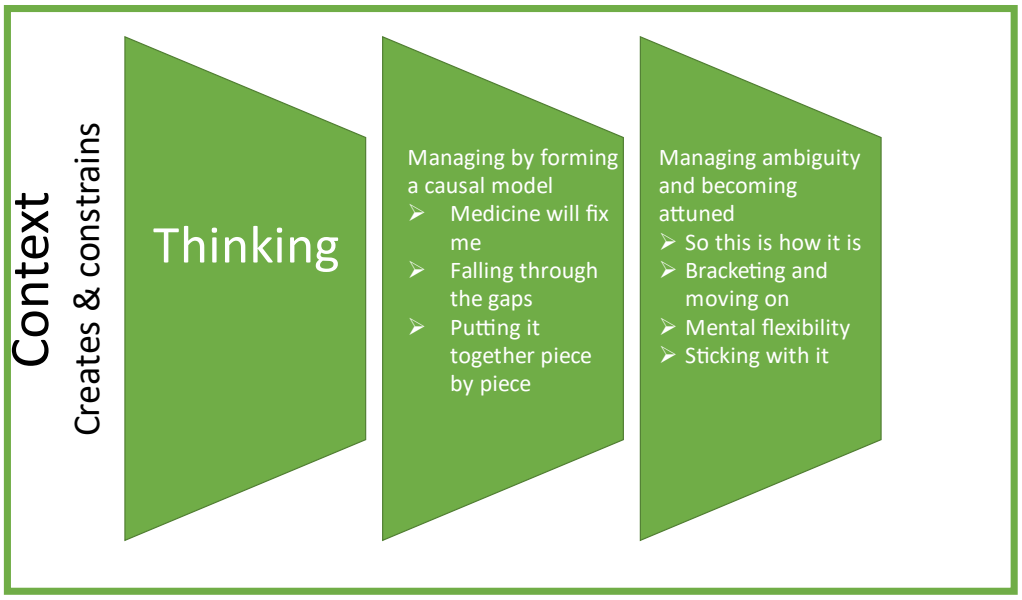


Figure 6 *Thinking strategies which underpin managing, created and constrained by the stroke survivor's context.*

Stroke challenged what people thought they knew about themselves and how the world works, their beliefs about the role of rehabilitation, recovery, and what a legitimate illness looks like. Active, reflective examination of these personal and cultural beliefs was required in light of new and contradictory evidence in order to move forward and manage (Dewey, 1997). First, participants experienced shock and doubt as beliefs were challenged, they searched their prior knowledge and experiences for explanations and comparisons, in order to solve the present problem. The problem caused them to pause, and all possible solutions that came to mind were compared against prior experience and beliefs. How the problem was defined, based on the person's causal model of stroke, determined the end point and the process of problem solving (Dewey, 1997). This process required work, energy, and the ability to tolerate uncertainty.

Problems such as stroke come out of the blue and people did not have a basis to draw on, leading to confusion.

Managing by forming a causal model

Chapter five outlined participants' feeling, thinking, and acting on the foundation of a personalised causal model for their stroke at the 6-month interviews. Four themes were constructed exploring the need for acknowledgement, person centred services, a causal model, and ongoing services. At that time participants were feeling disrupted and not able to think of what to do in response to their stroke and the need to manage alone. Their cultural knowledge was disrupted, relevant information was not available, and they were often managing multiple conditions. Previous ways of thinking and problem solving were not always helpful. Tentative models were constructed by some participants who were able to tolerate some ambiguity and move on. Others appeared stuck and were paralysed by the lack of a causal model, information, and support. The causative model formed by some participants was used to assess if professional advice was going to be helpful.

The realisation that not only does medicine not have all the answers in relation to the cause of stroke, but it also cannot fix it, became another problematic situation to manage. Participants did not expect to have a stroke, nor did they expect that there were not services to support recovery and managing. Without ongoing support and services participants felt abandoned and disillusioned. Going forward from the feeling, thinking, and acting work done at the 6-month time point, some participants were able to look beyond traditional medicine because they felt that they *mattered* and had the *resources* to underpin the search for finding what is out there as a substitute for stroke services.

Medicine will fix me

Over the three years data was co-constructed with participants, participants described a gradual realisation that there was no medical 'cure' for stroke. Some things are unknown and will remain so and it is up to them to find a way forward. For some participants the problem of developing a causal model and believing that medicine and rehabilitation have the answers was not resolved and they felt stuck and unable to find a way forward alone. No plan of action could be formulated (Hébert, 2015) without the underpinning model of causation. Letting go of the cultural knowledge that medicine was able to fix their stroke was balanced and in tension with the feeling that there should be much more that is possible in terms of recovery. Participants searched for alternative treatments, and it seemed important to try and do everything possible.

The following stories are drawn from a participant and his significant other, who developed a causal model prior to the 6-month interview but some aspects remained unknown. The feeling that they *did not matter* persisted, nor did they have the *resources* required to find their own way easily.

6-months after stroke

> *We were painting the house over the whole weekend. He felt sick from Tuesday-ish and then had the stroke on the Friday. The stroke doctor at the hospital said it was from having his head back all day painting all the eaves and the surfeits. (Jenny)*
>
> *I used to work seventy hours a week and then on the weekends I'd go hard around the home. That's part of the reason I'm in this predicament. I didn't know how to slow down. Over Christmas I had neck stress, and I should have got that sorted out. A lot of the answers from doctors were 'it's partly your condition' I still don't know what my condition is apart from I had a stroke. It's not going to fix itself overnight. But all that sort of stuff should have been done by rehab. They're meant to be specialists. Otherwise we self-diagnose. (Michael, 48 years)*
>
> *He come home and started going swimming and going to the gym. It was a case of take it upon yourself to do it. I suppose we were lucky we went to the doctor and he got his green prescription and it was a bit cheaper. He loves welding and doing a bit of woodwork and I asked him to build some stuff for work. He said no I can't, and I thought 'well you know I think we need to start giving things a go.' Because it's a*

real big confidence thing too. But I don't want him to overdo it because something might happen. (Jenny)

I just went down there and kept my body moving and 'cause they said you got to use it otherwise it will stop. I've talked to a lot of people that have had strokes as well and they said 'don't sit around'. There's not really a lot out there for stroke victims that I've found. Unless you come to somewhere like the neuro clinic, you don't find out about stuff. (Michael, 48 years)

Falling through the gaps

Participants described the experience of discovering there were limited or no services available to support them in managing the consequences of stroke, as *falling through the gaps*. They thought it was unfair after paying taxes over a lifetime, that the expected free services and formal supports did not exist. Services and programmes they did find, were at times not conveniently located, did not have enough support to make them work, or did not meet their needs.

Following the initial disruption of stroke, some participants worked out - based on the feeling that they matter, that they were going to have to look for alternatives to the mainstream system. They gradually realised that they are on their own with the problem of how to manage after stroke and some began to think about and draw from their resources in different ways. The process of learning to draw on their own resources happened over some time and developed alongside an increasing sense of disillusionment with western medicine.

12-months after stroke

We don't receive income from the government, so funds are tight. If funds weren't so tight, I'd get more physio for my shoulder. I worry about money all the time. (Michael, 48 years)

I told the doctor "I think I may have had another stroke" and he said "no you haven't it's just part of your symptoms" but I could tell in myself things had changed. I slurred a lot; my strength had changed. I had more numbness in my face. I would have preferred to have been put back in the machine and have another scan. So it didn't give me any faith in any of them. It wouldn't play on my mind if I knew for sure. They could say "yes your scans have changed a little." Ok I would accept it. I got to the stage where I got tired of hearing that's part of your symptoms. So I don't tend to go back and see another doctor for another 6 months. (Michael, 48 years)

Putting it together piece by piece

Creating your own programme of rehabilitation involves deciding to conduct a personal search for services and support and putting it together piece by piece. Some participants were able to locate mainstream and general services and put together their own programme for recovery, which was underpinned by the formation of a causal model. For going about the difficult task of finding support, participants needed to discover services and people who might be able to help with their recovery. They needed to be able to think creatively about what could be utilised as therapy or support and where to try and find it. This knowledge was about being able to find services and resources which could be converted into things which were helpful to recovery. Finding what is out there involved drawing on cultural knowledge or finding new ways to think about stroke in order to work out the best way to respond and was an active problem-solving process.

24-months after stroke

> *Since the stroke I get a lot of burning sensation in that leg and knee. For 2 years when I walk it feels like someone is sticking a poker in my butt. I've had people work on it and had acupuncture. I don't ask many people about it anymore because they just say it's part of your condition. But when you ask them 'what is the condition' they can't really answer. (Michael, 48 years)*
>
> *They still seem to think it's all in my head, but I still think I have had little ones after that as well. My balance was quite good at one stage but then it just went downhill. But you tell them about all this sort of stuff but they… don't send you for tests. Which I think is a bit stink. It might be that I'm not having enough drugs, but it could be that my body is used to those drugs and needs a change. (Michael, 48 years)*

There was a tension within the process of constructing a personal rehabilitation programme from what is out there. Western understandings of story lines such as this point forwards to a time when the picture is whole, and the story finished. Participants looked for the pieces and kept working and wondering about what should go in and how well they fitted together based on their causal model. There was for some an expectation that they would discover the destination as they put the last piece in, which could be different from the pattern that was there before.

36-months after stroke

> *I still think about why I had the stroke. I've still got the burning sensation in my leg it's mainly in this knee. Since I have been working it's got worse. Everybody I have talked to who has got a hip problem it starts with their hip and the burning sensation is like knives in the knee. So I have accepted it, its part in parcel of my hip always been there but I am just more aware of it now than what I used to be before the stroke.... Combination of the arthritis and the stroke. Instead, the doctor is saying 'it's just part of your condition.' now I understand what the condition is, I need a hip replacement. Everyone I've talked to who's actually had a hip replacement the pain has gone away in the leg. (Michael, 48 years)*

> *You have always got the worry of how worse is it going to get before the doctors send you off to have specialised tests so it can be rectified? I had no energy about 4 months ago, but I was making myself do things. They sent me off for tests and it came back that my iron level was down to 27 and they gave me iron tablets and they did blood tests and the next one it should have been up, but it went down to 19. They kept going down. So they sent me off for a test and they come back with "no you are fine. But we still can't answer the question why you are dropping in iron levels." So we bought a juicer and I have been having these vegetable shakes and my level came up. Now I feel a lot better. I've taken it in my own hands to figure out what the heck is what. Basically, your mind is helpful for recovery. You can sit there and dwell on whatever or you can get there and make it happen. If I don't get out there and do it or give it a go, it will always bother me. (Michael, 48 years)*

Managing ambiguity and becoming attuned

For some people, uncertainty of outcome, and ambiguity about the cause of their stroke and therefore the way forward, was emotionally troubling. Reflection was required to confront and act rather than avoid thinking about the uncertainty or become stuck ruminating on it. Increased and new understandings about the world enabled actions that were different from habitual and traditional actions.

Participants who managed, brought with them or developed, the ability to tolerate ambiguity and uncertainty. They were supported and influenced by their resources and ways of coping and doing. There was something about their thinking and experiences, that gave them a feeling of effectiveness - that if they took action, that action would benefit them, and the results would be visible. They felt able to take action to underpin their recovery and that gave a sense of potency or control (Bury, 1991). Participants who seemed to be able to sit with uncertainty about the future, may have been more

flexible in the way that they did things, envisaging alternate futures to the one that they had planned prior to the disruption of stroke. A new normal was negotiated over time and as tolerating ever present ambiguity was difficult to manage, some fell back into feeling stuck and frustrated and then picked themselves up again.

A participant's attunement to their body and mind, the ability to see the specific problem that needed to be worked on, then matching it with an activity to remedy it, seemed pivotal to developing effective strategies and managing. They were in touch with how their body felt and had greater knowledge of themselves, noticing and measuring improvement. Getting to know this new post stroke body and mind required a careful plan of experimentation. The reflective thinking that resulted in the formation of a causal model is connected to the participant being attuned to what they needed and what would be good for a person like them to do in their context.

6-months after stroke

> *I had some slightly high blood pressure, and the cholesterol was slightly high but not alarmingly high. I was worried it could happen again and it might. I'm at the point now where I can almost forget that it's happened. So I might not stop myself doing physical things as I might have before now. You physically do feel a little bit bruised and a bit tender about it. (Linda, 60 years)*
>
> *Even though I'd changed my diet since this stroke and I'd been on the warfarin, I ended up with higher cholesterol, so I have started on statins since then too and I've felt heaps better. I'm off the warfarin now too which is really nice. So many foods interfere with its action and are really good for strengthening the arteries, but they don't work with warfarin so now I can actually get some of that practice in. I don't know if it's going to help but at least I feel I can do something. (Linda, 60 years)*
>
> *I sort of consider myself recovered. I think I do. I think I feel even better physically than before. (Linda, 60 years)*

12-months after stroke

By 12 months after stroke, Linda was much more confident and certain in her attunement to her body and improvement. She was aware of the impairments that had

improved and by how much. She was also aware of the deficits which remained and had strategies to manage them so that she continued moving forward.

> *I think what has changed in the last 6 months is my physical strength and a certain amount of confidence. I am a lot fitter. I'm doing long three-hour bush walks and I've done a half marathon in good time. There's still a little bit of weakness in my arm. I notice that when I play tennis. But that's ok it's going to improve. I have good vegetable gardens in here, which I'm really thrilled about. So I'm sort of feeding myself a bit. You know, growing my own food? If you've had high cholesterol it is important. Because you don't want to keep having it and nor do you want to have to be on drugs. I take statins on alternate days now instead of every single day. I'd like to get off them completely. If I can find a doctor brave enough to let me. (Linda, 60 years)*
>
> *Something that is still an after effect from the stroke, when I've got a lot going on or a lot of people around me, I get into a dither. I have to make sure I'm well organized and well thought out ahead of time because I'm not quite so good at keeping it together if I have to do a lot of things off the cuff. Sometimes if there's more people around than I'm used to I don't think of many things to say. I am a bit different in that respect too and I don't know what that's about, but I have noticed it. (Linda, 60 years)*

24-months after stroke

By 24-months post stroke this participant was so certain of her attunement and therefore the actions needed at that point in time, that she felt safe making changes to the risk modifying medication, without medical input. She trusted her attunement and was able to move forward in a way that was in alignment with her beliefs about her health.

> *I have done quite a lot of house painting and that's going alright strength wise. I must go and play tennis again and see how that is going. I have been doing a lot of yoga in the meantime and that uses strength on my right side and that feels fine. (Linda, 60 years)*
>
> *The other big change is I have taken myself off those medications. I have actually been feeling a lot better within myself since that. Which is now almost 6 months. I realised no doctor was going to agree that I could, so I just made a decision. I have done it quietly and I am fine. I did have one test a while after that and it was ok. I should be due for another one any minute now so I will go and have that done. I think it's quite good getting off medication because it stops you thinking about that thing that you thought you had wrong with you and you can move on. That helps quite a lot, instead of being caught up in the fear of it happening again. (Linda, 60 years)*

I don't know if the cholesterol is a really big thing. I think it might have just been something that was going on as well. The stroke might have just happened. I think it might have been a side product of something. But I might not know, I have just decided that. But anyway, I feel fine and I think that must be the main thing. A bit of ginger tea every now and that will do the same trick hopefully. (Linda, 60 years)

I have also noticed that my mood is much better since I have not been on medication. I am just happier, content. I noticed it in my thinking. I think I felt slightly socially inadequate, now I am comfortable. (Linda, 60 years)

Bracketing and moving on

Some participants were able to come to a state of being where they considered themselves to be recovered enough, that they no longer needed to think about their stroke so frequently. They were able to put their fear of recurrent and more disabling stroke to the side and stroke no longer dominated their thoughts and emotions as it had in the beginning. Although some mild impairments remained, they were of little consequence within their new life. This is on the background that although the risk of another stroke remains there are strategies in place to keep it at bay. There was no longer an urgent need to rethink everything so that a significantly more disabling stroke would not occur. The role of medicine in reducing risk is re-storied over time, from feeling better and safer on statins, this participant at 36-months now had doubts about her role in reducing risk.

There remained, even at the 3-year anniversary of her stroke, this vague feeling that it might happen again, which was unpleasant to think about. For the fear to not to get in the way of everyday life, people *'bracketed it'*. There are some aspects of risk for which, nothing can be done about so participants moved it to the back of their minds and did not let it cause them to become stuck and overwhelmed. The feeling of vulnerability took too much energy and participants had to use their energy wisely to manage.

36-months after stroke

I am very well, and I have been very well. I feel better physically. I can mow my lawns; I can take off the grass catcher full of grass and empty

it quite well now. I am emotionally stronger. I am much better able to cope with ups and downs and be more assertive than I have been for a very long time. (Linda, 60 years)

I have taken myself off all of my medications and I have stayed off them. I did go to the doctor at the end of last year and the cholesterol was still a bit high and she gave me a prescription, but I found that I couldn't fill it. Because I actually feel fine and the cholesterol had gone down a couple of points and I thought "I am just going to carry on the way I am." I do think my diet is one of the factors in bringing it down. It has come down but only by 2 points, so it's quite slow. (Linda, 60 years)

I do still take a very low dose of aspirin. Otherwise I medicate myself with herbs and supplements. I don't want to take the statins and I am going to change doctor and find one that supports that approach. (Linda, 60 years)

I'm not so scared anymore. I very vaguely feel fearful of having another stroke, but not so much that I am going to go on statins. It is still there but I don't even know that it was a risk factor. I mean who knows why the cholesterol goes up. The jury is not out on that yet is it? Just a drug company thing. It's not just that high that I am inclined to worry too much. (Linda, 60 years)

Mental flexibility

Participants who managed had a mental flexibility that allowed them to consider using new strategies or previous strategies in new ways. Participants expressed a need to choose from options that reflected their individual journeys, but often there was little to choose from. Some managed to make use of mainstream services, tolerating the parts that felt like a poor fit with what they needed in order to make use of the parts that were useful. Being able to do this depended on having some mental flexibility when thinking about what might help and the ability to locate options and put these options and parts of options together piece by piece.

It was a complex thinking process to be able to realise a programme is not a perfect fit for them, but they were benefiting from some aspects. The ability to reflect on the aspects that were helping, a willingness to accept the aspects that are not, meant participants went through a process of weighing things up, which required attunement and cognitive capacity. These strategies developed over the three years that data was collected.

6-months after stroke

> *I've been through the two-month rehab programme which has started me getting physically stronger and I just feel so much better now. For me it wasn't terribly interesting, but that's okay…I thought it was a little bit simplistic…But on the other hand you know, sometimes it's a bit helpful... it seems that still there is a lot of people that don't have good knowledge about nutrition and so it probably is very helpful. I didn't find any of it new... It's really good that something like that is happening and it certainly got me back into a structured programme of physical exercise… I had actually dropped quite a lot of my fitness and strengthening work and so to be doing it again is actually feels like the best thing. So it's great for that. (Linda, 60 years)*

12-months after stroke

The feeling of benefit and changed behaviour remained 6 months later.

> *The programme I did was great. That was one of the best things I did. I think it was developing a routine and having something to go do and the social aspect and but mostly it was just…getting back into doing something physical. That was really good for me. (Linda, 60 years)*

So this is how it is

Participants thinking ***'so this is how it is'***, was a kind of acceptance of the current situation alongside a sense of hope for improvement in the future. Participants believed that progress was possible and knew where they were in terms of their recovery based on their attunement. Despite naming situations that challenge as problematic, Dewey did not necessarily view them as negative, instead they could be an opportunity to engage in exploration that may be experienced as having some pleasurable features and contribute to growth (Farrell, 2012). Some participants were able to accept that things were different, which was a thinking strategy for understanding the experience of stroke that conflicted with their prior cultural knowledge about stroke. Some people were able to fit stroke into their life story. They talked about accepting the current situation early in the interviews and did not appear to get stuck. Their acceptance was not a surrendering to stroke, rather an active and purposeful thinking strategy, a way of exercising deliberate control. This thinking both led to and stemmed from giving grief and shock space within the body and mind, they allowed themselves to feel the emotions.

Participants who managed by thinking *'this is how it is'* viewed the difference between the new future they had envisaged and their current level, as a personal challenge and moved on from there. Participants concluded that this was how it was right now, and they had to work with what they had. Letting go freed up some mental space for new, creative and innovative ways of responding, which was a move away from the type of traditional treatments that fit with a medical model way of responding. So the emotional work made way for the thinking work, and actions or strategies flowed from there.

This participant had the resources to adjust and bring forward his retirement plan, also connected to *feeling prepared*.

12-months after stroke

> *Things have been going very well really since my stroke but it's something that I definitely didn't anticipate in my 40's. I did have other quite serious plans. Part of my field of vision is missing. Once I came out of rehab and saw an ophthalmologist, she confirmed that the nerves between my brain and my eyes have been severed and there's no correction that can be done, so this is how it is, and that means that driving is out. (John, 59 years)*

> *About three or four years ago I saw a quote which I put in my diary. It was 'life is what happens when you're making other plans'. I'm very thankful I…read that then because when I woke up in hospital and realized what had happened, I just used to think back at that, and I still do now. I think that's helped me a lot to get through and realize it's just life mate. Now it's up to me. I look at it as a challenge. Pretty big challenge, but I've just got to get on with it. There's worse off than me. I'm just so thankful I'm alive. I think the best thing is, and I think I've been like it from day one really and I fully don't understand why. I accepted it very early on and I just thought well it's just one of life's challenges. (John, 59 years)*

24-months after stroke

Becoming, the process of thinking through and examining new potential and future possibilities, reasserted the feeling of *being of use* and that he *mattered*.

> *I couldn't do justice to an employer I don't feel. It's funny I just had this thing that I just want to help old people and I would rather do things voluntary and that's what I am doing with my daughter and my son, I help out. I would happily do it for people I don't know. That's just me. (John, 59 years)*

I have got to take it on the chin and move on. In the past I know I have always been a fairly reserved shy sort of a person. But now everyone tells me I have got all the time in the world and before that I was so busy, I never had a great deal of time to just chat and talk to people. Even to say a simple good morning. Where before I wouldn't really bother, but now I make a point of it. (John, 59 years)

It's just nice to be friendly, I just want to be someone who, because I have never had time to do it before and now, I just feel I want to do that. I never got depressed about this. I have just taken it on the chin. (John, 59 years)

Managing by sticking with it

If energy was not being spent on the ongoing need to form a causal model and feeling outraged by unfairness of the system, then perhaps there was energy for carrying on alone. Some participants were able to find the energy, and others whose stroke was perhaps more severe, had their significant other help them to have the energy to keep going, even though it seemed like progress had really slowed down.

36-months after stroke

I have always had this thing where I like to accomplish something in a day or feel like my day has been worthwhile. Otherwise I feel like I have slackened, the harder you work the luckier you get. (John, 59 years)

Sophie Pascoe lost her leg at 3 years of age. She said, "it's the best thing that happened to me." I thought, I guess she has grown up with it. This life that she has got now she obviously wouldn't have had it. and that just helped me again. I always appreciate that there is someone worse off. You don't put your hand up for these things but I'm coping fine. That's just the big thing out of it all is I just want to see my kids prosper, that's the main thing. (John, 59 years)

Conclusions

This chapter presented the two sub themes that were developed from analysis of how people's thoughts process influenced how they managed following stroke. The next chapter presents the subthemes related to acting to manage stroke. Feeling and thinking, in ways that are barriers to managing needed to be worked through and resolved before participants could take action to manage their stroke and manage after stroke.

Chapter 11: Findings two layer 3: Part B

Acting to manage after stroke

"What's the point of life if you are not giving something?"

This chapter presents the second theme of my longitudinal study analysis exploring the active things participants did to manage their stroke.

Participants needed to both let go of old knowledge about stroke and managing, and realise that new knowledge was needed, to make room for the new knowledge. Resources were needed for participants to feel that they mattered and to be able to start the search for explanations and solutions. The discovery that there were little to no services available to help them manage, resulted in a sense of injustice and reinforced the feeling that they were undeserving or did not matter.

Participants: Longitudinal study: Part B

Seven stroke survivors and five significant others were purposively sampled from the larger dataset including, five men and seven women for the whole longitudinal study. Participant characteristics for this findings chapter are detailed in Table 4 below.

Table 4 *Participant characteristics: Findings: Part B longitudinal study*

Participant, Age	Interviews	Theoretical & purposive sampling	Storyline
Evelyn 84 years	Interviewed at 6-, 12-, 24-, 36-months Did not nominated a significant other	Converted resources into rehab	Casual model Moving slowly forward
Rose **69 years & husband Tom**	Interviewed together at 6-,12-, 24-, 36-months	Well-resourced and connected	We try everything that helps
Barbara **66 years**	Interviewed at 6-, 12-, 24-, 36-months Did not nominate a significant other	Practical strategies Socially well connected Belonging (Wilcock, 1999)	Better to give than receive People are nourished by other people
Angela **43 years & husband Mark**	Interviewed separately at -12, SO only at 24-months Together at 36-months	Becoming (Wilcock, 1999), faith	Making time to be
Raymond 63 years & wife Carole	Interviewed separately at 6-, 12-, 24-, 36-months	Few strategies Received rehabilitation & self-management services No forethought, thinking ahead, planning (Bandura, 1991, Bury, 1982) No mission or ability to visualise an alternative future	Feeling stuck

Key themes: Acting to manage after stroke

Two key themes were constructed during this analysis to depict the action participants took to manage their stroke. The action stemmed from and was based on the thinking work participants needed to do to envisage a return to some aspects of their pre-stroke life, or different ways of acting to manage their life after stroke.

3. Managing by creating structure, purpose and meaning
4. Managing by making time to be

Participants described ways by which they acted to return to, adjust, or create new routines and directions for their changed life story and daily life. The new ways of acting were carefully considered, balanced, and enabled by also *making time to be*, that is to slow down when needed. To be, rather than act for a time. To reflect on what they do, how they act and who they are.

Thinking differently sometimes led to acting differently as participants realised they needed to draw on their own resources to manage. Some thought of ways to retrieve or add *structure, purpose and meaning* to their days. Constructing 'doing' (Hammell, 2004), based on their values, beliefs and identity allowed participants to realise that they also needed to *make time to be* (Wilcock, 1999) in order to *become* more or different, using previously untapped potential despite the disruption, and manage life after stroke (Wilcock, 1998), as shown in Figure **7**. Sometimes the urgency of the forces at work propelled participants to act in instinctive and habitual ways, but what if habits of feeling, thinking, and acting did not map onto the problem of trying to recover after stroke?

Figure 7 Strategies for acting which enable managing, created and constrained by the stroke survivor's context

Problematic situations could be an obstruction, requiring stroke survivors to overcome inertia and exposed a need for steadying and guiding, so that they could act in response to stroke. Participants initially experienced an urgent need to address their feelings of disruption and then some were able to think of ways to move forward and go about the complex and often lengthy task of enacting their plans. Dewey's reflective thinking has been likened to being able to use a compass to chart the way. A useful skill that allowed some participants to know where they were at a given moment and plot a course for the future (Farrell, 2012), which participants required to weave the layers together, act and manage.

A person's values, attitudes and beliefs form their rules for action and are part of the filter through which the world is seen. Personal knowings and ways of responding are a result of the cultural environment and life experiences (Saldana, 2013). Beliefs underpinned participants ways of actively managing; some actions were developed by careful consideration of evidence. Others actions were passed down from society via family and are tradition, modelled, accepted and mostly unconscious until the disruption of stroke forced the person to think about, reflect on and question their

beliefs about the best course of action (Dewey, 1997). The examination of beliefs, their value and use in this new situation, the comparison of this stroke situation against memories, prior strategies and ways of solving problems took time, energy and cognitive capacity.

Managing by creating meaning, structure and purpose

The feelings of disruption to participants' life stories and identity needed to be addressed in order to move forward. Participants' doing needed to be underpinned by 'being'(Hitch et al., 2014). That is, the doing needed to have meaning and purpose and be connected to their values.

Having a mission

Connecting with, and a necessary basis for acting to create purpose, meaning and structure was having a mission, or a significant goal to work towards that helped participants know which direction to go in. As the concrete measurable steps were achieved and participants reflected on the achievement then their vision of themselves in the future was adjusted slowly over time. This ability to regulate their emotions, thinking and action, allowed them to have both hope that things will be better in the future but also realistic about their current abilities and the need to take one step at a time. Space is created for both hope and accepting a different way of doing it for now. Participant's mission guided them, it was vital it reflected their values, otherwise they did not manage to move forward. Participants also seemed to re-establish the continuity of their life story in a way that was congruent both with the past and the new ways of acting (Bury, 1991; Ellis-Hill et al., 2008).

6-months after stroke

This participant had a lifelong interest in art and worked hard to return to classes.

> *It was a blood clot in the cerebellum. That's what caused it. I've just made up my mind it was cholesterol…I just more or less decided it was that and cutting lavender [laughs], working very hard.* (Evelyn,84 years)

> *I went to a class yesterday, my first class this year, although it's a four-hour drawing class I went for two hours. My daughter took me and then she came and picked me up after two hours. And… that was marvellous. And it's a class that's only three times in a term, so I thought it would be suitable. It isn't like going every week, if I can do that this term and next term, and then next year I hope to do more, weekly one.* (Evelyn, 84 years)

> *I've been to the cinema. Which it was very easy and handy. So every month I'll try something which I feel I can cope with. It's no good going… down to the wharf…which I'd love to do…I think there'd be a lot of walking involved in that.* (Evelyn, 84 years)

Doing it by degrees

Attunement was required in order to think about doing it by degrees, or one small step at a time. Participants were sometimes able to assess their abilities and formulate goals based on their *causal model*. They thought about achieving their mission by breaking long-term goals down into manageable chunks or short-term goals. They reflected on and noticed what they enjoyed doing, reprioritised what was important and spent their energy wisely. Having a big overarching goal was needed as well as the ability to break it down into steps. So *doing it by degrees* involved thinking about what the first manageable step to work towards achieving the overall mission, needed to be. Participants must then *notice* that they have achieved it, and the impact of the action. Being *attuned* so that progress and improvements could be observed.

This participant was able to evaluate which aspects of stroke recovery would be addressed when re-engaging in the occupations which made up her daily, weekly and seasonal routines prior to stroke. She carefully balanced her needs for physical activity, creative outlet and socialising and connecting with others.

12-months after stroke

> *Yesterday…I started my first painting class for this year and that's going to be every week. And that was quite an effort to get there, get my stuff there and go do my painting. But it worked very well. It was very successful… (Evelyn, 84* years*)*

> *I drove myself round there. Two weeks ago, I started driving. I went out early on Saturday morning or Sunday morning. Was very quiet…First of all I just went around the block. And then I went a bit further…the problem is my right leg. I was fairly worried in case I wouldn't be able*

to tell which was the brake and which was the accelerator and if I could move it quickly. I have to concentrate very hard. But I went through the park and that was very good practice because there's bumps. You have to slow down. And there's spins of bending road and little round abouts and I thought it was like a little obstacle course and I thought that was very good for me so I did that as often as I could. Like once each day. And then the next hurdle I went to was getting petrol. I got petrol and then I went… to painting which is very close. So [now]I've been doing a bit more than it would take to get to painting. But I don't feel as though I could…drive say to the Botanical Gardens. I think that would be too far and too much of a challenge. (Evelyn, 84 years*)*

24-months after stroke

A lack of confidence was compensated for by seeking the opinions of trusted others.

Painting class… is 3 hours and I do about 2 and a half. But in the holidays, we have… a painting day which is 9:30 to 4 and I have been to 2 so far in January and I get there at 9:30 and I come away about 2 o'clock instead of 4. But I don't concentrate all the time, it's very exhausting. There's a few more breaks. But I can concentrate for a couple of hours which is quite good really because a lot of people painting can't do that. (Evelyn, 84 years*)*

The doctor game me permission to go [driving] quite a long time before January. But…I'm not able somehow to just jump in the car and go anywhere like I used to. It's the only driving I do and it's really just around the corner. But when my son came, I told him that when I come home from the class, I come back the long way through the park which has lots of bumps and bends and things which is good practice. The only problem I am left with is this leg is not back to normal. So it's good practice going through the park but I only do that just to go there. I have been to the doctors, but I haven't got to the stage where if you want something you just go alright and get it. I can't do that, I don't know why. Because I went driving with my son and he said "well you are fine." I'm safe I know I'm safe but then I haven't come across an emergency or anything like that… I haven't really got back to how I used to drive. But when I am out there, I am safe but I haven't got the confidence to… just jump in the car. (Evelyn, 84 years*)*

36-months after stroke

Evelyn was able to self-monitor her progress towards achieving her goals. Analyse and plan the next steps required.

