“They didn’t tell me much”: a constructivist grounded theory of the healthcare experience after stroke for older people with limited English proficiency

by

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Table of abbreviations

CALD	Culturally and Linguistically Diverse
CNAHS	Central Northern Adelaide Health Service
HRC	Hampstead Rehabilitation Centre
LEP	Limited English Proficiency
LOTE	Language Other Than English
RAH	Royal Adelaide Hospital
SMRH	St. Margaret's Rehabilitation Hospital
TQEH	The Queen Elizabeth Hospital
USA	United States of America

Summary

The growing number of older people from migrant backgrounds in Australia and other English-speaking countries presents an increasing need to provide healthcare to people who have limited English proficiency (LEP). Older people are more likely to experience major health events such as stroke, which require complex healthcare interventions. The complexity is heightened for an older person with LEP, yet there is little information available about how healthcare can be tailored to optimise stroke recovery for this group of people. The aim of my study was to develop a substantive theory of how healthcare after stroke is experienced by older people with LEP, to inform healthcare practice.

A constructivist grounded theory approach was used. Participants were recruited from four inpatient healthcare facilities in a metropolitan region of South Australia. Participants included 13 older people with LEP from seven different language groups, and one English proficient older person from a culturally and linguistically diverse background. In-depth, semi-structured interviews were conducted with participants at an average of eight weeks after they were discharged from inpatient healthcare. Follow up interviews were then completed with 10 participants at an average of 21 weeks after their discharge to allow clarification of data from their first interview and explore emerging concepts from the analysis. Seven informal carers were co-participants in study interviews. Professional interpreters assisted with the conduct and interpretation of 19 interviews. Data were analysed and the theory was developed using a constant comparative method.

The developed theory comprises three major conceptual processes which combine to tell how older people with LEP experience their healthcare after stroke. The process of *'hanging on to the familiar'* describes the reluctance with which participants left their familiar lives after their stroke to enter the uncertainty of healthcare*. 'Being told and being a good patient'* portrays how participants responded to a healthcare model which positioned them passively and expected their trust. And *'weighing up the value of care'* explains how participants independently evaluated their healthcare for its relevance to what they wanted in their recovery, with consequences for their stroke management. Concepts of the 'familiar' and 'trusted others' are prominent within these processes, encompassing contexts and people who provided comfort and certainty to participants during their healthcare. Language was not given explicit

prominence by participants but was an important influence interwoven through the theory.

My study provides a preliminary theoretical understanding of how healthcare after stroke for older people with LEP can be improved. Recommendations address the need for this group of people to be more involved in their healthcare and its planning after stroke. Leadership from health professionals in the use of professional interpreters is essential to achieving this. The important role of trusted others also needs recognition and involvement in stroke healthcare. A key recommendation from my study is for healthcare after stroke to be both culturally competent and patient-centred to recognise the individual needs, and to benefit the recovery of, all people with stroke.

Signed declaration

I declare that:

this thesis presents work carried out by myself and does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university;

to the best of my knowledge it does not contain any materials previously published or written by another person except where due reference is made in the text; and all substantive contributions by others to the work presented, including jointly authored publications, is clearly acknowledged.

Signed: 

Date: 27/07/2012

Publications and presentations arising from this thesis

Publications

Fryer, C., Mackintosh, S., Batchelor, F., Hill, K. & Said, C. 2012, "The effect of limited English proficiency on falls risk and falls prevention after stroke", *Age and Ageing,* vol. 41, no. 1, pp. 104-107.

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Conference podium presentations

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Fryer, C., Mackintosh, S., Stanley, M. and Crichton, J. 2011, "'Just walking, no physio': why older people with limited English proficiency undervalue their physiotherapy after stroke", *3rd National Australian Physiotherapy Conference,* Brisbane, Australia, 27-30 October 2011.

Fryer, C., Mackintosh, S., Stanley, M. and Crichton, J. 2011, "'I feel better at home': the potential of home rehabilitation for people with limited English proficiency", *9th Asia/Oceania Regional Congress of Gerontology and Geriatrics,* Melbourne, Australia, 23-27 October 2011.

Fryer, C., Mackintosh, S., Stanley, M. and Crichton, J. 2011, "'I understand all the major things': how older people with limited English proficiency decide their need for language assistance during healthcare after stroke", *9th Asia/Oceania Regional Congress of Gerontology and Geriatrics,* Melbourne, Australia, 23-27 October 2011.

Fryer, C., Mackintosh, S., Batchelor, F., Hill, K., Said, C. and Whitehead, C. 2011, "Does a person's English proficiency affect their falls risk after stroke?", *South Australian Falls Prevention Forum*, Adelaide, Australia, 8 April 2011.

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Fryer, C., Mackintosh, S. and Stanley, M. 2009, "What is in the qualitative toolkit for researching a multilingual ageing population? A literature review", *8th National Conference of Emerging Researchers in Ageing,* Melbourne, Australia, 23 October 2009.

Health service presentations

Fryer, C., Mackintosh, S., Stanley, M. and Crichton, J. 2011, "'Just walking, no physio': why older people with limited English proficiency undervalue their physiotherapy after stroke", *Physiotherapy Departments of Royal Adelaide Hospital and Hampstead Rehabilitation Centre,* Adelaide, Australia, 7 April 2011.

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1 Introduction

International migration and the accelerated ageing of populations have created a growing need for healthcare research to address issues relevant to older people in multicultural communities. Older people are more likely to experience major health events such as stroke, which require significant healthcare interventions and other services to maintain their quality of life and an independent lifestyle (SA Health 2010). The Australian Clinical Guidelines for Stroke Management (NSF 2010) acknowledge that cultural and linguistic diversity need to be considered during a person's healthcare after stroke, however, specific guidelines for people who have difficulty speaking English are not provided. Instead, health professionals are given the broad recommendation that they should offer "information tailored to meet their needs using relevant language and communication formats" (p.8). Just how they should tailor information and what communication formats are relevant is not provided in the guidelines and so there is little knowledge that health professionals can meaningfully apply in practice for a group of people who are likely to experience difficulties during their healthcare.

People with limited English proficiency (LEP) from culturally and linguistically diverse (CALD) backgrounds are often disadvantaged in the quality of their healthcare and health outcomes (Bowen 2001, John-Baptiste et al. 2004, Wilson et al. 2005, Levin 2006, Ngo-Metzger et al. 2007, Ngo-Metzger, Sorkin & Phillips 2009, Shi, Lebrun & Tsai 2009). Indeed, they may potentially be even more disadvantaged in complex health situations such as after a stroke when they need to make a transition from inpatient healthcare back to a community setting in a less able state. Despite this, there is little research to inform the provision of quality healthcare after stroke to this group of people. Evidence to inform Australian healthcare policy, services, interventions and implementation that are relevant to older people from CALD backgrounds is limited (Garrett et al. 2010) as the research frequently excludes

consideration of people with LEP and their health issues due to the difficulty of including them in research processes (Feldman et al. 2008, Glickman et al. 2011).

Yet, the Australian Charter of Healthcare Rights recognises that Australian society is made up of people from "different cultures and ways of life" and asserts that everyone can expect to access high quality and safe healthcare services that address their needs (Australian Commission on Safety and Quality in Health Care 2008). It is a principle of equity that is repeated by the new national multicultural policy which acknowledges that Australia is, and will remain, a country of cultural and linguistic diversity (Department of Immigration and Citizenship 2011). Given the importance of healthcare to an individual's recovery from stroke, knowledge about what is important to the healthcare experience of this group of older people is crucial for addressing the gap in research knowledge and informing safe and effective healthcare practice. If more was known about how older people with LEP experience their healthcare after stroke, and how their experience is shaped by others, then healthcare professionals would be better informed about how to provide healthcare to meet their needs. This study is one step forward in addressing that gap.

My study is introduced in the following manner in this chapter. First, an explanation is given of the study's beginnings in my observations of clinical practice. Second, the context of the study is explained, including the construct of LEP, my position as the researcher, and the demographic and healthcare settings that the study sits within. The study's aims and research question are then stated before the chapter concludes with an outline of how the thesis is organised.

1.1 Starting points

The idea for my study emerged in 2007 while I was working as a research physiotherapist on a large randomised controlled trial, investigating the efficacy of a program to prevent people falling when they returned home from rehabilitation after stroke (Batchelor et al. 2009). My role was to conduct initial assessments and intervention programs with participants a few weeks after they had gone home. Several participants were from CALD backgrounds and it was soon obvious that they were experiencing difficulty understanding and managing their healthcare. They had returned to live in the community with disabilities, yet were unsure what healthcare they needed to continue their recovery, what was available to them or how to access

it. Much of my time during their trial intervention was spent advocating on their behalf to access appropriate community healthcare services which had been identified in their initial trial assessments.

The participants from different CALD backgrounds all had difficulty speaking English and I hypothesised that their limited English language ability was linked to the difficulties they were experiencing. It then raised further questions of what was happening during healthcare after stroke to create a disadvantage for this group of people, and how could it be addressed in healthcare practice?

Turning to the literature for help to understand and manage the situation, I was frustrated to find little information about healthcare after stroke for people who had difficulty speaking English. There was considerable published evidence from other areas of healthcare which showed that people with 'limited English proficiency' (LEP) were disadvantaged in healthcare access, quality and satisfaction, but few studies had attempted to explain how the disadvantage occurred. No study specifically addressed the complex healthcare situation after stroke when many issues surrounding recovery from disability and returning to live in the community need to be resolved in a potentially bewildering array of services. At the time of my searching, the Australian "Clinical Guidelines for Acute Stroke Management" advised that people from CALD backgrounds "require special attention and resources" (NSF 2007a, p. 4) but gave no guidance as to what the special needs or required resources were. Still looking for answers, I thought that the data from the trial I had been working on may provide some insight as to what was happening.

1.1.1 A preliminary investigation

Data from the randomised controlled trial provided an opportunity for a preliminary investigation of healthcare after stroke for older people with LEP and to bring attention to a potential area of disadvantage in healthcare. When the trial was complete, I analysed the data to determine if having LEP had influenced participants' falls risk, falls prevention strategies or their planned use of health and support services in the community after stroke. The initial assessment measures from the trial were statistically compared for 20 participants who had used an interpreter during their assessment (LEP group) and 136 participants who were proficient in English (EP group) (Fryer et al. 2012a) (see full article in Appendix A). The nine languages

spoken in the LEP group were reflective of the linguistic diversity in Australia's ageing multicultural communities: Croatian (1), Greek (1), Hakka (1), Italian (7), Macedonian (2), Mandarin (2), Russian (1), Spanish (1), and Vietnamese (4). Participants were assessed in their own homes a mean of 15 days following their discharge from rehabilitation after an acute stroke. Further detail of the trial's assessment and analyses is provided in Fryer et al (2012a) and the trial's published protocol (Batchelor et al. 2009).

The demographic characteristics of the two groups (LEP group and EP group) were not significantly different except for living arrangements (see table in Appendix B). A higher proportion of the LEP group were 'living with family' at home (LEP 60%, EP 14.7%, X^2 P<0.001). Initial analysis indicated that the LEP group had a significantly higher falls risk, as measured using the Falls Risk for Older People in the Community (FROP-com) tool (Russell et al. 2008)(LEP 23.8, EP 21.4, *t*-test P=0.021). However, further analysis indicated that the LEP group had lower scores on the Abbreviated Mental Test Score (AMTS) component of the FROP-com. Concerned that some of the questions used in the AMTS may have lacked relevance for participants from CALD backgrounds (Parker & Philp 2004), I re-analysed the FROP-com scores with the AMTS removed and the falls risk was no longer significantly different between the groups (LEP 22.6, EP 20.9, *t*-test P=0.105).

The LEP group was physically less able and less active than the EP group. Significantly more of them reported needing assistance with activities of daily living (Table 1.1). Their activity levels, as measured by the Human Activity Profile tool (Fix & Daughton 1988), were significantly lower than the EP group and they were significantly slower on both their walking speed over five metres (Steffen, Hacker & Mollinger 2002) and the Timed Up and Go measure of mobility (Shumway-Cook, Brauer & Woollacott 2000)(Table 1.1). Also, significantly more participants in the LEP group had lost more than 3kg in weight since their stroke (12/60%, 47/34.8%, X^2 P=0.03).

Table 1.1 Physical function of participants in randomised controlled trial.

	LEP group[a] (n=20)	**EP group[b] (n=136)**	**Statistical test**	**P value**
Requires assist with activities of daily living, number of participants	14 (70%)	56 (41.8%)	X^2	0.018
Requires assist with instrumental activities of daily living, number of participants	20 (100%)	124 (92.5%)	X^2	-[c]
5 metre walk speed, metres/min, mean (SD[d])	22.46 (14.55)	33.39 (18.54)	t-test	0.013
Timed Up and Go, seconds, mean (SD)	38.02 (21.33)	26.12 (16.89)	t-test	0.006
Step test (worst performance), number of steps, mean (SD)	2.85 (2.98)	3.81 (3.75)	t-test	0.277
HAPAAS[e], mean (SD)	17.3 (9.25)	27.36 (13.37)	t-test	<0.001

[a]LEP group = limited English proficient group, [b]EP group = English proficient group, [c]*P* value not reported as more than 20% of cells contain frequency < 5, [d]SD = standard deviation, [e]HAPAAS = Human Activity Profile Adjusted Activity Score.

Both groups averaged between seven and eight strategies in place to prevent falls and injury (LEP 7.4, EP 8.0), however, significantly fewer of the LEP group were using the strategy of exercising at home or in the community (LEP 11/55.0%, EP 106/77.9%, X^2 P=0.027). A comparison of the groups for falls prevention strategies is given in Appendix C. The LEP group accessed less health and social services in the home (Table 1.2), although home help was the only individual service to be used significantly less by them (LEP 2/10%, EP 60/44%, X^2, P=0.004). A comparison of the use of individual services is provided in Appendix D.

Table 1.2 Falls prevention strategies and use of services by participants in randomised controlled trial.

	LEP group[a] (*n*=20)	**EP group[b] (*n*=136)**	**Statistical test**	***P* value**
Total number of falls prevention strategies in place, mean (SD[c])	7.4 (2.72)	7.95 (1.92)	t-test	0.389
Total number of services provided in community, mean (SD)	3.65 (1.98)	3.84 (1.56)	t-test	0.621
Total number of services provided in home, mean (SD)	1.95 (1.05)	2.68 (1.80)	t-test	0.013

[a]LEP group = limited English proficient group, [b]EP group = English proficient group, [c]SD = standard deviation

This data provided preliminary confirmation that a person's healthcare after stroke may be disadvantaged by having LEP. It suggested that people with LEP may be going home with less physical capability than others after stroke. The acceptance of fewer services in the home by the LEP group and a higher proportion living with extended family implied that informal carers may be 'filling the gap' in support services. And the significantly lower proportion of participants with LEP who were exercising was a concern for their overall stroke recovery as well as potentially preventing them from reducing their falls risk.

Although the analysis was a subgroup analysis which needs a larger planned investigation to statistically confirm the findings, it was a first step in identifying a problem which had not previously been recognised in stroke healthcare research or practice. However, the underlying processes of the disadvantage remained unknown and the results gave little knowledge that could be directly applied to change practice. There was still a need to understand how the disadvantage had occurred.

1.1.2 The next step

Having identified the need to understand what was happening during healthcare after stroke for older people with LEP, there was the methodological question of how such a study could be conducted. Given that there was little research on the topic to provide a predetermined theory for investigation, an inductive and exploratory

approach was required. The study also needed to be able to incorporate the language and cultural diversity of participants in its process and construct knowledge that could be applied to a complex healthcare context. It had previously been suggested that insights into healthcare processes which are beyond the measure of survey or audit assessments can be gained from listening to, and analysing, the experiences of patients (Plack 2005, Howell et al. 2007). A qualitative research approach appeared to fit all these criteria and so was chosen for the study. My methodological choice is further discussed in chapter 2. Within the approach and reporting of the study, the construct of 'limited English proficiency' was a key idea and integral to identifying the people who were the focus of the research. As such, its meaning in the study is now clarified.

1.2 The construct of 'limited English proficiency'

'Limited English proficiency' is a category that is widely used in research from the United States of America (USA) to identify people who have difficulty speaking English (e.g. Wilson et al. 2005, Ngo-Metzger et al. 2007, Masland, Kang & Ma 2011). It functions as a "social aggregate category" where the common feature between the people in the group is the objective property which the person employing the category, the researcher, has determined to be relevant (Sealey & Carter 2004, p. 110). Using LEP as a category met the practical need to identify a sample of older people from CALD backgrounds who were likely to have difficulty communicating in English with their healthcare providers. The definition of LEP that was chosen for the study is given in the box below (Figure 1.1) (and see chapter 2). But the use of the category did not mean or assume that the participants shared a cultural understanding of what it meant to be 'limited English proficient'. As such, an explanation for its use is required (Sealey & Carter 2004).