I couldn't walk that far up there you know. But even when I could walk that far I am less tired now than I used to be…I do something every day. I can cope with a lot more going on than I did a year ago. I mean my daughter says, "look what you do now." We might go somewhere Saturday morning and then somewhere else in the afternoon and I can cope with that. I was too tired before… If I have a good night's sleep, I feel like I can do a lot more. But I do all the cooking and the washing and the ironing and all that. And the gardening. And I go shopping with

my daughter, I do all that. I do everything accept cleaning. And even that I sometimes have a go. (Evelyn, 84 years*)*

Daring to be more

Participants needed to notice when they were at *attunement*, possessed the knowledge that recovery takes time and accepted that *this is how it is* right now, before they could then *dare to be more*. Trying hard required *feeling that they could be effective* in their efforts and considerable drive, - in order to dare to be more or achieve more than western medicine expected for them.

Some participants were able to envisage a more recovered self and richer future even though health professionals may have predicted further improvement was not possible or likely. Participants who dared to be more were able to take some risks and try new things. It takes considerable resolve to go against the medical profession and is an attitude based on the *feeling and belief that they matter.*

People make choices that are selected from the set made available to them by their social position. Couple Rose and Tom acted in several ways to challenge professional beliefs about her potential to improve. They found acupuncture, a personal trainer, and tried travelling, swimming, spas, homeopathic medicine, yoga and other activities. These alternatives were not specific stroke services, but because of their drive and *resources* and fuelled by thinking more was possible, they were able to create a programme for recovery by putting together pieces from multiple places. Part of the drive was thinking that it was important to have tried everything possible, apply *resources* and take personal responsibility, in order to have no regrets. The programme was ongoing, increasing in complexity and difficulty, and was based on previously valued occupations and reflective of the rhythms and routines of their life before stroke.

The combination of feeling, thinking, and acting was an ongoing cycle, daring to be more an attitude that extended over the whole time period with the acting becoming more demanding as she regained strength and function and came to terms with a new

way of being and doing. Her husband's support and assistance were vital to working through the feelings and helped her change her thinking and therefore her acting. For example, improving her walking, which involved addressing her fear of falling on steps and stairs. Not only did she need to dare to be more in terms of the limitations placed on her recovery from health professionals, but she needed to dare to be more in terms of her fears.

6-months after stroke

> *I was very lucky because my husband found a pool that I could walk in which helped me very much, I didn't learn to walk straight away but it was easier to get around. It was something we thought of ourselves to do. (Rose, 69* years*)*
>
> *You've got the support of the water and you don't have the fear of falling, and warm water is relaxing. For the first couple of days she would hold onto the side of the pool, but then on the third day she decided to let go and walk down the middle of the pool and exercise that way, and that really did work because it gave her confidence and balance. (Tom)*
>
> *My husband decided we would go on holiday and see if we can do lengthy walks and swimming, that was the idea that I learn to swim again. I love swimming and I couldn't do it, but I could go in a circle because this hand wasn't very good. My husband had the idea to lean on a noodle and so I dared to be more… (Rose, 69* years*)*
>
> *But the one thing that I'm always careful about is steps, there were two steps I could not get onto them by myself, without falling. After a while he said, "what do you think we'll go overseas"? I said, "I don't know if I could get up into the tram and the train". But I went... (Rose, 69* years*)*
>
> *I think it is very important to get over the mental block about things like the steps, because if you tell your mind that you can't do it then you can't do it, it's just a matter or saying "I can do it, and if I can't do it at least I will make an attempt and try to do it". (Tom)*
>
> *Yes, but going on a step is, you try the attempt, and you are flat on your face. (Rose, 69* years*)*
>
> *Then get up and try it again (laughing). (Tom)*

12-months after stroke

Daring to be more required the participant to *stick with it* over long periods of time, supported by their *attunement* to their body so they could see slow and steady

improvement. They needed to be able or supported to push through when progress was slow.

> *This leg is not getting better. No one has looked at it or touched it. My doctor said that it's as good as it will ever get. Well, I'm not satisfied with that. It has improved definitely but sometimes I walk sideways because my body is not working with my legs… (Rose, 69* years*)*
>
> *We can't expect miracles overnight. It's a long steady road and provided that we keep on doing what we're doing, things will improve. But you have to be positive about it. You can't say 'I'm not getting any better. I don't want to do this, and I don't want to do things or want to see people.' (Tom)*
>
> *He is the coach and has driven everything… (Rose, 69* years*)*
>
> *I'm not really a tyrant. I just want to make sure that things happen. (Tom)*

24-months after stroke

At the 24-month interview, the participant has done a great deal of the feeling and thinking work around accepting the long and steady road and again dared to be more, by pushing for more despite the fear and difficulty finding alternatives to traditional stroke services. Maintaining the feeling that 'normal' or new normal was possible, whilst also being realistic. She was able to link to a vision of her future recovered self to short term goals or having a mission and doing it by degrees. As the degrees or short-term goals were achieved, the mission or ideal future self is slowly adjusted over time.

> *six months ago, I said to my doctor "I want to get better." He said, "you can't get any better because you had a very severe stroke." I said, "what who told you that?" "I've never heard that." So I cried a bit… (Rose, 69* years*)*
>
> *In rehab I learnt how to not be scared of getting up off the chair and that sort of thing, but I didn't learn things. I was wanting quicker progress. The personal trainer pushes me, he made me run. I was hoping I could do around the bays, but I don't think so. It takes time. He's also very good with my foot and working on that and he's improved it heaps… (Rose, 69* years*)*
>
> *I fell at yoga; I thought it was funny. It was a bit scary, but I am used to it now. Balancing I am no good at and that's what they do a lot. It's not good enough I want to be just like everybody else and not look like my walking is not very good, getting better all the time but my family is saying "oh you have improved" but I don't think [so]... (Rose, 69* years*)*

36-months after stroke

Using mainstream exercise classes, as the only person with a disability, takes a great deal of courage and it could be difficult to see improvement when participants compared themselves to others without stroke. Again, the participant's significant other provided important feedback and reminders of how far she has come which facilitated her *sticking with it*, sticking with trying new treatments and activities and sticking with keeping going with the work of recovery three years after stroke.

> *You received treatment overseas as well. Our apartment was on the 3rd floor, we had 92 steps to go up and down. At least 3 times a day. And your walking has improved. (Tom)*
>
> *I've been getting a bit sick of yoga because I can't do some of the things because my leg isn't good and I have to put my foot like that taking me 2 minutes and everybody that done the next thing and so I don't like that... (Rose, 69* years*)*
>
> *Just do what you can do. If you are not learning things, nothing will change. Put it this way, at this stage there is nothing we can't do. I think whatever we tried it always had a little positive influence on her recovery and that's all we can do. We tried outpatient rehab, we have tried personal trainers, and we have tried acupuncture. We have tried movement and exercises and medical massage and now we are trying this brain stimulator. So we just keep on trying. (Tom)*
>
> *Yes, sometimes I don't want to do what he wants me to do but I go for it… (Rose, 69* years*)*
>
> *Just one day at a time. (Tom)*

Reciprocity

Participants who 'know' that social connection is important experienced comfort from the feelings of disruption that come with stroke via the number, quality, and closeness of their social ties. Having regular contact with people who know and care for them mitigated feelings of vulnerability. Making the social environment work for them depended on a *feeling that they mattered* and were deserving of support and assistance. A sense of reciprocity in that they had contributed to society and helped others in the past, seemed a necessary basis for seeking and accepting support. Reciprocity is a component of social capital, where helping others now, results in assistance and support in the future (Abbott & Freeth, 2008). This experience was

underpinned by the *feeling that they were of use* to others, which was fundamental to meaningful doing (Wilcock, 1998).

6-months after stroke

> *Once I get out of the house and get amongst people, I'm much more positive. I need space of my own, but I also need a lot of communication with other people so that's why I volunteer for a charity. I'm lucky probably every third day I get visitors, but every day I get four different phone calls from people, and we have a chat. I've started back making meals for the oldies at the Red Cross. I do that because there's a lot of old people that don't bother to cook for themselves and they were so pleased, and it makes me cook for myself. (Barbara, 66* years*)*

> *I think however you treat people you generally get treated back that way. When I cooked that soup it was the first meal I cooked since I was out of hospital. I know it was only pumpkin soup, but the satisfaction gives you a boost to go on - I'll try Sheppard's pie next, and you do. (Barbara, 66* years*)*

Not all participants experienced stroke as a static disability or as a gradual improvement over time. For some participants it was a condition that got worse. For these participants managing required they work out how to create structure, meaning and purpose by making their social environment work for them in different ways than before stroke. They also needed to find new ways of achieving their mission so that they could continue to feel of use to others and therefore worthy of accepting help in order to manage.

12-months after stroke

> *I stopped my volunteer work at Christmas but because there is a couple of other ladies that retired and we're going to have morning coffees. We had one here last week and I think there was six of us here. It was really good. So we're going to do that on a fortnightly basis. (Barbara, 66* years*)*

> *I still keep up knitting and painting, I'm not knitting at the moment but I'm making pom pom balls. I'm making those for the shop in different sizes and I make all the labels because I can sit down and do it. So I do things for the shop rather than go in now. (Barbara, 66* years*)*

> *Our little group, I think we are all people that get more out of giving than receiving… I remember my friend said you must let people do things for you because people get pleasure out of giving.' But I didn't*

> *realize I probably wasn't very good at receiving, because… I really feel good about myself when I do something for anybody… however simple it is. (Barbara, 66* years*)*

24-months after stroke

The impact of stroke on prior habits, routines and ways of doing became clearer the more time passed. This required participants to continuously and consciously find new ways of reciprocating the assistance they needed.

> *I devote a Monday to baking and cooking and I do something for my daughter and my friend, at the time, something simple. You are giving something back besides them giving to you. My daughter generally brings 2 meals at least a week over for me and my friend can't but she says, "here's some plants for your garden" or "here's some books for you to read" and that's how we work it. (Barbara, 66* years*)*

> *Its things that you take for granted. I can't even wash the ceilings or anything like that so my son in law just says, "you need a bit of paint outside we will have to get that organised". Before I would say "don't worry about it I'll do it." Now I've learnt to say, "ok if you want to do it you go ahead." (Barbara, 66* years*)*

36-months after stroke

Doing things in alignment with participants' values, identity, and vision of themselves in the future, was constant over the three years we followed them. Participants who managed in this way continued to reflect on what made them who they are and found ways of creating meaning and purpose in alignment with their biography, new and old. Participants who found ways to reaffirm their identity seemed to manage better than those who did not. Strategies around finding new ways to reciprocate and give of themselves were important but also the search for and need to feel something of what they were, which was recognisable and acceptable to them was an essential part of this process. Aspects of their prior life that had meaning to them, related to their spirit and who they wished to return to in some way or continue being despite stroke, of once initial disruption of their biography has been come to terms with.

> *Volunteering and helping others has been a thing in my life that's why I still go and see my old neighbour. Because I had to give it up the charity shop after I had the 3rd stroke because I can't stand for long periods of time. I still do things but it's more home. I have always bought my children up to give because eventually there will come a*

> *time when somebody wants to give to you, and you will need that help. I would say my quality of life is good. I've still got people that I can meet up with or they come around for coffee and I have got my family, my daughter does so much for me. And I still can go and see my old neighbour and take her little treats. So, you adapt, and you do what you can do. (Barbara, 66* years*)*

Managing by making time to 'be'

After the initial period of managing the disruption of stroke, it was possible for some participants to regain or find inner balance via being in harmony with the social and natural environments (Dewey, 1934). Noticing beauty in the world both human and non-human required the restoration of reflection (Dewey, 1934). Participants who made time to be were sometimes able to reflect on how and why they did things the way they did. The reflective thinking made room for doing things a different way which enabled them to become more like themselves again and live more closely in alignment with their values (Hitch et al., 2014).

The struggle to achieve harmony and complete the thinking work, was not ignored but embraced as a way of becoming alive again. Participants who managed were able to view their new life, with all its complications as beauty and opportunity rather than a problem and lived more fully and vitally (Dewey, 1934). The hard work of recovery needed to be balanced with making time to be, noticing, and practicing gratitude, and becoming.

Noticing and being

Taking or allowing the time to think about their acting or doing led to an increased awareness of the present moment. Allowing time to be facilitated and was necessary to reflect on what participants did, and the meaning of what they did, which revealed values (Wilcock, 1998). Participants noticing and being occurred when they were thinking and doing in mindful ways. They talked about noticing beauty in the physical environment and in close social connections, and what they bring. They noticed when activities were fun and the healing effects of being in nature and in a similar relationship with yourself as with the natural world (Wilcock, 1998). Being was noticing

and knowing what participants themselves bring to relationships with others and other aspects of the environment (Wilcock, 1998). Time to reflect was required for participants to come to know the need to connect with the natural environment and move beyond cultural expectations and pressures to do less or do differently after stroke (Wilcock, 1998) or be busy all of the time with the work of rehabilitation and recovery. Reflecting within the space of being allowed participants to see alternative stories and potentials for their lives.

12-months after stroke

> *Before I had my stroke, I was someone who did ten things all at once and managed it well and I looking at myself today, I can't do more than two things and then I start to forget. The positive side, if there is a positive, is that I'm more present in the work I do. In that sense I'm more focused and I'm in the here and now. (Angela, 43* years)
>
> *I went back to school after my stroke and finished my last year and I have to say that was the best piece of work that I did in all my years of studying because I didn't have ten things on my plate. The senior lecturer almost didn't let me come back. I said 'Look I've learned a really good lesson about self-care. So you just have to let me take responsibility for that. (Angela, 43* years*)*
>
> *So it's kind of nice just having three things to do: Work, study and the family and giving myself permission to do that. (Angela, 43* years*)*
>
> *I've had some really quality time in the last twelve months. Spending more time with my family. Part time work and the work I was doing was really good quality work. Just being right there. I think I'm making the time just to go out because I'm grateful, I'm thankful so I get out there and walk a bit and just get in touch with the environment. I'm mindful. Don't push myself the old habits are still there, and I just have to remind myself. (Angela, 43* years
>
> *I had time to look at self-acceptance…I don't need to be that old person. I sometimes look at my colleagues and they're so switched on and I think 'I used to be like that.' I stop myself and I think 'Guess what? You're not that person. You are who you are now.' I'm still good at what I do. I actually think I'm better. In terms of work I would actually say that the person here is more quality than the old person. Because she was doing a whole lot of other things and well, this one can't. (Angela, 43* years*)*
>
> *She was closer after the stroke. More personal with everything. More caring about herself. Usually if someone rang up, she would go and do whatever people needed, and she knew she couldn't do that anymore…I just basically pulled her off every committee she was a part of. She didn't want to go to work until she had finished her study and I said fine, I'll simplify our life to make things work. (Mark)*

The doctors were saying as much as she can relax, which is why everything is turned off, the curtains are closed. She realised how important it was for her mind, her eyes and everything to shut down to rest the brain. Something she has never been aware of. So we make that a pretty integral part of her life now to have total silence, when she's sleeping. Plus, her doctor has put her onto this other thing that, sleep relaxes your body, rejuvenates the body but the soul doesn't get rest, so she goes through a lot of listening to meditation DVD's and relaxing her whole body spiritually too so she's loving that. (Mark)

It's just sort of relaxing your whole soul your body, everything. Deep rest, total silence, darkness. Deep internal peace. She is finding it very healing, and she is waking up the next day really rested. Her blood pressure has been right down, so her doctor is impressed with how that's going. (Mark)

Practicing gratitude

Practicing gratitude was consciously feeling thankful for the assistance and kindness of others, and the beauty in the physical environment. The action that seemed to flow on from that was making time to be. Making time for connecting with nature, slowing things down, being beside the water, connecting with their spirit and meaning, with others and places in new, meaningful and helpful ways. Many participants managed the shock and uncertainty by reflecting, being still for a time. Although they also knew that they need to challenge themselves physically and cognitively and they found ways to do this through their everyday activities. They tried to find a balance between 'being and doing', finding a way to be in order to do (Wilcock, 1999).

Creating a way to be of use to others to reciprocate the help and support they had received, and expected to receive in the future was vital to coming to this place of relative rest, comfort and stillness. Realising that there are ways in which they can positively respond to stroke facilitates the process of constructing a new normal. This helped to leave behind the disappointment in medical and rehabilitation services, which

did not provide expected support and comfort. Feeling safe to take risks and dare to be more in order to get on with reconstructing a life is a feature of this thinking and acting.

At 2 years after stroke, this participant was still searching for balance and experimenting with how to manage uncertainty about another stroke in the future. Coming to a place of rest, thinking and action. Thinking that this is how it is right now, things can be good or even better, but also knowing where to push in terms of recovery.

24-months after stroke

> *I'm doing a bit of reading around trying to exercise my brain, as well as meditation, just trying to get myself a bit better. It has been a really full-on year for me but I'm mindful that I have limitations. Finding somewhere quiet and absolutely resting my brain. Sitting by water is really good for me because I connect with water. Trying to find some balance in my life is really helpful. (Angela, 43* years*)*
>
> *At the end of the whole meditation thing, I wasn't anxious anymore about the need to read about mild stroke. I was a bit more settled in myself. So I think in myself I am more accepting of where things are. Though I struggle when I want to do a bit more and I physically can't. It's like there's this brick wall and I just can't get through. I know I have to do a bit more work to… realise that I need to understand a little bit more about that and to try to gently exercise my brain a bit more. I don't want to get lazy there or anything like that and I kind of have questions around that brain injuries and later in life dementia. (Angela, 43* years*)*
>
> *I think quality of life for me is to be able to take time out for yourself. To spend quality time with yourself and family and close friends to do the things you want to do. To pursue your dreams no matter how far you complete it. But just to make the start and give it a go. And to be able to create that safe zone around you, that sacred space around…and have fun. Sacred space is that the head space and physical space and time space to connect with whatever sacredness is to you. To actually know what that is for yourself. (Angela, 43* years*)*
>
> *She is doing well with her own health and monitoring herself. Her stress levels she knows the borderline, but she will push it right to the edge to the point where she is having headaches and whereas I try and catch it before that. I either immediately remove her from the situation or else, like what I am doing now I am telling her [what] she is going to have to give up. (Mark)*
>
> *She loves being close to the water so that's a good thing. Trickling water just knocked out all the physical world... That calming soothing feeling for her mind. But that meditation thing it's brilliant she swears by it. I do too. You can have sleep, but sleep is really rest for the body, but the meditation is rest for the soul. It's a real deep healing and it just soothes; it just knocks out everything in her life. (Mark)*

Becoming

Through engaging in occupations that reflected their values, participants were able to remember, experience and reconstruct their life story (Wilcock, 1993). Being in the present meant participants could see their past superimposed onto a new future. Their biography was constructed of not just who they were but also who they wished to be in the future (Wilcock, 1993). It is through being and doing that some see a way to work towards flourishing, or becoming (Wilcock, 1993). A necessary process to flourishing in the future is making time to be. Embracing interdependence for a future of personal and maybe societal change and a 'transformation' of abilities and capabilities uncovered by stroke for managing (Ellis-Hill et al., 2008; Wilcock, 1998). The doing and being do not happen in sequential order but are layers of becoming a different, but the same person in the now and the future.

36-months after stroke

Ironically sometimes making time to be and experiencing and appreciating the benefits, can mean a return to the usual busy and perhaps unthinking and unreflective ways of doing from life before stroke. A new future, a becoming, is made possible by the being and doing (Hitch et al., 2014; Wilcock, 1998).

> *We decided to come here. Best choice I have made, it's just so much slower. I am working part time. I haven't been meditating for a little bit. I need to get back to it because I am right by the lake… It's the same old I need to find time, but time is always there I just never do it. (Angela, 43* years*)*

> *It's interesting sometimes… that mock kitchen that they had set up at in hospital and you kind of do a test run before you go home. if I had to do that again I would probably fail. My husband, 3 or 4 times he said that to me. I know I have to but there's other things. I guess the family demands well I go to cook something and then I go to serve everything up, all the pots back to the stove. (Angela, 43* years*)*

> *If it didn't happen to me then maybe I wouldn't have operated from another space that I do partially now. Because I wasn't what I used to be cognitively I had to rely on the other parts of me, spiritual and all sorts. So I have had an opportunity to be exposed, it took my world to a different space. (Angela, 43* years*)*

Participants who appeared to manage and move forward

In summary, the ‘managers’ were reflective, self-reactive, and strategic (Bandura, 1991). They had some control over their thoughts, feelings, motivation, and actions. They were self-monitoring and assessed themselves as to what they were safely able to do in terms of physical, cognitive, and emotional abilities, and the limits of their energy (Bandura, 1991). Participants who managed to move forward were able to set goals and plan the required actions to achieve those goals. The managers also seemed to have a firm sense of their identity and their personal and social standards and values, which resulted in a high level of self-directedness (Bandura, 1991). They engaged in valued activities and saw their success as due to their own efforts and abilities (Bandura, 1991).

Their position in society had allowed them to create a lifestyle that was anticipatory and proactive (Bandura, 1991). They have a ‘style’ (Bury, 1991) of coping or groups of strategies in which they had confidence, which involved active and social leisure pursuits. They understood the importance of a close family, friendship and being socially connected, and worked at making and keeping social networks. They were able to *make the environment work for them* and had the resources to do so. Some had a spouse or significant other and they were able to *work as a team.*

Foresight and planning, setting up of the environment prior to having a stroke meant that these were not thinking and doing tasks which took a lot of energy following stroke. They lived in safe pleasant surroundings that gave them time and space to be. Managing was balancing a complex set of relationships between context, style, habits, creativity and being (Cutchin & Dickie, 2011). Managers had realised that it was not possible to return to the place they were just before their stroke. Learning to manage produced a new context and a new way of knowing (Frank, 2011).

Participants who did not appear to manage and remained stuck

Some of the participants who do not manage as well, did not have a casual model and remained stuck with the thinking that medicine should be able to fix them, while others blamed themselves. Those who did not move forward did not see that their efforts resulted in progress or recovery and may not piece together an alternative to traditional services. Some did not have resources to draw on and expended much of their depleted energy feeling stuck, vulnerable, and let down by the system, which reinforced the belief that *they did not matter*. There was no guiding compass nor vision of a reconstructed life after stroke.

In the following story the participant and his significant other chose to be interviewed separately. For this participant and his wife, the cause of stroke seemed clear. They did not speculate, or hypothesise, they were certain that his actions were to blame. Their causal model still allowed for some hope that with enough hard work, strength would be regained, and the old life was not lost. Life was on hold, waiting for a time when things could go back to the way they were.

Despite some privilege, as homeowners living in a nice suburb, completing two self-management programmes, accessing community services, and being supported by the stroke foundation, important thinking work did not appear possible. There was no sense of, *so this is how it is*, to their story, more a defeated acceptance without hope of change or a return to how it was, despite some improvement.

6-months after stroke

> *He was playing with his medication, that's why he had the stroke. He stopped taking it and just said, 'I'm fine' and he played with it for years, but I couldn't tell him. He should have been insured but he wouldn't because he said ACC… So, he's got a lot of guilt. I try to let him know all the time that it's happened, just get on with it. You can't turn the clock back…what if? There aren't any. But we're happy (laugh). (Carole)*
>
> *The company I used to work for got me along to repack their shelves and tidy it up, nothing too substantial but just to get me out of here, I think…but I try to play on the computer which I been trying to learn, but*

I get sick of that, [the rehab staff] said to do the patience game on the computer so that's what I do but I get sick of that too. But that's about all really. (Raymond, 63 years)

The morning goes away quickly because I've got that organised with the chores around the house and I go for a walk for approximately ¾ of an hour to an hour every day. It's just the afternoons really that takes the time. You can see out there now I've got the lawns to mow which doesn't take that long, still part of the day… just to keep busy and get working and to make some money I think well it's just doing stuff is very important in life isn't it, just to be busy is good cause you know I used to do like 50 hours a week so and down to nothing now is pretty hard going. (Carole)

It's pretty hard on my wife because she is the sole earner, so she is the one who has got to be busy, busy, busy, keep going, keep going, keep going. I did start to do a meal now and again but now she comes home and all she prepares it usually the night before or like for today I've just got to put it on, or peel potatoes or whatever. So as much as I can do myself is good, you know like doing the washing I can handle that, and that helps but it is still not enough is it? I don't feel anyway. (Raymond, 63 years*)*

12-months after stroke

At 12 months post stroke, barriers to reconstructing a new life seemed insurmountable. Setbacks were experienced as roadblocks that they found difficult to navigate around. They were not able to think differently about how they were going to manage, and although they had some resources to draw on, they were not able to use them in creative ways to manage differently and on their own. Stroke so challenged what they thought they knew about the world and how it worked, that were not able to move forward, nor attend to the necessary emotional and biographical work, or think reflexively about how to manage differently.

The mission must be grounded in the person's values, such as serving others; otherwise the thinking does not result in action. Participants reflected on personal meanings of wellbeing, purpose, values in order to develop a plan for a worthwhile life. From this thinking a plan develops of how they might achieve a life of purpose and meaning (Sylvester, 2011), and involved a careful plan of experimentation (Bury, 1991).

Many participants talked about actions they could take, but they did not enact them by the end of data collection. This seemed to be due to not having a mission that was connected to their values or what they perceived of as a life that is worth living. It was more filling in time, rather than something that had arisen out of themselves and felt like what they should be spending this part of their life doing. Their own values, beliefs and attitudes linked to a mission were needed to propel them on towards the possibility of a life worth living.

From early on, even with the work of recovery to complete, there appeared to be no mission, no search for a mission and limited opportunities for *reciprocity* and experiencing the *feeling of being of use* for Carole and Raymond. Together they created structure, but without meaning and purpose there was no sense of moving forward with any momentum. Raymond did not seem to be sufficiently attuned to his body and recovery to notice improvement. Rather he was stuck thinking about the deficits that remained, with no life goal or mission he was unable to visualise a new self with stroke incorporated into his identity.

> *(where to from here?) I don't know. Don't look any further ahead. I didn't think there would be any changes… three months ago but he's changed significantly so… But he'll never work again. I think you've just got to accept that this is what is and just get on with it. And I think once you do that life's easier. Because otherwise you're just dwelling on the negative. (Carole)*
>
> *They're suggesting I get out into society and help do voluntary work and whatever but it's just getting there you know with only one car? And there's no buses that go in the direction. So I thought I might see if I can go and play bowls or something like that. Because you can catch the bus to bowls… I think you do need [social contact] that now. Because I've been here for a year. Down here in this little hole. (Raymond, 63* years*)*
>
> *It will just fill in the day I think…especially in the afternoons…and maybe get me to do stuff on the weekends. You can only walk so far and the same old walk every day. I get a bit sick of that. I want to get better, and I want to get stronger. (Raymond, 63* years*)*
>
> *I just think if I get a [small project done] that's… good. But no other goals…I know I won't be going back to work anyway. Because I know how I was… And now I'm nothing. (Raymond, 63* years*)*

A good life? Going back to how I was. (laughs) Working and being busy [are the important things]. I mean you can only clean the windows now and again. You can't clean them every damn day. There's only so much T.V you can watch as well. (Raymond, 63 years*)*

24-months after stroke

Their way of responding seemed to be based on the western thinking that the individual helps and is responsible for themselves. Independence rather than interdependence was valued and sought. Some experimentation with strategies was present in their stories, but it lacked the flexible thinking that characterised managing. They did not speak of pulling through, to this new problem of stroke, habits, skills and preferences from earlier stages of their lives. Although some planning or imagining of a preferred future and retirement was evident, preparation for an old age appeared absent. Things were not set up in advance. There was no talk of looking ahead or foresight, no feeling of preparedness.

They talked of being connected to a limited number of people in their close family and circle of friends. But there were no close ties to create the feelings of belonging and stability present in other stories. A sense of closeness and attachment appeared foundational for feeling worthy of pursuing opportunities to grow and become something new. Raymond did not appear to have much confidence or *feeling of effectiveness* that his efforts would translate into an improvement, meaning that ways of increasing strengths and function, despite resulting in no or very slow improvement, were not changed and, new activities were not tried out.

Financially I do [take one day at a time]. I just have to train myself not to think about some things. It always is [on my mind] but I will never say anything to him cause like the other day…he said, "move on, just go and find somebody else who will look after you". You know so, which I wouldn't do. I choose not to do it. Something usually turns up. I would like it to hurry up and turn up. (Carole)

The mornings all booked up really. So, except on a day like today which is pottering around. But by the time I do my chores and get dinner prepared and that, if I go to the gym it takes up a big hunk of the morning. (Raymond, 63 years*)*

I think I have improved heaps. But that's my aim, why I am going to the gym, to strengthen my left-hand side. The walking is a good thing too,

I've just got to get faster and faster that's all. The only thing I want to do this year is to run. Sort of run from one running post to another, which I haven't tried yet. (Raymond, 63 years*)*

36-months after stroke

Perhaps due to a causal model based on self-blame, there seemed to be a feeling of not being deserving of the application of reduced resources to increase his quality of life. Without reciprocity, or experiences of helping others in the past and contributing to society there was no *feeling of being of use to others*. No way of reaffirming his identity or possibility of being able to reciprocate in ways that were recognisable or acceptable to him.

Noticing and being were not a feature of his thinking, regret rather than reflection dominated. He appeared stuck with cultural expectations about working, contributing, being busy and productive, with no alternative story for his future life. No new way of being in the world was discovered in the space between noticing and being and becoming.

But perhaps there was a glimmer of hope by 3 years after stroke. At this time Carole noticed he was able to help with their grandchildren more. Perhaps providing a way to reciprocate and therefore accept, a more interdependent way of being in relationship with others, accompanied by a change in priorities away from economic to social capital.

He's now more confident with the grandchildren so he participates quite a bit as a grandparent. Which is good. He's playing golf and more confident in himself. He's played golf for the last couple of weekends. Something he'd never have done before. Probably more standing on his own two feet maybe. (Carole)

I've left him a book upstairs; a rugby book and I've suggested he read one or two pages a day but I'm not sure if he is. He's never read books in his life, but I just thought that he needs to do that just to…for his concentration. I must ask him actually if he's doing it. Tomorrow he's going to go and help her do some painting in one of the bedrooms for one of the grandchildren. He would never have done that a while ago. (Carole)

Don't know to be honest [if it would be possible to work]. A year ago, definitely not, now I don't know. Maybe something a couple of hours a day but…who's going to give him a couple of hours a day? And then he needs a car. Wouldn't work anyhow. (Carole)

I think I have got worse to be honest because I have been going back to the doctor all the time and he said he thought it maybe my medication because I am all dizzy in the head, I can't think straight, and I can't remember... So he said he will change my medication which he seems to do every time. But I still don't feel any better, so I don't know whether that's working or not. It's terrible. Because I am sort of walking around in the cloud all the time. (Raymond, 63 years*)*

One of my goals this year was to start running but I haven't been able to do that yet. My brain won't let my leg run. I've tried it I started doing lamp post to lamp post but that didn't last very long, and I can't duck and dive. So, if the kids kick a ball, I can't sort of dive to get it. (Raymond, 63 years*)*

[I still go to the] gym, but I am getting sick of that as well. My wife said I should get into yoga or something like that. Doesn't really interest me. I have never been interested in any of that. I have never been in the gym either I'm only doing it because I want to get stronger. (Raymond, 63 years*)*

One thing I have learnt since I have had my stroke is you have got to ask people to do stuff which I never did before. I was very independent. My doctor said I might be like this the rest of my life who knows. I hope not. I said she [should] just put me in a home and then she can get on with her own life. But she said "no, no I'm good." So that's good. Mind you I probably wouldn't be doing anything different to what I am doing here if I was in a home. (Raymond, 63 years*)*

Conclusions

Social connection was essential to managing, it provided comfort and an antidote to disruption. But was only effective and acceptable if it was based on reciprocity. Ideally this reciprocity should be given and experienced in the present but sometimes their giving of themselves from the past would do, if all else failed. Participants could accept help if they felt worthy and deserving. For those able to pause and live in the moment for a time, connecting or reconnecting to others, the natural world and their identity created the possibility of becoming more themselves and moving beyond rehabilitation and managing to live again or anew. Space and privilege were needed to reflect on what they needed and what would be helpful. Those with less resources had to work much harder at finding and creating alternative ways of managing than those who had more.