Definition of 'limited English proficiency'

The person prefers to speak a language other than English for their healthcare, and they reply to the question "How well do you speak English?" by nominating "well", "not well" or "not at all" (less than "very well").

Figure 1.1 Definition of 'limited English proficiency'.

'Limited English proficiency' is a socially constructed category with implications for how people are represented. The word 'limited' may imply that a person with LEP is to blame for lacking something, or that any difficulties they experience could be simply rectified by an effort to learn English (Corvalan & Chirino 2009). This is a naïve view of a complex situation that is influenced by many factors, including broader social systems. The use of the term 'LEP' in the study was not a presumption that having difficulty speaking English would be the most important issue in the healthcare experience for participants. Nor was it intended to summarise the individual identity of participants. Rather, LEP was used as a salient feature to identify a particular group of people whose experiences and needs had not been represented in previous stroke healthcare research and who were the focus of the investigation. It was also a category that is recognised within the healthcare field and so enhanced the accessibility and utility of research reports to healthcare practice.

Another social aggregate category used in the study, this time of Australian origin, was 'cultural and linguistically diverse' or 'CALD'. The category has been used officially in Australia since 1996 to identify someone who is an immigrant to the country (Garrett et al. 2010). The use of 'CALD' acknowledges that people and groups can differ from each other in many ways, including religion, ethnicity, intergenerational and contextual issues, as well as language (NHMRC 2005). The category is recognised in Australian research and policy to refer to people who have migrated to Australia from non-English speaking countries and so again enhances the accessibility and utility of research reports. However, in using CALD within the study, I recognise that its terminology can emphasise difference to the Australian cultural norm (Garrett et al. 2010) and so I must clarify that the study does not seek to further marginalise a group of people who have already been excluded in healthcare research and practice. The use of CALD was inevitably bounded by what constructs were available, acceptable and would provide transparency and transferability of the research in its contemporary context.

Using the categories of LEP and CALD to define the target group of the study was central to the conceptual idea of what was being investigated. Their use was just one of many decisions that I made as a researcher and which had a critical influence on the study's processes and its findings. In the next section of this introductory chapter,

I position myself as the researcher of the study and acknowledge the lens of experience and beliefs that I brought to the study.

1.3 Myself as the researcher

I came to this study as a physiotherapist and researcher within the positivist tradition, wanting to know more about a problem that I had identified during my research work and aspiring to generate knowledge that had meaning for healthcare practice. In my ten years of working clinically in a variety of hospital and rehabilitation contexts, I had witnessed at first-hand the significant effects that major health events, such as stroke, have on people's lives. My belief in conducting this study was that healthcare and health professionals can play a beneficial role in enabling people to achieve the full potential of their recovery after stroke. It was a belief which underpinned my interpretations in the study and the recommendations I then made for practice.

As a physiotherapist, I could have been one of the health professionals that feature in the experiences of study participants; a young, monolingual therapist in the public health system, treating whoever was admitted to the ward that I covered. In my clinical practice, a person with LEP was just another patient in a diverse caseload whose physical recovery I managed to the best of my ability but with little awareness of the difficulties they may have experienced. It was not until the time I spent working on the clinical trial that I developed an interest and some insights into the complexity and inequities of healthcare for people with LEP. It was an experience that led me to reflect on my own practice as a physiotherapist and researcher.

So I entered this study as somewhat an 'insider' to the healthcare situation after stroke that I was researching but an 'outsider' to the people who I was researching (Tinker & Armstrong 2008). I differed from study participants in a variety of ways including our age, cultural backgrounds, language spoken, physical ability, education level…and the list goes on. However, I did not view this as a deficit to the study. I used my awareness of difference to make sure that I understood participants' stories as they wished me to understand rather than to assume an interpretation. I also believe that it encouraged participants to explain their experience to me rather than to assume that I understood from my own experience (Tinker & Armstrong 2008, Underwood, Satterthwait & Bartlett 2010). There was also much that I did share with

participants such as the pride they took in their children's achievements, an enjoyment of gardening and, on one occasion, I was able to empathise with a participant's reported experience of severe shingles pain from my own experience of the same condition. However, my awareness of the differences inspired me to be reflexive through the research process and its account, as further discussed in chapter 3.

Similarly, it was only during my work on the clinical trial that I came to appreciate the value and extent of assistance that professional interpreters could provide in communicating with people with LEP. During my doctoral study, I respected the professional interpreters as fellow professionals with unique knowledge and skills that were integral to the successful conduct of the study. I approached and managed the involvement of each professional interpreter in the study just as I managed the rest of the research team; with clear communication of the expectations of their role and opportunities for mutual feedback on the research process. More information on the role of interpreters in the study is provided in chapter 3.

The study was a time when I engaged with the research process and with the people I met in the field and in other research, clinical and academic settings. In terms of my research approach, I was exposed to different social research philosophies including interpretive, critical and deconstructivist thought. This challenged my epistemological beliefs to recognise that there was more than one measurable truth and led me to embrace a constructionist perspective for the study (see chapter 2, section 2.2).

I was not alone in the construction of knowledge in this study. Participants and interpreters were co-constructors of the interview data and my doctoral supervisors were important influences on the research process and data analysis. I deliberately chose a supervisory team who would bring a mix of perspectives and experiences to benefit the rigour and success of the study. Dr. Shylie Mackintosh, a physiotherapist and researcher, had been a mentor in my own development as a researcher and contributed her substantial clinical and research knowledge of stroke and the health issues of older people. Dr. Mandy Stanley, an occupational therapist and researcher, contributed her extensive experience in exploring issues relevant to the health of older people using a grounded theory approach. And Dr. Jonathan Crichton, an

Applied Linguist, had an interest in healthcare communication and was an invaluable source of knowledge about communication across cultural difference. He was also the important lay voice amongst the clinicians, ensuring there were no assumptions of healthcare practice in the analysis which went unquestioned.

Conducting the study was certainly a challenging endeavour, just as a doctoral study should be. I experienced times of feeling overwhelmed by the demands of the research process and the amount of data I had collected. I worried about faithfully interpreting participants' experiences and I became stuck in the process of rendering the study findings into an understandable and useful form. It was the support of supervisors, colleagues and the qualitative researchers who have written about their own experiences with such methodological challenges that helped me to complete the study. I was also driven by my commitment to represent a group of people who have previously been invisible in the research of healthcare after stroke, and who made their own commitment to generously share their stories with me. The primary purpose of this thesis was to introduce and communicate an understanding of how older people with LEP experience their healthcare after stroke. The developed theory is to inform practice and so it is not confined to this bound tome but has been, and will continue to be, shared with others through talks, papers, email conversations, letters, newsletters and presentations.

The significance of the study and its findings to the fields of contemporary healthcare research and practice can only be interpreted with an understanding of the context within which the study is situated. Now that the beginnings of the study have been introduced, the chapter continues with an explanation of the demographic and healthcare context of the study.

1.4 A demographic revolution

The population is ageing. By 2025 the world's population aged over 60 years will have increased from around 600 million people in 2003 to around 1.2 billion people (World Health Organisation 2003). The World Health Organisation has termed this global phenomenon of accelerated population ageing to be a "demographic revolution" that will have major challenges for each country's health and social policy (World Health Organisation 2003, p. 18).

Within the ageing population of mainly English-speaking countries there is a further demographic revolution as migrant populations also age at accelerated rates. The proportion of older people from CALD backgrounds has been projected to increase significantly over the next few decades in Australia (Gibson et al. 2001) and in other mainly English-speaking countries such as New Zealand (Ministry of Social Development 2001), England and Wales (Lievesley 2010), Canada (Durst 2005) and the United States of America (USA) (Vincent & Velkoff 2010). These countries face similar challenges in research, policy and practice to provide quality healthcare to increasingly diverse aged communities; challenges that will remain of importance for the next decades.

Specifically to Australia, people who have migrated to the country form a large and diverse group within the nation's population. Approximately one quarter of Australia's resident population is formed by migrants from over 200 countries and who speak more than 160 languages (ABS 2011). Many of these people arrived in successive waves of migration after World War II. At first they came from countries in North-West Europe, including the United Kingdom and Germany, followed by large numbers from Southern and Eastern Europe, including Italy, Greece and Yugoslavia. In the 1970s, many migrants arrived from South-East Asian countries such as Vietnam, the Philippines and Cambodia (ABS 2011). The majority of these migrants came to Australia when they were of working age and it is only as they have retired that addressing the needs of older migrants has been realised as an important issue for healthcare.

Australia's population of older people from CALD backgrounds is increasing (Figure 1.2). By 2026, they will account for approximately 21 percent of all older Australians and most (74 percent) will speak a language other than English as the main language spoken at home (Gibson et al. 2001). The diversity of languages spoken by older people with LEP will also increase as different migrant communities move into the older age cohorts at different times. In 2010, groups who had migrated from Southern and Eastern Europe had the highest proportion of people aged 65 years or older (42 percent), followed by North-West Europe (28 percent) and North Africa and the Middle East (12 percent). But as European migration peaked in the years post World War II, the number of older people from these countries will gradually decrease in the community over the next few decades and the population of older people with LEP

will be formed by the ageing of more recent Asian and Sub-Saharan Africa migration groups (ABS 2011).

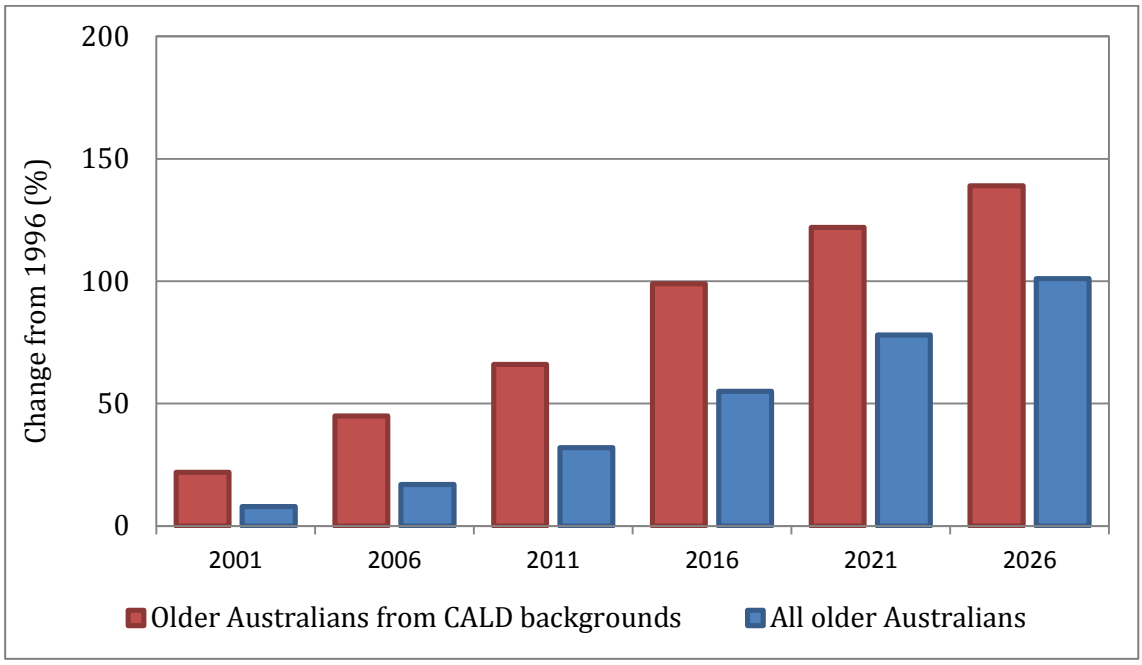


Figure 1.2 Projected increases in population of older Australians from CALD backgrounds and all older Australians aged 65+ years, shown as percentage change from 1996 totals (Data source Gibson et al. 2001, p. 4-5).

The dynamic nature of the language profile of ageing migrant populations suggests that issues which are relevant across different cultural groups, such as achieving quality healthcare for people with LEP, need to be investigated as a basis for policies and practice that will be relevant in a changing future. The languages spoken by older people with LEP from CALD backgrounds will constantly change for the next several decades in Australia not just at a nationwide level but also within local communities.

1.4.1 The local context

Older South Australians are a group profoundly influenced by decades of international migration. In the 20 years between 1996 and 2006, the number of older people in South Australia grew by 19 percent; from 196,725 to 233,132 people. Within that group, the number of older people who were born in non-English speaking countries increased by 30 percent from 33,382 to 43,472 people (Hugo et al. 2009). This is a pattern of growth that is expected to continue for South Australia for at least the next decade.

My study was specifically situated within the Central Northern Adelaide Health Service (CNAHS) of South Australia. At the time of participant recruitment, CNAHS was the largest of South Australia's metropolitan health services with a resident population of 774,701 people which represented approximately half of the state's total population (Glover et al. 2005). Its geographical region covered the west, north and central east of the state's capital city, Adelaide, and it provided healthcare to the most culturally and linguistically diverse metropolitan area in both Adelaide and the state. Three percent of adults in CNAHS spoke English 'not well' or 'not at all' at the 2001 census compared with 1.8 percent for the state as a whole, and 2.3 percent across the Adelaide metropolitan area (Glover et al. 2005). The population is anticipated to remain the most linguistically diverse within South Australia for the foreseeable future, and is likely to increase in diversity as refugee-humanitarian settlers from Sudan, Ethiopia, and Eritrea settle in disproportionately large numbers in Adelaide, and mostly in the CNAHS region (Glover et al. 2005).

The CNAHS resident population, like that of the state as a whole, is ageing. The proportion of people aged over 55 years will increase until at least 2020 (CNAHS 2007) and they will continue to speak diverse languages. In 2001, it was projected that the main languages that would be spoken by older people from CALD backgrounds in western and northern metropolitan Adelaide in 2011 would be Italian, Greek, German, Polish and Vietnamese (Gibson et al. 2001). Yet this does not represent the full diversity of the region as 33 different, non-indigenous languages were spoken in just the western area of Adelaide at the 2006 Census (ABS 2006). Given the demographic revolution of ageing populations at a global, national and local level, there is a need to address healthcare issues that are relevant to older people. For example, as populations age, the burden of cardiovascular disease, including stroke, increases (World Health Organisation 2003).

1.5 Stroke

Older people are more at risk of experiencing a stroke (AIHW 2011), a sudden health event that has a considerable impact on individuals, families and the greater community. A stroke occurs when blood supply to a part of the brain is compromised causing damage to the brain and often affecting functions such as movement of body parts, vision, swallowing and communication. It is a leading cause of death and

disability, accounting for nearly 10 percent of all deaths worldwide (Johnston, Mendis & Mathers 2009). While most of the disease burden of stroke is now borne by developing countries, it remains a leading cause of death and disability in mainly English-speaking countries such as Australia and the USA (Johnston, Mendis & Mathers 2009). And because Australia's population is known to be rapidly aging, the absolute numbers of new stroke cases are expected to increase substantially over the next several years (Dewey et al. 2002). Stroke continues to have substantial consequences for health and wellbeing, particularly for older people (Feigin et al. 2003).

Stroke has a significant effect on the health of older Australians. It is estimated that 60,000 Australians suffer a stroke each year (NSF 2011) and nearly three quarters of this group are people aged between 60 and 85 years (AIHW 2010)(Figure 1.3). In 2007–08, there were 34,945 hospitalisations in Australia with a principal diagnosis of stroke (AIHW 2011) and stroke continues to affect people after their discharge from hospital. The most common types of disability resulting from stroke were restriction in physical activities, incomplete use of limbs, difficulty gripping or holding items and speech difficulties (AIHW 2011).