Learnings from layer 3

Currently self-management programmes are narrowly focussed on ‘health behaviours’ rather than healthy living. A more holistic approach is required that encompasses all that people do, not just what they do to manage their health condition, and accounts for the contextual influences on what they can chose to do from the range of options available. To support and empower people self-management may need to be underpinned by theories and practices that address health inequality.

People who are physically active, participate in life and are socially well connected and supported experience better health and wellbeing than those that do not (Kandt, 2018). Rehabilitation, self-management and health promotion need to address the ‘causes of causes’ rather than focussing only on individuals’ behaviours (Kandt, 2018). Also needed is policy that supports redistribution of resources, and accessible education and health systems (Kandt, 2018). Understanding the resources people have available to them is insufficient, it is also necessary to examine the choices people have, determined by their individual situation. What the resources can be converted into and how they are used should also be understood if the field of self-management is to advance (Frohlich et al., 2001).

This chapter detailed the way in which participants acted in response to stroke when reconstructing life. This acting was based on thinking work, which was underpinned by feeling work, that participants needed to do to find a way forward. The following chapter brings together the three layers of this doctoral work and comes to conclusions about new knowledge generated that can be used to inform practice and research going forward.

Chapter 12: Discussion and Conclusions

Beyond managing to flourishing

> *"In some ways I'm quite glad that I had the stroke. It's taught me to appreciate what I have, what I can do and shown me that nothing is impossible"*

At the beginning of my thesis, I outlined my process for conducting this research. The process was not linear but layered as the three phases informed each other in an iterative way. Although my format is somewhat unconventional, it allowed me to learn new ways of thinking with theory and enabled me to progressively build my understandings as new insights emerged. The layered approach used allowed me a way to link them and bring coherence to and select from a very large amount of data. The inclusion of two publications as chapters made my study bigger and more complex, however it demonstrated how much my clinical knowledge and thinking were challenged and changed by the experience of working on the Stroke Experience Study and the specific sub-analysis conducted as part of my thesis.

In this final chapter I bring together the three layers to illustrate the novel contribution this doctoral research makes to the field and how the findings from each layer combine to yield a great understanding of the concept of managing after stroke. This work challenges and contributes to contemporary understandings of managing after stroke by suggesting a shift is needed away from traditional biomedical understandings and current rehabilitative practices to an ecological approach. I will outline support for this claim through a return to the literature and drawing together learnings from participant's experiences from this doctoral work.

Participants were still working on managing when the study ended three years after their stroke. Some of them were also managing subsequent strokes. Some continued to slowly move forward, others remained stuck, managing some aspects but not others. There were occasional surges and epiphanies in their thinking, but for the most part participants needed to draw on their resources – social, cultural, and economic, as best

they could in order to manage few or more aspects of life after stroke. Sometimes habitual ways of feeling, thinking and acting helped to draw the layers together. For others previous ways of overcoming challenges were not a good match for the problem of managing after stroke, and people remained stuck. The careful, complex, and creative interweaving of the layers required for managing was difficult to achieve alone.

Managing was not a dichotomy, with some participants managing some aspects better than others. Nor was it a linear process from the initial shock and disruption to managing, rather a continuous process of feeling, thinking, and acting or not acting. Context, feeling, thinking and acting were interlinked and interdependent layers of the total experience of reconstructing life after stroke. The resources that participants had around them seemed to make a difference to who moved forward and acted to interwork the layers, and who did not. There were not any participants who managed all aspects of their life after stroke, all the time. Conversely there were no participants who were unable to take any action at all to manage after stroke.

Returning to the literature

Despite the literature over the last decade increasing our knowledge of how to support people post-stroke, there is a still a significant gap in how we support self-management. For example, it has been reported that the relationship between self-efficacy, problem solving and goal setting and the impact on behaviour remains unclear (Plow et al., 2017). While single studies reported positive changes in self-efficacy and satisfaction with ability to carry out self-management tasks, when combined in systematic reviews the role of self-efficacy and ability to carry out self-management tasks was shown to be limited and generally of short duration (Lo et al., 2018). No specific skills or supports stood out as more effective than others (Taylor et al., 2014). The review recommended that self-management be embedded in usual care, which would require training and resources for both clinicians and organisations and include strategies for addressing cultural knowledge (Taylor et al., 2014). However, this

approach does not take into account that some stroke survivors rethink their values (Plow et al., 2017) and that biographical disruption, fatigue, the process of adjustment, and reduced social opportunities continue to get in the way of flourishing and take time to process (Wassenius, 2020). For others a loss of identity and roles, fear of subsequent stroke, and loss of confidence are connected to self-esteem one year after stroke (Horne et al., 2014).

A recent meta-analysis synthesised evidence from 17 studies completed in the last 20 years, investigating self-management programmes for stroke survivors (Oh et al., 2021). The meta-analysis demonstrated that conventional self-management programmes resulted in a small increase in ability to complete activities of daily living but had no impact on health-related quality of life, instrumental activities of daily living, or depression (Oh et al., 2021). Trials underpinned by the Lorig model, which is largely unchanged from its inception, continue to be conducted. The ways that the programme has been adapted for stroke survivors and the interventions used, are being described in more detail and therefore application of theory is more visible (Fugazzaro et al., 2021). Cultural change amongst professionals continues to be required and stroke survivors with communication and cognitive deficits are still excluded from taking part (Fugazzaro et al., 2021).

A further broader scoping review pointed to further issues. Across the 54 studies investigating self-management programmes for stroke survivors, mostly published after 2014 and conducted in high income countries, there continued to be considerable diversity in duration and content, with no research comparing different programmes, rather a programme was compared to usual care (Ruksakulpiwat & Zhou, 2021). Most studies reported an improvement in symptom management but no impact on compliance with medication and stroke knowledge (Ruksakulpiwat & Zhou, 2021). The growing number of studies investigating self-management programmes delivered via telehealth point to similar difficulties. A recent systematic review of telehealth applied to

stroke found ten studies with 427 participants (Hwang et al., 2021) and reported diversity in format (video conferencing, email, text) and duration and most excluded those with cognitive and communication impairments. There was some positive impact on a range of outcomes for individual studies, but there was no consistency overall (Hwang et al., 2021). Additionally, despite the extensive research effort, the concept of self-management continues to be unfamiliar to stroke survivors (Lo et al., 2021).

Nonetheless, some positive indicators may be gleaned from the literature. Finding ways to promote psychological growth such as meaning making, hope, and resilience has been found to promote adaptation to chronic illness and disability (Martz & Livneh, 2016), and interventions that address difficulty sleeping, managing stress, beliefs about the cause of stroke, or support emotional recovery and social activity over quite long periods of time, have been found to be helpful. In this regard, it has been hypothesized that *feeling better* may contribute to *doing better* in terms of managing risk factors and quality of life, even when impairments made it difficult to engage in health behaviours (Plow et al., 2017). However, most stroke survivors do not have access to clinicians like dietitians, sleep specialists, psychologists (Plow et al., 2017), and other professionals they may have contact with in the community may not feel they have the knowledge and training to help manage psychosocial issues (Sekhon et al., 2022).

An additional thread in the more recent self-management literature is the long-term adjustment of stroke survivors. There is acknowledgement of societal expectations to be busy and productively occupied, with those that succeed in assuming responsibility for their own recovery believing that their hard work would pay off, employing a strategy of careful experimentation, and persevering over long periods of time (Wassenius, 2020). Over the years following a stroke, people need to develop cognitive and psychological rather than practical strategies for feeling useful. For some who more or less manage, a new or revised identity is constructed via activities such as volunteering and finding ways to connect with others (Lo et al., 2021).

Overall, the literature reveals the intricacy and complexity of recovery after stroke. A rapid and in-depth review of the evidence for self-management programmes for people with long-term conditions including stroke found that self-management is a set of complex interventions. Complexity is required to account for individual variance in experience, culture, and values and to be founded on a positive relationship between the person, the health professional and the services they are accessing (Taylor et al., 2014). A taxonomy of self-management supports and interventions has been developed that may assist with describing and understanding the multiple components that are included or needed and the way in which components of care are delivered (Pearce et al., 2016).

Summary of key findings: Feeling, thinking, acting

The findings of my doctoral research have augmented this recent research by shifting our understanding of what it means to 'self-manage' after stroke.

Layer 1 Feeling impacting on thinking about how to manage

In layer one, I learnt that at 6-months after stroke, participants were still experiencing significant and distressing biographical disruption. They described needing health professionals to acknowledge their distress and to spend more time helping them to understand what had happened to them. However, for most people in our study there were no formal services after discharge from acute services and many felt unable to manage their psychosocial needs alone. Our participants were a representative sample of the stroke population, and in keeping with that 70-80% of participants were classified as mild to moderate and did not receive rehabilitation and other services (Rochette et al., 2007). These findings are consistent with other research that reports the need for support not only in the early stages but as an ongoing intervention (Pearce et al., 2015). The participants who participated in my study expected help and support from all of the services they encountered rather than a specific service. They expected all the clinicians they came into contact with to attend to their loss, but this rarely occurred.

They needed confidence in the services they did receive, and to feel that they were a good fit with their challenges to benefit from them.

Participants described needing to know how and why their stroke occurred and that they needed an explanation from a trusted clinician and more than one opportunity to talk about and create a model for the cause of their stroke. A causal model was needed as a foundation for managing. Participants struggled to work out how to prevent further strokes and their fear of recurrent stroke prevented them from moving forward. Health anxiety is common not just in stroke survivors but for people with other chronic conditions and persists through time decreasing quality of life (Lebel et al., 2020). In the absence of acceptable biomedical explanations participants used cultural knowledge to understand their stroke and to think about what to do in response to it. They worried about doing too much, reducing stress and only had confidence in the authentic and knowledgeable advice from stroke survivors who were further along in their recovery. They actively sought out a stroke mentor as a source of information, although many were unable to find one. This is unfortunate as peer support has improved physical and psychosocial outcomes in previous research (Wan et al., 2021).

However cultural understanding of what it means to be ill can be unhelpful, such as resting in response to symptoms. A focus on a select few of obvious stroke signs and symptoms are promoted and perpetuated in the health service. Participants felt unable to relate to medical advice and information that did not feel relevant to them. For example, a focus on hemiplegia with little information on addressing the other consequences. Even messages such as FAST – face drooping, arm weakness, speech difficulty and take action, still promotes the idea of hemiplegia. The promotion of medical knowledge over everyday knowledge is problematic (Nespoli et al., 2020) as it does not point to a way forward that makes sense given a person's context and beliefs. Other research supports this assertion, that a stroke survivors' beliefs about the cause of their stroke and the right way to respond influence a person's take up of clinical

recommendations (Della Vecchia et al., 2019; Townend et al., 2006). Beliefs being heavily influenced by the person's context which needs to be considered so that barriers to recovery are addressed (Morris et al., 2017).

Layer 2: Collective thinking impacting on acting

In layer two I discovered that participants' contexts created or constrained ways of managing, and impacted on the choices participants had, based on the social, economic, and cultural resources available to them. Participants who had economic, social, and cultural capital to draw on following stroke, experienced biographical disruption but were able to choose ways in which to respond to stroke. They could address the three lines of work – biographical, every day and illness work (Corbin & Strauss, 1985), drawing on neighbours, friends, offers of assistance and other environmental assets. They had the resources to respond to the disruption in ways that fitted with their identities, values, and beliefs. People with lower social status and resources had less choice and sometimes no choice about how they responded. They had little choice of employment, lifestyle, and insufficient resources to draw on to prepare for their retirement, if they had in fact reached retirement age when their stroke occurred. A somewhat confronting finding of the study is thus that self-management is a luxury of the well-resourced. This finding is consistent with other research that recommends that social, economic and cultural capital must be measured and addressed before interventions for managing are created (Greenhalgh, 2009; Weaver et al., 2014).

Layer 3: Feeling and thinking impacting on flourishing

My longitudinal analysis in layer three of this work taught me that participants were still trying to manage three years after stroke. They needed to learn to draw on social, cultural, and economic resources, if available and to make room for new knowledge of what a successful recovery was in order to *become* someone new, but recognisable in

terms of values and beliefs. For the new knowledge to be acted on, a feeling that they matter needed to be present to underpin the *actions* that they took. Otherwise, there could be the feeling that they are a problem for which there is no solution. These findings revealed to me that managing may be comprised of most things that people do, not only their illness related work. Supporting people to manage requires knowledge of their context and the choices available to them within their context.

These findings support the notion that people with chronic conditions are not a problem, rather people who need what everyone else needs – a life of meaning, dignity and the nourishment gained from interacting with others including caring for each other (Nespoli et al., 2020). Care is a political act that does not have to relegate responsibility to the individual and avoid disturbing the current situation. Rather it could be about constructing a sense of wellbeing for the person, which involves enabling them to contribute to the greater good (Nespoli et al., 2020).

Novel contributions from drawing together the layers

Traditional self-management has not met the challenge of reconstructing a life of meaning after stroke. The findings of my research have provided an indication of why this may be the case. Even programmes designed to deliver adapted content that accounts for diversity in terms of inequities, have not produced the hoped-for benefits. Drawing together the three layers of my findings shows that self-management needs to be tackled on at least three levels that interact with each other.

This doctoral work met the challenge of Pearce et al and moved on from investigating the experience of stroke which has reached ‘saturation’ (Pearce et al., 2015). This study looked beyond that and asked questions about what people do to move forward, continue their recovery, and the things they did to manage. This thesis demonstrated that social resources really make a difference as to whether and how people manage.

What is surprising is that as much as is known about the struggle to manage let alone flourish, there has been no response to it except to expect individuals to work it out alone. To continue trying to design or refine a self-management programme for stroke based medical model of stroke seems ill advised based on these findings. Instead, what is needed are redesigned systems and services that are based on the story of disability that people live.

There has been little to no response in the stroke literature to the sociology of illness literature that highlights the need to account for contextual differences between the privileged and underprivileged – the social factors and social, economic, and cultural capital. Health resourcing is under pressure, the more neoliberal response is to provide the service to the people who are going to get the best outcome, which further advantages the advantaged. Even the programmes that have been refined for lower socioeconomic status, ethnicity specific, disadvantaged groups the content is still the same.

This study points to the danger of a cultural situation where we have handed health and wellbeing over to the medical system rather than utilising the people, spaces, and opportunities around us. People have always known that the everyday things that we do can have a positive effect on health such as music, sport, arts and crafts and this knowledge has traditionally sat outside of medical knowledge. Activities that are engaging and hold meaning and value have not traditionally in modern society been utilised as complementary to biomedicine (Wilcock, 2001). A cultural shift is needed to shift health and lay ways of feeling, thinking and acting in response to stroke.

A clinical response to stroke needs to be layered. Based on the findings of my thesis, I propose three approaches that need to be layered together to form a comprehensive and effective response to the difficulty and complexity of managing after stroke:

1. Embedding support and interventions that address psychosocial issues into usual care. Clinicians should seek to form strong collaborative alliances with their clients, address biographical disruption and assist them to form a helpful causal model. This doctoral research signals a move away from organising services by health condition and to the integration of social and medical services (Mann et al., 2017).
2. Measuring and optimising what people can actually do with their resources and utilise methods to identify and increase social capital. Interventions that target cultural knowledge and health literacy need to be developed and adapted for stroke and its comorbidities. Work towards increasing confidence in health systems, public health initiatives and messages needs to be done. Stroke survivors need help navigating the healthcare system.
3. The supported utilisation of mainstream resources for social inclusion. Underpinned by a focus on doing, being, becoming, belonging as well as lifestyle changes is indicated.

Strengths

A longitudinal design enabled me to look for the detail of managing over time and how it changes. I completed over 90% of the interviews and established a strong rapport with my participants. As a result, very few participants dropped out of this research. Some significant others requested to participate in the last round of interviews even though their stroke survivor had passed away, demonstrating commitment and belief in the study. A relationship maintained over a long period of time enriches and expands what participants feel able to say and what I could listen for. I sincerely hope that participants felt that their views and experiences mattered.

I bring to this study an occupational perspective, a curiosity about what people were doing and managing to get on with. I wondered about what people with stroke do and how they do it. How the environment influences what people do and how they think

about what they can do. This wondering was not only at the level of the individual but also more broadly to groups of people and communities. I looked for the meaning people assign to the things they do and the influence on their identities. An occupational perspective encompasses occupations that support health and wellbeing (Njelesani et al., 2014). I thought about what people do as at certain points in times and also what they might do in the future and become.

I had the opportunity to purposively select participants across the factors I wanted in terms of diversity. This doctoral study was drawn out of a much bigger study, participants were selected after months of conversations in supervision, during which I was able to examine and consider the diversity required for richer results at the conclusion of analysis. I was able to follow particular lines of reasoning through time and examine them in-depth. Analysis was concurrent with data collection which enabled me to test out theory, adapt interview questions and topic. It also meant I could trace the changes in my thinking over the course of the study (Thomson & Holland, 2003).

I was able to test out my sensitising concepts thoroughly and at every interview timepoint. I spent time analysing, thinking, and testing theory which gave me the time to develop and mature my own understandings about stroke and stroke rehabilitation. If the study had progressed rapidly, it would have been completed earlier but my understandings would have lacked depth and breadth.

Limitations

All studies have limitations, and this study is no exception. For example, the interview guide that I originally went into the first interviews with did not uncover new understandings. It took some time to read and think about what to ask our participants to generate the questions that were helpful.

In retrospect it would have been useful to have asked about the availability of resources for managing from the beginning of data collection. I wish I had taken more notice of participants' contexts, which would have led more quickly to how participants went about trying to manage. I also regret not asking much sooner in the interviews, for participants to describe a 'typical day'. Once I did ask, I was able to see how much longer everyday activities took, limiting the time available for tasks associated with managing and recovery and often leaving no time for rest, and restorative and leisure occupations.

A longitudinal study of this nature does not fit easily or comfortably within academic and institutional times frames. It was difficult to resist the pressure to settle quickly on superficial interpretations and not be derailed by the emotional fallout from changing rules and expectations, criticism, and the application of quantitative standards onto my longitudinal qualitative study. I needed to sit with the data and the stories for longer to yield findings of value and utility.

Taking the findings into practice

What these findings reveal is that supporting people to manage their stroke needs to happen across disciplines, on more than one occasion, in different parts of the healthcare system and be embedded into usual care. Managing after stroke is a complex process and more than one intervention is required. Part of the answer may be to rethink acute care, rehabilitation, and self-management rather than persisting with separate interventions. Support, education, and strategies for increasing health literacy, could be threads that run through all interactions with health and community services.

The relationship between health professionals and stroke survivors is a pivotal point and has been prioritised over type of intervention and outcomes (Bishop et al., 2021; Sylvestre & Gobeil). While well established in other fields, with concepts and methods borrowed from psychology and psychotherapy, there is still some work to do in the application of person-centred principles to stroke and other neurological conditions

(Bishop et al., 2021). A relational approach can increase engagement for the person with stroke, their clinicians, and the organisation (Bright et al., 2017; Kayes et al., 2022). An approach that has been tailored to the local context and accounts for the layered intersecting relationship of different kinds of knowledge, identities and power may be part of the answer to helping people manage a long-term condition such as stroke (de-Graft Aikins et al., 2010). An approach which embedded into usual care, would create many opportunities to support people to learn how to manage their stroke. With some extra training clinicians could provide psychosocial support and support for managing. Brief but repeated interventions like those delivered out of General Practitioner surgeries may be helpful (Reiter et al., 2018). This sort of approach is a structural change in the way healthcare is delivered, which is necessary for this population, as stroke survivors often have no other services they can access (Rochette et al., 2007; Tellier & Rochette, 2009).

If clinicians saw themselves as a resource rather than director of recovery, there would be more space for listening rather than telling and a move from control to support. This finding supports a metasynthesis of 41 studies, in that power needs to shift from only residing in the professional to a shared approach (Mudge et al., 2015). Finding out about people's values and setting goals connected to those values would be helpful, however this is difficult when services in New Zealand are structured around the biomedical model alone and focused on the treatment of impairments and increasing scores on outcome measures rather than seeking to discover who people are and what they value (Clapton & Kendall, 2002).

It is apparent that social disadvantage also needs to be addressed along with other 'causes of the causes' (Braveman & Gottlieb, 2014) of stroke. Interventions aimed at individuals do not account for those for whom acting is not possible due to their social position (Farias et al., 2019). These findings demonstrate that stroke services need to move away from the biomedical approach alone to also examining the social causes of

poor health outcomes (Farias et al., 2019). Services can continue trying to improve the health of individuals by providing only biomedical knowledge and interventions for them or see the solution as groups of people working together to address these social causes, who are thus empowered to influence health (Farias & Rudman, 2019). It could be that if some of a person's 'social' issues are addressed then they may be able to manage stroke themselves.

As long as stroke clinicians focus mostly on physical environment, and not the social, political and economic features of the environment, inequity will be perpetuated (Gerlach et al., 2018). Widening the clinicians gaze to address systemic barriers as well as capabilities and skills is needed (Gerlach et al., 2018). A broader gaze would involve resisting viewing stroke only through the lenses of biomedicine and neoliberalism, instead utilising theories that appreciate a more collectivist viewpoint and are underpinned by human rights (Malfitano et al., 2019). Therefore interventions should also target inequity and injustice as well as the impairments of individuals (Pollard & Sakellariou, 2014). Change at the societal level is needed to move towards goals around flourishing and enjoying life (Veal et al., 2018). Health professionals such as social workers and occupational therapists may need training and development to move back towards their 'social and activist roots' and to recognise and respond to social determinants of health and inequality (Galvaan & van der Merwe, 2021; Veal et al., 2018). Supporting people to access mainstream activities and resources, especially those that are low, or no cost would be important to capability informed rehabilitation. Advocating for these activities to be made more accessible and finding ways to enable stroke survivors to attend a range of activities, would require clinicians to think broadly about what might be helpful for increasing participation (Hocking & Townsend, 2015). Social inclusion is required for a sense of belonging and a sense of belonging is required for flourishing (Townsend & Marval, 2013). Clinicians are well placed to develop a 'knowledge bank' of local resources and could assist people to find mainstream resources that are a good match for them. Decolonising care from the

biomedical culture to also include alternative or complementary interventions (Nespoli et al., 2020) would also increase the range of options used to achieve wellbeing. Aiding stroke survivors to navigate community systems as well as healthcare systems is also an important role for clinicians.

For participants in the longitudinal study there appeared to be a strong connection between social contact and health and wellbeing, which has been demonstrated previously (Holt-Lunstad et al., 2010; Sarason & Sarason, 2009). Social capital is an important component of being able to manage after stroke and can be converted into ways of coping, finding meaning and purpose and accessing the community for social and leisure activities. However, receiving help without the opportunity to reciprocate is not 'helpful' and could even be unhelpful (Brown et al., 2003). Different ways of giving to others such as helping a neighbour or friend, supporting a loved one could increase positive outcomes (Norlander et al., 2016). Research and practice would benefit from a switch from focussing on independence to thinking about interdependence and ways of strengthening and utilising it (Rudman & Aldrich, 2017).

Social networks do not consist only of individuals that people already know, but are wider in terms of communities, institutions such as the library, sports centres, social groups and services and others. These networks serve a supportive function when people have confidence in them and perceive them as accessible and trustworthy and helpful to them and contribute to a sense of belonging (Sarason & Sarason, 2009). Clinicians could think about the aspects of stroke that might make it difficult to tap into social capital. Perhaps there are cognitive, fatigue, and communication difficulties after stroke that could be addressed in rehabilitation more explicitly and deliberately for this purpose (Sarason & Sarason, 2009).

The participants in this doctoral work and the stroke study were not aiming for managing, they wanted to flourish. If the goal is to move beyond reducing costs such as days in hospital or GP visits, then an approach that aims to create the societal

conditions where everyone can flourish is required. Stroke services could measure wellbeing and what people want to achieve in order to create intervention goals (Diener & Oishi). For example, the ICECAP-A – a capability and wellbeing measure for adults, and other similar tools to highlight ways of increasing resources and opportunities and redesign rehabilitation (Bloemen et al., 2021). Such measures and goals would enable clinicians to view participants and rehabilitation through the lens of capability theory (Bloemen et al., 2021). Measuring capability would indicate to funders and policy makers, where the need lies.

Implications for health policy

The health and disability system in New Zealand is transforming, with Te Pae Ora (Healthy Futures) Act 2022 establishing Health New Zealand, a new structure which replaces district health boards, aiming to improve the quality of services. A focus on population health, prevention and wellbeing is envisioned as the foundation for whole system change (Healthy Aging Strategy 2016, Health and Disability System Review 2020, Provisional Health of Disabled People Strategy, 2023). These changes were instigated in response to the Health and Disability System review and other evidence, which indicated that increased investment in public health initiatives was the best way to improve health nationally and reduce the strain on New Zealand's health system (Little et al., 2021). The intent of these policies is to support all New Zealanders to live longer and experience the best health outcomes possible (Te Pae Ora interim NZ Health Plan, 2022). This aim is consistent with the findings of this research and participants' need for flourishing and living well with the long-term impact of stroke, and not just surviving (Healthy Aging Strategy, 2016, Provisional Health of Disabled People Strategy, 2023), like Angela and Mark were able to do (Chapter 11) by drawing on their faith and other cultural resources to notice beauty, connect with nature and family.

Te Pae Ora builds on previous government policy such as the New Zealand Health Strategy 2016, which aimed to give people more choice and control in decision making

about their health. There has been a much stronger focus on working with groups locally using methods of co-design and shared leadership to develop and restructure services. My work contributes information about what the current experiences and challenges are for people who are trying to manage their recovery after stroke.

Policy statements provide a vision of delivery through more tailored services that are easier for users to navigate and are more sustainable for providers to deliver (Te Pae Ora interim NZ Health Plan, 2022). The integration of health and social care could create adaptable services that respond flexibly to changing needs and expectations of people managing after stroke (Te Pae Ora Interim NZ Health Plan, 2022). Insights from this research include that the means for improving outcomes for people after stroke are not only contained within the health system. Flourishing depends on the health system interacting much more with social systems that make resources accessible. Participants in this study who managed, found mainstream resources and needed services and resources to be close to home. For example, Sharon (Chapter 7) and her husband were able to move closer to health and other services, prior to having her stroke, which reduced feelings of disruption and vulnerability.

For joined up services to be a reality, healthcare practitioners, in addition to health knowledge, also need to know about local gyms, exercise and support groups, and other organisations who support people (Healthy Aging Strategy, 2016). Practitioners also need to have a much closer relationship with their local branch of the Stroke Foundation, and to actively refer to General Practitioners and services operating out of their practices. Providing clinical care of people and addressing their social needs has already started to move into localities like GP practices with the existing green prescription programme and new clinicians called Health Improvement Practitioners. My findings align with this policy direction, as participants who managed knew that social contact and close connections are essential for wellbeing and a resource to be drawn on. Reciprocating support, by assisting and supporting others, requires social

networks which exist outside of healthcare, such as those that sustained Barbara (chapter 11), who used her social connections to give, receive and reciprocate support.

In part, that will mean system wide changes to ensure better distribution of resources and addressing inequity in health outcomes (Health and Disability System Review, 2020), particularly for people with low socioeconomic status, Māori and Pacific Islanders. Strategies which reduce financial barriers and inequities, and target groups of people who have experienced significant disadvantage historically, are being developed (OECD, 2017). My findings strongly align with this policy direction as I found that the people with the fewest resources did not do as well (See chapter 4).

The Pae Ora (Healthy Futures) Act 2022 also outlines new accountability arrangements with the new vision for New Zealand's healthcare system. This includes different styles of leadership and focussing on work force development so that services are underpinned by best practice guidelines (Health and Disability System Review, 2020). To create a cultural change within healthcare to ensure practices are innovative, a different kind of thinking is required. This research provides some of this evidence, finding that societal level interventions are needed that address cultural knowledge, social determinants of health and social inclusion. For example, supporting people to make use of mainstream resources in their community and feel like they belong, like Rose was able to do with Tom's assistance and their considerable resources (Chapter 11). Overall, the findings of this research strongly align with the notion that managing after stroke and flourishing are dependent on societal conditions rather than individual motivation and requires a whole system approach, thuis indicating what is required of ongoing policy development.

Implications for future research

Sitting with data and being very thorough with my analysis over a long period of time enabled deeper understandings and connections. Reading and thinking with theory and writing over the years my study took, mean that I now see many directions and

possibilities for where to next, acknowledging that there is always more to know and understand (Richardson & St Pierre, 2008; Richardson & St. Pierre, 2000). I propose three areas that I believe are worthy of deeper examination.

What is needed now is for clinicians, academics, and researchers to create space for others to take up the challenge of living well after stroke. Not to oppose what has been developed so far, but to find ways of building collective knowledge to challenge what is possible. Participatory designs that aim to create practical solutions are required (Skempes et al., 2015). Research as well as practice needs to be collaborative and research and practice needs to lead to action that is liberating (Benjamin-Thomas et al., 2018). Social transformation underpinned by critical social theory seeks to make explicit the power relations that oppress and the societal conditions that make oppression possible (Benjamin-Thomas et al., 2018; Farias et al., 2019). This methodology aims to address the contextual influences and conditions that make oppression possible, as opposed to treating impairments in the individual (Benjamin-Thomas et al., 2018).

1. Participants need for a causal model that makes sense and provides a basis for action, points to reimagining written and other forms of information about stroke. Health researchers could collaborate with design for health researchers to develop information and other representations to improve experiences of staff and patients and increase understandings of stroke. Design has much to offer and could assist stroke survivors make sense of what has happened and clinicians who struggle to know how to help. A focus on health literacy, as well as making stroke guidelines accessible and helpful to clinicians, survivors and their families, could facilitate collaborative relationships and shared decision making (Mühlhauser, 2010).

2. Social mapping from health geography involving participatory community mapping to understand the barriers to a sense of belonging to places and social spaces, and acceptable roles (Fang et al., 2016) and increase social capital. The application of

capability theory to these ideas could illuminate what people feel they can do and be (Bailliard et al., 2020).

3. Reflective work that helps clinicians to see the relevance of equity and justice to their work and minimise the influence of their habitual ways of thinking and acting on person centred practice (Bailliard et al., 2020) et al., 2020). It has been suggested that the right and ethical response to neoliberal thinking and a shift of responsibility from governments to individuals, is critical qualitative inquiry which combines participatory methods with critical theory so that the social, economic, cultural and political forces that reinforce and perpetuate power dynamics that keep people oppressed are exposed (Farias et al., 2017; Galvaan & van der Merwe, 2021). It is an insufficient response to only highlight injustice, action against disparity is also required (Farias et al., 2017) and once exposed new ways of feeling, thinking and acting become possible (Galvaan & van der Merwe, 2021).

And in the end, I return to Dewey who told us that there is little point in a sole focus of intervention, research and practice on the individual divorced from their context (Lavalley, 2017), if the field is really determined to help people manage better. A sole focus on the individual is not right, interventions, policies, and funding need to find ways to account for and address the inequity some stroke survivors and people with long-term conditions experience (Lavalley, 2017). The focus should no longer be on the usual participants of self-management research, who manage anyway due to their privilege. An approach that tweaks a model which is over 40 years old, will likely not advance the field going forward. Instead, a layered, contextually informed model that utilises mid-range theories such as capability theory is proposed.

Conclusion

This work is innovative because it brings together ideas, concepts, and theory from areas of the literature not often connected and layered together. This layering of theory and findings reveals that the barriers to managing and flourishing do not rest within the

individual, this is a neoliberal discourse that benefits only white westerners who are privileged and mostly manage anyway.

Radical reform of professional and lay perspectives of the causes of stroke and the supports offered to stroke survivors is required to move forward with managing after stroke. A move away from impairments, and hemiplegia towards the impact of stroke on daily life and flourishing despite stroke. Current stroke services serve a minority of stroke survivors, those with significant physical impairments and significant resources.

Instead, the focus should be on addressing the universal experiences of cognitive fatigue, biographical disruption, and for many people, disadvantage. Rehabilitation and health services must elevate their vision and take political action. Stroke amplifies and makes visible, if viewed through a different lens, all the disadvantage some people experience. Clinicians and researchers must recognise disadvantage and seek to discover the mechanisms by which people have poor outcomes. Measure the outcomes that reveal inequity and address how the inequity impacts on outcomes.

The contextual factors that influence outcomes for patients are well analysed in the sociology of illness literature. However, those same factors including societal and political forces also have an impact on health systems, services and clinicians and are not as well examined or applied to rehabilitation and self-management. The leap I have made is to conclude that the only way to assist people to flourish after stroke is to transform rehabilitation into a site for social change. Viewing rehabilitation as a political and socially transformative act would require critical and participatory methodologies to change the way clinicians and services feel, think and act in response to stroke. This thesis suggests a new approach is needed for self-management programmes which is to embed person centred support into every interaction and increase capabilities.

Personal reflection

In a way, I feel like I have come full circle as I conclude my study, although I hope I am a different clinician and researcher. When I worked with stroke survivors in inpatient settings, I spent much of my time trying to find services and resources to refer them to on discharge, which from acute services could be only a few days after stroke. I also put a lot of energy into advocating for those who were more affected, to be admitted to rehabilitation. I now know that the services I was imagining and hoping would materialise do not exist and very likely will never exist. If I knew then what I know now, I would put my energy into forming closer therapeutic alliances, collaborating to establish goals, values, and priorities, and helping stroke survivors towards coming to a causal model that reflects how they see the world. For the well-resourced I would encourage and empower them to find mainstream opportunities for their self-directed rehabilitation. For all, I would map their networks and supports, and use outcome measures that provide information about capabilities. My thinking is more politicized than at the beginning of my doctoral studies. I now see possibilities to support people by increasing their capabilities and resources to improve their life which was disadvantaged prior to their stroke and is even more so after stroke. I see more deeply and clearly the transaction between people, occupations, and context. How interdependent people are and that there is no ‘self’ in self-management.

References

Abbott, S., & Freeth, D. (2008). Social capital and health: Starting to make sense of the role of generalized trust and reciprocity. *Journal of Health Psychology, 13*(7), 874-883. https://doi.org/10.1177/1359105308095060

Abel, T., & Frohlich, K. L. (2012). Capitals and capabilities: Linking structure and agency to reduce health inequalities. *Social Science & Medicine, 74*(2), 236-244. https://doi.org/10.1016/j.socscimed.2011.10.028

Ahern, K. (2012). Informed consent: Are researchers accurately representing risks and benefits? *Scandinavian Journal of Caring Sciences, 26*(4), 671-678. https://doi.org/10.1111/j.1471-6712.2012.00978.x

Ahuja, S. S., Clark, S., Morahan, E. M., Ono, M., Mulligan, H., & Hale, L. (2013). The journey to recovery: Experiences and perceptions of individuals following stroke. *New Zealand Journal of Physiotherapy, 41*(1), 36-43.

Aldrich, R. M. (2008). From complexity theory to transactionalism: Moving occupational science forward in theorizing the complexities of behavior. *Journal of Occupational Science, 15*(3), 147-156. https://doi.org/10.1080/14427591.2008.9686624

Allen, K., Hazelett, S., Jarjoura, D., Hua, K., Wright, K., Weinhardt, J., & Kropp, D. (2009). A randomized trial testing the superiority of a postdischarge care management model for stroke survivors. *Journal of Stroke and Cerebrovascular Diseases, 18*(6), 443-452. https://doi.org/10.1016/j.jstrokecerebrovasdis.2009.02.002

Allin, S., Shepherd, J., Tomasone, J., Munce, S., Linassi, G., Hossain, S. N., & Jaglal, S. (2018). Participatory design of an online self-management tool for users with

spinal cord injury: Qualitative study. *JMIR Rehabilitation and Assitive Technologies, 5*(1), e8158. https://doi.org/10.2196/rehab.8158

Alszewski, A., Alszewski, H., & Potter, J. (2004). The bereavement model, stroke and rehabilitation: A critical analysis of the use of a psychological model in professional practice. *Disability and Rehabilitation, 26*(18), 1067-1078. https://doi.org/10.1080/09638280410001703521

Anand, P. (2005). Capabilities and health. *Journal of Medical Ethics, 31*(5), 299-303. https://doi.org/10.1136/jme.2004.008706

Artinian, B. A. (1988). Qualitative modes of inquiry. *Western Journal of Nursing Research, 10*(2), 138-149. https://doi.org/10.1177/019394598801000203

Ashton, T. (2005). Recent developments in the funding and organisation of the New Zealand health system. *Australia and New Zealand Health Policy, 2*(1). https://doi.org/10.1186/1743-8462-2-9

Audulv, Å. (2013). The over time development of chronic illness self-management patterns: A longitudinal qualitative study. *BMC Public Health, 13*(1), 1-15. https://doi.org/10.1186/1471-2458-13-452

Audulv, Å., Asplund, K., & Norbergh, K.-G. (2012). The integration of chronic illness self-management. *Qualitative Health Research, 22*(3), 332-345. https://doi.org/10.1177/1049732311430497

Ayo, N. (2012). Understanding health promotion in a neoliberal climate and the making of health conscious citizens. *Critical Public Health, 22*(1), 99-105. https://doi.org/10.1080/09581596.2010.520692

Ayres, L., Kavanaugh, K., & Knafl, K. A. (2003). Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research, 13*(6), 871-883. https://doi.org/10.1177/1049732303013006008

Bailliard, A. L., Dallman, A. R., Carroll, A., Lee, B. D., & Szendrey, S. (2020). Doing occupational justice: A central dimension of everyday cccupational therapy practice. *Canadian Journal of Occupational Therapy, 87*(2), 144-152. https://doi.org/10.1177/0008417419898930

Bandura, A. (1991). Social cognitive theory of self-regulation. *Organizational Behavior and Human Decision Processes, 50*(2), 248-287. https://doi.org/10.1016/0749-5978(91)90022-l

Bandura, A. (1997). *Self-efficacy: The exercise of control*. Macmillan.

Bandura, A. (2001). Social cognitive theory: An agentic perspective. *Annual Review of Psychology, 52*(1), 1-26.

Banks, J. L., & Marotta, C. A. (2007). Outcomes validity and reliability of the modified Rankin scale: Implications for stroke clinical trials: A literature review and synthesis. *Stroke, 38*(3), 1091-1096. https://doi.org/10.1161/01.STR.0000258355.23810.c6

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: A review. *Patient Education and Counseling, 48*(2), 177-187. https://doi.org/10.1016/S0738-3991(02)00032-0

Battersby, M. W., Ask, A., Reece, M. M., Markwick, M. J., & Collins, J. P. (2001). A case study using the" problems and goals approach" in a coordinated care trial: SA HealthPlus. *Australian Journal of Primary Health, 7*(3), 45-48. https://doi.org/10.1071/PY01045

Battersby, M. W., Harvey, P., Mills, P. D., Kalucy, E., Pols, R., Frith, P. A., McDonld, P., Esterman, A., Tsourtos, G., & Donato, R. (2007). SA HealthPlus: A controlled trial of a statewide application of a generic model of chronic illness care. *The*

Milbank Quarterly, 85(1), 37-67. https://doi.org/10.1111/j.1468-0009.2007.00476.x

Battersby, M. W., Kit, J. A., Prideaux, C., Harvey, P. W., Collins, J. P., & Mills, P. D. (2008). Research implementing the Flinders model of self-management support with Aboriginal people who have diabetes: Findings from a pilot study. *Australian Journal of Primary Health, 14*(1), 66-74. https://doi.org/doi.org/10.1071/PY08009

Bayley, M. T., Hurdowar, A., Richards, C. L., Korner-Bitensky, N., Wood-Dauphinee, S., Eng, J. J., McKay-Lyons, M., Harrison, E., Teasell, R., & Harrison, M. (2012). Barriers to implementation of stroke rehabilitation evidence: Findings from a multi-site pilot project. *Disability and Rehabilitation, 34*(19), 1633-1638. https://doi.org/10.3109/09638288.2012.656790

Baylies, C. (2002). Disability and the notion of human development: Questions of rights and capabilities. *Disability & Society, 17*(7), 725-739. https://doi.org/10.1080/0968759022000039037

Beauchamp, A., Batterham, R. W., Dodson, S., Astbury, B., Elsworth, G. R., McPhee, C., Jacobson, J., Buchbinder, R., & Osborne, R. H. (2017). Systematic development and implementation of interventions to OPtimise Health Literacy and Access (Ophelia). *BMC Public Health, 17*(1), 230. https://doi.org/10.1186/s12889-017-4147-5

Becker, G., & Kaufman, S., R. . (1995). Managing an uncertain illness trajectory in old age: Patients' and physicians' views of stroke. *Medical Anthropology Quarterly, 9*(2), 165-187. https://doi.org/10.1525/maq.1995.9.2.02a00040 (New Series)

Bendz, M. (2003). The first year of rehabilitation after a stroke – from two perspectives. *Scandinavian Journal of Caring Sciences, 17*(3), 215-222. https://doi.org/10.1046/j.1471-6712.2003.00217.x

Benjamin-Thomas, T. E., Corrado, A. M., McGrath, C., Rudman, D. L., & Hand, C. (2018). Working towards the promise of participatory action research: Learning from ageing research exemplars. *International Journal of Qualitative Methods, 17*(1), 1609406918817953. https://doi.org/10.1177/1609406918817953

Bernard, P., Charafeddine, R., Frohlich, K. L., Daniel, M., Kestens, Y., & Potvin, L. (2007). Health inequalities and place: A theoretical conception of neighbourhood. *Social Science & Medicine, 65*(9), 1839-1852. https://doi.org/10.1016/j.socscimed.2007.05.037

Biggeri, M., Bellanca, N., Bonfanti, S., & Tanzj, L. (2011). Rethinking policies for persons with disabilities through the capability approach: The case of the Tuscany region. *ALTER - European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap, 5*(3), 177-191. https://doi.org/10.1016/j.alter.2011.05.002

Bishop, M., Kayes, N. M., & McPherson, K. M. (2021). Understanding the therapeutic alliance in stroke rehabilitation. *Disability and Rehabilitation, 43*(8), 1074-1083. https://doi.org/10.1080/09638288.2019.1651909

Bloemen, B., Pijpers, E., Cup, E., Groothuis, J., van Engelen, B., & van der Wilt, G. J. (2021). Care for capabilities: Implementing the capability approach in rehabilitation of patients with neuromuscular diseases. Study protocol of the controlled before-after ReCap-NMD study. *PLoS One, 16*(12), e0261475. https://doi.org/10.1371/journal.pone.0261475

Boehmer, K. R., Gionfriddo, M. R., Rodriguez-Gutierrez, R., Dabrh, A. M. A., Leppin, A. L., Hargraves, I., May, C. R., Shippee, N. D., Castaneda-Guarderas, A., & Palacios, C. Z. (2016). Patient capacity and constraints in the experience of chronic disease: A qualitative systematic review and thematic synthesis. *BMC Family Practice, 17*(1), 1-23.

Boger, E. J., Demain, S., & Latter, S. (2013). Self-management: A systematic review of outcome measures adopted in self-management interventions for stroke. *Disability and Rehabilitation, 35*(17), 1415-1428.

Bonita, R., Mendis, S., Truelsen, T., Bogousslavsky, J., Toole, J., & Yatsu, F. (2004). The global stroke initiative. *The Lancet Neurology, 3*(7), 391-393. https://doi.org/10.1016/S1474-4422(04)00800-2

Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a qualitative description approach in health care research. *Global Qualitative Nursing Research, 4*, 1-8. https://doi.org/10.1177/2333393617742282

Bramley, D., Hebert, P., Tuzzio, L., & Chassin, M. (2005). Disparities in indigenous health: A cross-country comparison between New Zealand and the United States. *American Journal of Public Health, 95*(5), 844-850. https://doi.org/10.2105/ajph.2004.040907

Bratzke, L. C., Muehrer, R. J., Kehl, K. A., Lee, K. S., Ward, E. C., & Kwekkeboom, K. L. (2015). Self-management priority setting and decision-making in adults with multimorbidity: A narrative review of literature. *International Journal of Nursing Studies, 52*(3), 744-755. https://doi.org/10.1016/j.ijnurstu.2014.10.010

Braveman, P., & Gottlieb, L. (2014). The social determinants of health: It's time to consider the causes of the causes. *Public Health Reports, 129*(1_suppl2), 19-31. https://doi.org/10.1177/00333549141291S206

Bright, F. A. S., Boland, P., Rutherford, S. J., Kayes, N. M., & McPherson, K. M. (2012). Implementing a client-centred approach in rehabilitation: An autoethnography. *Disability and Rehabilitation, 34*(12), 997-1004. https://doi.org/10.3109/09638288.2011.629712

Bright, F. A. S., Kayes, N. M., Cummins, C., Worrall, L. M., & McPherson, K. M. (2017). Co-constructing engagement in stroke rehabilitation: A qualitative study exploring how practitioner engagement can influence patient engagement. *Clinical Rehabilitation, 31*(10), 1396-1405. https://doi.org/10.1177/0269215517694678

Brown, S. L., Nesse, R. M., Vinokur, A. D., & Smith, D. M. (2003). Providing social support may be more beneficial than receiving it: Results from a prospective study of mortality. *Psychological Science, 14*(4), 320-327. https://doi.org/10.1111/1467-9280.14461

Bryman, A. (2006). Integrating quantitative and qualitative research: How is it done? *Qualitative Research, 6*(1), 97-113. https://doi.org/10.1177/1468794106058877

Burnett, E., & Corlett, J. (2017). Understanding risk perceptions and responses of the public and health care professionals toward Clostridium difficile: A qualitative interpretive description study. *American Journal of Infection Control*, *45*(2), 133-138. https://doi.org/10.1016/j.ajic.2016.07.020

Burton, C. R. (2000a). Living with stroke: A phenomenological study. *Journal of Advanced Nursing, 32*(2), 301-309. https://doi.org/10.1046/j.1365-2648.2000.01477.x

Burton, C. R. (2000b). Re-thinking stroke rehabilitation: The Corbin and Strauss chronic illness trajectory framework. *Journal of Advanced Nursing, 32*(3), 595-602. https://doi.org/10.1046/j.1365-2648.2000.01517.x

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness, 4*(2), 167-182. https://doi.org/10.1111/1467-9566.ep11339939

Bury, M. (1991). The sociology of chronic illness: A review of research and prospects. *Sociology of Health & Illness, 13*(4), 451-468. https://doi.org/10.1111/j.1467-9566.1991.tb00522.x

Bury, M. (2001). Illness narratives: Fact or fiction? *Sociology of Health & Illness, 23*(3), 263-285. https://doi.org/10.1111/1467-9566.00252

Cadilhac, D. A., Hoffmann, S., Kilkenny, M., Lindley, R., Lalor, E., Osborne, R. H., & Batterbsy, M. (2011). A phase II multicentered, single-blind, randomized, controlled trial of the stroke self-management program. *Stroke, 42*(6), 1673-1679. https://doi.org/10.1161/strokeaha.110.601997

Caelli, K., Ray, L., & Mill, J. (2003). 'Clear as mud': Toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods, 2*(2), Article 1. https://doi.org/10.1177/160940690300200201

alman, L., Brunton, L., & Molassiotis, A. (2013). Developing longitudinal qualitative designs: Lessons learned and recommendations for health services research. *BMC Medical Research Methodology, 13*(1). https://doi.org/10.1186/1471-2288-13-14

Came, H., & Griffith, D. (2018). Tackling racism as a "wicked" public health problem: Enabling allies in anti-racism praxis. *Social Science & Medicine, 199*, 181-188. https://doi.org/10.1016/j.socscimed.2017.03.028

Campbell, R., Adams, A. E., Wasco, S. M., Ahrens, C. E., & Sefl, T. (2010). "What has it been like for you to talk with me today?": The impact of participating in interview research on rape survivors. *Violence Against Women, 16*(1), 60-83. https://doi.org/10.1177/1077801209353576

Carlsson, G. E., Moller, A., & Blomstrand, C. (2009). Managing an everyday life of uncertainty - A qualitative study of coping in persons with mild stroke. *Disability*

and Rehabilitation, 31(10), 773-782. https://doi.org/10.1080/09638280802638857

Catalano, T., Dickson, P., Kendall, E., Kuipers, K., & Posner, T. N. (2003). The perceived benefits of the chronic disease self-management program among participants with stroke: A qualitative study. *Australian Journal of Primary Health, 9*(3), 80-89. https://doi.org/10.1071/PY03028

Chamberlain, K. (2000). Methodolatry and qualitative health research. *Journal of Health Psychology, 5*(3), 285-296. https://doi.org/10.1177/135910530000500306

Chapman, B., & Bogle, V. (2014). Adherence to medication and self-management in stroke patients. *British Journal of Nursing, 23*(3), 158-166. https://doi.org/10.12968/bjon.2014.23.3.158

Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness, 5*(2), 168-195. https://doi.org/10.1111/1467-9566.ep10491512

Charmaz, K. (1990). "Discovering" chronic illness: Using grounded theory. *Social Science and Medicine 30*(11), 1161-1172. https://doi.org/10.1016/0277-9536(90)90256-R

Charmaz, K. (1999). Stories of suffering: Subjective tales and research narratives. *Qualitative Health Research, 9*(3), 362-382. https://doi.org/10.1177/104973239900900306

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Sage Publications.

Chen, Y.-Y., Shek, D. T., & Bu, F.-F. (2011). Applications of interpretive and constructionist research methods in adolescent research: Philosophy, principles

and examples. *International Journal of Adolescent Medicine and Health, 23*(2),129-139. https://doi.org/10.1515/ijamh.2011.022

Chew-Graham, C. A., May, C. R., & Roland, M. O. (2004). The harmful consequences of elevating the doctor–patient relationship to be a primary goal of the general practice consultation. *Family Practice, 21*(3), 229-231. https://doi.org/10.1093/fampra/cmh301

Clapton, J., & Kendall, E. (2002). Autonomy and participation in rehabilitation: Time for a new paradigm? *Disability and Rehabilitation, 24*(18), 987-991. https://doi.org/10.1080/09638280210152058

Clark, F., Azen, S. P., Zemke, R., Jackson, J., Carlson, M., Mandel, D., Hay, J., Josephson, K., Cherry, B., Hessel, C., Palmer, J., & Lipson, L. (1997). Occupational therapy for independent-living older adults: A randomized controlled trial. *Journal of the American Medical Association, 278*(16), 1321-1326. https://doi.org/10.1001/jama.1997.03550160041036

Clark, N. M., & Gong, M. (2000). Management of chronic disease by practitioners and patients: Are we teaching the wrong things? *BMJ, 320*(7234), 572-575. https://doi.org/10.1136/bmj.320.7234.572

Clark, M. I., Spence, J. C., & Holt, N. L. (2011). In the shoes of young adolescent girls: Understanding physical activity experiences through interpretive description. *Qualitative Research in Sport, Exercise and Health*, *3*(2), 193-210. https://doi.org/10.1080/2159676X.2011.572180

Clarke, A. (2006). Qualitative interviewing: encountering ethical issues and challenges. *Nurse Researcher, 13*(4), 19-29. https://doi.org/10.12968/bjon.2014.23.3.158

Clarke, P. (2009). Understanding the experience of stroke: A mixed-method research agenda. *The Gerontologist, 49*(3), 293-302. https://doi.org/10.1093/geront/gnp047

Clayton, A. M., & Thorne, T. (2000). Diary data enhancing rigour: Analysis framework and verification tool. *Journal of Advanced Nursing*, *32*(6), 1514-1521. https://doi.org/10.1046/j.1365-2648.2000.01609.x

Coast, J., Kinghorn, P., & Mitchell, P. (2015). The development of capability measures in health economics: Opportunities, challenges and progress. *The Patient - Patient-Centered Outcomes Research, 8*(2), 119-126. https://doi.org/10.1007/s40271-014-0080-1

Cohen, J. L., van Houten Sauter, S., Devellis, R. F., & DeVellis, B. M. (1986). Evaluation of arthritis self-management courses led by laypersons and by professionals. *Arthritis & Rheumatism: Official Journal of the American College of Rheumatology, 29*(3), 388-393.

Coleman, K., Austin, B. T., Brach, C., & Wagner, E. H. (2009). Evidence on the chronic care model in the new millennium. *Health Affairs, 28*(1), 75-85.

Colorafi, K. J., & Evans, B. (2016). Qualitative descriptive methods in health science research. *HERD: Health Environments Research & Design Journal, 9*(4), 16-25. https://doi.org/10.1177/1937586715614171

Corbin, J., & Strauss, A. (1985). Managing chronic illness at home: Three lines of work. *Qualitative Sociology, 8*(3), 224-247. https://doi.org/10.1007/bf00989485

Coventry, P. A., Fisher, L., Kenning, C., Bee, P., & Bower, P. (2014). Capacity, responsibility, and motivation: A critical qualitative evaluation of patient and practitioner views about barriers to self-management in people with

multimorbidity. *BMC Health Services Research, 14*(1), 1-12. https://doi.org/10.1186/s12913-014-0536-y

Coventry, P. A., Small, N., Panagioti, M., Adeyemi, I., & Bee, P. (2015). Living with complexity; marshalling resources: A systematic review and qualitative meta-synthesis of lived experience of mental and physical multimorbidity. *BMC Family Practice, 16*(1), 1-12. https://doi.org/10.1186/s12875-015-0345-3

Creer, T. L., Renne, C. M., & Christian, W. P. (1976). Behavioral contributions to rehabilitation and childhood asthma. *Rehabilitation Literature, 37*(8), 226-232.

Creswell, J. W., Fetters, M. D., & Ivankova, N. V. (2004). Designing a mixed methods study in primary care. *Annals of Family Medicine, 2*(1), 7-12. https://doi.org/10.1370/afm.104

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Sage Publications.

Cutchin, M. P. (2007). From society to self (and back) through place: Habit in transactional context. *OTJR: Occupation, Participation and Health, 27*(1_suppl), 50S-59S. https://doi.org/10.1177/15394492070270s107

Cutchin, M. P., Aldrich, R. M., Bailliard, A. L., & Coppola, S. (2008). Action theories for occupational science: The contributions of Dewey and Bourdieu. *Journal of Occupational Science, 15*(3), 157-165. https://doi.org/10.1080/14427591.2008.9686625

Cutchin, M. P., & Dickie, V. A. (2011). Transactionalism: Occupational science and the pragmatic attitude. *Occupational Science: Society, Inclusion, Participation*, 23.

Daiute, C., & Lightfoot, C. (2004). *Narrative Analysis* https://doi.org/10.4135/9781412985246

Damush, T. M., Ofner, S., Yu, Z., Plue, L., Nicholas, G., & Williams, L. S. (2011). Implementation of a stroke self-management program: A randomized controlled pilot study of veterans with stroke. *Translational Behavioral Medicine, 1*(4), 561-572. https://doi.org/10.1007/s13142-011-0070-y

de-Graft Aikins, A., Boynton, P., & Atanga, L. L. (2010). Developing effective chronic disease interventions in Africa: Insights from Ghana and Cameroon. *Globalization and Health, 6*(1), 6. https://doi.org/10.1186/1744-8603-6-6

de Casterle, B. D., Gastmans, C., Bryon, E., & Denier, Y. (2012). QUAGOL: A guide for qualitative data analysis. *International Journal of Nursing Studies, 49*(3), 360-371. https://doi.org/10.1016/j.ijnurstu.2011.09.012

de Haan, R., Aaronson, N., Limburg, M., Hewer, R., & van Crevel, H. (1993). Measuring quality of life in stroke. *Stroke, 24*(2), 320-327. https://doi.org/10.1161/01.STR.24.2.320

de Haan, R., Horn, J., Limburg, M. M. D., Van Der Meulen, J. M. D., & Bossuyt, P. (1993). A comparison of five stroke scales with measures of disability, handicap, and quality of life. *Stroke, 24*(8), 1178-1181. https://doi.org/10.1161/01.STR.24.8.1178

De Silva, D. (2011). *Helping people help themselves*. The Health Foundation.

Della Vecchia, C., Préau, M., Carpentier, C., Viprey, M., Haesebaert, J., Termoz, A., Dima, A. L., & Schott, A.-M. (2019). Illness beliefs and emotional responses in mildly disabled stroke survivors: A qualitative study. *PLoS One, 14*(10), e0223681. https://doi.org/10.1371/journal.pone.0223681

Demain, S., Burridge, J., Ellis-Hill, C., Hughes, A.-M., Yardley, L., Tedesco-Triccas, L., & Swain, I. (2013). Assistive technologies after stroke: Self-management or

fending for yourself? A focus group study. *BMC Health Services Research, 13*(1), 334. https://doi.org/10.1186/1472-6963-13-334

Demain, S., Wiles, R., Roberts, L., & McPherson, K. M. (2006). Recovery plateau following stroke: Fact or fiction? *Disability and Rehabilitation, 28*(13-14), 815-821. https://doi.org/10.1080/09638280500534796

Derrett, S., & Colhoun, S. (2011). Being a quantitative interviewer: Qualitatively exploring interviewers' experiences in a longitudinal cohort study. *BMC Medical Research Methodology, 11*, 165. https://doi.org/10.1186/1471-2288-11-165

Desrosiers, J., Noreau, L., Rochette, A., Bourbonnais, D., Bravo, G., & Bourget, A. (2006). Predictors of long-term participation after stroke. *Disability and Rehabilitation, 28*(4), 221-229. https://doi.org/10.1080/09638280500158372

Devers, K. J. (1999). How will we know "good" qualitative research when we see it? Beginning the dialogue in health services research. *Health Services Research, 34*(5 Pt 2), 1153-1188. https://doi.org/10.1046/j.1365-2702.2000.00411.x

Dewey, J. (1934). Art as experience. *New York: Minton, Balch, and Company*.

Dewey, J. (1997). *How we think*. Courier Corporation.

Dickie, V., Cutchin, M. P., & Humphry, R. (2006). Occupation as transactional experience: A critique of individualism in occupational science. *Journal of Occupational Science, 13*(1), 83-93. https://doi.org/10.1080/14427591.2006.9686573

Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2007). Doing sensitive research: What challenges do qualitative researchers face? *Qualitative Research, 7*(3), 327-353. https://doi.org/10.1177/1468794107078515

Diener, E., & Oishi, S. i Tay, L.(2018). Advances in subjective well-being research. *Nature Human Behaviour, 2*, 253-260. https://doi.org/10.1038/s41562-018-0307-6

Diener, E., Oishi, S., & Lucas, R. E. (2015). National accounts of subjective well-being. *American psychologist, 70*(3), 234.https://psycnet.apa.org/doi/10.1037/a0038899

Diener, E., & Seligman, M. E. P. (2004). Beyond money:Toward an economy of well-being. *Psychological Science in the Public Interest, 5*(1), 1-31. https://doi.org/10.1111/j.0963-7214.2004.00501001.x

Dierckx de Casterlé, B., Gastmans, C., Bryon, E., & Denier, Y. (2012). QUAGOL: A guide for qualitative data analysis. *International Journal of Nursing Studies, 49*(3), 360-371. https://doi.org/10.1016/j.ijnurstu.2011.09.012

Doane, G. H., & Varcoe, C. (2005). Toward compassionate action: Pragmatism and the inseparability of theory/practice. *Advances in Nursing Science, 28*(1), 81-90.

Dodson, S., Good, S., & Osborne, R. (2015). Health literacy toolkit for low and middle-income countries: A series of information sheets to empower communities and strengthen health systems.

Donaldson, L. (2003). Expert patients usher in a new era of opportunity for the NHS: The expert patient programme will improve the length and quality of lives. *British Medical Journal, 326*(7402), 1279-1280. https://doi.org/10.1136/bmj.326.7402.1279

Donnellan, C., Martins, A., Conlon, A., Coughlan, T., O'Neill, D., & Collins, D. R. (2013). Mapping patients' experiences after stroke onto a patient-focused intervention framework. *Disability and Rehabilitation, 35*(6), 483-491. https://doi.org/10.3109/09638288.2012.702844

Dowswell, G., Lawler, J., Dowswell, T., Young, J., Forster, A., & Hearn, J. (2000). Investigating recovery from stroke: A qualitative study. *Journal of Clinical Nursing, 9*(4), 507-515. https://doi.org/10.1046/j.1365-2702.2000.00411.x

Dresser, R. (2003). Research oversight and adults with cognitive impairment. *Hastings Center Report, 33*(6), 9-10.

Drolet, M. J. (2014) The axiological ontology of occupational therapy: A philosophical analysis , Scandinavian Journal of Occupational Therapy, 21:1, 2-10, DOI: 10.3109/11038128.2013.831118

Dubois, J.-L., & Trani, J.-F. (2009). Extending the capability paradigm to address the complexity of disability. *ALTER - European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap, 3*(3), 192-218. https://doi.org/10.1016/j.alter.2009.04.003

Dyall, L., Feigin, V., & Brown, P. (2008). Stroke: A picture of health disparities in New Zealand. *Social Policy Journal of New Zealand*(33), 178-191.

Edwards, D. F., Hahn, M., Baum, C., & Dromerick, A. W. (2006). The impact of mild stroke on meaningful activity and life satisfaction. *Journal of Stroke and Cerebrovascular Diseases, 15*(4), 151-157. https://doi.org/10.1016/j.jstrokecerebrovasdis.2006.04.001

Eilertsen, G., Kirkevold, M., & Bjørk, I. T. (2010). Recovering from a stroke: A longitudinal, qualitative study of older Norwegian women. *Journal of Clinical Nursing, 19*(13/14), 2004-2013. https://doi.org/10.1111/j.1365-2702.2009.03138.x

Ejiogu, N., Norbeck, J. H., Mason, M. A., Cromwell, B. C., Zonderman, A. B., & Evans, M. K. (2011). Recruitment and retention strategies for minority or poor clinical research participants: Lessons from the healthy aging in neighborhoods of

diversity across the life span study. *The Gerontologist, 51*(suppl 1), S33-S45. https://doi.org/10.1093/geront/gnr027

Ellingson, L. L. (2008). *Engaging crystallization in qualitative research: An introduction*. Sage.

Elliott, J. (2005). *Using narrative in social research: Qualitative and quantitative approaches*. Sage.

Ellis-Hill, C., Payne, S., & Ward, C. (2008). Using stroke to explore the life thread model: An alternative approach to understanding rehabilitation following an acquired disability. *Disability and Rehabilitation, 30*(2), 150-159. https://doi.org/10.1080/09638280701195462

Ellis-Hill, C., Robison, J., Wiles, R., McPherson, K. M., Hyndman, D., & Ashburn, A. (2009). Going home to get on with life: Patients and carers experiences of being discharged from hospital following a stroke. *Disability and Rehabilitation, 31*(2), 61-72. https://doi.org/10.1080/09638280701775289

Emanuel, E. J., Wendler, D., & Grady, C. (2000). What makes clinical research ethical? *JAMA, 283*(20), 2701-2711. https://doi.org/10.1001/jama.283.20.2701

Entwistle, V. A., & Watt, I. S. (2013). Treating patients as persons: A capabilities approach to support delivery of person-centered care. *American Journal of Bioethics, 13*(8), 29-39 11p. https://doi.org/10.1080/15265161.2013.802060

Ericson, R., Barry, D., & Doyle, A. (2000). The moral hazards of neo-liberalism: Lessons from the private insurance industry. *Economy and Society, 29*(4), 532-558. https://doi.org/10.1080/03085140050174778

Evans, J. J. (2011). Positive psychology and brain injury rehabilitation. *Brain Impairment, 12*(2), 117-127. https://doi.org/10.1375/brim.12.2.117

Ewing, G., Rogers, M., Barclay, S., McCabe, J., Martin, A., & Todd, C. (2004). Recruiting patients into a primary care based study of palliative care: Why is it so difficult? *Palliative Medicine, 18*(5), 452-459. https://doi.org/10.1191/0269216304pm905oa

Faircloth, C. A., Boylstein, C., Rittman, M., Young, M. E., & Gubrium, J. (2004). Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health and Illness, 26*(2), 242-261. https://doi.org/10.1111/j.1467-9566.2004.00388.x

Farias, L., Laliberte Rudman, D., Pollard, N., Schiller, S., Serrata Malfitano, A. P., Thomas, K., & van Bruggen, H. (2019). Critical dialogical approach: A methodological direction for occupation-based social transformative work. *Scandinavian Journal of Occupational Therapy, 26*(4), 235-245. https://doi.org/10.1080/11038128.2018.1469666

Farias, L., & Rudman, D. L. (2019). Challenges in enacting occupation-based social transformative practices: A critical dialogical study. *Canadian Journal of Occupational Therapy, 86*(3), 243-252. https://doi.org/10.1177/0008417419828798

Farias, L., Rudman, D. L., Magalhães, L., & Gastaldo, D. (2017). Reclaiming the potential of transformative scholarship to enable social justice. *International Journal of Qualitative Methods, 16*(1), 1609406917714161. https://doi.org/10.1177/1609406917714161

Farrell, T. S. (2012). Reflecting on reflective practice:(Re) visiting Dewey and Schön. *TESoL Journal, 3*(1), 7-16.