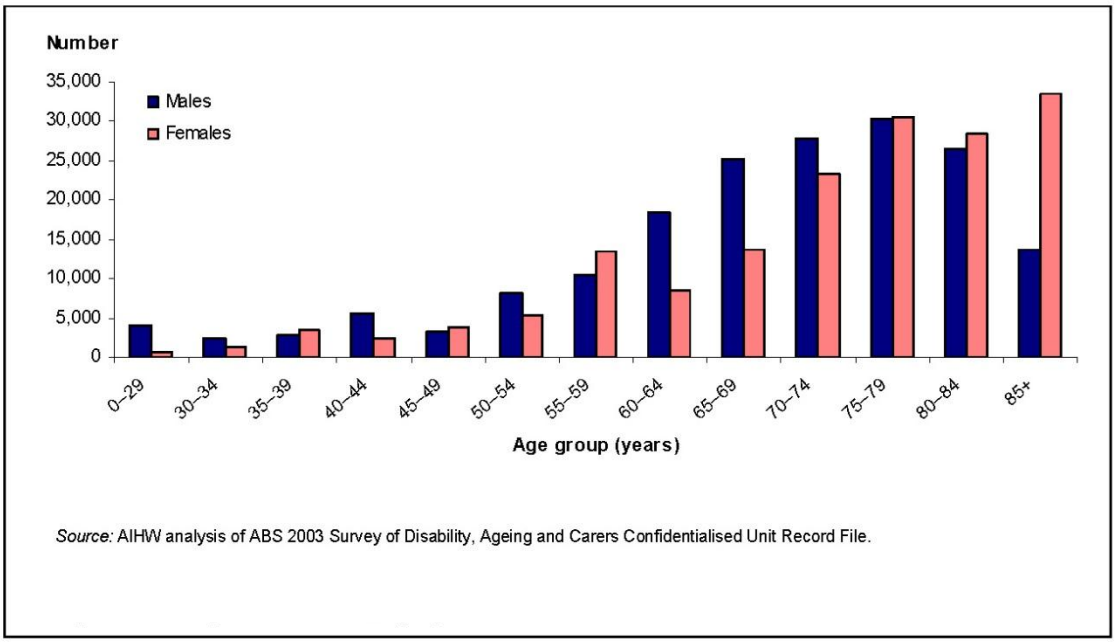


Figure 1.3 Number of Australians suffering stroke in 2003, by age and sex (Senes 2006, p. 46).

While stroke affects older people from CALD backgrounds, the mortality rates from stroke for people from CALD backgrounds are presently lower than for the rest of the Australian population (AIHW 2010). But it is a pattern that is changing. Examination of the temporal trends of stroke incidence in Perth, Western Australia, from 1989-2001 found that increasing numbers of people from CALD backgrounds, particularly from Asian countries, were represented in the profile of stroke patients over the time period (Islam et al. 2008). This may be explained by the increased ageing of migrant populations but it could also be that the health advantage which migrants bring with them diminishes with their length of stay in Australia (Young 1992). And so stroke and its healthcare are increasingly relevant and important issues in the context of ageing migrant communities in Australia. Indeed, healthcare after stroke may be considered to be of increased importance for older people with LEP in migrant communities due to the integral role of communication in its processes.

1.5.1 Communication in healthcare after stroke

The effectiveness of healthcare after stroke relies on successful communication between health professionals and the person with stroke. Healthcare after stroke aims to promote maximum recovery, and prevent complications or subsequent strokes, as well as to assist the reintegration of the person into the community (NSF 2010); however, it occurs in the challenging context of a sudden and disabling life event. This requires the needs of the person with stroke to be communicated and negotiated with a team of health professionals over a trajectory of several different healthcare settings. Managing such communication in healthcare is recognised to be a "formidable challenge" for all participants even when one language is spoken and shared (Candlin 2000, p. 10).

Communication during healthcare after stroke is known to be a problematic area of practice. An audit of the healthcare provided to 50 patients in an Australian stroke unit in 2005 found that health professionals complied least with clinical guidelines which involved communicating with and giving information to patients and their families, including processes such as discharge planning and family meetings (Luker, Grimmer-Somers 2009b). Poor communication with their health professionals has been repeatedly identified by English-speaking people with stroke and their carers to be a source of much dissatisfaction (Anderson & Marlett 2004, Smith, Forster &

Young 2009, White, Magin & Pollack 2009). Yet, without successful communication the needs and characteristics of the individual cannot be assessed or accommodated. Poor communication processes and their consequences are likely to disadvantage most the people who already experience communication difficulty, such as people with LEP.

When the patient does not share proficiency in the same language as their health professional the possibility for miscommunication can be increased (Gass & Varonis 1991). This is particularly relevant for older people with LEP in English-speaking countries such as Australia (AIHW 2010) as even those migrants who are bilingual may lose their English language ability as they get older (Schmid & Keijzer 2009), especially during health crises (Orb 2002). Healthcare after stroke in Australia is provided within a system that does not offer acute or rehabilitation services specific to a person's language or cultural group. For an older person with LEP, the many issues surrounding their healthcare after stroke need to be resolved in an unfamiliar language and in a bewildering arrangement of healthcare services. It is likely then that older people with LEP will experience difficulties during their healthcare after stroke but, as has been stated previously in this chapter, there is little research to inform how and when the difficulties may occur and how they can be addressed in healthcare practice. In seeking to address this gap, it is essential that the aims of the study and the question it is asking are consistent with the knowledge that is being sought. In the next section of this chapter, I explain the aims and research question of the study.

1.6 Aim of study and research question

Given the need for research to inform quality healthcare practice that meets the contemporary context of an increasingly diverse ageing population, the aim of the study was to develop a substantive theory that would fill a gap in the knowledge of healthcare after stroke and provide direction for practice. The purpose of the developed theory was to provide an understanding of how healthcare after stroke is experienced by older people with LEP from CALD backgrounds which was clinically relevant and could inform improvements in healthcare practice. The study also aimed to demonstrate an example of rigorous research practice using a qualitative approach that was inclusive of diversity in its sample and approach.

Consistent with the aims of the study, the research question was,

How do older people with limited English proficiency experience their healthcare after stroke?

1.7 Outline of thesis

In keeping with the aims of the study, the thesis is presented as an analytical story to be accessible to those who wish to gain knowledge for improving healthcare after stroke for older people with LEP, and as a useful resource for researchers who are planning to conduct in-depth research using interviews with a group of people who speak multiple languages. To this end, the thesis is structured as follows.

The review of the literature in chapter 2 is in two parts. The first part provides an overview of the topic area: a review of the literature about how older people with LEP experience their healthcare after stroke and a review of what is known about the experience of people with LEP in other areas of healthcare, and what is known about the broader healthcare experience after stroke. The second part of chapter 2 focuses on methodological issues. It provides a justification of the philosophical approach which guided the study and reports a methodological systematic review of the literature which was undertaken to inform the study's methods.

In chapter 3, I explain how the study design and its methods were used to realise a constructivist grounded theory approach to understanding the healthcare experience of a linguistically diverse group of people. The rigour and ethical considerations of the study are also discussed.

The findings of the study are presented in chapter 4 in four parts. An overview of the developed theory is followed by individual elaborations of each of the three processes which make up the theory and which together explain how healthcare after stroke is experienced by older people with LEP.

In chapter 5, the relevance of the theory to contemporary knowledge in the field of healthcare after stroke and for people with LEP is discussed. Based on this discussion, I make recommendations for improving healthcare after stroke for older people with LEP and for future research in this area. The limitations of the study are

acknowledged and its recommendations summarised at this point. The thesis ends with a conclusive statement for the study.

1.8 Chapter conclusion

The significance of my study lies in its potential to inform and improve healthcare after stroke for a group of older people who are part of Australia's ageing and increasingly diverse population. By aiming to understand the healthcare experience after stroke for older people with LEP, the study brings attention to a group of people who are likely to be disadvantaged in their healthcare but so far have rarely been given the attention in research or clinical guidelines that they deserve. The need to understand healthcare for older people with LEP is an issue that is not going to go away, as Australia, along with other mainly English speaking nations, will continue to be home to an ageing CALD population.

2 Review of the literature

The purpose of this chapter is to review both the literature relevant to the study's substantive topic, healthcare after stroke for older people with LEP, and the literature which informed the study. As explained in the previous chapter, I decided to use a qualitative methodology for my study. Specifically, a constructivist grounded theory approach was chosen and the review of the literature was conducted according to the same approach (Charmaz 2006). Constructivist grounded theory recognises the advice given by original grounded theorists Glaser and Strauss (1967) to delay the literature review until after the analysis is complete so that collected data is not seen through the lens of earlier ideas. However, it also acknowledges that the contemporary demands of research proposals and ethics committees require that researchers have reviewed literature in the field prior to starting their study (Charmaz 2006). Constructivist grounded theory researchers are advised then to let this early literature review "lie fallow" until the categories and their relationships in the study's analysis have been developed (Charmaz 2006, p.166). Therefore, while this literature review is placed at the front of my thesis, parts of the review were not completed until after data analysis had begun when I updated the review in response to ideas that were emerging from the analysis. Conducting the review in this way served to situate the study within a contemporary frame of reference and provide the foundation for a useful discussion of the developed theory's relevance and contributions to the field, as given in the final chapter of this thesis.

The chapter is presented in two parts. In the first part, I justify the importance of the study by reviewing what is currently known about the healthcare experience after stroke for older people with LEP. I establish that there are many gaps in research knowledge of the subject and identify issues which are pertinent to the study topic. In the second part of the chapter, I justify the philosophical approach that was chosen for the study and explain the practical approach which was used to conduct a

qualitative study with a group of linguistically diverse older people when language groups were not determined prior to the start of the study. I begin the first part of the literature review by arguing the importance of asking the research question, "How do older people with LEP experience their healthcare after stroke?"

2.1 A justification of the research question

There is little clarity in clinical guidelines for health professionals who are working with people who have LEP. As raised in the last chapter, the 2010 Australian guidelines for healthcare after stroke recommend that a person's cultural and linguistic diversity needs to be considered in relation to communication during rehabilitation after stroke (NSF 2010, p. 89), and the previous Australian guidelines suggested that the needs of people from CALD backgrounds may "require special attention and resources" (NSF 2005, p. 4). However, there was, and still is, no evidence-based guidelines available as to what these special needs or resources are. Yet the potential disadvantage in healthcare after stroke for people with LEP, and the challenges for health professionals who provide their care, has not gone away. And, as I have argued in chapter 1, is not going to be resolved without further research.

This section of the literature review begins with a focus on the healthcare experience after stroke for older people with LEP, where there is scant research and then broadens to review literature on other healthcare experiences for people with LEP, and to review the wider literature about how healthcare after stroke is experienced. Together, these areas of the literature review form a critical assessment of the current knowledge relating to the healthcare experience after stroke for older people with LEP and provide a foundation for discussion of the study's findings in chapter 5.

2.1.1 Healthcare after stroke for older people with LEP

While there is much research which examines the relationship between race or ethnicity and stroke, these studies focus on the epidemiology or biological and genetic relationships between stroke and ethnicity (Chenoweth, Gietzelt & Jeon 2002) and do not recognise the role of language in their investigations. Therefore, they offer limited contribution to the practice of healthcare for people with LEP. The research which relates to healthcare after stroke for older people with LEP forms a piecemeal picture

of disadvantage occurring for this group and there is little information which explains why it may be occurring or how to address it.

Awareness of stroke

The picture of the healthcare experience after stroke for older people with LEP begins with the available research about people's awareness of stroke and its healthcare requirements. A recent review of 39 studies investigating stroke awareness in several countries found that those who were older, had low education and were from a minority ethnic group consistently lacked knowledge of the risk factors and symptoms of stroke (Jones et al. 2010). People with LEP were excluded from most studies because telephone surveys were used to collect data and so language proficiency was not considered in the review's analyses.

However, two studies from the USA highlighted the crucial role of language proficiency in the prevention and management of stroke. DuBard, Garrett and Gizlice (2006) analysed data from the 'Behavioral Risk Factor Surveillance System' survey for 24,201 people from English-speaking backgrounds, 698 English-speaking people from a Hispanic background (ESH) and 528 people with LEP from a Hispanic background. When participants were asked whether "sudden numbness or weakness of face, arm, or leg, especially on one side" is a stroke symptom, only 58 percent of the people with LEP responded correctly, compared to 83 percent of the ESH group, and 89 percent and 92 percent of the English-speaking black and white groups respectively. The difference between the groups was statistically significant (X^2, $P<0.001$), even when the analysis was adjusted for confounders including demographic factors, access to healthcare, known risk factors and health behaviours.

In the second study, Fang et al. (2009) surveyed 183 people from CALD backgrounds who were taking Warfarin to prevent stroke and found that having LEP was independently associated with not knowing why the Warfarin had been prescribed (odds ratio = 2.4). Forty percent of participants inaccurately perceived what a stroke was, for example confusing it with a heart attack or simply not having any idea what it was. Those who had inaccurate responses were more likely to be older, have less than a college education, have poor health literacy and be LEP. Both these studies highlight that being an older person and not speaking the main language of the country and its healthcare system can be a risk factor for having a poor awareness of stroke and its

management despite them being within the high-risk age group for stroke occurrence. More detail in the picture of healthcare for older people with LEP is gained by reviewing the known outcomes of healthcare after stroke.

Outcomes of healthcare after stroke for older people with LEP

Information about the effectiveness of healthcare after stroke for older people with LEP is limited in its amount and clarity, but likely disadvantage is indicated by the findings of four studies. Having LEP has been associated with a significantly longer length of stay in hospital after stroke than for English proficient patients (an additional 3.6 days) in a large retrospective analysis of Canadian hospital data from the 1990s (John-Baptiste et al. 2004). The researchers suggested two reasons for this. First, that inpatient healthcare for people with LEP somehow differed to that for English-speaking people, although no specific processes could be identified from the data; or second, that there may have been less outpatient healthcare resources available to people with LEP and so more needed to be resolved in hospital before their discharge. However, the disadvantage was not replicated by a smaller and more recent Australian study which compared hospital and rehabilitation length of stay after stroke between 58 older people from non-English speaking backgrounds (NESBs) and 128 people from English-speaking backgrounds (Shen et al. 2005). The difference in findings between the two studies may be influenced by their different geographic and temporal contexts, and the Australian study did not specifically consider participants' proficiency in English, although a majority of the participants from NESBs (67 percent) used an interpreter to complete the study's questionnaire. An absence of any further investigations of this healthcare outcome leaves the certainty and mechanism of the disadvantage unclear.

The Australian study did report a strong trend for people from NESBs to have poorer functional ability when discharged from inpatient healthcare after stroke than the people from English-speaking backgrounds (NESB FIM 74.8±40.9, ESB FIM 87.3±38.1, *t* test P=0.053) (Shen et al. 2005). But, again, the picture is complicated. An American study of people admitted to a rehabilitation facility with stroke between 1995 and 2001 (Bhandari et al. 2005) did not find any difference in functional outcomes at discharge for people from CALD backgrounds. However, they did report the functional ability of Asian American stroke survivors was significantly poorer than for Hispanic, black or white Americans when reassessed three months after discharge

(16% less improvement in FIM than white group, *P*<.005). The researchers did not identify any reasons for the difference in functional recovery and, like the Australian study, proficiency in English was not considered separately in the analysis. However, a majority of people in the Asian American group (57 percent) were reported to have no or partial English language skills, compared with only a minority of the Hispanic group (36.4 percent) suggesting that language ability may have influenced functional outcomes.

The occurrence of disparity in functional ability after stroke for people with LEP is supported by my analysis of healthcare outcomes for people at high risk of falling who returned to live in the community after stroke (Fryer et al. 2012a) (Appendix A). I found that participants with LEP from CALD backgrounds were going home frailer after stroke and participating in less rehabilitative exercise following discharge from inpatient healthcare. This suggests that disparities may exist in access to, or the quality of, inpatient or community rehabilitation healthcare services after stroke for people with LEP from CALD backgrounds; but what these disparities are or why they may exist are questions that cannot be answered from this data. More information about what is happening during healthcare can be gained by listening to the healthcare experiences of patients (Plack 2005, Howell et al. 2007, Kersten et al. 2010) and so research that has asked older people with LEP about their healthcare experience after stroke is now reviewed.

The experience of healthcare after stroke for older people with LEP

Only two studies have attempted to understand healthcare after stroke for older people with LEP by asking people about their experience. Both studies have reported dissatisfaction with communication and information. A study in the UK by Perry et al. (1999) interviewed 15 people who spoke Hindi or Gujarati and 13 English-speaking people about their perceptions of healthcare in the community after stroke. The ages of participants were not given but nearly half the sample was aged over 75 years. Participants from all three language groups perceived they were given inadequate information about recovery from stroke and the availability of community services, and they reported having difficulty identifying the health professionals responsible for their care. Unmet emotional and psychological needs were also reported by all three language groups but it was particularly the participants who did not use English for their interview who reported feelings of being socially isolated and depressed.