Feigin, V. L., Krishnamurthi, R. V., Barker-Collo, S., McPherson, K. M., Barber, P. A., Parag, V., Arroll, B., Bennett, D. A., Tobias, M., Jones, A., Witt, E., Brown, P., Abbott, M., Bhattacharjee, R., Rush, E., Suh, F. M., Theadom, A.,

Rathnasabapathy, Y., Te Ao, B., Parmar, P. G., Anderson, C., Bonita, R., & Group, A. I. (2015). 30-Year trends in stroke rates and outcome in Auckland, New Zealand (1981-2012): A multi-ethnic population-based series of studies. *PLoS One, 10*(8), e0134609. https://doi.org/10.1371/journal.pone.0134609

Fisher, W. P., & Stenner, A. J. (2011). Integrating qualitative and quantitative research approaches via the phenomenological method. *International Journal of Multiple Research Approaches, 5*(1), 89-103. https://doi.org/10.5172/mra.2011.5.1.89

Fleming, M., & Mattingly, C. (Eds.). (1994). *The underground practice*. F. A. Davis.

Foster, G., Taylor, S. J., Eldridge, S., Ramsay, J., & Griffiths, C. J. (2007). Self-management education programmes by lay leaders for people with chronic conditions. *Cochrane Database of Systematic Reviews*(4). https://doi.org/10.1002/14651858.cd005108.pub2

Foster, M., Kendall, E., Dickson, P., Chaboyer, W., Hunter, B., & Gee, T. (2003). Participation and chronic disease self-management: Are we risking inequitable resource allocation? *Australian Journal of Primary Health, 9*(3), 132-140. http://dx.doi.org/10.1071/PY03037

Frank, G. (2011). The transactional relationship between occupation and place: Indigenous cultures in the American southwest. *Journal of Occupational Science 18*(1), 3-20. https://doi.org/10.1080/14427591.2011.562874

Frankel Pratt, S. (2016). Pragmatism as ontology, not (just) epistemology: Exploring the full horizon of pragmatism as an approach to IR theory. *International Studies Review, 18*(3), 508-527. https://doi.org/10.1093/isr/viv003

Frohlich, K. L., Corin, E., & Potvin, L. (2001). A theoretical proposal for the relationship between context and disease. *Sociology of Health & Illness, 23*(6), 776-797. https://doi.org/10.1111/1467-9566.00275

Fryer, C. E., Luker, J. A., McDonnell, M. N., & Hillier, S. L. (2016). Self management programmes for quality of life in people with stroke. *Cochrane Database of Systematic Reviews, 2016*(8), e266-e267, Article Cd010442. https://doi.org/10.1002/14651858.CD010442.pub2

Fu, D., Fu, H., McGowan, P., Shen, Y.-e., Zhu, L., Yang, H., Mao, J., Zhu, S., Ding, Y., & Wei, Z. (2003). Implementation and quantitative evaluation of chronic disease self-management programme in Shanghai, China: Randomized controlled trial. *Bulletin of the World Health Organisation, 81*, 174-182.

Fugazzaro, S., Denti, M., Accogli, M. A., Costi, S., Pagliacci, D., Calugi, S., Cavalli, E., Taricco, M., Bardelli, R., & on behalf of Look after Yourself Project. (2021). Self-management in stroke survivors: Development and implementation of the look after yourself (LAY) intervention. *International Journal of Environmental Research and Public Health, 18*(11), 5925. https://doi.org/10.3390/ijerph18115925

Funnell, M. M. (2010). Peer-based behavioural strategies to improve chronic disease self-management and clinical outcomes: Evidence, logistics, evaluation considerations and needs for future research. *Family practice, 27*(suppl_1), i17-i22. https://doi.org/10.1093/fampra/cmp027

Furler, J., Walker, C., Blackberry, I., Dunning, T., Sulaiman, N., Dunbar, J., Best, J., & Young, D. (2008). The emotional context of self-management in chronic illness: A qualitative study of the role of health professional support in the self-management of type 2 diabetes. *BMC Health Services Research, 8*(1), 214. https://doi.org/10.1186/1472-6963-8-214

Galvaan, R., & van der Merwe, T. R. (2021). Re-orienting occupational therapy: Embracing generative disruption and revisiting a posture that acknowledges

human dignity. *South African Journal of Occupational Therapy, 51*, 99-103. https://doi.org/10.17159/2310-3833/2021/vol51n2a13

Garrison, J. (2003). Dewey's theory of emotions: The unity of thought and emotion in naturalistic functional" co-ordination" of behavior. *Transactions of the Charles S. Peirce Society, 39*(3), 405-443. http://www.jstor.org/stable/40320949

Gergen, K. J. (1999). *An invitation to social construction*. Sage.

Gerlach, A. J., Teachman, G., Laliberte-Rudman, D., Aldrich, R. M., & Huot, S. (2018). Expanding beyond individualism: Engaging critical perspectives on occupation. *Scandinavian Journal of Occupational Therapy, 25*(1), 35-43. https://doi.org/10.1080/11038128.2017.1327616

Gibbons, C. J., Stirman, S. W., Brown, G. K., & Beck, A. T. (2010). Engagement and retention of suicide attempters in clinical research: Challenges and solutions. *Crisis, 31*(2), 62-68. https://doi.org/10.1027/0227-5910/a000018

Gibson, P. G., Powell, H., Wilson, A., Abramson, M. J., Haywood, P., Bauman, A., Hensley, M. J., Walters, E. H., & Roberts, J. J. L. (2002). Self-management education and regular practitioner review for adults with asthma. *Cochrane Database of Systematic Reviews*(3). https://doi.org/10.1002/14651858.CD001117

Giddings, L. S., & Grant, B. M. (2006). Mixed methods research for the novice researcher. *Contemporary Nurse, 23*(1), 3-11. https://doi.org/10.5172/conu.2006.23.1.3

Gillham, S., & Endacott, R. (2010). Impact of enhanced secondary prevention on health behaviour in patients following minor stroke and transient ischaemic attack: A randomized controlled trial. *Clinical Rehabilitation, 24*(9), 822-830. https://doi.org/10.1177/0269215510367970

Glass, T. A., & McAtee, M. J. (2006). Behavioral science at the crossroads in public health: Extending horizons, envisioning the future. *Social Science and Medicine, 62*(7), 1650-1671. https://doi.org/10.1016/j.socscimed.2005.08.044

Goldkuhl, G. (2012). Pragmatism vs interpretivism in qualitative information systems research. *European Journal of Information Systems, 21*(2), 135-146. https://doi.org/10.1057/ejis.2011.54

Gopinath, M. (2018). Thinking about later life: Insights from the capability approach. *Ageing International, 43*(2), 254-264. https://doi.org/10.1007/s12126-018-9323-0

Gray, J. M. (1998). Putting occupation into practice: Occupation as ends, occupation as means. *American Journal of Occupational Therapy, 52*(5), 354-364. https://doi.org/10.5014/ajot.52.5.354

Graziotti, A. L., Hammond, J., Messinger, D. S., Bann, C. M., Miller-Loncar, C., Twomey, J. E., Bursi, C., Woldt, E., Ann Nelson, J., Fleischmann, D., & Alexander, B. (2012). Maintaining participation and momentum in longitudinal research involving high-risk families. *Journal of Nursing Scholarship, 44*(2), 120-126. https://doi.org/10.1111/j.1547-5069.2012.01439.x

Greenhalgh, T. (2009). Patient and public involvement in chronic illness: Beyond the expert patient. *British Medical Journal, 338*, b49. https://doi.org/10.1136/bmj.b49

Greenhalgh, T. (2015). Health literacy: Towards system level solutions. *British Medical Journal, 350* (h1026). https://doi.org/10.1136/bmj.h1026

Greenhalgh, T., Campbell-Richards, D., Vijayaraghavan, S., Collard, A., Malik, F., Griffin, M., Morris, J., Claydon, A., & Macfarlane, F. (2011). New models of self-management education for minority ethnic groups: Pilot randomized trial of a

story-sharing intervention. *Journal of Health Services Research & Policy, 16*(1), 28-36. https://doi.org/10.1258/jhsrp.2010.009159

Griffiths, C., Foster, G., Ramsay, J., Eldridge, S., & Taylor, S. (2007). How effective are expert patient (lay led) education programmes for chronic disease? *British Medical Journal, 334*(7606), 1254-1256. https://doi.org/10.1136/bmj.39227.698785.47

Grohn, B., Worrall, L. E., Simmons-Mackie, N., & Brown, K. (2012). The first 3-months post-stroke: What facilitates successfully living with aphasia? *International Journal of Speech-Language Pathology, 14*(4), 390-400. https://doi.org/10.3109/17549507.2012.692813

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59-82. https://doi.org/10.1177/1525822X05279903

Gustafsson, L., & Bootle, K. (2013). Client and carer experience of transition home from inpatient stroke rehabilitation. *Disability and Rehabilitation, 35*(16), 1380-1386. https://doi.org/10.3109/09638288.2012.740134

Hafsteinsdóttir, T. B., Vergunst, M., Lindeman, E., & Schuurmans, M. (2011). Educational needs of patients with a stroke and their caregivers: A systematic review of the literature. *Patient Education and Counseling, 85*(1), 14-25. https://doi.org/10.1016/j.pec.2010.07.046

Hall, P. A., & Lamont, M. (2009). *Successful societies: How institutions and culture affect health*. Cambridge University Press.

Hammell, K. R. W., & Iwama, M. K. (2012). Well-being and occupational rights: An imperative for critical occupational therapy. *Scandinavian Journal of*

Occupational Therapy, 19(5), 385-394. https://doi.org/10.3109/11038128.2011.611821

Hammell, K. W. (2004). Dimensions of meaning in the occupations of daily life. *Canadian Journal of Occupational Therapy, 71*(5), 296-305. https://doi.org/10.1177/000841740407100509

Hancock, R. E. E., Bonner, G., Hollingdale, R., & Madden, A. M. (2012). 'If you listen to me properly, I feel good': A qualitative examination of patient experiences of dietetic consultations. *Journal of Human Nutrition and Dietetics, 25*(3), 275-284. https://doi.org/10.1111/j.1365-277X.2012.01244.x

Hanger, H., Paterson, L., McBride, S., & Sainsbury, R. (1998). What do patients and their carers want to know about stroke? A two-year follow-up study. *Clinical Rehabilitation, 12*(1), 45-52. https://doi.org/10.1191/026921598668677675

Hart, E. (2001). System induced setbacks in stroke recovery. *Sociology of Health & Illness, 23*(1), 101-123. https://doi.org/10.1111/1467-9566.00243

Harwood, M., Weatherall, M., Talemaitoga, A., Barber, P. A., Gommans, J., Taylor, W., McPherson, K. M., & McNaughton, H. (2012). Taking charge after stroke: Promoting self-directed rehabilitation to improve quality of life – a randomized controlled trial. *Clinical Rehabilitation, 26*(6), 493-501. https://doi.org/10.1177/0269215511426017

Healthy Aging Strategy 2016. https://www.health.govt.nz/publication/healthy-ageing-strategy

Healthy Aging Strategy 2016. https://www.health.govt.nz/publication/halthy-ageing-strategy

Heaton, J. (Ed.). (2008). *Secondary analysis of qualitative data: An overview* (Vol. 33). GESIS - Leibniz-Institute for the Social Sciences.

Hébert, C. (2015). Knowing and/or experiencing: A critical examination of the reflective models of John Dewey and Donald Schön. *Reflective Practice, 16*(3), 361-371. https://doi.org/10.1080/14623943.2015.1023281

Henderson, A., & Jackson, M. (2004). Restorative health: Lessening the impact of previous abuse and violence in the lives of vulnerable girls. *Health Care for Women International, 25*(9), 794-812. https://doi.org/10.1080/07399330490493322

Herrmann, M., Curio, N., Petz, T., Synowitz, H., Wagner, S., Bartels, C., & Wallesch, C.-W. (2000). Coping with illness after brain diseases a comparison between patients with malignant brain tumors, stroke, Parkinson's disease and traumatic brain injury. *Disability and Rehabilitation, 22*(12), 539-546. https://doi.org/10.1080/096382800416788

Hirsche, R. C., Williams, B., Jones, A., & Manns, P. (2011). Chronic disease self-management for individuals with stroke, multiple sclerosis and spinal cord injury. *Disability and Rehabilitation, 33*(13/14), 1136-1146. https://doi.org/10.3109/09638288.2010.523103

Hitch, D., Pépin, G., & Stagnitti, K. (2014). In the footsteps of Wilcock, part two: The interdependent nature of doing, being, becoming, and belonging. *Occupational Therapy In Health Care, 28*(3), 247-263. https://doi.org/10.3109/07380577.2014.898115

Hocking, C., & Jones, M. (2023) In G. Gillen, & C. Brown. *Willard and Spackman's occupational therapy* (pp. 1-15). Lippincott Williams & Wilkins.

Hocking, C., & Sutton, D. (2023) Contribution of occupation to health and well-being. In G. Gillen, & C. Brown. *Willard and Spackman's occupational therapy* (pp. 1-13). Lippincott Williams & Wilkins.

Hocking, C., & Townsend, E. (2015). Driving social change: Occupational therapists' contributions to occupational justice. *World Federation of Occupational Therapists Bulletin, 71*(2), 68-71. https://doi.org/10.1179/2056607715Y.0000000002

Hocking, C., & Wright-St Clair, V. (2011). Occupational science: Adding value to occupational therapy. *New Zealand Journal of Occupational Therapy, 58*(1), 29.

Hodson, T., Gustafsson, L., & Cornwell, P. (2019). Unveiling the complexities of mild stroke: An interpretative phenomenological analysis of the mild stroke experience. *Australian Occupational Therapy Journal, 66*(5), 656-664. https://doi.org/10.1111/1440-1630.12607

Holt-Lunstad, J., Smith, T. B., & Layton, J. B. (2010). Social relationships and mortality risk: A meta-analytic review. *PLoS Medicine, 7*(7), e1000316. https://doi.org/https://doi.org/10.1371/journal.pmed.1000316

Hooper, B., & Wood, W. (2002). Pragmatism and structuralism in occupational therapy: The long conversation. *American Journal of Occupational Therapy, 56*(1), 40-50. https://doi.org/10.5014/ajot.56.1.40

Hooper, B., Wood, W., Schell, B., & Gillen, G. (2014). The philosophy of occupational therapy: A framework for practice. *Willard and Spackman's occupational therapy*, 35-46.

Horgan, N. F., O'Regan, M., Cunningham, C. J., & Finn, A. M. (2009). Recovery after stroke: A 1-year profile. *Disability and Rehabilitation, 31*(10), 831-839. https://doi.org/10.1080/09638280802355072

Horne, J., Lincoln, N. B., Preston, J., & Logan, P. (2014). What does confidence mean to people who have had a stroke? – A qualitative interview study. *Clinical Rehabilitation, 28*(11), 1125-1135. https://doi.org/10.1177/0269215514534086

Howe, K. R. (2011). Mixed Methods, Mixed Causes? *Qualitative Inquiry, 17*(2), 166-171. https://doi.org/10.1177/1077800410392524

Huijbregts, M. P. J., McEwen, S., & Taylor, D. (2009). Exploring the feasibility and efficacy of a telehealth stroke self-management programme: A pilot study. *Physiotherapy Canada, 61*(4), 210-220. https://doi.org/10.3138/physio.61.4.210

Hunt, M. R. (2009). Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research, 19*(9), 1284-1292. https://doi.org/10.1177/1049732309344612

Huppert, F. A., Marks, N., Clark, A., Siegrist, J., Stutzer, A., Vittersø, J., & Wahrendorf, M. (2009). Measuring well-being across Europe: Description of the ESS well-being module and preliminary findings. *Social Indicators Research, 91*(3), 301-315. https://doi.org/10.1007/s11205-008-9346-0

Hwang, N.-K., Park, J.-S., & Chang, M.-Y. (2021). Telehealth Interventions to support self-management in stroke survivors: A systematic review. *Healthcare, 9*(4), 472. https://doi.org/10.3390/healthcare9040472

Ikiugu, M. N., & Schultz, S. (2006). An argument for pragmatism as a foundational philosophy of occupational therapy. *Canadian Journal of Occupational Therapy, 73*(2), 86-97. https://doi.org/10.2182/cjot.05.0009

Ironside, P. M., Scheckel, M., Wessels, C., Bailey, M. E., Powers, S., & Seeley, D. K. (2003). Experiencing chronic illness: Cocreating new understandings.

Qualitative Health Research, 13(2), 171-183. https://doi.org/10.1177/1049732302239597

Jackson, A. Y., & Mazzei, L. A. (2013). Plugging one text into another: Thinking with theory in qualitative research. *Qualitative Inquiry, 19*(4), 261-271. https://doi.org/10.1177/1077800412471510

Jaycox, M. P. (2020). Nussbaum, anger, and racial justice: On the epistemological and eschatological limitations of white liberalism. *Political Theology, 21*(5), 415-433. https://doi.org/10.1080/1462317X.2020.1747810

Johnson Listwan, S., Colvin, M., Hanley, D., & Flannery, D. (2010). Victimization, social support, and psychological well-being: A study of recently released prisoners. *Criminal Justice and Behavior, 37*(10), 1140-1159. https://doi.org/10.1177/0093854810376338

Johnston, M., Bonetti, D., Joice, S., Pollard, B., Morrison, V., Francis, J. J., & MacWalter, R. (2007). Recovery from disability after stroke as a target for a behavioural intervention: Results of a randomized controlled trial. *Disability and Rehabilitation, 29*(14), 1117-1127. https://doi.org/10.1080/03323310600950411

Joice, S. (2012). Self-management following stroke. *Nursing Standard, 26*(22), 39-46. https://doi.org/10.7748/ns2012.02.26.22.39.c8919

Jones, F. (2006). Strategies to enhance chronic disease self-management: How can we apply this to stroke? *Disability and Rehabilitation, 28*(13-14), 841-847. https://doi.org/10.1080/09638280500534952

Jones, F., & Brimicombe, L. (2014). Every interaction counts: The 'Bridges' approach to stroke self-management. *International Journal of Therapy and Rehabilitation, 21*(4), 158-159. https://doi.org/10.12968/ijtr.2014.21.4.158

Jones, F., Gage, H., Drummond, A., Bhalla, A., Grant, R., Lennon, S., McKevitt, C., Riazi, A., & Liston, M. (2016). Feasibility study of an integrated stroke self-management programme: A cluster-randomised controlled trial. *BMJ Open, 6*(1), e008900. https://doi.org/10.1136/bmjopen-2015-008900

Jones, M. R., Horner, R. D., Edwards, L. J., Hoff, J., Armstrong, S. B., Smith-Hammond, C. A., ... & Oddone, E. Z. (2000). Racial variation in initial stroke severity. *Stroke*, *31*(3), 563-567. https://doi.org/10.1161/01.STR.31.3.563

Jones, F., Livingstone, E., & Hawkes, L. (2013). 'Getting the balance between encouragement and taking over' — Reflections on using a new stroke self-management programme. *Physiotherapy Research International, 18*(2), 91-99. https://doi.org/10.1002/pri.1531

Jones, F., Mandy, A., & Partridge, C. (2009). Changing self-efficacy in individuals following a first time stroke: Preliminary study of a novel self-management intervention. *Clinical Rehabilitation, 23*(6), 522-533. https://doi.org/10.1177/0269215508101749

Jones, F., Postgesb, H., & Brimicombe, L. (2016). Building bridges between healthcare professionals, patients and families: A coproduced and integrated approach to self-management support in stroke. *NeuroRehabilitation, 39*(4), 471-480. https://doi.org/10.3233/NRE-161379

Jones, F., & Riazi, A. (2011). Self-efficacy and self-management after stroke: A systematic review. *Disability and Rehabilitation, 33*(10), 797-810. https://doi.org/10.3109/09638288.2010.511415

Jones, F., Riazi, A., & Norris, M. (2013). Self-management after stroke: Time for some more questions? *Disability and Rehabilitation, 35*(5), 257-264. https://doi.org/10.3109/09638288.2012.691938

Jorm, A. F., Kelly, C. M., & Morgan, A. J. (2007). Participant distress in psychiatric research: A systematic review. *Psychological Medicine, 37*(7), 917-926. https://doi.org/10.1017/S0033291706009779

Juritzen, T. I., Grimen, H., & Heggen, K. (2011). Protecting vulnerable research participants: A Foucault-inspired analysis of ethics committees. *Nursing Ethics, 18*(5), 640-650. https://doi.org/10.1177/0969733011403807

Kadlec, A. (2006). Reconstructing Dewey: The philosophy of critical pragmatism. *Polity, 38*(4), 519-542. https://doi.org/10.1057/palgrave.polity.2300067

Kandt, J. (2018). Social practice, plural lifestyles and health inequalities in the United Kingdom. *Sociology of Health & Illness*. https://doi.org/10.1111/1467-9566.12780

Kayes, N. M., Cummins, C., McPherson, K. M., Worrall, L., & Bright, F. A. S. (2022). Developing connections for engagement in stroke rehabilitation. *Brain Impairment, 23*(1), 42-59. https://doi.org/10.1017/BrImp.2021.27

Kayes, N. M., & McPherson, K. M. (2010). Measuring what matters: Does 'objectivity' mean good science? *Disability and Rehabilitation, 32*(12), 1011-1019. https://doi.org/10.3109/09638281003775501

Kendall, E., Catalano, T., Kuipers, P., Posner, N., Buys, N., & Charker, J. (2007). Recovery following stroke: The role of self-management education. *Social Science & Medicine, 64*(3), 735-746. https://doi.org/10.1016/j.socscimed.2006.09.012

Kendall, E., Ehrlich, C., Sunderland, N., Muenchberger, H., & Rushton, C. (2011). Self-managing versus self-management: Reinvigorating the socio-political dimensions of self-management. *Chronic Illness, 7*(1), 87-98. https://doi.org/10.1177/1742395310380281

Kendall, E., & Rogers, A. (2007). Extinguishing the social?: State sponsored self-care policy and the chronic disease self-management programme. *Disability & Society, 22*(2), 129-143. https://doi.org/10.1080/09687590601141535

Kennedy, A., Bower, P., Reeves, D., Blakeman, T., Bowen, R., Chew-Graham, C., Eden, M., Fullwood, C., Gaffney, H., & Gardner, C. (2013). Implementation of self management support for long term conditions in routine primary care settings: Cluster randomised controlled trial. *British Medical Journal, 346*. https://doi.org/10.1136/bmj.f2882

Kennedy, A., Chew-Graham, C., Blakeman, T., Bowen, A., Gardner, C., Protheroe, J., Rogers, A., & Gask, L. (2010). Delivering the WISE (Whole Systems Informing Self-Management Engagement) training package in primary care: Learning from formative evaluation. *Implementation Science, 5*(1), 1-15. https://doi.org/10.1186/1748-5908-5-7

Kennedy, A., Rogers, A., & Bower, P. (2007). Support for self care for patients with chronic disease. *BMJ: British Medical Journal, 335*(7627), 968. https://doi.org/10.1136/bmj.39372.540903.94

Kielhofner, G. (2005). A scholarship of practice: Creating discourse between theory, research and practice. *Occupational Therapy In Health Care, 19*(1-2), 7-16. https://doi.org/10.1080/J003v19n01_02

Kielhofner, G. (2009). *Conceptual Foundations of Occupational Therapy Practice*. F.A. Davis Company. https://books.google.co.nz/books?id=x0OiPQAACAAJ

Kim, H., Sefcik, J. S., & Bradway, C. (2017). Characteristics of qualitative descriptive studies: A systematic review. *Research in Nursing & Health, 40*(1), 23-42. https://doi.org/10.1002/nur.21768

Kirkevold, M. (2002). The unfolding illness trajectory of stroke. *Disability and Rehabilitation, 24*(17), 887-898. https://doi.org/10.1080/09638280210142239

Kleinman, A., & Kleinman, J. (1991). Suffering and its professional transformation: Toward an ethnography of interpersonal experience. *Culture, Medicine and Psychiatry, 15*(3), 275-275. https://doi.org/10.1007/BF00046540

Koch, T., Jenkin, P., & Kralik, D. (2004). Chronic illness self-management: Locating the 'self'. *Journal of Advanced Nursing, 48*(5), 484-492. https://doi.org/10.1111/j.1365-2648.2004.03237.x

Korpershoek, C., Jaap, & Hafsteinsdóttir, T. B. (2011). Self-efficacy and its influence on recovery of patients with stroke: A systematic review. *Journal of Advanced Nursing, 67*(9), 1876-1894. https://doi.org/10.1111/j.1365-2648.2011.05659.x

Krishnamurthi, R., Jones, A., Barber, P. A., Barker-Collo, S., McPherson, K. M., Bennett, D., Rush, E., Suh, F., Starkey, N., & Theadom, A. (2014). Methodology of a population-based stroke and TIA incidence and outcomes study: The Auckland Regional Community Stroke Study (ARCOS IV) 2011–2012. *International Journal of Stroke, 9*(1), 140-147. https://doi.org/10.1111/ijs.12108

Krishnamurthi, R., Witt, E., Barker-Collo, S., McPherson, K. M., Davis-Martin, K., Bennett, D., Rush, E., Suh, F., Starkey, N., Parag, V., Rathnasabapathy, Y., Jones, A., Brown, P., Te Ao, B., Feigin, V. L., & Group, A. I. P. (2014). Reducing recurrent stroke: Methodology of the motivational interviewing in stroke (MIST) randomized clinical trial. *International Journal of Stroke, 9*(1), 133-139. https://doi.org/10.1111/ijs.12107

Lamb, M., Buchanan, D., Godfrey, C. M., Harrison, M. B., & Oakley, P. (2008). The psychosocial spiritual experience of elderly individuals recovering from stroke: A systematic review. *International Journal of Evidence-Based Healthcare, 6*(2), 173-205. https://doi.org/10.1111/j.1744-1609.2008.00079.x

Lavalley, R. (2017). Developing the transactional perspective of occupation for communities: “How well are we doing together?”. *Journal of Occupational Science, 24*(4), 458-469. https://doi.org/10.1080/14427591.2017.1367321

Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The person-environment-occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy, 63*(1), 9-23. https://doi.org/10.1177/000841749606300103

Lawn, S., & Schoo, A. (2010). Supporting self-management of chronic health conditions: Common approaches. *Patient Education and Counseling, 80*(2), 205-211. https://doi.org/10.1016/j.pec.2009.10.006

Lawrence, M. (2010). Young adults' experience of stroke: A qualitative review of the literature. *British Journal of Nursing (BJN), 19*(4), 241-248. https://doi.org/10.12968/bjon.2010.19.4.46787

Lebel, S., Mutsaers, B., Tomei, C., Leclair, C. S., Jones, G., Petricone-Westwood, D., Rutkowski, N., Ta, V., Trudel, G., & Laflamme, S. Z. (2020). Health anxiety and illness-related fears across diverse chronic illnesses: A systematic review on conceptualization, measurement, prevalence, course, and correlates. *PLoS One, 15*(7), e0234124. https://doi.org/10.1371/journal.pone.0234124

Lecouturier, J., Rodgers, H., Murtagh, M. J., White, M., Ford, G. A., & Thomson, R. G. (2010). Systematic review of mass media interventions designed to improve public recognition of stroke symptoms, emergency response and early treatment. *BMC Public Health, 10*(1), 784. https://doi.org/10.1186/1471-2458-10-784

Leech, N. L., Onwuegbuzie, A. J., & Combs, J. P. (2011). Writing publishable mixed research articles: Guidelines for emerging scholars in the health sciences and

beyond. *International Journal of Multiple Research Approaches, 5*(1), 7-24. https://doi.org/10.5172/mra.2011.5.1.7

Legerski, J. P., & Bunnell, S. L. (2010). The risks, benefits, and ethics of trauma-focused research participation. *Ethics and Behavior, 20*(6), 429-442. https://doi.org/10.1080/10508422.2010.521443

Lennon, S., McKenna, S., & Jones, F. (2013). Self-management programmes for people post stroke: A systematic review. *Clinical Rehabilitation, 27*(10), 867-878. https://doi.org/10.1177/0269215513481045

Leventhal, H., Leventhal, E. A., & Contrada, R. J. (1998). Self-regulation, health, and behavior: A perceptual-cognitive approach. *Psychology & Health, 13*(4), 717-733. https://doi.org/10.1080/08870449808407425

Lincoln, Y. (2007). Naturalistic Inquiry In G. Ritzer. *The Blackwell Encyclopedia of Sociology*.

Lindsberg, P. J., & Grau, A. J. (2003). Inflammation and infections as risk factors for ischemic stroke. *Stroke, 34*(10), 2518-2532. https://doi.org/10.1161/01.STR.0000089015.51603.CC

Provisional Health of Disabled People Strategy 2023. https://www.health.govt.nz/publication/provisional-health-disabled-people-strategy

Lo, S. H. S., Chang, A. M., & Chau, J. P. C. (2018). Stroke self-management support improves survivors' self-efficacy and outcome expectation of self-management behaviors. *Stroke, 49*(3), 758-760. https://doi.org/doi:10.1161/STROKEAHA.117.019437

Lo, S. H. S., Chau, J. P. C., & Chang, A. M. (2021). Strategies adopted to manage physical and psychosocial challenges after returning home among people with

stroke: A qualitative study. *Medicine (Baltimore), 100*(10), e25026. https://doi.org/10.1097/md.0000000000025026

Logie, C., Llana, J., Wangari, T., & Loutfy, M. R. (2012). Opportunities, ethical challenges, and lessons learned from working with peer research assistants in a multi-method HIV community-based research study in Ontario, Canada. *Journal of Empirical Research on Human Research Ethics, 7*(4), 10-19. https://doi.org/10.1525/jer.2012.7.4.10

Lorig, K. (1993). Self-management of chronic illness: A model for the future. *Generations, 17*(3), 11-14.

Lorig, K. (1996). Chronic disease self-management. *American Behavioral Scientist, 39*(6), 676-683. https://doi.org/10.1177/0002764296039006005

Lorig, K., & Holman, H. R. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine, 26*(1), 1-7. https://doi.org/10.1207/s15324796abm2601_01

Lorig, K., Lubeck, D., Kraines, R. G., Seleznick, M., & Holman, H. R. (1985). Outcomes of self-help education for patients with arthritis. *Arthritis & Rheumatism: Official Journal of the American College of Rheumatology, 28*(6), 680-685. https://doi.org/10.1002/art.1780280612

Lorig, K., Seleznick, M., Lubeck, D., Ung, E., Chastain, R. L., & Holman, H. R. (1989). The beneficial outcomes of the arthritis self-management course are not adequately explained by behavior change. *Arthritis & Rheumatism: Official Journal of the American College of Rheumatology, 32*(1), 91-95. https://doi.org/10.1002/anr.1780320116

Lorig, K., Sobel, D. S., Stewart, A. L., Brown Jr, B. W., Bandura, A., Ritter, P., Gonzalez, V. M., Laurent, D. D., & Holman, H. R. (1999). Evidence suggesting

that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. *Medical care*, 5-14. https://doi.org/10.1097/00005650-199901000-00003

Macintyre, S. (1997). The black report and beyond what are the issues? *Social Science & Medicine, 44*(6), 723-745. https://doi.org/10.1016/S0277-9536(96)00183-9

Mahawish, K., Barber, P. A., McRae, A., Slark, J., & Ranta, A. (2018). Why the new 'living' Australian stroke guidelines matter to New Zealand. *New Zealand Medical Journal, 131*, 1487.