A more recent Australian study has also reported the lack of information from health professionals as an important issue for both people with LEP and English-speaking stroke survivors. Chenoweth et al. (2003) used a closed-ended survey to identify the healthcare expectations and needs after stroke for 80 participants from CALD backgrounds who spoke a language other than English for the study (Greek, Chinese, Italian and Hungarian) and 20 participants from English-speaking backgrounds. The ages of participants were not given. Both groups reported receiving very little information about stroke, its healthcare management, expected recovery or stroke prevention. But while the English-speaking group expressed strong negative feelings about the lack of information they were provided and the disinterest of staff in meeting their needs, the participants with LEP were satisfied with their healthcare experience and did not share the other group's expectation for more healthcare services that what they had received. Unlike Perry's (1999) finding that stroke survivors had unmet emotional needs, many of the participants with LEP in Chenoweth et al.'s (2003) study reported that they had no need for social support from community services such as assistance with transport or meeting with other stroke survivors, perhaps for the same reason suggested by Fryer et al. (2012a) that family may fill these gaps in services for older people with LEP.

It is notable that both studies situated the experience of people with LEP in a context of dissatisfaction and difficulties with healthcare after stroke also being experienced by English-speaking people. This suggests that healthcare after stroke is a complex and problematic area of healthcare practice even without the extra complexity of the patient and health professional not sharing a preferred language. What is known about the wider experience of stroke healthcare, from people who speak the same main language that is spoken during their healthcare, is reviewed in section 2.1.3.

For older people with LEP, it is proposed from this review that they can lack information, feel isolated and have unmet emotion needs during their healthcare after stroke yet can still express satisfaction with their healthcare and not seek further services. However, the methodological approaches taken in the studies by Perry (1999) (content analysis) and Chenoweth et al. (2003) (survey) limit the information they can provide as to why these healthcare outcomes after stroke can exist for older people with LEP in this context of problematic practice, or what changes in healthcare are needed to address them. Therefore, these are still unanswered questions which

need to be addressed with a specific focus on this group of stroke survivors and a methodological approach that allows the healthcare experience after stroke for older people with LEP to be understood.

Given the limited information about the experience of healthcare after stroke for older people with LEP, research from the broader context of healthcare for people with LEP is now reviewed. This section of the review will establish that healthcare is consistently problematic for these people and will highlight the issues that are likely to be relevant to the focus of my study, that is, how older people with LEP experience their healthcare after stroke.

2.1.2 Other healthcare experiences for people with LEP

Having LEP has been shown to adversely affect the healthcare received by patients in many areas of healthcare practice. Importantly, there is research which has started to explore why that may be. As the trajectory of healthcare after stroke encompasses acute hospital, inpatient rehabilitation and community settings, and involves interactions with a multidisciplinary mix of health professionals, studies which involve these different settings and health professionals may provide insights to issues with potential relevance to my study focusing on stroke.

Disparities in outcomes of healthcare for people with LEP

There is a pattern of poorer healthcare outcomes across clinical areas for people with LEP compared to those who speak English proficiently. Having LEP has been associated with longer lengths of stay in hospital (John-Baptiste et al. 2004), less access to healthcare in the community (Ponce, Hays & Cunningham 2006, DuBard & Gizlice 2008, Shi, Lebrun & Tsai 2009, Kim et al. 2011), less diagnostic tests ordered in the Emergency Department with less explanation and follow up appointments given (Ramirez, Engel & Tang 2008), fewer healthcare services used for mental health disorders (Bauer, Chen & Alegría 2010), poor symptom management in palliative and breast cancer care (Chan & Woodruff 1999, Yi, Swartz & Reyes-Gibby 2011), less preventative healthcare (Cheng, Chen & Cunningham 2007, DuBard & Gizlice 2008), less health information during outpatient clinic visits (Ngo-Metzger et al. 2007), increased risk of intubation for asthmatics (LeSon & Gershwin 1996), differences in prescribed medications and lower rates of optimal pain medication (Bowen 2001). It is perhaps then not surprising that people with LEP have consistently been found to

report being less satisfied with the healthcare they receive than English-speaking people (Levin 2006, Harmsen et al. 2008, Ramirez, Engel & Tang 2008, Ngo-Metzger, Sorkin & Phillips 2009, Pitkin Derose et al. 2009). A study that did not report a difference in satisfaction with healthcare was the study of Australian stroke survivors by Chenoweth et al. (2003) referred to in the previous section. Perhaps the difference in reported satisfaction is related to differences in the contexts of the studies, such as the age of the participants with LEP as older people tend to be more satisfied with their healthcare (Campbell, Ramsay & Green 2001, Johansson, Oléni & Fridlund 2002) or differences in healthcare context or study methods between the Australian study and the other studies from the USA, Netherlands and South Africa.

The association between having LEP and being disadvantaged in healthcare outcomes is not just limited to the patient's own language ability. Having a carer who has LEP can also negatively impact a person's healthcare. During family conferences in an intensive care unit, families with members with LEP were observed to be at increased risk of receiving less information about their loved one's critical illness for decision-making as well as less emotional support from the health professionals present (Thornton et al. 2009).

Australian research and policy attention to the healthcare experience of people with LEP is increasingly being positioned within a framework of patient safety (Johnstone & Kanitsaki 2006, Garrett et al. 2008c, Garrett 2009, Johnstone & Kanitsaki 2009). Recent international studies have found that people who have difficulty communicating, either due to LEP or a disability, are three times more likely to experience a preventable adverse event in hospital than those without a communication problem (Bartlett et al. 2008), and people with LEP are more likely to experience an adverse event that causes them serious harm (Cohen et al. 2005, Divi et al. 2007). Being older, irrespective of language spoken, has also been shown to increase the likelihood of having a preventable adverse event (Thomas & Brennan 2000). Adverse events involving people with LEP are often related to medications (Wilson et al. 2005, Divi et al. 2007, Bartlett et al. 2008), poor clinical management such as inappropriate treatment or delay (Bartlett et al. 2008) or miscommunication between patient and health professional (Wilson et al. 2005, Divi et al. 2007).

These studies from healthcare contexts other than after stroke establish that people with LEP are consistently disadvantaged during healthcare when English is the main language spoken. It is a problem that has been identified in community healthcare as well as inpatient settings. Beyond the specific findings of healthcare outcomes, there remains the question of how the disadvantage occurs.

How people with LEP experience their healthcare

Investigations into the healthcare experience of people with LEP have largely focused on identifying 'language barriers' in the interpersonal context between patient and health professional or in a person's ability to access healthcare. While there is substantial research evidence that communication difficulties play an integral role in causing healthcare disparity for people with LEP, it is not the full story. A more complex understanding of healthcare for people with LEP is emerging which recognises the influence of other social, cultural, economic and geographical factors on healthcare quality and accessibility. This understanding is increasingly being adopted in recommendations for improving healthcare for people with LEP (Ngo-Metzger 2003, Johnstone & Kanitsaki 2006, Garrett et al. 2008a, Priebe et al. 2011).

To understand how people with LEP experience their healthcare, it is useful to understand what they value in their healthcare. Garrett et al. (2008a) reported that 49 older people with LEP and ten carers from several different CALD background primarily appreciated being engaged with positively and involved in their healthcare, receiving information and compassionate, kind and respectful treatment from health professionals, and the involvement of their family. Butow et al. (2010) reported similar views expressed by patients with cancer from three language groups, with the addition of some participants wishing that health professionals would recognise and explore health and illness ideas that lay outside the dominant biomedical paradigm of Western medicine. The upshot of this research is that there is unfortunately a mismatch between what people with LEP are reported to value in their healthcare and what they are reported to experience in their healthcare.

Communication difficulties are consistently identified as having a negative impact on the healthcare experience of people with LEP. People with LEP can have difficulty understanding health professionals, making themselves understood and asking questions (MacKinnon 1998, Gerrish 2001, Wilson et al. 2005, Levin 2006, Garrett et

al. 2008a), thereby making it problematic to establish rapport and trust with health professionals (Butow et al. 2010) and to engage in collaborative treatment planning (Wardin 1996). The risk of miscommunication between patients and health professionals is heightened when the patient has LEP (Gass & Varonis 1991). All 52 of the consultations between London general practitioners and patients with LEP that were examined by Moss and Roberts (2005) contained major and often extended misunderstandings, compared with only 19 of the 180 recorded consultations with English-speakers. The identified misunderstandings were attributed to issues of language and self-presentation rather than culturally-specific health beliefs.

Miscommunication and misunderstanding does not just affect interpersonal interactions within the healthcare experience. People with LEP can have difficulty understanding healthcare documents such as medication prescriptions labels (Mitka 2007, Masland, Kang & Ma 2011), or in navigating the healthcare system (Butow et al. 2010). A lack of awareness of available services by people with LEP is a threat to them having equitable healthcare access (Dolman et al. 1996, Orb 2002, Chenoweth et al. 2003).

Access to healthcare can also be disadvantaged by geographic or economic issues for people with LEP. The need to access a language concordant health professional, or one who will use a professional interpreter, can mean that people with LEP must travel outside of their local area requiring access to transport they may not be familiar with or cannot afford (Asanin & Wilson 2008). People with LEP may avoid healthcare situations, or the transport needed to get to them, to bypass language-discordant situations (MacKinnon 1998, Asanin & Wilson 2008). In some countries where the main language is English, such as the USA and Canada, the cost of primary healthcare may restrict its accessibility for people with LEP (Asanin & Wilson 2008, DuBard & Gizlice 2008, Pitkin Derose et al. 2009). However, this factor is not prominent in Australian healthcare research. One factor in several studies is the negative influence that a difference in cultural background between the person with LEP and the health professional can have on the person's healthcare experience.

Cultural isolation during healthcare can be experienced by people with LEP independent of their English language proficiency. They may have different beliefs concerning health and healthcare to their treating health professionals (Ngo-Metzger

2003, Suurmond & Seeleman 2006, Asanin & Wilson 2008, Butow et al. 2010) or feel that they are treated differently because of their CALD background (Butow et al. 2010). Prejudiced attitudes of health professionals towards patients from CALD backgrounds have been highlighted as a potential cause of adverse events for this patient group (Lee, Sullivan & Lansbury 2006, Sze-Mun Lee, Sullivan & Lansbury 2006, Johnstone & Kanitsaki 2008, Suurmond et al. 2010). People from CALD backgrounds, especially those with LEP, are less likely to receive an empathetic response from doctors, establish rapport with doctors, receive sufficient information from them or be encouraged to participate in medical decision making (Ferguson & Candib 2002). Indeed, doctors at a primary care clinic were more likely to ignore comments made by people with LEP despite this patient group making less comments during an interaction (Rivadeneyra et al. 2000). Health professionals may hold back information which they believe a person with LEP will not understand (Suurmond & Seeleman 2006), and a health professional who is frustrated or irritated because of language barriers can give non-verbal cues such as turning away from the patient or having an irritated tone of voice which can communicate to the patient a lack of interest in them and their problems (Ngo-Metzger, Sorkin & Phillips 2009).

Despite an increased likelihood of a preventable adverse event occurring during healthcare for people with LEP, they can be unable or unwilling to make a complaint about an event and so official complaint data may underrepresent this group of people (Taylor, Wolfe & Cameron 2004). Serious problems with healthcare may not be reported due to a mix of factors including feelings of powerlessness related to their difficulty with communicating, a positive comparison of healthcare in the new country compared with the old, patriotism for the new country, cultural norms that proscribe acceptance, politeness or social desirability, self-denigration for not having learnt English, and a fear of reprisals if they spoke up to complain (Garrett et al. 2008d). So if problems exist in an area of healthcare for older people with LEP, the information provided by official complaint data cannot be solely relied on to identify them.

The use of strategies by the patient or health professional to address the language discordance between them is an important influence on the healthcare experience for people with LEP. Two strategies which have received significant attention are the use of interpreters and bilingual health professionals.

Interpreters

Working with professional interpreters is a fundamental recommendation to reduce healthcare disadvantage for people with LEP (Brach & Fraser 2000, Karliner et al. 2007, Priebe et al. 2011). Professional interpreters are bilingual individuals who are trained for their interpreting role and paid by the healthcare provider to facilitate information between patients and health professionals (Dysart-Gale 2005, Karliner et al. 2007). Their use in primary healthcare or acute hospital settings has been associated with an increased utilisation of healthcare services, improved patient satisfaction with their healthcare and improved clinical outcomes for people with LEP compared to when informal or no interpreters are used (Jacobs et al. 2001, Flores 2005, Karliner et al. 2007, Ngo-Metzger et al. 2007, Bagchi et al. 2011). Conversely, when people with LEP need but do not get an interpreter, the quality of their healthcare is compromised and they frequently wish the health professional had explained things better (Flores 2005). However, the subject has not been investigated within an Australian healthcare context and no study has specifically explored the use of professional interpreters in a neurological or rehabilitation healthcare setting.

Cost concerns, practical organisational difficulties and a lack of confidence in the interpreter's competence for the situation are reported by health professionals as barriers to them working with professional interpreters (Burbano O'Leary, Federico & Hampers 2003, Lee, Lansbury & Sullivan 2005, Johnstone & Kanitsaki 2008, Bischoff & Hudelson 2010, Meeuwesen et al. 2010). Despite research evidence of the benefits of working with professional interpreters for improving the quality of healthcare for people with LEP, interpreters are underused in healthcare settings both internationally and in Australia (Gerrish 2001, Burbano O'Leary, Federico & Hampers 2003, Sze-Mun Lee, Sullivan & Lansbury 2006, Taberski 2006, Kuo et al. 2007, Garrett et al. 2008b, Diamond & Jacobs 2010, Kale & Syed 2010, Gray et al. 2011, Phillips & Travaglia 2011, Schenker et al. 201,). The idea of not working with professional interpreters can become normalised in health professionals' practice (Gerrish et al. 2004, Diamond et al. 2009) and informal interpreters may be relied on (Tschurtz et al. 2011), perhaps with indirect pressure from healthcare administration to reduce costs (Wardin 1996, Bischoff & Hudelson 2010). Or health professionals may fail to identify when an interpreter is needed (Bonacruz Kazzi & Cooper 2003, Standiford et al. 2009). Barriers to working professional interpreters have been

observed to be mitigated if health professionals are trained in the use of interpreters (Gerrish et al. 2004, Karliner, Pérez-Stable & Gildengorin 2004, Standiford et al. 2009) or have established working relationships with interpreters and interpreter agencies (Hadziabdic et al. 2010).

The underuse of professional interpreters in healthcare cannot be solely attributed to a lack of action by health professionals. People with LEP often make up their own minds about their language proficiency for the healthcare situation (Edwards, Temple & Alexander 2005) and may not wish to use an interpreter despite having difficulty comprehending medical information (Bonacruz Kazzi & Cooper 2003). They can lack knowledge of the role of professional interpreters or how to access them during healthcare (MacKinnon 1998, Edwards, Temple & Alexander 2005), or may prefer to use an informal interpreter. An Australian study of interpreter use in emergency and inpatient wards found nearly half of the 205 participants with LEP preferred to have a family or friend interpret for them (Garrett et al. 2008b).

The patient's perspective on using an interpreter has received little attention. The few small studies suggest that people with LEP want to be able to trust their interpreter, and that they evaluate an interpreter's trustworthiness not just based on language skill but also by considering the interpreter's character, attitude and ability to guide them through their healthcare (Edwards, Temple & Alexander 2005, Hadziabdic et al. 2009, Butow et al. 2010). These expectations of the interpreter role contrast with the prevalent ideology for interpreters to act as neutral conduits of information (Hennink 2008, Hsieh 2008, Hadziabdic et al. 2010). Sometimes professional interpreters are perceived to meet patient expectations (Hadziabdic et al. 2009, Butow et al. 2010) but for others it may be a family member or friend, with a history of shared understandings and obligations, who is trusted to act as interpreter (Edwards, Temple & Alexander 2005, Greenhalgh, Robb & Scambler 2006, Butow et al. 2010). Using family and friends as informal interpreters is also perceived by people with LEP to provide practical advantages of ready availability, no cost and help with everyday matters (Edwards, Temple & Alexander 2005, Hadziabdic et al. 2009).

Patient preference for an informal interpreter contrasts with the predominantly negative attitude in the literature towards their use. Informal interpreters are reported to misinterpret or omit up to half of all doctors' questions, be more likely to

commit errors with potential clinical consequences, have a higher risk of not mentioning medication side effects (Flores 2005) and hinder communication between the patient and health professional (Meeuwesen et al. 2010, Priebe et al. 2011). Although people with LEP do recognise some drawbacks with using informal interpreters during healthcare, such as lack of medical knowledge and concerns about confidentiality, they may still prioritise the trusted relationship they share (Edwards, Temple & Alexander 2005). More research is needed to evaluate the use and possible training of informal interpreters from the social networks of patients with LEP, taking into account the "range of different viewpoints and interests which transcend the mere process of translation" (Meeuwesen et al. 2010, p. 203). Importantly in healthcare practice, patient preference for interpreter use needs to be balanced with patient safety (Garrett et al. 2008b) and considered alongside the clinical situation, degree of language gap, and available resources (Schenker et al. 2008).

The presence of an interpreter does not guarantee that mutual understanding will be attained between the patient and health professional. While interpreters are recognised as important to achieving quality healthcare for people with LEP, they also increase the complexity of an already complex communicative situation (Greenhalgh, Robb & Scambler 2006) with consequences for the interpersonal relationship between participants in the interaction (Rivadeneyra et al. 2000). There also can be problems with different expectations of the interpreter role and inaccurate translations (Butow et al. 2010). However, even an accurate and literal translation of words will not prevent misunderstandings due to differences in health beliefs and practices (Angelelli 2004, Hansen 2007), poor health literacy (Sudore et al. 2009, Sorlie & Lopez 2011), low education (Brugge et al. 2009) or poor communicative practices. As noted in Schenker et al.'s (2011) study of interpreter use in two USA hospitals, interpreters are not needed if health professionals barely speak to their patients.

Bilingual health professionals

Having access to a health professional who speaks their preferred language has been demonstrated to be just as effective as health professionals working with professional interpreters for achieving quality healthcare for people with LEP (Ferguson & Candib 2002, Flores 2005, Wilson et al. 2005, Crossman et al. 2010, Schenker et al. 2010), although what is known from research is limited to the experience of patients in the

USA and patient interactions with doctors or nurses. Bilingual health professionals can be preferred by people with LEP to using interpreters (Greenhalgh, Robb & Scambler 2006). However, the use of bilingual health professionals can unfairly restrict patient choice in who provides their healthcare (MacKinnon 1998). There is little research available which addresses the perspectives and preferences of the patient about using bilingual health professionals.

When health professionals only have limited second language skills, enough perhaps to establish rapport, they may not have sufficient ability to ensure accuracy or to communicate complex information. Yet health professionals often do rely on limited language skills to communicate with patients with LEP (Sze-Mun Lee, Sullivan & Lansbury 2006, Diamond et al. 2009, Diamond & Reuland 2009), even if they recognise them to be inadequate (Burbano O'Leary, Federico & Hampers 2003). Although it is not certain how aware health professionals are of their language ability (Diamond & Reuland 2009).

Bilingual health professionals, and other bilingual staff, can also be used as informal interpreters on an ad hoc basis for other health professionals. However, they are rarely assessed for their competence in this role (Tschurtz et al. 2011) and a lack of training for the interpreter role can negatively affect the communication between patient and health professional (Sze-Mun Lee, Sullivan & Lansbury 2006, Hadziabdic et al. 2009).

In mainstream healthcare services such as those provided after stroke, especially in communities where multiple languages are spoken, bilingual health professionals are only feasible for a few of the many languages spoken by people who present for healthcare (Gerrish et al. 2004, Wilson et al. 2005, Ngo-Metzger, Sorkin & Phillips 2009). Other strategies, such as access to professional interpreters, will always be needed for situations when the preferred language of people with LEP is not shared by the health professional (Wilson et al. 2005). And it is has been shown that bilingual health professionals do not completely mitigate problems which people with LEP may have in comprehending healthcare situations (Wilson et al. 2005).

As has been already mentioned, there are more factors than language which influence successful healthcare communication and the successful navigation of a complex healthcare system and its interactions. To highlight issues in stroke healthcare which

may have importance in the experience for patients with LEP, the review now addresses what is known from the broader literature about the experience of healthcare after stroke.

2.1.3 Healthcare after stroke

Healthcare after stroke is a complex phenomenon. It involves a period spanning one or more healthcare settings when a person is undergoing profound personal changes. The most effective healthcare after stroke to promote survival, regain independence and return home, is provided in organised stroke units by a multidisciplinary team of allied health professionals (physiotherapist, occupational therapist, speech pathologist, dietitian, social worker, and psychologist), a stroke physician, and specialist nursing staff (Stroke Unit Trialists' Collaboration 2007). But the quality of healthcare is more than can be measured by the achievement of six month survival or discharge destination, and the healthcare needs of people with stroke persist past their discharge from an organised stroke unit (Vincent et al. 2007, Divani et al. 2011). Insights from research with people who proficiently speak the same main language that is spoken during their healthcare, that is the main language for healthcare signage, documents and interactions with health professionals, provides a denser and more complete picture of issues of importance for people in their healthcare after stroke than is provided by the literature on healthcare after stroke for people with LEP. It is likely that many of the same issues will be present for both groups after stroke, as tentatively suggested in the studies by Perry (Perry et al. 1999) and Chenoweth (2003), but this is not yet known.

Awareness of stroke

Rapid access to emergency healthcare is imperative to achieve optimal outcomes after stroke (Kwan, Hand & Sandercock 2004) but people often fail to recognise their stroke symptoms or they delay seeking emergency healthcare (Kwan, Hand & Sandercock 2004, Sprigg et al. 2009, White, Magin & Pollack 2009, Teuschl & Brainin 2010). A stroke has been perceived as hitting people “without any warning” to prepare (Bendz 2003, p. 217). Generally, people are unaware of stroke symptoms and what to do about them, even when they are at high-risk of stroke, such as people with diabetes (Jones et al. 2010, Spark et al. 2011). The action that people take after stroke is more dependent on the severity of their symptoms (Kitko, Hupcey 2008, Moloczij

et al. 2008, Teuschl & Brainin 2010) and personal decision-making (Moloczij et al. 2008) rather than their knowledge of stroke symptoms and stroke management. The presence and influence of another person also has been recognised to play an important role in getting people to seek emergency healthcare (Zerwic, Young Hwang & Tucco 2007, Moloczij et al. 2008, Teuschl & Brainin 2010). Older people tend to be less aware of what to do after stroke and more likely to contact their family or local doctor rather than seek emergency healthcare (Jones et al. 2010). And so it appears that it is problematic even for people who proficiently speak the language that is spoken during their healthcare to access healthcare after stroke. The review now turns to people's experiences once they have entered healthcare.

How people experience their healthcare after stroke

Healthcare after stroke aims to promote maximum recovery and prevent complications or subsequent strokes. It also aims to help the person with stroke to reintegrate into the community (NSF 2007a) although this is a dimension of recovery which patients often perceive to be poorly addressed by their healthcare (Bendz 2000, Ellis-Hill & Horn 2000, Cott 2004, Morris, Payne & Lambert 2007, Vincent et al. 2007, White, Magin & Pollack 2009). Issues of primary importance in the experience of healthcare after stroke, from research with people who speak the same language as their healthcare, have been identified under the themes of 'information', 'staff attitudes' 'availability of care' and 'considering the whole person in context' (Morris, Payne & Lambert 2007). These themes provide a starting point for the review of what is currently known about how healthcare after stroke is experienced.

Information

Many people with stroke report problems with being adequately informed about their condition and its management. A lack of information about stroke can lead to people feeling uncertain about their healthcare, fearful of future stroke, and feeling stigmatised by their stroke (White, Magin & Pollack 2009), limited in their ability to participate in their healthcare (Peoples, Satink & Steultjens 2011) and having unrealistic expectations of their recovery (Wiles et al. 1998, Wiles et al. 2002). Studies have consistently reported that people are dissatisfied with the information they receive after stroke and that this is a long-term unmet need for many stroke survivors (Hanger et al. 1998, Wiles et al. 1998, Perry et al. 1999, Rodgers, Bond & Curless 2001, Chenoweth et al. 2003, Smith, Forster & Young 2009, White, Magin & Pollack

2009, McKevitt et al. 2011). This is despite a Cochrane systematic review, first published in 2001, concluding that giving information to patients about their stroke, its treatment and available services improves patient and carer knowledge of stroke, improves patient satisfaction with the information they have received during healthcare, and reduces patient depression scores (Smith, Forster & Young 2009).

Perceived barriers to people accessing information during healthcare after stroke have been identified in an Australian study (Eames et al. 2010) as a combination of poor availability of information, barriers in the hospital environment such as the busyness of staff, as well as patient and carer factors including poor recall of information that they had been given. The study also identified that patients with stroke were unsure whose responsibility it was to access the information they needed and that the way in which information was presented to them was important for understanding. It may not be possible to provide the individualised information on prognosis and recovery that people want during healthcare due to the difficulty of making detailed predictions of recovery after stroke (Wiles et al. 1998), but the process for effectively providing information that is available, such as general prognosis of recovery and resources available in the community, could still be improved. There is no clear strategy for how to do this, especially for those patients with communication difficulties who are routinely excluded from investigative studies. However, it does appear from the research evidence so far that actively involving patients and their families in a strategy which allows time for follow up and clarification of information is likely to be most effective (Smith, Forster & Young 2009).

In contrast to the findings above, the majority of 188 Swedish-speaking people surveyed after an acute stroke in Sweden reported receiving adequate information from health professionals (Almborg et al. 2009). The response is perhaps indicative of a Swedish patient cohort or it may be influenced by specific healthcare processes of which the details were not provided. However, the study also found that the satisfactory provision of information did not always translate to the Swedish patients being given the opportunity to participate in discussions concerning their healthcare treatments, goal setting or discharge plans. The authors suggest that information-giving may be a one-way mode of communication by health professionals which still leaves patients uninvolved in important healthcare decisions.

Anderson and Marlett (2004) have recognised there is a communication shortfall in healthcare provided to people after a stroke, and they argue there is a need to improve how health professionals communicate with patients and their families beyond simply giving information. They suggest that effective communication may improve clinical outcomes by helping people to rebuild a positive identity after their stroke. They advocate for health professionals to share the control of healthcare with stroke patients and their families, and help them to find their own solutions to problems. Further research is needed to understand how effective communication can be achieved between the patient and health professional after stroke.

Staff attitudes

Health professionals' attitudes are very important to a person's experience of stroke healthcare. Displays of kindness, respect and individualised attention by health professionals can help the patient with stroke to feel cared for and to maintain their dignity during healthcare (Pound et al. 1995, Peoples, Satink & Steultjens 2011). Patients often trust in health professionals as experts in stroke (Bendz 2000) and so are more positive about their healthcare experience when they feel that they have been guided by them (Morris, Payne & Lambert 2007, Ellis-Hill et al. 2009). However, this can lead to patients taking a passive role in their healthcare after stroke (Olofsson, Andersson & Carlberg 2005); a position that some patients are content with (Peoples, Satink & Steultjens 2011) but which can result in patients feeling disconnected with their healthcare (Röding et al. 2003, Olofsson, Andersson & Carlberg 2005).

Availability of care

Health professionals are frequently perceived to be overworked and too busy during inpatient healthcare to be able to provide all that patients perceive they need after stroke, especially in regards to providing information (Olofsson, Andersson & Carlberg 2005, Morris, Payne & Lambert 2007). The different settings and transitions between settings in healthcare can also be important influences on the experience of people after stroke. Home-based rehabilitation is increasingly being advocated as a healthcare option with improved outcomes in function and perceived health for the person with stroke and improved carer satisfaction compared with rehabilitation in other settings (Hillier, Inglis-Jassiem 2010, Ytterberg et al. 2010). But for those patients who don't have organised home-based rehabilitation, the transition from

inpatient healthcare to home is often identified as a difficult period filled with practical problems as well as psychosocial adjustments by the person with stroke and their carer/s (Bendz 2000, Sabari, Meisler & Silver 2000, Allen et al. 2002, Cott 2004, Cott, Wiles & Devitt 2007, NSF 2007b, Pringle, Hendry & McLafferty 2008). People can feel unprepared for their discharge from inpatient care after stroke and abandoned with little knowledge of, or access to, community services (Perry et al. 1999, Chenoweth et al. 2003, NSF 2007b, Ellis-Hill et al. 2009). This is distressing for some people with stroke and their families as they are overwhelmed by attempts to navigate community healthcare, while others have a level of resilience and a capacity to independently manage the problematic situation (Luker & Grimmer-Somers 2009b).

Considering the whole person in context

A mismatch between the priorities for recovery held by people with stroke and those of health professionals has been consistently shown (Bendz 2000, Bendz 2003, McKevitt et al. 2004, Morris, Payne & Lambert 2007, Vincent et al. 2007, White, Magin & Pollack 2009). The importance of physical recovery is recognised by both groups but while health professionals tend to narrowly focus on improving functional capacities in everyday life, the person with stroke will have broader psychosocial concerns about regaining the community and social roles they held before their stroke and a need for stimulation, variety and family contact in their lives (Bendz 2003, Morris, Payne & Lambert 2007, Peoples, Satink & Steultjens 2011). People appreciate healthcare after stroke that is tailored to their individual needs (Wiles et al. 1998, Sabari, Meisler & Silver 2000, Peoples, Satink & Steultjens 2011). It is suggested that healthcare can be made more meaningful and effective for the patient and their situation by using shared goal-setting and decision-making between patient and health professional (Bendz 2003, Brock et al. 2008, Young, Manmathan & Ward 2008, Ellis-Hill et al. 2009). However, these strategies can be challenging to achieve in practice after stroke because: people with stroke have difficulty understanding the terminology of goal setting and defining goals, especially in the early stages after their stroke; there are often discrepancies between the health professional's and the person with stroke's goals; and health professionals perceive there is limited time available for them to do goal-setting (Bendz 2000, Parry 2004, Wohlin Wottrich et al.

2004, Leach et al. 2010, Weyer, Ballinger & Playford 2010, Laver et al. 2011, Rosewilliam, Roskell & Pandyan 2011).

In conclusion, given the evidence presented for consistent disadvantage in healthcare for people with LEP and the complexity of issues that affect other people after stroke, it is likely that an older person with LEP will be disadvantaged in their healthcare after stroke. The sparse research which is available specific to this topic suggests as much. But there remains the question of how the disadvantage occurs during healthcare after stroke when the person's ability to speak English is limited? There is, as yet, no clear answer available from the research to inform improvements in health care practice. It is the aim of this study to provide one by developing a substantive theory to answer the question of how older people with LEP experience their healthcare after stroke. In the next part of the chapter, I justify the practical and philosophical approaches that were taken for the study.

2.2 A justification of the approach

The paucity of research exploring the healthcare experience of people with LEP from different CALD backgrounds poses not only a gap in clinical knowledge but also provided little precedence for how to conduct a rigorous study to address the gap. An aim of my study was to inform healthcare practice, and so it was important that the knowledge developed by the study was relevant to the context of healthcare after stroke. Acute and rehabilitation healthcare after stroke are not streamed according to language group and so I did not confine my study sample to specific language groups but chose to include people with LEP irrespective of which language they preferred to speak. In the next part of the thesis, I present a systematic review of studies using in-depth interviews with older people from multiple language groups which informed the study's methods. The philosophical approach that was taken for the study, and why I determined the approach to be a good fit to the methodological requirements of the study, is explained in the final chapter section.

2.2.1 Conducting qualitative research in a multilingual context: a systematic review of the literature

Including people from multiple language groups in a study, when the languages spoken are not determined before starting the research, is a unique situation in qualitative cross-language studies and clearly different from the traditional anthropological ethnography of one cultural group with established discrete languages. The cultural and linguistic diversity of the participant sample restricts a researcher's ability to immerse in a single culture and its language(s) or to have sole reliance on the language skills of research team members. Engaging people from multiple language groups in qualitative research has been successfully demonstrated in healthcare using focus group methodology (Garrett et al. 2008a), yet there is little guidance from the research literature as to how to conduct rigorous research using in-depth interviews in this cross-language situation.

Language is a fundamental tool for in-depth interviews; representing both the data and the communication process by which data is generated between the researcher and participant (Hennink 2008). Language carries particular meanings that incorporate a person's values and beliefs (Temple, Edwards 2002) and is a means for bridging the interpretive gap between participant and researcher to gain a better understanding of the phenomenon under study (Sarangi 2007). When the researcher and participant do not share a preferred language there is extra complexity and challenge in the research process to ensure the quality and trustworthiness of interview data and its interpretation. As Patton (2002, p. 392) has stated, "It is tricky enough to be sure what a person means when using a common language, but words can take on a very different meaning in other cultures." This does not mean it should not be, or cannot be, undertaken. However, it does mean that researchers need to be critically aware of related methodological issues (Mabel 2006).