Malfitano, A. P. S., de Souza, R. G. d. M., Townsend, E. A., & Lopes, R. E. (2019). Do occupational justice concepts inform occupational therapists' practice? A scoping review. *Canadian Journal of Occupational Therapy, 86*(4), 299-312. https://doi.org/10.1177%2F0008417419833409

Mann, F., Bone, J. K., Lloyd-Evans, B., Frerichs, J., Pinfold, V., Ma, R., Wang, J., & Johnson, S. (2017). A life less lonely: The state of the art in interventions to reduce loneliness in people with mental health problems. *Social Psychiatry and Psychiatric Epidemiology, 52*(6), 627-638. https://doi.org/10.1007/s00127-017-1392-y

Martz, E., & Livneh, H. (2016). Psychosocial adaptation to disability within the context of positive psychology: Findings from the literature. *Journal of Occupational Rehabilitation, 26*(1), 4-12. https://doi.org/10.1007/s10926-015-9598-x

Maxwell, J. A. (2008). *Designing a qualitative study* (Vol. 2). The SAGE handbook of applied social research methods.

Mayo, N. E., Wood-Dauphinee, S., Ahmed, S., Carron, G., Higgins, J., Mcewen, S., & Salbach, N. (1999). Disablement following stroke. *Disability and Rehabilitation*, *21*(5-6), 258-268. https://doi.org/10.1080/096382899297684

Mays, N., & Pope, C. (2000). Assessing quality in qualitative research. *British Medical Journal, 320*(7226), 50-52. https://doi.org/10.1136/bmj.320.7226.50

McKenna, S., Jones, F., Glenfield, P., & Lennon, S. (2015). Bridges self-management program for people with stroke in the community: A feasibility randomized controlled trial. *International Journal of Stroke, 10*(5), 697-704. https://doi.org/10.1111/ijs.12

McPherson, K. M. (2006). What are the boundaries of health and functioning – and who should say what they are? *Disability and Rehabilitation, 28*(23), 1473-1474. https://doi.org/10.1080/09638280600925928

McPherson, K. M., Brander, P., Taylor, W. J., & McNaughton, H. K. (2004). Consequences of stroke, arthritis and chronic pain--are there important similarities? *Disability and Rehabilitation, 26*(16), 988-999. https://doi.org/10.1080/09638280410001702414

McPherson, K. M., & Kayes, N. M. (2012). Qualitative research: Its practical contribution to physiotherapy. *Physical Therapy Reviews, 17*(6), 382-389. https://doi.org/10.1179/1743288x12y.0000000044

Menon, A., Bitensky, N. K., & Straus, S. (2010). Best practise use in stroke rehabilitation: From trials and tribulations to solutions! *Disability and Rehabilitation, 32*(8), 646-649. https://doi.org/10.3109/09638280903214640

Mercer, S. W., Guthrie, B., Furler, J., Watt, G. C., & Hart, J. T. (2012). Multimorbidity and the inverse care law in primary care. *British Medical Journal, 344*, e4152. https://doi.org/doi.org/10.1136/bmj.e4152

Miettinen, R. (2006). Epistemology of transformative material activity: John Dewey's pragmatism and cultural-historical activity theory. *Journal for the Theory of*

Social Behaviour, 36(4), 389-408. https://doi.org/10.1111/j.1468-5914.2006.00316.x

Millar, J. (2007). The dynamics of poverty and employment: The contribution of qualitative longitudinal research to understanding transitions, adaptations and trajectories. *Social Policy and Society 6*(4), 533-544. https://doi.org/10.1017/S1474746407003879

Milne, J., & Oberle, K. (2005). Enhancing rigor in qualitative description. *Journal of Wound Ostomy & Continence Nursing, 32*(6), 413-420. https://doi.org/10.1097/00152192-200511000-00014

Mingers, J. (2001). Combining IS research methods: Towards a pluralist methodology. *Information Systems Research, 12*(3), 240. https://doi.org/10.1287/isre.12.3.240.9709

Ministry of Health. (2022a). *Management of Multimorbidity*. https://www.health.govt.nz/our-work/diseases-and-conditions/long-term-conditions/management-multimorbidity

Ministry of Health. (2022b). *NZ Health System. Overview*. https://www.health.govt.nz/new-zealand-health-system/overview-health-system

Mitchell, F. (2015). Reflections on the process of conducting secondary analysis of qualitative data concerning informed choice for young people with a disability in transition. *Forum: Qualitative Social Research, 16*(3), 1-12. https://doi.org/10.17169/fqs-16.3.2300

Mitra, S. (2006). The capability approach and disability. *Journal of Disability Policy Studies, 16*(4), 236-247. https://doi.org/10.1177/10442073060160040501

Moen, T. (2006). Reflections on the Narrative Research Approach. *International Journal of Qualitative Methods, 5*(4), 56-69. https://doi.org/10.1177/160940690600500405

Morgan, H. M., Entwistle, V. A., Cribb, A., Christmas, S., Owens, J., Skea, Z. C., & Watt, I. S. (2017). We need to talk about purpose: A critical interpretive synthesis of health and social care professionals' approaches to self-management support for people with long-term conditions. *Health Expectations, 20*(2), 243-259. https://doi.org/10.1111/hex.12453

Morris, J. H., Oliver, T., Kroll, T., Joice, S., & Williams, B. (2017). Physical activity participation in community dwelling stroke survivors: Synergy and dissonance between motivation and capability. A qualitative study. *Physiotherapy, 103*(3), 311-321. https://doi.org/10.1016/j.physio.2016.05.001

Morrison, R. (2022) An early occupational science? A pragmatic interpretation of the ideas of Eleanor Clarke Slagle / ¿Una temprana Ciencia Ocupacional? Una interpretación pragmatista de las ideas de Eleanor Clarke Slagle, Journal of Occupational Science, 29:2, 225-251, DOI: 10.1080/14427591.2021.1996894

Morrison, V., Pollard, B., Johnston, M., & MacWalter, R. (2005). Anxiety and depression 3 years following stroke: Demographic, clinical, and psychological predictors. *Journal of Psychosomatic Research, 59*(4), 209-213. https://doi.org/10.1016/j.jpsychores.2005.02.019

Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology Special Issue: Knowledge in Context: Qualitative Methods in Counseling Psychology Research, 52*(2), 250-260. https://doi.org/10.1037/0022-0167.52.2.250

Morse, J. M. (2000). Determining sample size. *Qualitative Health Research, 10*(1), 3-5. https://doi.org/10.1177/104973200129118183

Morse, J. M. (2010). How different is qualitative health research from qualitative research? Do we have a subdiscipline? *Qualitative Health Research, 20*(11), 1459-1464. https://doi.org/10.1177/1049732310379116

Mudge, S., Kayes, N. M., & McPherson, K. M. (2015). Who is in control? Clinicians' view on their role in self-management approaches: A qualitative metasynthesis. *BMJ Open, 5*(5), e007413. https://doi.org/10.1136/bmjopen-2014-007413

Mühlhauser, I. (2010). From authority recommendations to fact-sheets—a future for guidelines. *Diabetologia, 53*(11), 2285-2288. https://doi.org/10.1007/s00125-010-1891-9

Mujica-Mota, R. E., Roberts, M., Abel, G., Elliott, M., Lyratzopoulos, G., Roland, M., & Campbell, J. (2015). Common patterns of morbidity and multi-morbidity and their impact on health-related quality of life: Evidence from a national survey. *Quality of Life Research, 24*(4), 909-918. https://doi.org/10.1007/s11136-014-0820-7

Murray, J., Ashworth, R., Forster, A., & Young, J. (2003). Developing a primary care-based stroke service: A review of the qualitative literature. *Br J Gen Pract, 53*(487), 137-142.

Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitative description - the poor cousin of health research? *BMC Medical Research Methodology, 9*, 52-52. https://doi.org/10.1186/1471-2288-9-52

Nespoli, G., Paro, C. A., Lima, L. d. O., & Silva, C. R. A. (2020). Towards pedagogy of care: Reflections and notes through popular education in health. *Interface-Comunicação, Saúde, Educação, 24*. https://doi.org/10.1590/interface.200149

Neuhauser, L. (2017). Integrating participatory design and health literacy to improve research and interventions. *Information Services & Use, 37*, 153-176. https://doi.org/10.3233/ISU-170829

Newbould, J., Taylor, D., & Bury, M. (2006). Lay-led self-management in chronic illness: A review of the evidence. *Chronic Illness, 2*(4), 249-261. https://doi.org/10.1177/17423953060020040401

Njelesani, J., Tang, A., Jonsson, H., & Polatajko, H. (2014). Articulating an occupational perspective. *Journal of Occupational Science, 21*(2), 226-235. https://doi.org/10.1080/14427591.2012.717500

Noar, S. M. (2006). A 10-Year retrospective of research in health mass media campaigns: Where do we go from here? *Journal of Health Communication, 11*(1), 21-42. https://doi.org/10.1080/10810730500461059

Nordentoft, H. M., & Kappel, N. (2011). Vulnerable participants in health research: Methodological and ethical challenges. *Journal of Social Work Practice, 25*(3), 365-376. https://doi.org/10.1080/02650533.2011.597188

Norlander, A., Carlstedt, E., Jönsson, A.-C., Lexell, E. M., Ståhl, A., Lindgren, A., & Iwarsson, S. (2016). Long-term predictors of social and leisure activity 10 years after stroke. *PLoS One, 11*(2), e0149395. https://doi.org/10.1371/journal.pone.0149395

Norris, M., & Kilbride, C. (2013). From dictatorship to a reluctant democracy: Stroke therapists talking about self-management. *Disability and Rehabilitation, 36*(1), 32-38. https://doi.org/10.3109/09638288.2013.776645

Nuñez, D. E., Keller, C., & Ananian, C. D. (2009). A review of the efficacy of the self-management model on health outcomes in community-residing older adults with

arthritis. *Worldviews on Evidence-Based Nursing, 6*(3), 130-148 119p. https://doi.org/10.1111/j.1741-6787.2009.00157.x

Nussbaum, M. C. (2011). Perfectionist liberalism and political liberalism. *Philosophy & Public Affairs, 39*(1), 3-45.

NVivo qualitative data analysis software. (2012).

Oatley, K., & Johnson-Laird, P. N. (1987). Towards a cognitive theory of emotions. *Cognition and Emotion*, *1*(1), 29-50. https://doi.org/10.1080/02699938708408362

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acadamy Medicine.2014;89(9):1245-1251.

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Academic Medicine. 2014;89(9):1245-1251. DOI: 10.1097/ACM.0000000000000388

O'Brien, R., Wyke, S., Watt, G. G., Guthrie, B., & Mercer, S. W. (2014). The 'everyday work'of living with multimorbidity in socioeconomically deprived areas of Scotland. *Journal of Comorbidity, 4*(1), 1-10. https://doi.org/10.15256/joc.2014.4.32

OECD (2017, March). Health Policy Health Review. Health-Policy-in-New-Zealand-March-2017.pdf (oecd.org)

O'Leary, A., Shoor, S., Lorig, K., & Holman, H. R. (1988). A cognitive-behavioral treatment for rheumatoid arthritis. *Health Psychology, 7*(6), 527. https://doi.org/10.1037/0278-6133.7.6.527

Oh, H. X., De Silva, D. A., Toh, Z. A., Pikkarainen, M., Wu, V. X., & He, H.-G. (2021). The effectiveness of self-management interventions with action-taking components in improving health-related outcomes for adult stroke survivors: A systematic review and meta-analysis. *Disability and Rehabilitation*, 1-16. https://doi.org/10.1080/09638288.2021.2001057

Orehek, E., & Kruglanski, A. W. (2018). Personal failure makes society seem fonder: An inquiry into the roots of social interdependence. *PLoS One, 13*(8), e0201361. https://doi.org/10.1371/journal.pone.0201361

Ormerod, R. (2006). The history and ideas of pragmatism. *Journal of the Operational Research Society, 57*(8), 892-909. https://doi.org/10.1057/palgrave.jors.2602065

Pallesen, H. (2014). Body, coping and self-identity. A qualitative 5-year follow-up study of stroke. *Disability and Rehabilitation, 36*(3), 232-241. https://doi.org/doi:10.3109/09638288.2013.788217

Parekh, A. K., Goodman, R. A., Gordon, C., & Koh, H. K. (2011). Managing multiple chronic conditions: A strategic framework for improving health outcomes and quality of life. *Public Health Reports, 126*(4), 460-471. https://doi.org/10.1177/003335491112600403

Parke, H. L., Epiphaniou, E., Pearce, G., Taylor, S. J., Sheikh, A., Griffiths, C. J., Greenhalgh, T., & Pinnock, H. (2015). Self-management support interventions for stroke survivors: A systematic meta-review. *PLoS One, 10*(7), e0131448. https://doi.org/10.1371/journal.pone.0131448

Paterson, B. L. (2001). The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship, 33*(1), 21-26. https://doi.org/10.1111/j.1547-5069.2001.00021.x

Paterson, M., Higgs, J., & Wilcox, S. (2005). The artistry of judgement: A model for occupational therapy practice. *The British Journal of Occupational Therapy, 68*(9), 409-417. https://doi.org/10.1177/030802260506800905

Pearce, G., Parke, H. L., Pinnock, H., Epiphaniou, E., Bourne, C. L., Sheikh, A., & Taylor, S. J. (2016). The PRISMS taxonomy of self-management support: Derivation of a novel taxonomy and initial testing of its utility. *Journal of Health Services Research & Policy, 21*(2), 73-82. https://doi.org/10.1177/1355819615602725

Pearce, G., Pinnock, H., Epiphaniou, E., Parke, H. L., Heavey, E., Griffiths, C. J., Greenhalgh, T., Sheikh, A., & Taylor, S. J. (2015). Experiences of self-management support following a stroke: A meta-review of qualitative systematic reviews. *PloS one, 10*(12), e0141803. https://doi.org/10.15256/joc.2014.4.32

Peoples, H., Satink, T., & Steultjens, E. (2011). Stroke survivors' experiences of rehabilitation: A systematic review of qualitative studies. *Scandinavian Journal of Occupational Therapy, 18*(3), 163-171. https://doi.org/10.3109/11038128.2010.509887

Pereira, S., Foley, N., Salter, K., McClure, J. A., Meyer, M., Brown, J., Speechley, M., & Teasell, R. (2014). Discharge destination of individuals with severe stroke undergoing rehabilitation: A predictive model. *Disability and rehabilitation, 36*(9), 727-731. https://doi.org/10.3109/09638288.2014.902510

Pereira, S., Ross Graham, J., Shahabaz, A., Salter, K., Foley, N., Meyer, M., & Teasell, R. (2012). Rehabilitation of individuals with severe stroke: Synthesis of best evidence and challenges in implementation. *Topics in Stroke Rehabilitation, 19*(2), 122-131. https://doi.org/10.1310/tsr1902-122

Plano Clark, V. L., & Creswell, J. W. (2008). *The mixed methods reader*. Sage Publication.

Plow, M., Moore, S. M., Sajatovic, M., & Katzan, I. (2017). A mixed methods study of multiple health behaviors among individuals with stroke. *PeerJ, 5*, e3210. https://doi.org/10.7717/peerj.3210

Polkinghorne, D. E. (1995). Narrative configuration in qualitative analysis. *International Journal of Qualitative Studies in Education, 8*(1), 5-23. https://doi.org/10.1080/0951839950080103

Pollard, N., & Sakellariou, D. (2014). The occupational therapist as a political being. *Cadernos de Terapia Ocupacional da UFSCar, 22*(3), 643-652. https://doi.org/10.4322/cto.2014.087

Potvin, L., & Jones, C. M. (2011). Twenty-five years after the Ottawa charter: The critical role of health promotion for public health. *Canadian Journal of Public Health, 102*(4), 244-248. https://doi.org/10.1007/BF03404041

Pound, P., Gompertz, P., & Ebrahim, S. (1998). A patient-centred study of the consequences of stroke. *Clinical Rehabilitation, 12*(4), 338-347. https://doi.org/10.1191/026921598677661555

Pound, P., Gompertz, P., & Ebrahim, S. (1999). Social and practical strategies described by people living at home with stroke. *Health & Social Care in the Community, 7*(2), 120-128. https://doi.org/10.1046/j.1365-2524.1999.00168.x

Prawat, R. S. (2000). The two faces of Deweyan pragmatism: Inductionism versus social constructivism. *Teachers College Record, 102*(4), 805-840. https://doi.org/10.1111/0161-4681.00078

Provisional Health of Disabled People Strategy 2023. https://www.health.govt.nz/publication/provisional-health-disabled-people-strategy

Punna, M., Kettunen, T., Bagnall, A.-M., & Kasila, K. (2019). Implementation and outcomes of lay health worker–led self-management interventions for long-term conditions and prevention: A systematic review. *Health Education & Behavior, 46*(6), 1045-1072. https://doi.org/10.1177/1090198119863842

Ravesloot, C., Seekins, T., Cahill, T., Lindgren, S., Nary, D. E., & White, G. (2007). Health promotion for people with disabilities: Development and evaluation of the living well with a disability program. *Health Education Research, 22*(4), 522-531. https://doi.org/10.1093/her/cyl114

Ravesloot, C., Seekins, T., & White, G. (2005). Living well with a disability health promotion intervention: Improved health status for scnsumers and lower costs for health care policymakers. *Rehabilitation Psychology, 50*, 239-245. https://doi.org/10.1037/0090-5550.50.3.239

Ravesloot, C., Seekins, T., & Young, Q.-R. (1998). Health promotion for people with chronic illness and physical disabilities: The connection between health psychology and disability prevention. *Clinical Psychology & Psychotherapy, 5*(2), 76-85. https://doi.org/10.1002/(SICI)1099-0879(199806)5:2

Reed, M., Harrington, R., Duggan, Á., & Wood, V. A. (2010). Meeting stroke survivors' perceived needs: A qualitative study of a community-based exercise and education scheme. *Clinical Rehabilitation, 24*(1), 16-26. https://doi.org/10.1177/0269215509347433

Reiter, J. T., Dobmeyer, A. C., & Hunter, C. L. (2018). The primary care behavioral health (PCBH) model: An overview and operational definition. *Journal of Clinical Psychology in Medical Settings, 25*(2), 109-126. https://doi.org/10.1007/s10880-017-9531-x

Richards, H. M., & Schwartz, L. J. (2002). Ethics of qualitative research: Are there special issues for health services research? *Family Practice 19*(2), 135-139. https://doi.org/10.1093/fampra/19.2.135

Richards, L. (1998). Closeness to data: The changing goals of qualitative data handling. *Qualitative Health Research, 8*(3), 319-328. https://doi.org/10.1177/104973239800800303

Richardson, L., & St. Pierre, E. A. (2000). Writing: a method of inquiry In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 923-948). Thousand Oaks, CA: Sage.

Richardson, L., & St Pierre, E. (2008). A method of inquiry. *Collecting and interpreting qualitative materials, 3*(4), 473.

Richardson, L., & St. Pierre, E. A. (2000). Writing: a method of inquiry In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 923-948). Sage.

Richman, K. A., Alexander, L. B., & True, G. (2012). Proximity, ethical dilemmas, and community research workers. *AJOB Primary Research, 3*(4), 19-29. https://doi.org/10.1080/21507716.2012.714837

Rimke, H. M. (2000). Governing citizens through self-help literature. *Cultural Studies, 14*(1), 61-78. https://doi.org/10.1080/095023800334986

Rimmer, J. H., Braunschweig, C., Silverman, K., Riley, B., Creviston, T., & Nicola, T. (2000). Effects of a short-term health promotion intervention for a predominantly African-American group of stroke survivors. *American Journal of Preventive Medicine, 18*(4), 332-338. https://doi.org/10.1016/S0749-3797(00)00129-X

Robison, J., Wiles, R., Ellis-Hill, C., McPherson, K. M., Hyndman, D., & Ashburn, A. (2009). Resuming previously valued activities post-stroke: Who or what helps?

Disability and Rehabilitation, 31(19), 1555-1566. https://doi.org/10.1080/09638280802639327

Rochette, A., Desrosiers, J., Bravo, G., St-Cyr-Tribble, D., & Bourget, A. (2007). Changes in participation after a mild stroke: Quantitative and qualitative perspectives. *Topics in Stroke Rehabilitation, 14*(3), 59-68. https://doi.org/10.1310/tsr1403-59

Roy, A., Schultz, T. J., Carson, K. V., Smith, B. J., Powell, H., Wilson, A., & Walters, H. E. (2011). Asthma self management education with either regular healthcare professional review or written action plans or both in adults [Protocol]. *Cochrane Database of Systematic Reviews*(12). https://doi.org/10.1002/14651858.CD009479

Rudman, D. L., & Aldrich, R. M. (2017). Discerning the social in individual stories of occupation through critical narrative inquiry. *Journal of Occupational Science, 24*(4), 470-481. https://doi.org/10.1080/14427591.2017.1369144

Ruger, J. P. (2010). Health capability: Conceptualization and operationalization. *American Journal of Public Health, 100*(1), 41-49. https://doi.org/10.2105/AJPH.2008.143651

Ruggeri, K., Garcia-Garzon, E., Maguire, Á., Matz, S., & Huppert, F. A. (2020). Well-being is more than happiness and life satisfaction: A multidimensional analysis of 21 countries. *Health and Quality of Life Outcomes, 18*(1), 192. https://doi.org/10.1186/s12955-020-01423-y

Ruksakulpiwat, S., & Zhou, W. (2021). Self-management interventions for adults with stroke: A scoping review. *Chronic Diseases and Translational Medicine 7*(03), 139-148. https://doi.org/10.1016/j.cdtm.2021.03.001

Rutherford, S. J., Hocking, C., Theadom, A., & McPherson, K. M. (2018). Exploring challenges at 6 months after stroke: What is important to patients for self-management? *International Journal of Therapy and Rehabilitation, 25*(11), 565-575. https://doi.org/10.12968/ijtr.2018.25.11.565

Rutherford, S. J., Theadom, A., Jones, A., Hocking, C., Feigin, V., Krishnamurthi, R., Kent, B., Barker-Collo, S., & McPherson, K. M. (2013). Capturing the stories behind the numbers: The Auckland Regional Community Stroke Study (ARCOS IV), a qualitative study. *International Journal of Stroke, 9*(1), 64-70. https://doi.org/10.1111/ijs.12164

Sadler, E., Wolfe, C. D., & McKevitt, C. (2014). Lay and health care professional understandings of self-management: A systematic review and narrative synthesis. *SAGE Open Med, 2*, 2050312114544493. https://doi.org/10.1177/2050312114544493

Saldana, J. (2013). *The Coding Manual for Qualitative Researchers* (2nd ed.). Sage.

Sandelowski, M. (1993). Theory unmasked: The uses and guises of theory in qualitative research. *Research in Nursing & Health, 16*(3), 213-218. https://doi.org/10.1002/nur.4770160308

Sandelowski, M. (1995). Qualitative analysis: What it is and how to begin. *Research in Nursing & Health, 18*(4), 371-375. https://doi.org/10.1002/nur.4770180411

Sandelowski, M. (1995). Triangles and crystals: On the geometry of qualitative research. *Research in Nursing & Health, 18*(6), 569-574. https://doi.org/10.1002/nur.4770180612

Sandelowski, M. (1998). Writing a good read: Strategies for re-presenting qualitative data. *Research in Nursing & Health, 21*(4), 375-382.

https://doi.org/10.1002/(SICI)1098-240X(199808)21:4%3C375::AID-NUR9%3E3.0.CO;2-C

Sandelowski, M. (2000a). Focus on research methods. Combining qualitative and quantitative sampling, data collection, and analysis techniques in mixed-method studies. *Research in Nursing & Health, 23*(3), 246-255. https://doi.org/10.1002/1098-240X(200006)23:3%3C246::AID-NUR9%3E3.0.CO;2-H

Sandelowski, M. (2000b). Whatever happened to qualitative description? *Research in Nursing & Health 23*(4), 334-340. https://doi.org/10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g

Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research In Nursing& Health, 33*(1), 77-84. https://doi.org/10.1002/nur.20362

Sandelowski, M., & Leeman, J. (2012). Writing usable qualitative health research findings. *Qualitative Health Research, 22*(10), 1404-1413. https://doi.org/10.1177/1049732312450368

Sarason, I. G., & Sarason, B. R. (2009). Social support: Mapping the construct. *Journal of Social and Personal Relationships, 26*(1), 113-120. https://doi.org/10.1177%2F0265407509105526

Sarre, S., Redlich, C., Tinker, A., Sadler, E., Bhalla, A., & McKevitt, C. (2014). A systematic review of qualitative studies on adjusting after stroke: Lessons for the study of resilience. *Disability and Rehabilitation, 36*(9), 716-726. https://doi.org/10.3109/09638288.2013.814724

Satink, T., Cup, E. H., Ilott, I., Prins, J., de Swart, B. J., & Nijhuis-van der Sanden, M. W. (2013). Patients' views on the impact of stroke on their roles and self: A

thematic synthesis of qualitative studies. *Archives of Physical Medicine and Rehabilitation, 94*(6), 1171-1183. https://doi.org/10.1016/j.apmr.2013.01.011

Schmieding, N. J. (1987). Problematic situations in nursing: Analysis of Orlando's theory based on Dewey's theory of inquiry. *Journal of Advanced Nursing, 12*(4), 431-440. https://doi.org/10.1111/1365-2648.ep13107529

Seekins, T., Smith, N., McCleary, T., Clay, J., & Walsh, J. (1990). Secondary disability prevention: Involving consumers in the development of a public health surveillance instrument. *Journal of Disability Policy Studies, 1*(3), 21-36. https://doi.org/10.1177/104420739000100302

Sekhon, J. K., Oates, J., Kneebone, I., & Rose, M. L. (2022). Counselling education for speech-language pathology students in Australia: A survey of education in post-stroke aphasia. *Aphasiology, 36*(12), 1417-1446. https://doi.org/10.1080/02687038.2021.1967280

Sen, A. (1999). Health in development. *Bulletin of the World Health Organisation, 77*(8), 619-623.

Sharma, M. (2005). Reifying capability theory in disability and rehabilitation research. *Asia Pacific Disability Rehabilitation Journal, 16*(2), 125-135.

Shaw, J., & Baker, M. (2004). “Expert patient”—dream or nightmare? *British Medical Journal, 328*(7442), 723-724. https://doi.org/10.1136/bmj.328.7442.723

Shaw, J. A., Connelly, D. M., & Zecevic, A. A. (2010). Pragmatism in practice: Mixed methods research for physiotherapy. *Physiotherapy Theory and Practice, 26*(8), 510-518. https://doi.org/10.3109/09593981003660222

Short, S. E., & Mollborn, S. (2015). Social determinants and health behaviors: Conceptual frames and empirical advances. *Current Opinion in Psychology, 5*, 78-84. https://doi.org/10.1016/j.copsyc.2015.05.002

Siegert, R. J., & Ward, T. (2010). Dignity, rights and capabilities in clinical rehabilitation. *Disability and Rehabilitation, 32*(25), 2138-2146. https://doi.org/10.3109/09638288.2010.483037

Siegert, R. J., Ward, T., Levack, W. M. M., & McPherson, K. M. (2007). A good lives model of clinical and community rehabilitation. *Disability and Rehabilitation, 29*(20-21), 1604-1615. https://doi.org/10.1080/09638280701618794

Siegert, R. J., Ward, T., & Playford, E. D. (2010). Human rights and rehabilitation outcomes. *Disability and Rehabilitation, 32*(12), 965-971. https://doi.org/10.3109/09638281003775360

Silva, C. F., & Howe, P. D. (2012). Difference, adapted physical activity and human development: Potential contribution of capabilities approach. *Adapted Physical Activity Quarterly, 29*(1), 25-43. https://doi.org/10.1123/apaq.29.1.25

Sim, J. (2010). Addressing conflicts in research ethics: Consent and risk of harm. *Physiotherapy Research International, 15*(2), 80-87. https://doi.org/10.1002/pri.483

Skempes, D., Stucki, G., & Bickenbach, J. (2015). Health-related rehabilitation and human rights: analyzing states' obligations under the United Nations convention on the rights of persons with disabilities. *Archives of Physical Medicine and Rehabilitation, 96*(1), 163-173. https://doi.org/10.1016/j.apmr.2014.07.410

Smith, B., Sparkes, A. C., Phoenix, C., & Kirkby, J. (2012). Qualitative research in physical therapy: A critical discussion on mixed-method research. *Physical Therapy Reviews, 17*(6), 374-381. https://doi.org/10.1179/1743288x12y.0000000030

Smith, J., Forster, A., & Young, J. (2009). Cochrane review: Information provision for stroke patients and their caregivers. *Clinical Rehabilitation, 23*(3), 195-206.

St. Pierre, E. A., & Jackson, A. Y. (2014). Qualitative data analysis after coding. *Qualitative Inquiry, 20*(6), 715-719. https://doi.org/10.1177/1077800414532435

Steinhauser, K. E., Clipp, E. C., Hays, J. C., Olsen, M., Arnold, R., Christakis, N. A., Lindquist, J. H., & Tulsky, J. A. (2006). Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research. *Palliative Medicine, 20*(8), 745-754. https://doi.org/10.1177/0269216306073112

Stewart, H., Gapp, R., & Harwood, I. (2017). Exploring the alchemy of qualitative management research: Seeking trustworthiness, credibility and rigor through crystallization. *The Qualitative Report, 22*(1), 1-19. https://doi.org/10.46743/2160-3715/2017.2604

Stone, S. D. (2005). Being as doing: Occupational perspectives of women survivors of hemorrhagic stroke. *Journal of Occupational Science, 12*(1), 17-25. https://doi.org/10.1080/14427591.2005.9686544

Stroke Foundation of New Zealand and New Zealand Guidelines Group. (2010). *Clinical Guidelines for Stroke Management*. Stroke Foundation of New Zealand.

Sullivan-Bolyai, S., Bova, C., & Harper, D. (2005). Developing and refining interventions in persons with health disparities: The use of qualitative description. *Nursing Outlook, 53*(3), 127-133. https://doi.org/10.1016/j.outlook.2005.03.005

Sylvester, C. (2011). Therapeutic recreation, the international classification of functioning, disability, and health, and the capability approach. *Therapeutic Recreation Journal, 45*(2), 85-104.

Sylvestre, A., & Gobeil, S. (2020). The therapeutic alliance: A must for clinical practice. *Canadian Journal of Speech-Language Pathology & Audiology, 44*(3), 125-137.

Tanner, D., Ward, L., & Ray, M. (2018). 'Paying our own way': Application of the capability approach to explore older people's experiences of self-funding social care. *Critical Social Policy, 38*(2), 262-282. https://doi.org/10.1177/0261018317724344

Tattersall, R. (2002). The expert patient: a new approach to chronic disease management for the twenty-first century. *Clinical Medicine, 2*(3), 227. https://doi.org/10.7861/clinmedicine.2-3-227

Taule, T., & Råheim, M. (2014). Life changed existentially: A qualitative study of experiences at 6–8 months after mild stroke. *Disability and Rehabilitation, 36*(25), 2107-2119. https://doi.org/doi:10.3109/09638288.2014.904448

Taylor, D. M., Cameron, J. I., Walsh, L., McEwen, S., Kagan, A., Streiner, D. L., & Huijbregts, M. P. (2009). Exploring the feasibility of videoconference delivery of a self-management program to rural participants with stroke. *Telemedicine and e-Health, 15*(7), 646-654. https://doi.org/10.1089/tmj.2008.0165

Taylor, S. J. C., Pinnock, H., Epiphaniou, E., Pearce, G., Parke, H. L., Schwappach, A., Purushotham, N., Jacob, S., Griffiths, C. J., Greenhalgh, T., & Sheikh, A. (2014). A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS – Practical systematic Review of Self-Management Support for long-term conditions. https://doi.org/10.3310/hsdr02530 (Health Services and Delivery Research)

Te Pae Ora Interim New Zealand Health Plan 2022. https://www.tewhatuora.govt.nz/publications/te-pae-tata-interim-new-zealand-health-plan-2022/

Tellier, M., & Rochette, A. (2009). Falling through the cracks: A literature review to understand the reality of mild stroke survivors.(Grand Rounds)(Report). *Topics in Stroke Rehabilitation, 16*(6), 454(459). https://doi.org/10.1310/tsr1606-454

Theadom, A., Rutherford, S. J., Kent, B., McPherson, K. M., & Group, A. I. (2018). The process of adjustment over time following stroke: A longitudinal qualitative study. *Neuropsychological Rehabilitation*, 1-11. https://doi.org/10.1080/09602011.2018.1440609

Thille, P. H., & Russell, G. M. (2010). Giving patients responsibility or fostering mutual response-ability: Family physicians' constructions of effective chronic illness management. *Qualitative Health Research, 20*(10), 1343-1352. https://doi.org/10.1177/1049732310372376

Thirsk, L. M., & Clark, A. M. (2014). What is the 'self'in chronic disease self-management? *International Journal for Nursing Studies, 51*(5), 691-693. https://doi.org/10.1016/j.ijnurstu.2013.10.008

Thomson, R., & Holland, J. (2003). Hindsight, foresight and insight: The challenges of longitudinal qualitative research. *International Journal of Social Research Methodology, 6*(3), 233-244. https://doi.org/10.1080/1364557032000091833

Thorne, S. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods, 3*(1), 1-11. https://doi.org/10.1177/160940690400300101

Thorne, S. (2008). *Interpretive Description*. Left Coast Press, Inc.