Methodological rigour is the means by which researchers show integrity and competence in their research (Tobin & Begley 2004) and so enhance the usability of the research findings for readers (Sandelowski 2004). Rigour incorporates Lincoln and Guba's (1985) idea of 'trustworthiness' and the constructs of credibility, transferability, dependability and confirmability; where methodological rigour is not simply a judgement at the end of the research but is attended to throughout the research process (Morse et al. 2002). Hennink (2008, p. 22) has suggested that to

improve methodological rigour in cross-cultural (and cross-language) qualitative research, the researcher needs to attend to language and communication issues throughout the entire research process.

In the absence of clear guidelines for rigorous research in the cross-language context of my study, I conducted a systematic review of published healthcare studies using in-depth interviews with older people from multiple language groups, when languages were not determined prior to recruitment, to inform the study methods. The systematic review has been published in the Journal of Advanced Nursing (Fryer et al. 2012b) and a copy of the article is included in Appendix E. The aims of the systematic review were to:

1. Appraise the quality of study methods
2. Determine the strategies used to ensure methodological rigour.

Review design

A systematic review of study methods, similar to a meta-method study as explained by Paterson, Canam and Jillings (2001), was used. Each study was individually appraised for quality and then an overall comparison and contrast of methods was completed. Paterson and colleagues (2001, p. 72) recommend the meta-method design to "reflect critically on how qualitative research methods have been applied during a specific period of time and in relation to a specific question or issue." In this review, I applied the same procedures of study appraisal and comparison to reflect critically on in-depth interviews in qualitative research with a specific population.

Data abstraction and quality appraisal of studies was guided by the McMaster University Occupational Therapy Evidence-Based Practice Research Group's protocol for the critical review of qualitative research (Letts et al. 2007a, Letts et al. 2007b). The protocol's Critical Review Form (Letts et al. 2007a) was adapted for the objectives of this review by incorporating recommendations from the literature for conducting cross-language qualitative research using in-depth interviews. The form is given in Appendix F. Data on study purpose, design, sampling, data collection, data analyses and overall rigour were sought for the review.

In the absence of published guidance on the reporting of systematic reviews of qualitative research, the reporting of the review was guided by the PRISMA statement

(Moher et al. 2009). The concept of 'risk of bias' as used in the PRISMA statement was interpreted for the purpose of this qualitative review as the appraisal of trustworthiness for individual studies.

Review search methods

Nine electronic databases were searched for references: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus (including all Medline titles), Embase, Web of Science, Ageline, PsycINFO, Sociological abstracts, Google Scholar and Allied and Complementary Medicine (AMED). The review searched the full time span accessible for each database or the period 1840 to September 2009 to enable the broadest capture of papers. The search used keywords 'ethnic*'or 'cultural*' and 'aged' or 'old*' or 'elder*', combined with the keywords 'qualitative' and 'health'. The exact search terms and search limiters differed between databases due to the availability of search options, as shown in the table given in Appendix G. Broad search terms were used to ensure all studies meeting the inclusion criteria were captured in initial searches.

Studies were included in the review if they met the following criteria:

- Participants included at least one person aged 60 years or older.
- Participants included at least two people who preferred to speak a language that was different to each other and was not the native language of the country in which the research was conducted.
- Languages spoken by participants were not determined prior to the start of the research.
- In-depth individual interviews were used for data collection.
- Investigated topic was relevant to healthcare.
- Published in the English language in a peer-reviewed journal.

If the specific languages spoken by participants were not stated, the study was still eligible for inclusion provided it was clear that more than one non-native language had been spoken by participants. For example, if the country or region of the languages were given.

Papers which reported using close-ended questionnaires or surveys for data collection were excluded from the review. If the age of participants or number of non-native languages spoken by participants could not be determined from a reading of the full paper then it was excluded. Papers which reported other data collection processes as well as in-depth interviews were included and only methodology associated with the in-depth interviews was abstracted and appraised.

One reviewer (CF) conducted the database searches, screened titles and abstracts, and removed irrelevant papers. Full texts of potentially relevant articles were independently appraised by two reviewers (CF and SM, or CF and MS) using the "Critical Review Form for Qualitative Interview Studies with a Multilingual Sample" (Appendix F). Any disagreements regarding study inclusion or appraisal were discussed and resolved through consensus of the reviewers.

Data abstraction was undertaken independently by two reviewers (CF and SM, or CF and MS) using the "Critical Review Form for Qualitative Interview Studies with a Multilingual Sample" (Appendix F). Data abstraction was checked between reviewers and any disagreements were discussed and resolved through consensus of the reviewers.

Review quality appraisal

Full texts of all studies included in the review were independently appraised by two reviewers (CF and SM, or CF and MS) using the "Critical Review Form for Qualitative Interview Studies with a Multilingual Sample" (Appendix F). The quality appraisal of each paper was discussed between reviewers and any disagreements in appraisal were resolved through consensus of the reviewers.

The "Critical Review Form for Qualitative Interview Studies with a Multilingual Sample" was developed from the McMaster University "Critical Review Form – Qualitative Studies (version 2.0)" (Letts et al. 2007a) and incorporating recommendations from the literature for conducting cross-language qualitative research using in-depth interviews. Recommendations consisted of expert opinions based on their own experiences conducting cross-language research with single or multiple language groups as well as one relevant literature review (Wallin & Ahlström 2006). All sources of literature recommendations are identified and referenced on the Critical Review Form (Appendix F).

The quality appraisal of each study was summarised in a table and grouped according to methodological process. One reviewer (CF) compared and contrasted the individual quality appraisals to identify themes and patterns in research process and rigour. The overall appraisal was then discussed between the three reviewers (CF, SM and MS) on several occasions to ensure credibility of the findings and to summarise the appraisal in a narrative manner.

Review results

Searches yielded 7539 potentially relevant records, from which 211 full text articles were retrieved and considered for inclusion in this review (see Figure 2.1). From the 211 retrieved articles, nine satisfied the inclusion criteria and were critically appraised. The flow diagram for the review process and reasons for exclusion of 202 articles are given in Figure 2.1. Twenty-seven potentially relevant studies did not provide enough detail to establish if at least two non-native languages had been spoken by participants.

The nine included studies were conducted in four countries with established and growing immigrant populations (Table 2.1). At least 12 different languages were represented across the sample groups. A strong focus on a single minority language group, Spanish, in cross-language healthcare research from the USA meant that no studies from this country met the review's inclusion criteria of at least two languages spoken that were not native to the country in which the research was conducted.

The areas of healthcare investigated by the included studies represent areas of relevance and concern to older people: cancer (Papadopoulos & Lees 2004, Manderson, Markovic & Quinn 2005); chronic heart failure (Pattenden, Roberts & Lewin 2007); home and respite care (Mackinnon, Gien & Durst 1996, Netto 1998, Brotman 2003); mental health (Franks, Gawn & Bowden 2007); pain (Löfvander, Lindström & Masich 2007) and quality of life (Moriarty & Butt 2004). A summary of the quality appraisal of the nine included studies specifically relevant to cross-language research methods is provided in Table 2.2 and are discussed in the following sections.

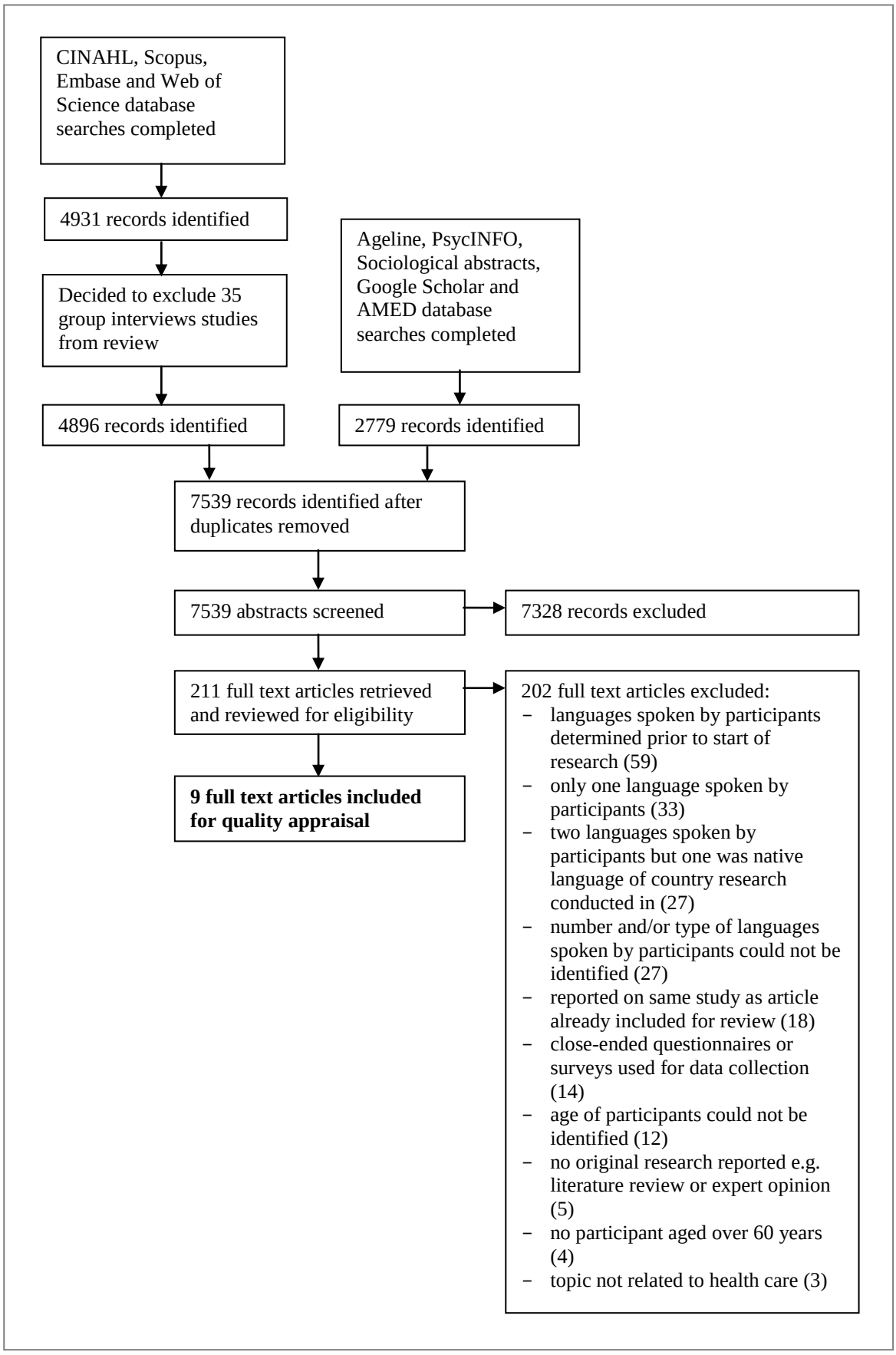


Figure 2.1 Flowchart of literature search strategy and results.

Table 2.1 Profile of studies included in the systematic review.

Study	Mackinnon, Gien & Durst 1996	Netto 1998	Brotman 2003	Moriarty & Butt 2004	Papadopoulos & Lees 2004	Manderson, Markovic & Quinn 2005	Franks, Gawn & Bowden 2007	Löfvander, Lindström & Masich 2007	Pattenden, Roberts & Lewin 2007
Country	Canada	UK	Canada	UK	UK	Australia	UK	Sweden	UK
Languages spoken by participants	Chinese dialects	From Afro-Caribbean, Bangladeshi, Chinese, Indian, Pakistani, and other Asian ethnic groups.	From Black, Chinese, Greek, Italian, and South Asian origins	Chinese, English, Gujarati, Hindi, Punjabi, Urdu	English, Greek, Sylheti	From Asia, Europe, Middle East, North America and the Pacific	From Africa, Britain, Eastern Europe, Portugal, and South America.	Arabic, Swedish, Sorani, Turkish, Urdu	English, Gujerati, Punjabi
Purpose	Describe experiences of Chinese elderly cared for by their families	Investigate the need for, and use of, respite by carers of ethnic older people	Examine the work processes of an organisation which provides elder care	Look at inequalities in quality of life among people from different ethnic groups	Explore meanings and experiences of cancer for men from different ethnic groups	Explore how immigrant and Australian women explain the onset of gynaecological cancer	Determine barriers to access mental health services by refugees, asylum seekers and migrant workers	Explore the main features and concepts of pain among immigrant and Swedish patients	Understand experiences and needs of a diverse group with chronic heart failure

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Table 2.2 Quality appraisal of studies included in the systematic review[a].

Study	Mackinnon, Gien & Durst 1996	Netto 1998	Brotman 2003	Moriarty & Butt, 2004	Papadopoulos & Lees, 2004	Manderson, Markovic & Quinn 2005	Franks, Gawn & Bowden 2007	Löfvander, Lindström & Masich 2007	Pattenden, Roberts & Lewin 2007
Study design stated	✓[a]	×	✓	×	✓	×	✓	×	×
Theoretical perspective identified	×[b]	✓	✓	✓	✓	✓	✓	×	✓
Cultural appropriateness of theoretical perspective considered	NS[c]	NS	✓	✓	NS	NS	✓	NS	NS
Sampling									
Purposive sampling strategy described	✓	✓	✓	✓	✓	✓	✓	✓	✓
Strategy appropriate to language profile of community	NS	NS	NS	NS	✓	NS	NS	✓	✓
Recruitment in preferred language	×	NS	✓	NS	NS	NS	NS	NS	×
Informed consent in preferred language	NS	NS	✓	NS	NS	NS	NS	NS	NS
Data Collection									
Clear and complete description of:									
- site	✓	×	✓	×	×	×	✓	✓	✓
- participants	×	×	×	×	✓	×	×	✓	Patients ✓ carers ×
- language assistants	×	×	✓	×	×	×	×	×	×
- role of researcher	×	×	×	×	×	×	×	×	×
- role of language assistants	×	×	✓	×	×	×	×	×	×
- data collection procedures	×	×	×	×	×	×	×	×	×
Cultural sensitivity demonstrated	✓	×	×	✓	×	×	✓	×	×
Language assistants									
- bilingual researcher/s	×	×	×	×	✓	×	×	×	✓
- (professional) interpreter/s	✓	✓	×	×	×	×	×	✓	✓
- trained bilingual non-professional/s	×	×	✓	✓	×	×	×	×	×
- family member/s	×	×	×	×	✓	×	×	×	×
- not stated	×	×	×	×	×	✓	✓	×	×
No. of assistants/language	NS	NS	NS	NS	2	NS	NS	NS	2
Training provided	✓	NS	NS	NS	NS	NS	NS	NS	NS
Debriefs conducted	×	NS	×	NS	NS	NS	NS	NS	NS
Interviews in preferred language	Some	Some	✓	✓	✓	✓	Some	✓	✓
Performance of bilingual interviewers monitored	N/a	N/a	NS	NS	NS	NS	NS	N/a	NS
Language group involved in developing interview guide	NS	NS	NS	NS	NS	NS	NS	NS	NS
Agreed translation of interview guide	✓	NS	NS	✓	NS	NS	NS	NS	NS
Interview guide pilot tested	×	×	✓	✓	×	×	×	×	×
Standardised translation of interviews	NS	NS	NS	NS	NS	NS	NS	NS	✓
Interview translations monitored for quality	×	×	×	×	×	×	×	×	×
Researcher reflexivity	×	×	×	×	×	×	×	×	×
Language assistant reflexivity	×	×	×	×	×	×	×	×	×
Data analysis									
Clear and complete description	✓	×	✓	×	✓	✓	✓	×	✓
Language group involved	×	×	×	×	×	×	×	×	×
Decision trail reported	×	×	×	×	×	×	✓	×	×
Findings consistent with data	×	×	✓	×	×	✓	✓	✓	✓
Meaningful picture provided	×	×	✓	✓	×	✓	×	×	✓
Evidence of:									
- credibility	×	×	✓	×	×	×	×	×	✓
- transferability	×	×	×	×	×	×	×	✓	✓
- dependability	×	×	×	×	×	×	✓	×	×
- confirmability	✓	×	×	×	×	×	✓	×	×

[a] ✓ = appraisal item completed within the study, [b] x = study's authors have explicitly stated reasons for not doing it, [c] NS = item was 'Not Stated'.

Study design

Four of the nine studies described their study design as: qualitative exploratory (Mackinnon, Gien & Durst 1996); case study (Papadopoulos & Lees 2004); institutional ethnography (Brotman 2003); and grounded theory (Franks, Gawn & Bowden 2007). The remaining five studies did not make explicit their study design within the text of the articles but appeared to be a qualitative descriptive design. A theoretical research perspective was provided by most studies (7/9). The cultural appropriateness of the perspective relevant to the research question and study sample was only addressed by three papers: Moriarty and Butt (2004) introduced 'racism' to the quality of life model they used; the standpoint of older ethnic women was privileged by Brotman (2003) in her institutional ethnography; and Franks, Gawn and Bowden (2007) considered the context of an immigrant study population in their community psychology perspective.