Thorne, S. (2011). Toward methodological emancipation in applied health research. *Qualitative Health Research, 21*(4), 443-453. https://doi.org/10.1177/1049732310392595

Thorne, S. (2016). Interpretive description: Qualitative research for applied practice. Taylor & Francis Group.

Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International journal of qualitative methods*, *3*(1), 1-11. https://doi.org/10.1177/160940690400300101

Thorne, S., Paterson, B., Acorn, S., Canam, C., Joachim, G., & Jillings, C. (2002). Chronic illness experience: Insights from a metastudy. *Qualitative Health Research, 12*(4), 437-452. https://doi.org/10.1177/104973202129120007

Tobias, M., Cheung, J., Carter, K., Anderson, C., & Feigin, V. L. (2007). Stroke surveillance: Population-based estimates and projections for New Zealand. *Australian And New Zealand Journal Of Public Health, 31*(6), 520-525. https://doi.org/10.1111/j.1753-6405.2007.00136.x

Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing, 48*(4), 388-396. https://doi.org/10.1111/j.1365-2648.2004.03207.x

Townend, E., Tinson, D., Kwan, J., & Sharpe, M. (2006). Fear of recurrence and beliefs about preventing recurrence in persons who have suffered a stroke. *Journal of Psychosomatic Research, 61*(6), 747-755. https://doi.org/10.1016/j.jpsychores.2006.09.006

Townsend, A. (2012). Applying Bourdieu's theory to accounts of living with multimorbidity. *Chronic Illness, 8*(2), 89-101. https://doi.org/10.1177/1742395311420178

Townsend, A., Wyke, S., & Hunt, K. (2006). Self-managing and managing self: Practical and moral dilemmas in accounts of living with chronic illness. *Chronic Illness, 2*(3), 185-194. https://doi.org/10.1177/17423953060020031301

Townsend, E., & Marval, R. (2013). Can professionals actually enable occupational justice? *Cadernos de Terapia Ocupacional da UFSCar, 21*(2), 215. https://doi.org/10.4322/cto.2013.025

Tracy, S. J. (2010). Qualitative quality: Eight “Big-Tent” criteria for excellent qualitative research. *Qualitative Inquiry, 16*(10), 837-851. https://doi.org/10.1177/1077800410383121

Tran, V.-T., Barnes, C., Montori, V. M., Falissard, B., & Ravaud, P. (2015). Taxonomy of the burden of treatment: A multi-country web-based qualitative study of patients with chronic conditions. *BMC medicine, 13*(1), 115. https://doi.org/10.1186/s12916-015-0356-x

Turner, A., & Knight, J. (2015). A debate on the professional identity of occupational therapists. *British Journal of Occupational Therapy, 78*(11), 664-673. https://doi.org/10.1177/0308022615601439

Twiddy, M., House, A., & Jones, F. (2012). The association between discrepancy in illness representations on distress in stroke patients and carers. *Journal of Psychosomatic Research, 72*(3), 220-225. https://doi.org/10.1016/j.jpsychores.2011.12.004

Vadiee, M. (2012). The UK “Expert Patient Program” and self-care in chronic disease management: An analysis. *European Geriatric Medicine, 3*(3), 201-205. https://doi.org/10.1016/j.eurger.2012.02.003

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences, 15*(3), 398-405. https://doi.org/10.1111/nhs.12048

Vassilev, I., Rogers, A., Sanders, C., Kennedy, A., Blickem, C., Protheroe, J., Bower, P., Kirk, S., Chew-Graham, C., & Morris, R. (2011). Social networks, social

capital and chronic illness self-management: A realist review. *Chronic Illness, 7*(1), 60-86. https://doi.org/10.1177/1742395310383338

Veal, D., King, J., & Marston, G. (2018). Enhancing the social dimension of development: Interconnecting the capability approach and applied knowledge of social workers. *International Social Work, 61*(4), 600-612. https://doi.org/10.1177/0020872816651703

Wachters-Kaufmann, C., Schuling, J., The, H., & Meyboom-de Jong, B. (2005). Actual and desired information provision after a stroke. *Patient Education & Counseling, 56*(2), 211-217. https://doi.org/10.1016/j.pec.2004.02.012

Wagner, E. H. (2019). Organizing care for patients with chronic illness revisited. *Milbank Q, 97*(3), 659-664. https://doi.org/10.1111/1468-0009.12416

Wagner, E. H., Austin, B. T., & Von Korff, M. (1996). Organizing care for patients with chronic illness. *The Milbank Quarterly*, 511-544. https://doi.org/10.2307/3350391

Wakefield, M. A., Loken, B., & Hornik, R. C. (2010). Use of mass media campaigns to change health behaviour. *The Lancet, 376*(9748), 1261-1271. https://doi.org/10.1016/S0140-6736(10)60809-4

Wall, H. K., Beagan, B. M., O'Neill, H. J., Foell, K. M., & Boddie-Willis, C. L. (2008). Addressing stroke signs and symptoms through public education: The stroke heroes act FAST campaign. *Preventing Chronic Disease, 5*(2), A49. https://doi.org/10.1177/2050312114544493

Walter, F. M., & Emery, J. (2006). Perceptions of family history across common diseases: A qualitative study in primary care. *Family practice, 23*(4), 472-480. https://doi.org/10.1093/fampra/cml006

Wan, X., Chau, J. P. C., Mou, H., & Liu, X. (2021). Effects of peer support interventions on physical and psychosocial outcomes among stroke survivors: A systematic review and meta-analysis. *International Journal of Nursing Studies, 121*, 104001. https://doi.org/10.1016/j.ijnurstu.2021.104001

Ward, T., & Brown, M. (2004). The good lives model and conceptual issues in offender rehabilitation. *Psychology, Crime & Law, 10*(3), 243-257. https://doi.org/10.1080/10683160410001662744

Warner, G., Packer, T., Villeneuve, M., Audulv, A., & Versnel, J. (2015). A systematic review of the effectiveness of stroke self-management programs for improving function and participation outcomes: Self-management programs for stroke survivors. *Disability and Rehabilitation, 37*(23), 2141-2163. https://doi.org/10.3109/09638288.2014.996674

Wassenius, C. (2020). *Occupational engagement after stroke-a long-term perspective*

Wassink, H. L., Chapman, G. E., Levy-Milne, R., & Forster-Coull, L. (2004). Implementing the British Columbia nutrition survey: Perspectives of interviewers and facilitators. *Canadian Journal of Dietetic Practice and Research, 65*(2), 59-64. https://doi.org/10.3148/65.2.2004.59

Watkins, J. (2017). Clinical guidelines for stroke management 2017. *Melbourne Australia, National Manager Clinical Services, stroke foundation*. https://doi.org/10.3310/hsdr02530

Weatherall, R. (2019). Writing the doctoral thesis differently. *Management Learning, 50*(1), 100-113. https://doi.org/10.1177/1350507618799867

Weaver, R. R., Lemonde, M., Payman, N., & Goodman, W. M. (2014). Health capabilities and diabetes self-management: The impact of economic, social,

and cultural resources. *Social Science and Medicine, 102*(0), 58-68. https://doi.org/10.1016/j.socscimed.2013.11.033

Wellman, B., & Wortley, S. (1990). Different strokes from different folks: Community ties and social support. *American journal of Sociology, 96*(3), 558-588. https://doi.org/doi/10.1086/229572

Wilcock, A. (1993). A theory of the human need for occupation. *Journal of Occupational Science, 1*(1), 17-24. https://doi.org/10.1080/14427591.1993.9686375

Wilcock, A. (1999). Reflections on doing, being and becoming*. *Australian Occupational Therpy Journal, 46*(1), 1-11. https://doi.org/10.1046/j.1440-1630.1999.00174.x

Wilcock, A., & Hocking, C. (2015). *An occupational perspective of health* (3rd ed.). Slack Incorporated.

Wilcock, A. A. (1998). Reflections on doing, being and becoming. *Canadian Journal of Occupational Therapy, 65*(5), 248-256. https://doi.org/10.1177/000841749806500501

Wilcock, A. A. (2001). Occupational science: The key to broadening horizons. *British Journal of Occupational Therapy, 64*(8), 412-417. https://doi.org/10.1177/030802260106400808

Wiles, J. L., Leibing, A., Guberman, N., Reeve, J., & Allen, R. E. S. (2011). The meaning of “aging in place” to older people. *The Gerontologist, 52*(3), 357-366. https://doi.org/10.1093/geront/gnr098

Wilson, D. S., Talsma, A., & Martyn, K. (2011). Mindful staffing: A qualitative description of charge nurses’ decision-making behaviors. *Western Journal of Nursing Research, 33*(6), 805-824. https://doi.org/10.1177/0193945910396519

Wilson, P. M. (2001). A policy analysis of the expert patient in the United Kingdom: Self-care as an expression of pastoral power? *Health & Social Care in the Community, 9*(3), 134-142. https://doi.org/10.1046/j.1365-2524.2001.00289.x

Wilson, P. M. (2011). Patient experience in long-term conditions: Revealing invisible perspectives. *Primary Health Care Research & Development, 12*(03), 185-186. https://doi.org/10.1017/S1463423611000235

Wilson, P. M., Kendall, S., & Brooks, F. (2007). The expert patients programme: A paradox of patient empowerment and medical dominance. *Health & Social Care in the Community, 15*(5), 426-438. https://doi.org/10.1111/j.1365-2524.2007.00701.x

Wilson, P. M., & Mayor, V. (2006). Long-term conditions. 2: Supporting and enabling self-care. *British Journal of Community Nursing, 11*(1), 6-10. https://doi.org/10.12968/bjcn.2006.11.1.20277

Wolf, T. J., Baum, C. M., Lee, D., & Hammel, J. (2016). The development of the Improving Participation After Stroke Self-Management Program (IPASS): An exploratory randomized clinical study. *Topics in Stroke Rehabilitation, 23*(4), 284-292. https://doi.org/10.1080/10749357.2016.1155278

Wolf, T. J., Spiers, M. J., Doherty, M., & Leary, E. V. (2017). The effect of self-management education following mild stroke: An exploratory randomized controlled trial. *Topics in stroke rehabilitation, 24*(5), 345-352. https://doi.org/10.1080/10749357.2017.1289687

Wong, S. R., & Fisher, G. (2015). Comparing and using occupation-focused models. *Occupational Therapy In Health Care, 29*(3), 297-315. https://doi.org/10.3109/07380577.2015.1010130

Woolf, S. H., & Braveman, P. (2011). Where health disparities begin: The role of social and economic determinants—and why current policies may make matters worse. *Health Affairs, 30*(10), 1852-1859. https://doi.org/10.1377/hlthaff.2011.0685

World Health Organization. (2002). *The World health report: 2002: Reducing the risks, promoting healthy life.*

World Health Organization. (2022). *Noncommunicable diseases*. http://bitly.ws/yGj3

Worrall, L., Brown, K., Cruice, M., Davidson, B., Hersh, D., Howe, T., & Sherratt, S. (2010). The evidence for a life-coaching approach to aphasia. *Aphasiology, 24*(4), 497-514. https://doi.org/10.1080/02687030802698152

Wray, N., Markovic, M., & Manderson, L. (2007). "Researcher saturation": The impact of data triangulation and intensive-research practices on the researcher and qualitative research process. *Qualitative Health Research, 17*(10), 1392-1402. https://doi.org/10.1177/1049732307308308

Yeung, P., & Breheny, M. (2016). Using the capability approach to understand the determinants of subjective well-being among community-dwelling older people in New Zealand. *Age and ageing*, *45*(2), 292-298. https://doi.org/10.1093/ageing/afw002

Appendix A: Ethical Approvals

Health and Disability Ethics Committees

2 August 2011

Northern X Regional Ethics Committee
Ministry of Health
3rd Floor, Unisys Building
650 Great South Road, Penrose
Private Bag 92 522
Wellesley Street, Auckland
Phone (09) 580 9105
Fax (09) 580 9001

Mailing Address:
Private Bag 92 522
Wellesley Street
Auckland 1141

email address
northernx_ethicscommittee@moh.govt.nz

Professor Kathryn McPherson
Person Centred Research Centre
Health and Rehabilitation Research Institute
Auckland University of Technology
Private Bag 92006
AUCKLAND 1142

Dear Kathryn

Re:	Ethics ref:	**NTX/11/07/058** (please quote in all correspondence)
	Study title:	Auckland regional community stroke study (ARCOS IV). Measuring and reducing the stroke burden in New Zealand; PIS/Cons v#2, 19/7/11
	Investigators:	Professor Kathryn McPherson (Principal), Associate Professor Valery Feigin, Professor Alice Theadom, Ms Suzanne Barker-Collo, Ms Varsha Parag, Professor Max Abbott, Professor Alan Barber, Ms Ruth Bonita, Dr Paul Brown, Associate Professor Bruce Arroll
	Sites:	Auckland University of Technology

Thank you for your letter dated 19 July and the amendments to the study requested by the Northern X Regional Ethics Committee received with the locality assessment from Auckland University of Technology. The changes were reviewed and given ethical approval by the Chairperson of the Northern X Regional Ethics Committee under delegated authority.

Approved Documents

- Protocol number [undated, received 8/6/2011]
- Participant Information sheet/Consent form version [2, dated 19/7/11]
- Consent form (Whanau/Family/Carer) version [2, dated 19/7/11]

This approval is valid until 30 December 2014, provided that Annual Progress Reports are submitted (see below).

Amendments and Protocol Deviations

All significant amendments to this proposal must receive prior approval from the Committee. Significant amendments include (but are not limited to) changes to:

- the researcher responsible for the conduct of the study at a study site
- the addition of an extra study site
- the design or duration of the study
- the method of recruitment
- information sheets and informed consent procedures.

Significant deviations from the approved protocol must be reported to the Committee as soon as possible.

Annual Progress Reports and Final Reports

The first Annual Progress Report for this study is due to the Committee by **2 August 2012**. The Annual Report Form that should be used is available at www.ethicscommittees.health.govt.nz. Please note that if you do not provide a progress report by this date, ethical approval may be withdrawn.

A Final Report is also required at the conclusion of the study. The Final Report Form is also available at www.ethicscommittees.health.govt.nz.

Statement of compliance

The committee is constituted in accordance with its Terms of Reference. It complies with the *Operational Standard for Ethics Committees* and the principles of international good clinical practice.

The committee is approved by the Health Research Council's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990.

We wish you all the best with your study.

Yours sincerely

Cheh Chua-Ethics Committees
Administrator
Northern X Regional Ethics Committee

MEMORANDUM

Auckland University of Technology Ethics Committee (AUTEC)

To: Kathryn McPherson

From: **Dr Rosemary Godbold** Executive Secretary, AUTEC

Date: 1 November 2011

Subject: Ethics Application Number 11/295 **Auckland Regional Community Stroke Study (ARCOS IV), measuring and reducing stroke burden in New Zealand: Part 3 qualitative study**

Dear Kathryn

I am pleased to advise that a subcommittee Auckland University of Technology Ethics Committee (AUTEC) approved your ethics application, subject to the following conditions:

1. Provision of a researcher safety protocol

I request that you provide me with a written response to the point raised in this condition at your earliest convenience, indicating either how you have satisfied this point or proposing an alternative approach. AUTEC also requires written evidence of any altered documents, such as Information Sheets, surveys etc. Once this response and its supporting written evidence has been received and confirmed as satisfying the Committee's points, you will be notified of the full approval of your ethics application.

When approval has been given subject to conditions, full approval is not effective until *all* the concerns expressed in the conditions have been met to the satisfaction of the Committee. Data collection may not commence until full approval has been confirmed. Should these conditions not be satisfactorily met within 6 months, your application may be closed and you will need to submit a new application should you wish to continue with this research project.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all written and verbal correspondence with us. Should you have any further enquiries regarding this matter, you are welcome to contact me by email at ethics@aut.ac.nz or by telephone on 921 9999 at extension 6902. Alternatively you may contact your AUTEC Faculty Representative (a list with contact details may be found at http://www.aut.ac.nz/research/research-ethics/ethics).

Yours sincerely

Dr Rosemary Godbold

Executive Secretary

Auckland University of Technology Ethics Committee

Cc: Valery Feigin. Alice Theadom, Max Abbott,

Appendix B: Qualitative Research Reporting Checklist

	Reporting Item	Page number
Problem formulation	#1 Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended. #2 Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended.	22-24 51-60 2-3
Problem formulation	#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement.	3-5
Purpose or research question	#4 Purpose of the study and specific objectives or questions.	5
Qualitative approach and research paradigm	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale	25-26, 51-57

	should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	
Researcher characteristics and reflexivity	#6 Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability.	6, 24, 57
Context	#7 Setting / site and salient contextual factors; rationale	67-68
Sampling strategy	#8 How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	68-70
Ethical issues pertaining to human subjects	#9 Documentation of approval by an appropriate ethics review board and participant consent, or explanation for	iv

	lack thereof; other confidentiality and data security issues.	
Data collection methods	#10 Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	24
Data collection instruments and technologies	#11 Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study.	69, 267
Units of study	#12 Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results).	71
Data processing	#13 Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts.	69-70, 101-102

Data analysis	#14 Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale.	69, 101-102
Techniques to enhance trustworthiness	#15 Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale.	146-151
Syntheses and interpretation	#16 Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory.	71-77, 102-118, 147-161
Links to empirical data	#17 Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings.	268-283
Integration with prior work, implications, transferability and contribution(s) to the field	#18 Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field.	33, 77-84, 116-119, 161, 186-207
Limitations	Trustworthiness and limitations of findings.	34, 81, 198-199

Conflicts of interest	#20 Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed.	32, 69-71
Funding	#21 Sources of funding and other support; role of funders in data collection, interpretation and reporting.	ii

Appendix C: Participant information and consent forms

CONSENT FORM (Participant)

REQUEST FOR INTERPRETER			
English	I wish to have an interpreter.	Yes	No
NZ Sign Language	I wish to have a sign language interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero.	Ae	Kao
Samoan	Oute mana'o ia iai se fa'amatala upu.	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai

1. I have read/had explained to me, and understand, the Information Sheet (Version 3, dated 23/04/12) for participants taking part in Part 3 of the ARCOS IV study.

2. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

3. I have had the opportunity to use family/whānau support or a friend to help me ask questions and understand the study.

4. I understand that taking part in this study is voluntary (my choice). I realise the study involves an interview about my experience of stroke and that I may choose not to answer any questions or withdraw from the study at any time and this will in no way affect my future health care.
5. I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
6. I give my approval for information to be obtained from the ARCOS IV Incidence study database.
7. I have had time to consider whether to take part.
8. I know whom to contact if I have any questions about the study.

I consent to my interview being audio-taped	Yes / No
I wish to receive a copy of the results. I understand that there may be a significant delay between data collection and the publication of the study results.	Yes / No

I _____ hereby consent to take part in this research.

Signature ..... Date: .....

I would like to nominate a family/whānau member or carer to also take part in this study:

Nominees name:…….. Contact telephone number……

Alternative telephone number……..

Address:……
……

Project explained by.…….....

Project role ……

Signature ..... Date ……

Note: A copy of the consent form to be retained by participant and a copy to be kept in the master study file

CONSENT FORM (Whānau /Family/Carer)

REQUEST FOR INTERPRETER			
English	I wish to have an interpreter.	Yes	No
N. Z. Sign Language	I wish to have a sign language interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero.	Ae	Kao
Samoan	Oute mana'o ia iai se fa'amatala upu.	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai
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Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai

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2. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

3. I have had the opportunity to use family/whānau support or a friend to help me ask questions and understand the study.

4. I understand that taking part in this study is voluntary (my choice). I realise the study involves an interview about my experience of supporting someone with a stroke and that I may choose not to answer any questions or withdraw from the study at any time and this will in no way affect my future health care.

5. I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
6. I have had time to consider whether to take part.
7. I know whom to contact if I have any questions about the study.

I consent to my interview being audio-taped	Yes / No
I wish to receive a copy of the results. I understand that there may be a significant delay between data collection and the publication of the study results.	Yes / No

I _____ hereby consent to take part in this research.

Signature ..... Date: .....

Project explained by.…….....

Project role ……

Signature ..... Date ……

Note: A copy of the consent form to be retained by participant and a copy to be kept in the master study file

CONSENT FORM (Participant)

REQUEST FOR INTERPRETER			
English	I wish to have an interpreter.	Yes	No
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3. I have had the opportunity to use family/whānau support or a friend to help me ask questions and understand the study.

4. I understand that taking part in this study is voluntary (my choice). I realise the study involves an interview about my experience of stroke and that I may choose not to answer any questions or withdraw from the study at any time and this will in no way affect my future health care.

5. I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

6. I give my approval for information to be obtained from the ARCOS IV Incidence study database.

7. I have had time to consider whether to take part.

8. I know whom to contact if I have any questions about the study.

I consent to my interview being audio-taped	Yes / No
I wish to receive a copy of the results. I understand that there may be a significant delay between data collection and the publication of the study results.	Yes / No

I _____ hereby consent to take part in this research.

Signature ..... Date: .....

I would like to nominate a family/whānau member or carer to also take part in this study:

Nominees name:…….. Contact telephone number……

Alternative telephone number……..

Address:……
……
……

Project explained by…….....

Project role ……

Signature ..... Date ……..

Note: A copy of the consent form to be retained by participant and a copy to be kept in the master study file

CONSENT FORM (whānau/Family/Carer)

REQUEST FOR INTERPRETER			
English	I wish to have an interpreter.	Yes	No
N. Z. Sign Language	I wish to have a sign language interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero.	Ae	Kao
Samoan	Oute mana'o ia iai se fa'amatala upu.	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai

1. I have read/had explained to me, and understand, the Information Sheet (Version 3, dated 23/04/12) for participants taking part in Part 3 of the ARCOS IV study.

2. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

3. I have had the opportunity to use family/whānau support or a friend to help me ask questions and understand the study.

4. I understand that taking part in this study is voluntary (my choice). I realise the study involves an interview about my experience of supporting someone with a stroke and that I may choose not to answer any questions or withdraw from the study at any time and this will in no way affect my future health care.

5. I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

6. I have had time to consider whether to take part.

7. I know whom to contact if I have any questions about the study.

I consent to my interview being audio-taped	Yes / No
I wish to receive a copy of the results. I understand that there may be a significant delay between data collection and the publication of the study results.	Yes / No

I _____ hereby consent to take part in this research.

Signature ..... Date: .....

Project explained by.…….....

Project role ……

Signature ..... Date ……..

Note: A copy of the consent form to be retained by participant and a copy to be kept in the master study file

Appendix D: Interview guide

Appendix A – Interview Guide

These questions are aimed as prompts – if a family/whanau member or significant other involved, they are invited to contribute to answering the questions.

We are interested in how you have been since your stroke. We are keen to hear about what has gone well and also what has not gone so well for you so we can help other people after their stroke and their family/whanau.

a) Since the stroke (or since we last spoke) how have things been going for you?

b) Can you tell me about things that have been difficult for you?
   a. Has anything helped you manage with this better?
   b. Have you other ideas of what might help?
   c. Is there anyone who particularly helped you with this issue/concern?

c) Can you tell me about things that are going well for you now?
   a. Can you tell me about strategies you use that help you do these things?

d) Are there things you are doing to stay well and be active since your stroke?

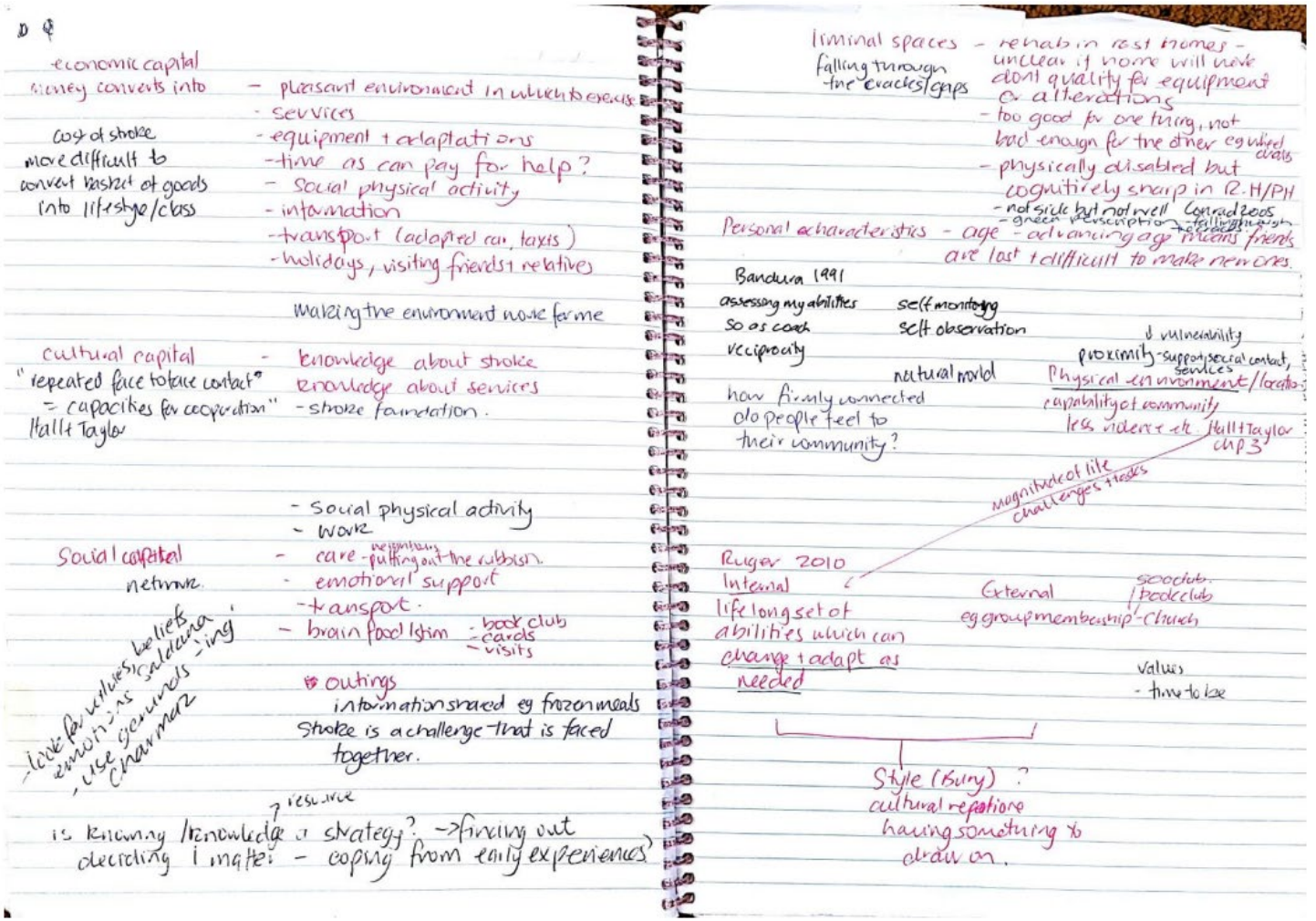
e) How do you think things are going for your family/significant other since your stroke?

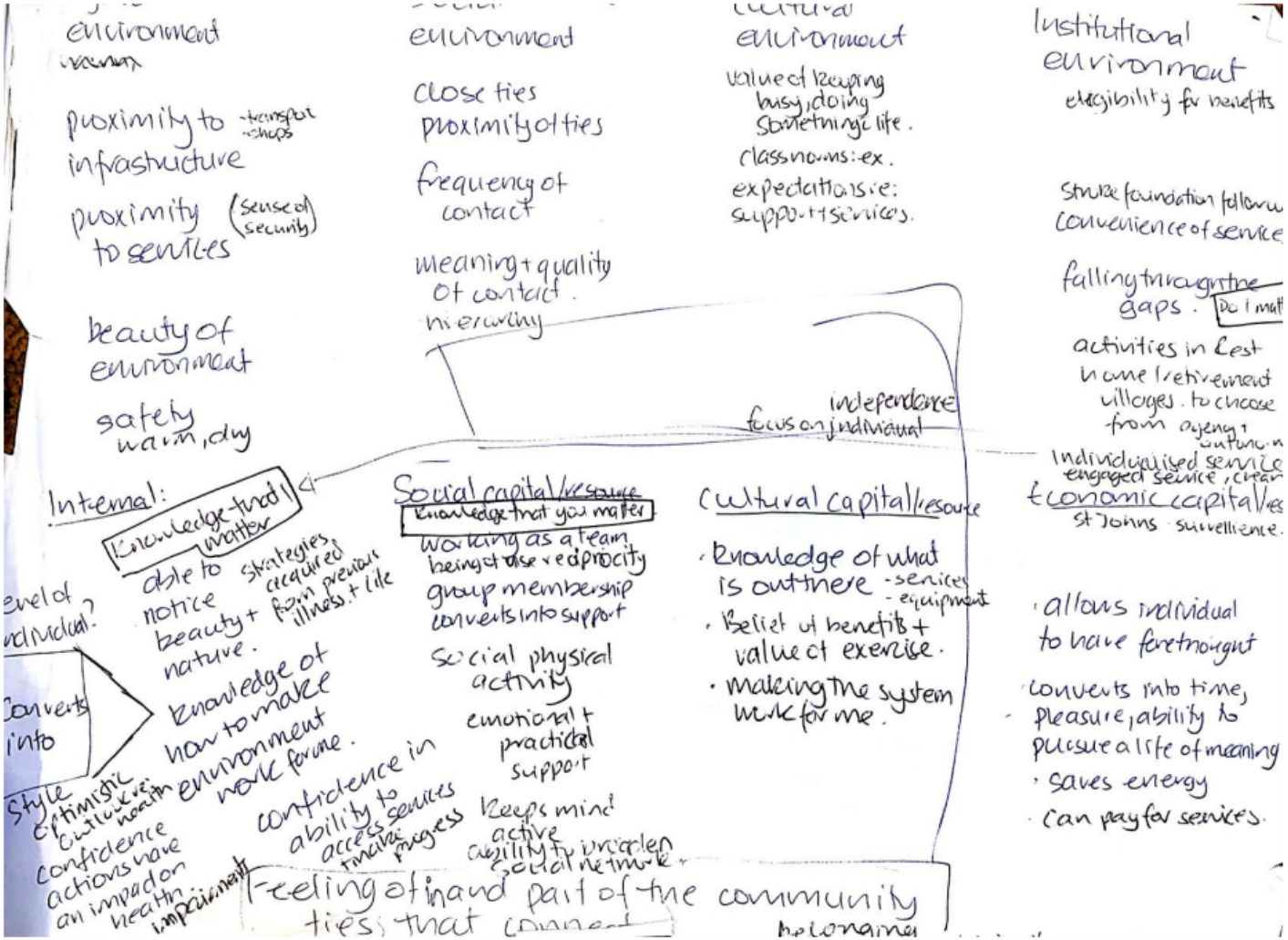
f) Is there anything else you would like to tell us about recovery after stroke?

If the family/whanau member or significant have not contributed much to the above conversation, add the following questions:

a) Is there anything else you would like to tell us about how X has managed since their stroke?
b) Are there things that have helped you manage since X had their stroke?