All studies used purposive sampling strategies including maximum variation, convenience, snowball and theoretical sampling. Only Brotman (2003) stated that participants' preferred languages were used during recruitment. Two studies reported that recruitment was conducted in the native language of the country in which the research was conducted in (Mackinnon, Gien & Durst 1996, Pattenden, Roberts & Lewin 2007). The remaining six studies did not clarify the language spoken when recruiting participants. Three studies explicitly stated informed consent was obtained from participants (Brotman 2003, Manderson, Markovic & Quinn 2005, Pattenden, Roberts & Lewin 2007), however, only one study confirmed that it was obtained in the preferred language of participants (Brotman 2003).

Data collection

Descriptions of data collection contexts and processes were limited in most studies. Clear descriptions of the study site were given in five studies; of the participants in three studies; and of the language assistants in one study (Table 2.2). Four studies lacked a clear language profile of participants, instead listing the geographical region associated with the participant's country of birth or language (Netto 1998, Brotman 2003, Manderson, Markovic & Quinn 2005, Franks, Gawn & Bowden 2007). The role of research team members, their previous experience with the research topic and their relationship to participants was not clarified in any study. The role of language assistants was only provided by Brotman (2003) in Canada who trained members of participants' indigenous communities to assist with recruitment, data collection and

data translation. However, the relationship between the language assistants and participants within their indigenous community was not described.

Three studies demonstrated cultural sensitivity in their data collection using processes such as acknowledging how each Chinese elder participant chose to culturally identify themselves (Mackinnon, Gien & Durst 1996), asking participants their own definition of ethnicity and what ethnicity meant to them (Moriarty & Butt 2004) and forming a research advisory group with members of the local participant communities to guide their research decision-making (Franks, Gawn & Bowden 2007).

Language assistants, that is, bilingual people who provide assistance with interpreting, translating or analysing language, were involved in each of the included studies. Professional interpreters were most commonly used (four studies), then bilingual researchers (two studies) and trained bilingual non-professionals e.g. community members (two studies). Two studies did not identify who the language assistants were. A family member provided language interpretation for an interview in the study by Papadopolous and Lees (2004). In their discussion, the authors noted concerns about family members being used as interpreters in medical situations however, the same authors provided no reflection on their own use of a family member. The number of language assistants involved in the research was stated in only two studies, both using two assistants. Research training was provided to language assistants in three studies. Debriefs between language assistants and researchers were either not conducted (two studies) or not stated (seven studies). Performance monitoring was not mentioned in the two studies which used trained bilingual interviewers.

By the nature of the inclusion criteria for the review, all the studies used multiple languages during the research however, three studies did not clarify if participants' preferred languages were always used during interviews, for example Netto (1998) used interpreters "where necessary". Both Mackinnon, Gien and Durst (1996) and Moriarty and Butt (2004) obtained an agreed translation of their interview guide across different language groups. It was interesting that despite this, Mackinnon, Gien and Durst (1996) noted the interpreters experienced difficulty in translating the word 'happy' in the context of one question and postulated this may have influenced the participants' lack of response to the question. Only two studies pilot tested their

interview guide and only one of these confirmed the guide was pilot-tested with older people who spoke different languages (Table 2.2).

No evidence of reflexivity on the part of researchers or language assistants in the research was provided by any of the included studies yet likely influences on the research findings were occasionally disclosed. Mackinnon, Gien and Durst (1996) noted that findings from their study of older Chinese people did not agree with the beliefs of the young interpreters involved in the study but the authors did not comment on how this disagreement may have affected the translation of participants' statements by the young interpreters. In another example, Papadopoulos and Lees (2004) used a participant's daughter as an interpreter for his interview about the meanings and experiences of his cancer without the authors' acknowledging how this may have affected the information provided by either party. And Netto (1998, p. 221) introduced her study by locating it in "the cultural insensitivity of the current service provision" without providing reference for her negative judgement of the health system or explanation of how this belief may have influenced her research.

Data analyses

With regards to analytical procedures, six studies provided a clear and complete description of how they analysed interview data (Table 2.2). Involvement of language assistants in the analysis of data was not mentioned by any authors. Findings were consistent with the presented data for six studies with the remaining three studies lacking explanatory data to support their conclusions. A meaningful picture of the phenomenon under study, that is a description of the theoretical concepts, relationships between concepts, and integration of relationships among meanings that emerged from the data (Letts et al. 2007b), was provided by four of the nine studies (Table 2.2). The remaining five studies lacked clear integration of their key concepts which limited the reader's ability to gain a meaningful overall picture of study findings.

Overall rigour

No study met all four constructs of trustworthiness (Lincoln & Guba 1985). Two studies enabled transferability of their findings by providing clear descriptions of the research site and participants. Three of the remaining studies (Mackinnon, Gien & Durst 1996, Brotman 2003, Manderson, Markovic & Quinn 2005) lacked transferability because of inadequate description of the languages spoken by

participants despite inclusion of other demographic information. Both Brotman (2003) and Pattenden (2007) demonstrated the credibility of their research using a combination of several strategies including the collection of data in participants' preferred language, using prolonged observation, standardising transcription and coding procedures, including negative cases, undertaking peer review, and triangulating data sources and the research team. Confirmability of research findings was demonstrated by Mackinnon, Gien and Durst (1996) who kept a personal log of observations and key points of their interviews and analytic memos. The research by Franks, Gawn and Bowden (2007) was the only study to demonstrate both confirmability and dependability, documenting their complete research process as both a reflective tool and audit trail.

Review strengths and limitations

It is recognised that including older people who do not speak the same preferred language as the researcher in participant samples is not a simple task (Matsuoka 1993, Adamson & Donovan 2002). The strength of the review is its attempt to systematically capture and appraise all reported examples of studies that have used in-depth interviews with older people who speak multiple languages, when languages were not determined prior to recruitment. By drawing on this information, suggestions have been made for achieving optimal practice in the complex research context that the study is conducted in.

While the review characterises the included studies as reflecting deficiencies in the management of language in research process, it needs to be qualified in a number of respects. The reviewers only appraised what was reported within the published article. Researchers often omit study details due to journal word limits and there is yet to be a consensus on the reporting requirements for qualitative research. However, it needs to be recognised that this lack of detail also hinders the reader's ability to independently appraise the rigour and usefulness of the research for application to their own healthcare settings or research approaches.

The research included in the review was limited to articles published in the English language and studies including older participants. Limiting searches to the English language was determined by time and resource constraints. Excluding articles in other languages could mean that other important insights may not have been

obtained. I focused the review on a single generational age group to ensure its relevance to the conduct of my study with older people from CALD backgrounds.

Review discussion

For the qualitative in-depth interview studies included in the systematic review, where languages were not determined prior to the start of recruitment, the language diversity of participants within the research process and the methodological rigour of the studies was poorly addressed. This compromises the application of the research findings for contemporary healthcare (Sandelowski 2004) and provides little direction on how to conduct rigorous in-depth interview studies in this unique multilingual context.

A major threat to rigour in each of the included studies was the absence of any critical reflection on the role of researchers and language assistants. In-depth interviews are recognised in qualitative research as a joint production of knowledge (Mishler 1986), where the generation and interpretation of data is influenced by the participants, the researcher and their relationship (Finlay 2002). Reflexivity is an integral tool for the researcher to analyse how such "subjective and intersubjective elements" influence the data and its interpretation (Finlay 2002, p. 531). This may especially be the case when researcher and participant do not share the same cultural and linguistic background (Adamson & Donovan 2002) and the interpretive gap is widened. Reflexivity is an immediate and dynamic self-awareness by the researcher during the research process to try and capture some of the instances and ways in which people and phenomena influence and constitute each other (Finlay 2002). Strategies for reflexivity during a study can include the researcher maintaining a journal of their perspectives and influences during the study as well as methodological decisions they made (Lincoln & Guba 1985), and including accounts of how they have probed the influence of their thinking and responses during the process in their reports of the study (Finlay 2002).

Extending reflexivity to include the role and influence of language assistants in cross-language interviews recognises that a third person is present in the conversation, bringing their own background and perspectives to the co-creative process (Temple & Edwards 2002, Larkin, Dierckx De Casterlé & Schotsmans 2007). By limiting the presence of language assistants to brief generic references in the methods or discussion notes, all but one of the included studies appeared to take a more positivist

approach of viewing language assistants as "neutral conveyors of messages" (Temple 2002, p. 845). This disregards their active role in the construction of qualitative interview data and so weakens each study's rigour (Hennink 2008). Cross-language research reflexivity can involve the perspectives of language assistants in methodological discussions (Temple 2002), using a framework as given by Hennink (2008).

Another major threat to study rigour was the lack of recognition of multilingual issues in the analysis of interview data. The use of translated data for qualitative analysis may compromise the depth of analysis and the credibility of its findings (Irvine, Roberts & Bradbury-Jones 2008) as subtle but important differences in meaning can be lost (Hennink 2008). Two studies addressed conceptual differences in the formation of interview guides, but no study discussed the potential loss of meaning from translating interview data to a common language (Smith, Chen & Liu 2008) or involved people who were fluent in the original language of the data in its analysis (Tsai et al. 2004). For studies with participants who are from multiple language groups, it is likely that analysis will occur with data that has been translated to the researcher's preferred language. This has consequences for the credibility of the analysis as well as for the status of the language and its user within the study (Temple & Young 2004). Clarity is needed about when the translation occurred, why it occurred, and how it was considered in analysis. It is recommended that the role of language assistants is extended to analysis wherever possible (Tsai et al. 2004, Hennink 2008). If available resources do not allow a linguistically diverse team to assist with analysis, an extensive debrief with language assistants after data collection can assist cultural and linguistic interpretation, or study findings can be taken back to participants for clarification (Adamson & Donovan 2002).

Research in a multilingual context poses ethical, as well as methodological, challenges (Edwards 1998, Liamputtong 2008). That eight of the nine studies included in this review did not report the use of participants' preferred languages during recruitment or informed consent raises questions about the ethical conduct of the research. Obtaining informed consent should provide prospective participants with adequate information in order for them to make an informed decision about whether to participate in the study (Kripalani et al. 2008). For people from culturally and linguistically diverse backgrounds, it must take into account how language is understood (NHMRC, ARC & AVCC 2007) whether presented verbally or in written

form (Liamputtong 2008). The potential for misunderstanding during recruitment and consent in cross-language studies also has implications for the credibility of collected data as the words participants use and the stories they tell in interviews are influenced by their relationship with the interviewer (Mishler 1986).

There was little innovation in research methods demonstrated by the included studies to meet the unique demands of multiple languages being spoken by their participants. One strategy for data collection was demonstrated by Pattenden, Roberts and Lewin (2007). They engaged a combination of different types of language assistants, both bilingual researchers and a professional interpreter, to meet the language needs of their study. Rigorous in-depth interview research with older people from multiple language groups when all the languages are not determined prior to recruitment requires smart use of language resources to manage the additional expense to the research budget. Larkin (2007, p. 473) described it as a careful balancing act of "maintaining the tension in the weave" between consideration of language issues and research process.

The cost of employing language assistants is a significant issue for conducting research with people from multiple language groups. To be financially capable of optimal practice in such studies, researchers must provide an estimate of costs for language resources in funding proposals (Bustillos 2009) and funding bodies need to recognise that the costs are legitimate and necessary to enable research participation for a previously excluded population (Sin 2004, Bustillos 2009). When the languages spoken by participants are not determined prior to recruitment, estimates of required resources can be made using the language profile of the population of interest.

Based on information from the review, recommendations from the literature and the practical experience of both myself and my supervisors in conducting research in a cross-language context, a suggested framework for best practice when conducting in-depth interviews with participants from multiple language groups was developed. The framework is provided in Appendix H. This framework, in collaboration with the more detailed literature recommendations which informed it, provided important guidance for the recruitment, data collection and analysis methods used in my study, as outlined in the next chapter.

The strategies, methods, and analysis of the study were also informed by a philosophical approach which acted as an interpretive framework for the entire research process (Lincoln & Guba 2000). Although all research is informed by assumptions about the nature of reality and how that reality can be known, these assumptions are not always acknowledged by the researcher or stated clearly for the reader. Providing a clear exposition of the philosophical approach to the study was integral to the transparent and reflexive research process which I aspired to throughout my study, and so an explanation of the philosophical approach of the study follows.

2.2.2 The philosophical approach to the study

A constructivist grounded theory research approach was determined to be the best match for the methodological requirements of my study. Constructivist grounded theory was chosen after considering the suitability of alternative social theories to the study's aim of understanding the experience of a culturally and linguistically diverse group of people. The study needed a philosophical approach which would be open to innovation in methods to meet the challenges of conducting in-depth interview research with people from multiple language groups. It was important that the approach provided a way to conceptually recognise and understand the active role of the interpreter in the co-construction of meaning within the study. It also needed to be able to recognise and incorporate the cultural and linguistic diversity of the group of older people who would be the focus of the study. Finally, the study's philosophical approach needed to facilitate production of knowledge that was relevant and applicable to healthcare practice. In this final section of the chapter, I explain why the underlying philosophical premises of a constructivist grounded theory approach met the needs of the study that have been outlined above.

A background to constructivist grounded theory

Grounded theory was developed by sociologists Barney Glaser and Anselm Strauss during the 1960s and introduced to researchers through their seminal text, "The Discovery of Grounded Theory" (Glaser & Strauss 1967). Influenced by Glaser's background in quantitative research with Paul F. Lazarsfeld and Strauss' studies in pragmatism and symbolic interactionism, they proposed a method of research which contrasted with their contemporaries' emphasis on statistical approaches and theory verification. Glaser and Strauss claimed that inductively generating theory using a

systematic method of general comparative data analysis was achievable and would produce middle range theory with relevance to daily practice (Glaser & Strauss 1967). The middle range theory they advocated was theory which provided abstractions of specific social phenomena. The original proponent of middle range theory, sociologist Robert K. Merton, positioned it as intermediate to the past grand theories of sociology which had no foundation in systematically analysed data and to the detailed descriptions of particulars which attempted no conceptual abstraction (Merton 1967, Charmaz 2006).

The general comparative method introduced in grounded theory was a systematic strategy of constantly comparing data with emerging concepts using simultaneous data collection and analysis. Glaser and Strauss proposed that theoretical concepts would emerge from the data during this constant comparison which could then be integrated into a theory. For the theory to have credibility, researchers were cautioned to maintain an "informed detachment" from their field work and not to force data into preconceived concepts or hypotheses (Glaser & Strauss 1967, p. 226). Glaser and Strauss promised that the competent use of their new approach would develop theory that was not only understandable and relevant to a field of practice, such as the relevance of their early study "Awareness of Dying" (Glaser & Strauss 1965) to nursing practice, but could be used to predict change in processes and control the consequences.

Virtually from the time of publishing "The Discovery of Grounded Theory", Glaser's and Strauss' individual approaches to grounded theory started to diverge into two distinct versions, later labeled as "Glaserian" and "Straussian" (Stern 1994). Glaser extended his ideas on the emergence of theory and theoretical sensitivity, introducing coding families to the analytical procedures (Glaser 1978, Kelle 2007). Strauss invented his own coding paradigm that structured data and clarified relationships between categories (Kelle 2007). In collaboration with Juliet Corbin, Strauss published a more prescriptive method of doing grounded theory (Strauss & Corbin 1990, Strauss & Corbin 1998).

Other students of Glaser and Strauss further developed the idea and methodology of grounded theory from those of its originators into a "constellation of methods" (Charmaz 2008c, p. 161). Early on, Leonard Schatzmann extended the idea of constant comparison of data in 'dimensional analysis' (1991). More recent

innovations of grounded theory have responded to postmodern critiques around objectivity, truth and universality. Kathy Charmaz and Antony Bryant have both emphasised social constructionist premises in 'constructivist grounded theory' (Bryant 2002, Charmaz 2003, 2006) and Adele Clarke has considered the interaction between social worlds, arenas and negotiations in 'situational analysis' (Clarke 2005). The approach of Strauss' colleague Juliet Corbin has also been influenced by postmodern insights, reflected in a more constructionist and self-reflective version of grounded theory in the third edition of "Basics of Qualitative Research" (Corbin, Strauss & Strauss 2008) than was advocated in earlier editions. Despite their differences, all these versions continue the original grounded theory approach to "begin with inductive logic, subject data to rigorous analysis, aim to develop theoretical analyses, and value grounded theory studies for informing policy and practice" (Charmaz 2009, p. 127). However, the ontological and epistemological premises of grounded theory have altered between the versions and it is the paradigm in which the grounded theory is located which influences the relationship between the researcher and the participants and the broad goal of the study (Wuest 2007). Therefore, researchers need to be explicit about the worldview that has informed the version of grounded theory they have used so that their audience may understand the situation and boundaries of the generated knowledge.