Appendix E: Analytic coding sensitising concepts




environment
proximity to infrastructure
proximity to services
beauty of environment
safety
environment
close ties
proximity of ties
frequency of contact
meaning + quality of contact
environment
institutional environment
eligibility for benefits
activities in rest home / retirement villages
Internal:
Knowledge-based
Social capital/resource
Knowledge that you matter
working as a team
group membership
Cultural capital/resource
Knowledge of what is out there
Belief of benefits + value of exercise
making the system work for me
allows individual to have forethought
saves energy
can pay for services
Feeling of in and part of the community

Appendix F: Selecting participants for the longitudinal study

AATH	**6, 12, 24, 36**	**Alice. Style – look for positives.**
ABLO	12, 24, 36	Alice. Great physical recovery which was not predicted. Interviews scant.
ACHA	6, 12, 24, 36 Male, Fijian Indian, interpreter	Wanting to work,
ADUF	6, 12, 24, 36 proxy female	Resource rich socially, QoL for Mum. Works very hard to achieve this.
ALEW	Missed 36	In council unit then rest home. Depressed? Māori but does not identify as such. Poorly resourced.
AWHE	6	Passed away
BEWI	6, 12, 24, 36 Male, Māori, some interviews with SO (wife) working age – returned to work eventually	Responded by doing lots and lots of exercise. Some inpatient rehab, but not that impressed, followed his own plan. Talked at all 4 interviews about wanting to talk to others with stroke so he knew what to expect in terms of recovery and to share strategies for own rehab. Money an issue.
BMCG	6, 12, 24, 36	Alice. Proxy. Alzheimer's, With husband in rest home by the end of the study.
BSHA	6, 12, 24, 36	Elderly, last one with son, moved from serviced apartment to PH, then had another stroke, big deterioration. Lost strategies and resources.
CCHR	6, 12, 24, 36	Last interview with wife as passed away. Rest home, personal growth. Wife expected stroke, shock for him, unable to have him home. Not much social or economic capital. Both medical profs speak articulately about the system. Know what to do but unable. Severe stroke. Really determined to gain independence in RH.
CCUM	6, 12, 24, 36 male	Severe stroke. Lots of economic and social capital. Reflective about comfort in hospital.
CHAR	6, 12, 24, 36 female	Retirement home, planning for decrease in function and vision. Alice.
CHIS	6, 12, 24, 36 Male	Alone, unable to drive, articulate about decreased cognition, strategy rich in some ways but legal wrangle with ex-wife consuming lots of energy. Needed a best mate.
CMCG	6, 12	Alice.
CWAU	6, 12, 24, 36 female	Single, not children, very very angry at system, resource rich but strategy poor for coping. Stuck but still somehow makes plans to manage. Cultural understandings about stroke, services. Almost a sense of entitlement to assistance/services – where does this come from? Wanting compassionate care? Someone to walk alongside and guide??mild cognitive impairment. Only one small glimmer of being of use, does not talk about acceptance.

CWRI	6, 12, 24, 36	Many practical and cognitive strategies. Being of use and reciprocity highly valued. Lots of social capital.
CZHO	Chinese, male	Daughter proxy. Talking to friends and being around family helpful.
DBEL	12 proxy	Coded by Alice
DMAC	6, 12 male	With wife. Passed away.
DMEA	6,12, 24, 36 No SO. Female	Articulate about goal planning, breaking tasks into steps. Reflective about abilities, carefully selects activities. Retirement village with lots of opportunities for outings, exercise classes and other activities.
DSKE	6, 12, 24, 36 Male SO wife	Together, found downsizing difficult.
EKOV	Female, SO husband 6, 12, 24, 36	SO as coach, hemiplegia, well-resourced but feels undeserving? Dementia? Hangs over. Very determined. Lots of own rehab, mainly for physical problems.
FGAN	6, 12, 24, 36 No SO female	Into alternative medicine. Felt she was depressed prior to stroke, and may have contributed to cause. Feels completely recovered from early on, so didn't have to think about it. LFT, did not like all of program.
GEST	6, 12, 24, 36 female	Alice retirement village with husband. Resourced and resourceful, fatigue.
GGIB	6, 12, 24, 36 male	Alice. Initially at home then rest home. Mild cognitive impairment.
GRUS	6, 12,	Alice. Passed away. Wife separate. Alzheimer's.
GSTA	6, 12, 24, 36 male	Many medical conditions, loss of identity a major theme, Italian. Retired still paying mortgage.
JCAR	6, 12, 24 male	Passed away before last interview. Widower, no children, overseas at time of stroke. Lots of shock and trauma. Very few strategies, unsure how to respond.
JKEM	6, 12, 24, 36 female	Older, with/out husband, reading, aphasia, no poetry any more. Alice.
JRAN	6, 12 Māori female	Refused further interviews as not coping. Prepare myself. Returned to work, decreased cognition.
JWAD	6, 12, 24, 36 female	Aphasia, some with husband. Moved south to downsize, strategies. Still working in 70s had to retire because of stroke, disrupted retirement plans and finance.
KASH	Female, young	Alice. Young children. identifies with BI, not working, married.
KGRA	6, 12, 24, 36 male	Elected to be interviewed separately. Finances major issue. Struggles to fill in the day, not many goals. Has had quite a lot of rehab including in the community.
KPAU	6, 12, 24, 36 Maori, female	Brings significant trauma history to stroke, contributed to difficulty trusting some health profs. Have CRT and LFT. Loved LFT. Adoption.
LPAL	Tongan	English poor. A few fairly effective strategies, very poor economic resources?
LSEA	6, 12, 24, male, private hospital	COPD, not well resourced but resourceful. Been on 'borrowed time' for many years, mindful in philosophy and outlook.
MADO	Missed 36 proxy private hospital	Alice

MCOA	6, 12, 24, 36	Alice. Initially proxy, interviewed with wife. Returned to work, breathing more of an issue than stroke.
MGRA	6, 12, 24, 36 female	Alice, strategies, confined to home, being of use. Frail.
MSTE	6, 12, 24, 36 female	Resource poor, strategy rich.
MSWA	12, 24 proxy daughter	Alice I did not interview
MTEO	Samoan 6, 24. female AV mal	Young, working. Very stuck as didn't hear the word stroke until after discharge.
NFIS	6, 12, 24, 36 female	At home with husband, lots of family and health issues, but manages quite well. Buddhist, tries to live in the moment. Articulate about 'it's not just about the stroke'. Seems to have formulated a new identity, multiple strokes over course of the study. Downsized before strokes.
NJAR	6, 12, 24, 36 Male	Alice. With SO wife, spinal stenosis, ?mood, well-resourced in terms of SO but strategy poor, identity.
PBAL	12, 24, 36	Severe physical and aphasia. Husband proxy, husband traumatised, no family support apparent.
PJON	6, 12, 24, 36 female	With husband. Significant cognitive impairment. SO not feeling able to provide as much care as needed.
PSTE	6 Male	Withdrew as distressed.
PTAP	6, 12, 24, 36 male	Did not nominate a SO, poorly resourced, heart condition missed by doctors – did not ask the right questions, stuck on this.
RHIL	6, 12, 24, 36 male	Alice aphasia, wife passed away during study. Also terminal dx. Resourceful.
SALL	6, 12, 24, 36 with/out SO husband young, female	History of mental health problems. Felt unsafe due to 'substandard care'.
SDEO	12, 24, 36 Male	Fijian Indian, family helped with interview. Difficult interviews, scant.
SPEN	6, 24, 36 Māori	Spiritual, relaxing, strategy and resource rich, very different style of coping than most others.
SSLA	6, 12, 24, 36 female	Alone, young, gave up work, identity, resource poor. Old before her time.
UCHA	6, 12	Alice. Not cooperative with interviews.
WKER	6, 12, 24, 36 male	Cognitive impairment, not many strategies, seeking medical cure/treatment.
WPER	6, 12, 24, 36 female	Young, single mother, working, Mum SO.
YMCL	6, 12, 24, 36 female 50	'Mild' but lots of cognitive impairment which impacts on work. Vulnerable position as in minimum wage work. Lots of medical/cognitive issues leading up to 'official' stroke. Lots of life issues which complicated but also created opportunity to give of self. This seemed to help recovery. Powerlessness.

Text in purple indicates the first list of participants identified as appropriate for the longitudinal study within this thesis. Participants were selected purposively from this list.

Appendix G: Coding memo

Underpinning, bring with and resources

The things that people bring with them to stroke, social and cultural context, their social capital, resources, habitual ways of thinking about things, and how they solve problems. The lens through which they look at the world, their usual style of managing, coping, and solving problems. At the societal level there is the cultural context and knowledge of what is stroke, its causes and how you respond to it. For example, that it is always severe, and you end up in a rest home. Preconceived ideas. A person's values, attitudes and beliefs which form their rules for action.

A person and their interconnections and significant others could possess many resources or few, their beliefs, attitudes, values and knowledge. For example, knowing that social connection is an important part of wellbeing, and ensuring that their lifestyle includes that. Beliefs such as exercise is good. There is the fear of recurrent stroke, so physical activity was seen to be a threat, so this is a complex cognitive process. But there is the view that maybe I need to be careful right now, how I exercise, but I still need to find a way to do it. I'm not sure if I can yet but I know that it is important, not sure when, how, where. Participants were seeking support with this complex cognitive process.

Habits and routines, ways of solving problems, that may or may not apply to stroke depending on where people have come from, the sorts of problems they have solved in the past. How successful they are and have been in the past, at solving problems is dependent on the resources available to them.

That there is some cultural things about the way we experience and interpret signs and symptoms, could also be impairments after stroke. That your resources for want of a better word, social, cultural capital/place within that influences your perception/how you experience it in your body, it is carried in your body.

Things that need managing

The shock, trauma, grief, suffering, the need to form a causal model, see yourself represented in the stories, feeling stuck, feeling at risk of another stroke, at risk of going into residential care, cognitive impairment, fearfulness. Needing to be close to hospital services, keep myself safe. Then there is the realisation that the services are not there that they thought might be, feeling like they are falling through the gaps, if I

was under ACC I'd be getting the support and services I feel I need. Because I own my own home, because I am mild I don't qualify, sense that this is wrong, unjust.

It does continue, does not get resolved – disillusionment with Western medicine and the feeling/belief that **rehab will fix me**. For some people it stays and for others it goes, if I just had some more physio, if I just had some more services, if someone could just tell me the answer. Some people realising that doctors don't know everything, there are some things that are unknown, for some people this belief stays throughout the interviews, if I had services I would be alright. For others there is a realisation that it is up to me.

The things that need managing are in addition to the stroke as well as the stroke.

Suffering

The result of the shock, trauma, and disruption as identified from the main study. It is still there because then there is the suddenly realisation that medicine can't fix me, is another thing to manage. They didn't expect to have a stroke and they also didn't expect that there would not be the services, and it's partly the fit with what is out there, main study code, but it is also a little bit different. What I thought I knew about the world is incorrect, so that was quite a big thing to have to manage. I am going to have to look somewhere else other than services or medicine, or rehab and that contributes to feeling stuck. OK so I am on my own with it, so now what? What resources do I have to pull on, or even coming to realisation that I am going to have to do it myself. Which does come from this prior context as well.

***Tolerance of ambiguity:**

The ability to tolerate ambiguity and uncertainty, there are some thinking things or cognitive processes, attitudinal, more than that. Influenced by their previous kind of style and way of doing things. There is something about their thinking, a **feeling of effectiveness**, if I do this action then it will …I think it is called outcome expectations that if I do this then it will benefit me and I will see a result. I can do things that will help and they will be effective and that gives a sense of control.

The mental flexibility around its ok to do it another way. The notion that it is going to take some time to adjust, my previous kind of life meant that I am the sort of person that matters, I've done things for others so it is ok for them to do things for me.

You almost need to notice where you are at before you can then dare to be more or dare to think you matter. Then the acceptance that it takes time. Yes because if you notice OK lots of things have improved some things need to improve more, then there is that feeling in yourself that actually I think I can improve more. Or this is where I need to focus my efforts, that it is possible because I am in touch with where I am now.

Rehab will fix me

When participants realise that they either can't access services, what is on offer does not fit and in fact medicine does not have all the answers, they feel disillusioned with western medicine. Some are able to look elsewhere because they feel/know that they matter and they have the resources to underpin the search **finding what is out there and** to pay for it.

Dare to be more:

Envisaging a better self in the future that might, even though her doctor has told her this is as good as she is going to get, I'm going to have bigger expectations than that, I'm going to take some risks and I am going to try some things that might be risky like swimming. Linked to goals, that I can better than this and I am going to keep on going. Some risky things, it might work, it might not but it is ok to give it a go. It takes a lot to almost go against the medical profession.

having a mission and doing things by degrees:

What I am doing right now is a good way to spend some of my time. Mission must be grounded in the person's values, such as serving others, otherwise the thinking does not result in action.

Having a big overarching goal and also being able to break down that goal into steps, so doing it by degrees- what little bit that is manageable am I going to chunk off first. Then **noticing** that I have achieved that.

I don't know whether there is 2 columns here or only one? Because these are kind of strategies in a way. Or abilities – goal planning. Yes because whether they work or not is dependent on the ability. It is not just having the strategy it is being able to do the strategy. There is almost 2 processes, you have got to think of it and then you have got to be able to action it.

So this is how it is:

a kind of acceptance, not that I can't get better but ok so there is no magic pill, amazing rehab program that would transform me so I am going to take it on as a personal challenge, and this is how it is right now, I've just got to work with what I have got. And that frees up a bit of mental space for new and creative, innovative, what else can I do, I'll go to yoga, move away from medical model type treatments.

The experience of comfort, noticing that the warm relationships I have with people are a comfort to me to link to the suffering. Noticing things like, I thought it would be good for me to recover the dining room chairs, have a mission, a big project and it was really fun. Noticing and reflecting. SO linked to attunement.

*****Attunement:**

to my body and my mind, seems quite pivotal and its, about noticing when I have improved, noticing what exactly is the issue that I need to be working on, so then I can match that up with an activity that will help me. Knowing your body, mind as well. Being much more in touch with yourself. How my body feels. Knowledge of the self.

Seems to be pivotal, being in touch with what you need and the improvements you have made.

Seeking cognitive stimulation – connected to attunement, I need to work on my thinking skills as well so I am going to find things like a new recipe to cook to challenge. A sort of strategy.

The attunement, the realisation that I still matter, those sorts of things are enablers to help people enact these more classical strategies. There has to be some thinking about the doing and who I am, before there can be a different kind of doing or a return to doing.

Then there is the rationing of energy.

Working as a team:

When you have a significant other to help you, keep going. As soon as that was not there it was hard for some people.

Stickability

Some have it, and other people who might be more severe their SO helps them to have the keeping going, even though it seems like progress has really slowed down.

This all means that they are able to find whatever rehab things that they are able to pay for, personal trainers. Applying that problem solving that they had before.

Looking for/creating structure and meaning (doing is a priority), imagining a life of meaning and worth in the future, its quite a tricky balance as there is that puritan work ethic rehab is hard work, discourses in the media that if I just put in enough effort I will get a full recovery. There is also balancing it with **making time to be, noticing** and reflecting, **practicing gratitude**, all those mindful things, noticing beauty in the physical environment, noticing the beauty in those close social connections and what they bring, noticing what things are fun, and those people who make sure they go for a walk in nature, or that they are beside the water sometimes. Balance with making sure, lots of people volunteer so that need to give back and be of use.

noticing and reflecting are probably different things.

2 responses? So realising that the systems are not there, and then you have got **making the system work for me**. So that doesn't really belong there it belongs further over here but it is so linked to ….this seems like a way of solving problems that they have used in the past, that they are applying to this new situation so it does belong there.

It feels like you either make the system work, or you go into this – ok this isn't going to work for me, the services are not there I have got to do something different. Well some people do a little bit of both, so that first lady that I keep coming back to, she went to LFT program, even though she is quite mild and didn't feel like she fitted in and didn't really like it all that that much when she talked about it at the 6 month interview, later on she realised that it was a really good thing to do because it got her back into doing regular exercise and physical activity even though at the time she was dissatisfied with it she went to the whole course and enjoyed talking to other people. I think it was her: when you are around other people with stroke it is no big deal because you are all the same kind of thing. Even though she felt people were looking at her and wondering why she was there.

Are people selecting what need from what is there and then having to find a way to fill in the gaps themselves. That is quite a complex process to be able to reflect on ok I don't really like it, it doesn't fit me but I am getting this X,Y and Z from it. I can imagine someone else thinking – that doesn't fit me and dropping out. But her ability to reflect on the aspects of that, that are helping her, she is willing to accept the aspects that are a bit crappy. She has gone through a process of weighing things up. Which can

imagine that someone else wouldn't have the time or ability to do it, especially when cognitively affected, quite an early stage that she is doing that. 6-12 months, I would not have thought that before, now I realise it is nothing in terms of time for recovery. People are taking 2 or 3 years to figure out how their thinking has changed if at all. But actually how each one of these does take a lot of cognitive and personal resource to get to grips with, which is so taxing that mental energy takes so much more from the person than physical activity.

Appendix H: Story

6-months

Every day has always been a battle for me, once I get out of the house and I get amongst people I'm much more positive. I do need space of my own, but I also need a lot of communication with other people so that's why I volunteer for a charity.

I'm lucky probably every third day I get visitors, but every day I get four different phone calls from people, and we have a chat, I felt much more energetic, to say because I started back in the Red Cross shop, people from the Red Cross picked me up and they brought me back.

I've started back making meals for the oldies at the Red Cross. soups, which I freeze, I take them up with me in those plastic containers, I do that because there's a lot of old people that don't bother to cook for themselves and they were so pleased and it makes me cook for myself.

I think it's the old story, however you treat people you generally get treated back that way. When I cooked that soup it was the first meal I cooked since I was out of hospital. I know it was only pumpkin soup, but the satisfaction and that gives you a boost to go on, I'll try Sheppard's pie next, and you do.

When you're on your own things seem to be worse. Whereas if you are socializing with people you come home, you're in a good mood, and you're happy and you potter around and you do things. I think it drives you to strive a bit further as well. I think socializing is really important. When a friend from the charity shop rang me the other day to see how I was going and I said I can't wait to get at that shop. You meet people who come in, you talk to the other girls, it's just amazing - three hours goes like that. You are tired when you're finished, but you also have achieved something, because you do the till and you see how much you've taken. It gives you an incentive to get up and get going in the morning

12-months

I stopped (my volunteer work) at Christmas but what we are doing is, because there is a couple of other ladies that retired and we're going to have morning coffees and we're going to have get togethers. We had one here last week and I think there was six of us here. It was really good. So we're going to do that on a fortnightly basis.

I still keep up (knitting and painting), I'm not knitting at the moment but I'm making those, have you ever seen them, them pom pom balls? I'm making those for the shop in different sizes and another thing I'm making for the shop, because I can sit down and do it, and I make all the labels. So I do things for the shop rather than go in now.

In our little group, I think we are all people that get more out of giving than receiving. Because I remember xxxx (name) said to me about, oh about five months ago when it was sort of the middle of the winter and that and she said 'xxxx (participant name) you must let people do things for you because people get pleasure out of giving.' But I didn't realize I probably wasn't very good at receiving. And you do, because I know I get a real, I really feel good about myself when I do something for anybody you know, however simple it is. And you feel quite chuffed. 'I never thought from that way.' She said 'Well people get pleasure out of doing or giving things for you.

24-months

I cook something for my daughter I devote a Monday to baking and cooking and I do (names friend) meal at the time, something simple, But you don't feel you are relying, you are giving something back besides them giving you. I mean my daughter generally brings 2 meals at least a week over for me and that's how we work. And (names friend) can't do but she says "here's some plants for your garden" or "here's some books for you to read"

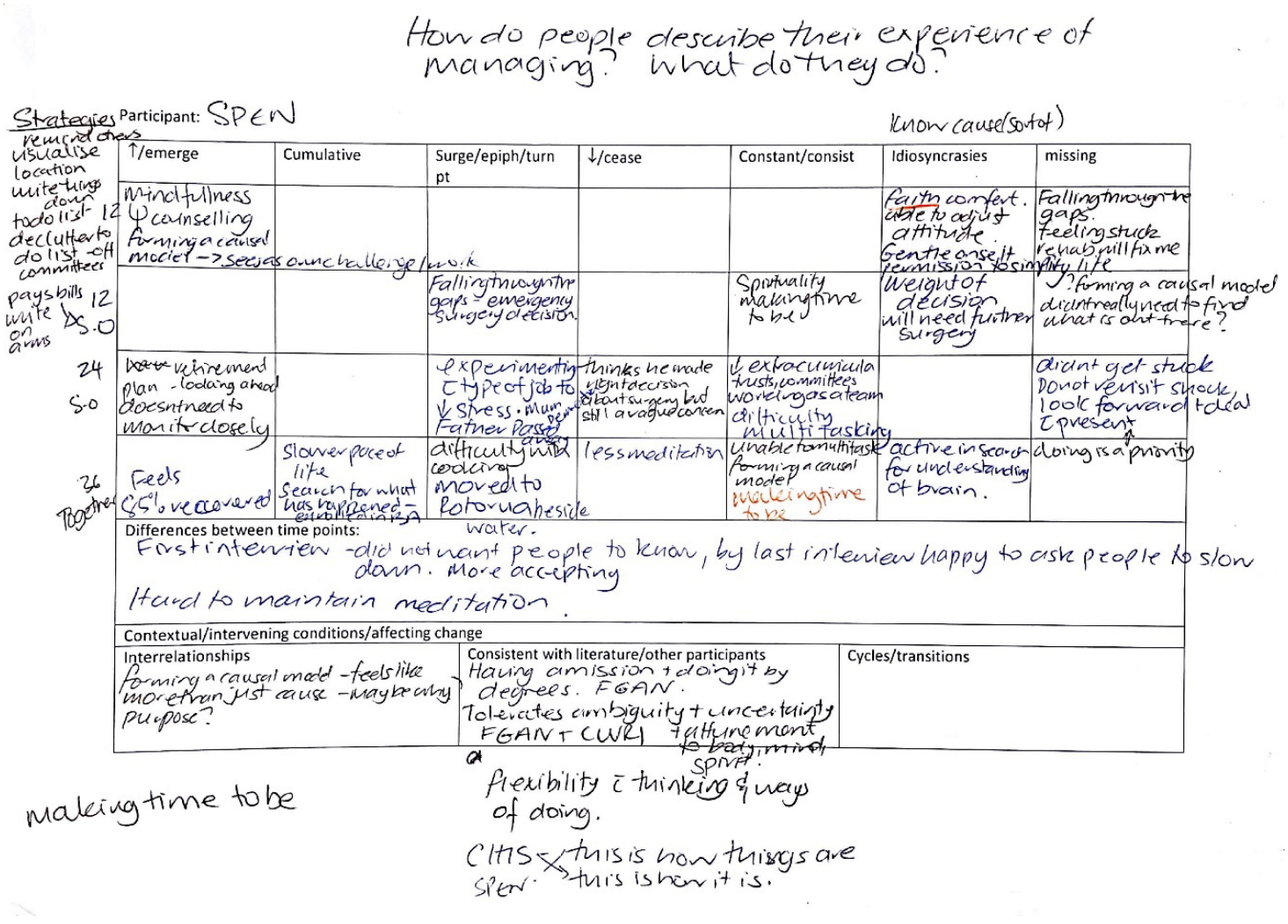
Its things that you take for granted. I can't even wash the ceilings or anything like that so (names son in law) just says "you need a bit of paint outside we will have to get that organised". "Oh yeah that's ok". Whereas before I would say "don't worry about it I'll do it." Now I say "ok." I've learnt to say "ok if you want to do it you go ahead."

36-months

(volunteering and helping others has been a) Thing of my life that's why I still go and see (old neighbour). Because I had to give it up after I had the 3rd stroke because I can't stand for long periods of time. my neighbour down there she has got a young girl and she knocked on the door the other day and she said "oh mum's not home." I said "do you want to come and sit and wait here? You are welcome to." I still do things but it's more home based if you know what I mean? And she says "can I use your phone?" And I say "yes" and quite a few of

the neighbours sort of say to me can I do odd little things like that and I say “oh yes, yes.” So and because my daughter always brings her sewing. Or “mum during the school holidays can you get the stains out of the boy’s school uniforms as a favour” and I say “yes just bring it over. So I still do things for other people because I really enjoy that. I have always bought my children up to give because eventually there will come a time when somebody wants to give to you and you will need that help. I would say my quality of life is good. I’ve still got people that I can meet up with or they come around for coffee and I have got my family, my daughter does so much for me. And I still can go and see my old neighbour and take her little treats. So, it’s just you adapt and you do what you can do.

Appendix I: Matrix example



How do people describe their experience of managing? What do they do?

Strategies: remind others, visualise location, write things down, to do list, declutter to do list, off committees, pays bills, write on arms

Participant: SPEN

Know cause (sort of)

↑/emerge	Cumulative	Surge/epiph/turn pt	↓/cease	Constant/consist	Idiosyncrasies	missing
Mindfulness Ψ counselling Forming a causal model → seeing as a challenge/work					Faith, confort. able to adjust attitude. Gentle arise it permission to simply life	Falling through the gaps. Feeling stuck Rehab will fix me ? forming a causal model do I/I really need to find what is out there?
		Falling through the gaps - emergency surgery decision.		Spirituality making time to be	Weight of decision will need further surgery	
retirement plan - looking ahead doesn't need to monitor closely		experimenting C type of job to ↓ Stress. Mum Father Passed away	thinks he made right decision about surgery but still a vague concern	↓ extracurricula trusts, committees working as a team difficulty multi tasking		didn't get stuck Do not revisit shock look forward to/at C present
Feels 95% recovered	Slower pace of life Search for what has happened -	difficulty with cooling moved to Rotorua beside water.	less meditation	Unable to multitask forming a causal model making time to be	active in search for understanding of brain.	doing is a priority

Differences between time points:
First interview - did not want people to know, by last interview happy to ask people to slow down. More accepting

Hard to maintain meditation.

Contextual/intervening conditions/affecting change

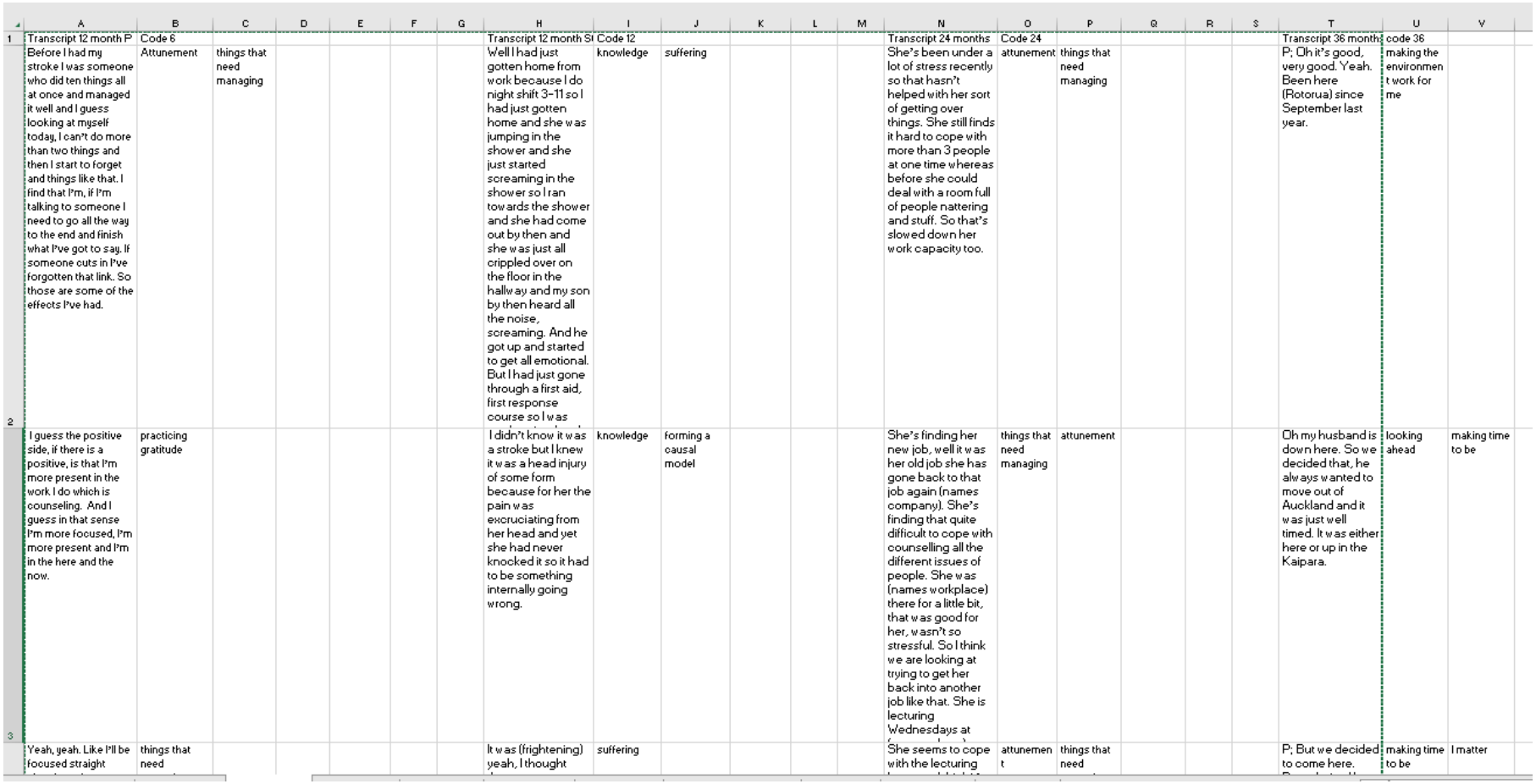
Interrelationships	Consistent with literature/other participants	Cycles/transitions
forming a causal model - feels like more than just cause - maybe also purpose?	Having a mission + doing it by degrees. FGAN. Tolerates ambiguity + uncertainty FGAN + CWR] + attunement to body/mind SPNP.	

making time to be

Flexibility C thinking & ways of doing.

CHIS ≠ this is how things are
SPEN: this is how it is.

Appendix J: Coding using excel



	A	B	C	H	I	J	N	O	P	T	U	V
1	Transcript 12 month P	Code 6		Transcript 12 month SI	Code 12		Transcript 24 months	Code 24		Transcript 36 months	code 36	
2	Before I had my stroke I was someone who did ten things all at once and managed it well and I guess looking at myself today, I can't do more than two things and then I start to forget and things like that. I find that I'm, if I'm talking to someone I need to go all the way to the end and finish what I've got to say. If someone cuts in I've forgotten that link. So those are some of the effects I've had.	Attunement	things that need managing	Well I had just gotten home from work because I do night shift 3-11 so I had just gotten home and she was jumping in the shower and she just started screaming in the shower so I ran towards the shower and she had come out by then and she was just all crippled over on the floor in the hallway and my son by then heard all the noise, screaming. And he got up and started to get all emotional. But I had just gone through a first aid, first response course so I was	knowledge	suffering	She's been under a lot of stress recently so that hasn't helped with her sort of getting over things. She still finds it hard to cope with more than 3 people at one time whereas before she could deal with a room full of people nattering and stuff. So that's slowed down her work capacity too.	attunement	things that need managing	P; Oh it's good, very good. Yeah. Been here (Rotorua) since September last year.	making the environment work for me	
3	I guess the positive side, if there is a positive, is that I'm more present in the work I do which is counseling. And I guess in that sense I'm more focused, I'm more present and I'm in the here and the now.	practicing gratitude		I didn't know it was a stroke but I knew it was a head injury of some form because for her the pain was excruciating from her head and yet she had never knocked it so it had to be something internally going wrong.	knowledge	forming a causal model	She's finding her new job, well it was her old job she has gone back to that job again (names company). She's finding that quite difficult to cope with counselling all the different issues of people. She was (names workplace) there for a little bit, that was good for her, wasn't so stressful. So I think we are looking at trying to get her back into another job like that. She is lecturing Wednesdays at	things that need managing	attunement	Oh my husband is down here. So we decided that, he always wanted to move out of Auckland and it was just well timed. It was either here or up in the Kaipara.	looking ahead	making time to be
	Yeah, yeah. Like I'll be focused straight	things that need		It was (frightening) yeah, I thought	suffering		She seems to cope with the lecturing	attunement	things that need	P; But we decided to come here.	making time to be	I matter