A constructivist grounded theory approach developed by Kathy Charmaz (2006), was chosen as the methodological approach to the study primarily because of its social constructionist orientation. A more detailed justification of my choice as it relates to the needs of the study is provided in the remainder of the chapter, prefaced for clarity of the discussion by a brief outline of the philosophical premises of constructivist grounded theory.

Philosophical premises of constructivist grounded theory

It is widely acknowledged that the original grounded theory was influenced by the respective schools of thought from its originators' earlier scholarship: Glaser's Columbia University positivism and Strauss' Chicago School pragmatism, ethnographic fieldwork and symbolic interactionism. Yet the lack of clear epistemological direction for the research approach meant that by the 1990s, grounded theory was being challenged for its positivist assumptions about an external reality, the privileged role of the researcher and its unproblematic representation of research participants (Charmaz 2008a). For contemporary

relevance, grounded theory needed to be revised to fulfill its potential for innovative social constructionist study (Charmaz 2008a). Although Urquhart has claimed that interpretive researchers had already been quietly doing this within the field of Information Systems (Urquhart 2007), constructivist grounded theory was openly developed by the sociologist Kathy Charmaz to locate grounded theory within a postmodern interpretive frame and to provide a clear epistemological framework for its methods (Bryant 2009). Charmaz has continued to develop the research approach both separately and in concert with researcher Antony Bryant. The philosophical premises of constructivist grounded theory are informed by the ideas of symbolic interactionism, pragmatism and social constructionism.

Symbolic interactionism and pragmatism

Constructivist grounded theory's philosophical premises have been built on the symbolic interactionist tradition and pragmatist philosophy embraced by Anselm Strauss. It has adopted the symbolic interactionist perspective of Herbert Blumer (1969) that assumes society, reality, and self are constructed through interaction. Blumer (1969) proposed that people act on the basis of the meanings that things (other people, objects, events) have for them. These meanings or symbols are derived from previous social interactions interpreted by the individual.

Symbolic interactionism has a pragmatist foundation which views reality as made by, and experienced, only through the activity of self-reflective beings. It centres action and process as the means by which the empirical world becomes meaningful (Strubing 2007, Corbin, Strauss & Strauss 2008) and, therefore, by which it can be understood. The pragmatist philosopher John Dewey (1929) recognised that human activity inevitably involves choices based on known or unknown preconceptions of the individual, making reality "continuous with the past", but "not its bare repetition" (p. 40). Therefore, constructivist grounded theory assumes that people can and do think about their actions rather than respond to mechanical stimuli or structure (Charmaz 2006) and so it encourages an exploration of the meanings of people's actions, both stated and tacit (Bryant & Charmaz 2007b).

The pragmatic foundation of constructivist grounded theory leads it to view all action as problematic. Therefore, researchers purposefully explore participant's definitions of their given reality and how they enact it; questioning both participants' and their own standpoints and assumptions (Charmaz 2009). Constructivist grounded theory

also interprets the analytic process of theorising as an active process produced by interacting individuals (Charmaz 2008b). The constructed theories, grounded in active processes, are recognised as qualified and contextual, and contingent on conditions (Bryant & Charmaz 2007b, Charmaz 2008b).

Social constructionism

The symbolic interactionist and pragmatist premises of constructivist grounded theory support its social constructionist approach to knowing about the empirical world (Charmaz 2008a). Social constructionism is a broad label for the concept that all knowledge is shaped, or created, by specific social historical and/or social interactional processes (Weinberg 2008). The term 'constructivist' has been used to distinguish the use of the concept in grounded theory from more conventional work of social constructionists that did not attend to methodological debates (Charmaz 2008d). Constructivist grounded theory's view of social constructionism does not ascribe to the extreme argument that there is no external reality, or the other extreme that all constructions are equal, but recognises that a person's understanding of the world is socially constructed (Bryant & Charmaz 2007a). Therefore, the empirical world may be constructed in multiple ways by the researcher and participant (Charmaz 2008a).

Social constructions of reality, as understood in constructivist grounded theory, are not arbitrary or ad hoc but are always constructed within a cultural context of particular historical or social conditions that shape people's views, actions, and collective practices (Charmaz 2008a). As emphasised by pragmatist philosophy, people are active, creative beings who can interpret and reinterpret their own lives; however, in line with Marxist thought, their choices and actions are constrained by social and temporal circumstances (Charmaz 2008d). Researchers construct grounded theories through past and present involvements and interactions with people, perspectives and research practices (Charmaz 2006). This constructivist and pragmatist perspective fosters reflexivity about the researcher's own positions as well as those of the research participants (Charmaz 2006, Charmaz 2009). As the resultant theory is constructed from the researcher's questions, choices and specific strategies, it is inseparable from the researcher's perspective (Charmaz 2008c). Therefore it is important for the researcher to attempt to make explicit, and interrogate, those choices.

Constructivist grounded theory is realist because it asks the researcher to attempt to get close to the inside of the experience for a participant so as to represent the studied phenomena as faithfully as possible to the diverse and complex 'realities' of the research participants (Bryant & Charmaz 2007a). Knowledge is constructed by gaining intimate familiarity with the phenomenon of the study; to look beyond participants' talk to the tacit meanings and actions of participants (Charmaz 2008b). Yet it is recognised that the researcher is unable to replicate the participants' experiences because the analysis will always be an interpretation from the researcher's own perspective (Charmaz 2006). Importantly, the researcher is positioned by constructivist grounded theory as an interpreter of the studied phenomenon, "not as the ultimate authority defining it" (Bryant & Charmaz 2007a, p. 52). There is no magical emergence of a unitary truth from the analysis of participant data; instead, the constructed grounded theory is viewed as a product of particular times, social conditions and interactional situations. By recognising the complexity of human life, constructed grounded theory can provide a credible, original, resonant, and useful understanding of a phenomenon (Charmaz 2009).

While the constructivist position does not answer all postmodern and poststructural critiques regarding knowledge claims (Charmaz 2008b, Bryant 2009), constructivist grounded theory has attempted to address epistemological concerns with difference, reflexivity, relationality, and positionality (Clarke & Friese 2007) to provide a valid and useful research approach for contemporary research issues and populations (Charmaz 2006). Importantly for my study, constructivist grounded theory supports innovation and flexibility in the research process. While it respects the core grounded theory components of constant comparative methods and researcher engagement, constructivist grounded theory encourages researchers to choose methods that will answer research questions with "ingenuity and incisiveness" (Charmaz 2006, p. 15).

The remaining sections of the chapter will explain how constructivist grounded theory's philosophical premises enable the incorporation of diversity, recognise the co-construction of meanings, and construct knowledge for practical application, therefore, making it an appropriate philosophical approach for the investigation of how a group of people from CALD backgrounds experience their healthcare after stroke.

Incorporating diversity

Researching the experiences of a group of older people from CALD backgrounds requires their diversity to be incorporated as a focus of the research so that it does not become lost in the research process (Barnes 1996). This applies to both the methods and the theory informing the research (Green et al. 2007), for, as already noted in the previous section, it is the philosophical premises of the study which influence the relationship between the researcher and the participants and the broad goal of the study (Wuest 2007).

Grounded theory is an approach well suited to explicitly incorporating cultural and linguistic diversity as a research focus (Green et al. 2007), particularly in the context of an ageing multicultural population (Dilworth-Anderson & Cohen 2009). Examples of grounded theory studies with a primary focus on the experience of people from CALD backgrounds include investigations of non-English speaking patients' experience of acute hospital care (Garrett et al. 2008a), Japanese working women's experience of caring for elderly parents (Hashizume 2010), older Korean American women's experience of pain (Dickson & Kim 2003) and how different cultural groups perceive and give meaning to dementia (Dilworth-Anderson & Cohen 2009).

The inductive nature of grounded theory allows interpretive research to focus on a minority group of people, their experience, voices, and issues, without requiring comparison with a dominant group or employing a theoretical framework that may not be culturally appropriate (Hsueh-Fen, Min-Tao & Clark 2004). As noted by researchers investigating perceptions of dementia held by different cultural groups,

> *Grounded theory enabled us to approach data analysis and interpretation without expectations and assumptions about what we thought the data should show. Instead, we were able to allow the data to show us what was important.* (Dilworth-Anderson & Cohen 2009, p. 495).

The approach can open up alternatives for thinking about a phenomenon (Wuest 2007).

However, the ability of grounded theory to faithfully and usefully portray a phenomenon relies on culturally-specific meanings and concepts being able to emerge within a research situation when the researcher's culture and/or language may differ significantly from that of the participants (Barnes 1996). It must be noted

that the possibility of cultural difference between researcher and participants is not isolated to comparisons of country of birth or language; culture is a dynamic concept which refers to the symbolic webs of meaning built on contemporary and historical legacies, social systems and discourses, acting as a framework for the interpretation and agency of people at different times and in different contexts (Mallinson & Popay 2007). Therefore a person's age, gender, and socioeconomic position can all be part of their cultural identity (Culley 2006).

The strength of constructivist grounded theory is its recognition of the importance of cultural context on the construction of meaning. Rather than adopting the positivist assumption of culture as a static variable, it takes the pragmatist perspective that people interact with their environments based on their cultural backgrounds and experiences (Kao, Hsu & Clark 2004). Constructivists actively look for liminal meanings and tacit actions of participants in their analysis of data, as well as explicit statements and actions (Charmaz 2009), and are encouraged not to reproduce their own assumptions about the worlds they are studying (Charmaz 2006). Therefore, any concepts derived through constructivist grounded theory are thought to be culturally relevant because they emerge from the cultural agendas and meanings that the participants assign to the phenomena being studied (Dilworth-Anderson & Cohen 2009).

Cultural meanings in a participant's data cannot be assumed from prepared knowledge of a specific cultural group. Constructivist grounded theory follows the inductive standpoint of Barney Glaser that all ideas need to earn their way into the analysis (1978). Therefore, cultural knowledge, as with all preconceived ideas, may be used as a starting point to look at the data but should not be automatic codes. For example, the researcher may ask of the data, "Have any cultural or age issues emerged that need analytic attention?" (Charmaz 2006, p. 68).

This does not negate the need for constructivist researchers to demonstrate cultural sensitivity when researching a group of people from CALD backgrounds. Cultural sensitivity entails knowing key values and stakeholders for each cultural group, using appropriate and respectful communication and having an openness to learn (Liamputtong 2008). The benefits of being culturally sensitive in research are avoiding harm to participants, and gaining reliable data (Liamputtong 2008) and rich interpretive theory (Hsueh-Fen, Min-Tao & Clark 2004, Barnes & Almasy 2005).

Cultural sensitivity is enacted in constructivist grounded theory by being intimately familiar with the phenomenon and examining the perspectives of participants, their historical locations and social circumstances, so they can be faithfully represented in the constructed theory (Charmaz 2006, Charmaz 2009), and using cultural knowledge as sensitising concepts to alert the researcher to certain possibilities and processes in interview questions, data, and analysis (Charmaz 2006).

Cultural sensitivity is also referred to as the researcher not being trapped in their own assumptions (Barnes 1996) and accepting the extraordinary as ordinary (Morse 2006). A constructivist premise is that each researcher brings their own perspectives to the theorising process which may impact on their understanding of diverse cultural groups (Dilworth-Anderson & Cohen 2009). A reflexive examination of one's own background and experiences, including cultural values, as promoted by constructivist grounded theory will explicate how a researcher's standpoints, positions, situations and interactions have influenced their theorising (Charmaz 2009). This reflexive stance informs how the researcher conducts their research, relates to participants, and represents the participants in research reports (Charmaz 2006).

Interpretive research involving people from CALD backgrounds is a challenging endeavour with complex theoretical and methodological considerations. Importantly, grounded theory embraces complexity in human behaviour and acknowledges that any methodology that attempts to understand situated experiences will also have to be complex (Corbin, Strauss & Strauss 2008). In the next section, I continue my discussion of how constructivist grounded theory's philosophical premises are appropriate to research with diverse groups of people by focusing on its recognition of the co-construction of meaning.

Co-constructing meaning

Two important epistemological considerations for interpretive research when researcher and participants are from different language groups is how knowledge of the studied phenomenon is generated across language differences and how the role of language assistants is considered in this construction. Although constructivist grounded theory literature has not directly addressed the cross-language research situation, pragmatist and constructivist perspectives on data and knowledge construction can inform its research practice.

In constructivist grounded theory, concepts and theory are constructed by the researcher out of stories co-constructed with research participants who are trying to explain and make sense out of their experiences (Corbin, Strauss & Strauss 2008). This co-construction of meaning occurs in a social interaction within a cultural context and is achieved through language (Charmaz 2006, Charmaz 2008a). When a preferred language is not shared between researcher and participant, the interaction will necessarily involve a language interpreter. From a constructivist perspective, the interpreter is not a neutral conduit of talk but a third active agent in the research interaction producing knowledge (Temple 2006).

In keeping with the pragmatist tradition, all three agents in the interaction are considered to bring their past, their perspectives and their expectations of the situation to the construction of meaning (Wadensjö 1998). This is not unproblematic. Meaning and how we situate ourselves in social worlds is not determined by the language spoken but neither is the language that is used completely irrelevant (Temple 2006). An utterance never has one meaning and can always be understood and interpreted beyond its expression (Wadensjö 1998). Interpreters make choices in the words they use to convey research participants' meaning. Many interpretations can be judged 'correct' but it is the conceptual equivalence, or "essence of the process" (Stern 2009, p. 57), that is integral to grounded theory data and its analysis (Temple 2006). Therefore, just as the researcher's choices have been recognised in the previous section as making a difference to the co-construction of meaning in the research situation, the choices of the language interpreter will also influence this co-construction. Rather than denying this influence, constructivists are reflexive about the role and viewpoints of the language interpreter, recognising that there is no neutral position from which to interpret and who does the interpretation does matter to the research (Temple & Young 2004).

The representation of position and voice in research is at the centre of postmodern research concerns (Clarke & Friese 2007) and requires the power relationships within cross-language research to be acknowledged (Temple & Young 2004). Although issues of representation of voice are not isolated to cross-language research situations, the legacy of colonialism and the silencing of minority voices in research cannot be ignored (Temple 2006). Constructivists recognise that the views and voices of participants, and interpreters, are integral to the construction of meaning in research, but also acknowledge the researcher as final renderer of the co-constructed

data to theory. This is not a depiction of the researcher as the privileged authority of the produced knowledge (Charmaz 2009) but acknowledgement that all data is mediated through the researcher (Kools 2008). The reflexive stance of constructivist grounded theory addresses the representation of participants and their data, and interpreters, within the research and in its reports (Charmaz 2006). For cross-language research this will include a reflexive consideration of when, or if, data is translated to the dominant language. The following section will continue the justification of constructivist grounded theory as a relevant approach to the study by establishing its ability to produce knowledge that is useful for practice.

Informing practice

From the original claim of grounded theory to develop a theory with fit and relevance to the practice of the layperson (Glaser & Strauss 1967), grounded theory, in whichever version, has continued to be used to investigate "ordinary problems of ordinary folk" (Charmaz 2009, p. 132). Most grounded theories are substantive theories which address a defined problem within a specific area of practice, such as the present study of how older people with LEP experience their healthcare after stroke. They have practical applicability and adaptability to inform specific contexts (Dey 2007). Grounded theories can also be developed into formal theories, through the comparative analysis of various substantive theories, to yield more general application and insights across areas of practice (Bourgeios 1979, Charmaz 2006). Whether substantive or formal, all constructivist grounded theories aim to have credibility, originality, resonance and usefulness to practice (Charmaz 2009).

The aim to develop knowledge for practice from research reflects the pragmatist position of the grounded theory approach. John Dewey (1929) believed that knowledge led to useful action, which in turn led to new problems to research and actively resolve. This approach suggests a nearly continuous interplay of practice and inquiry for generating theory that can be applied to practical situations (Corbin, Strauss & Strauss 2008). From a pragmatist view of human behaviour as complex, grounded theory provides a way to understand and communicate this complexity without "oversimplifying it out of existence" (Strauss 1993, p. 12).

As well as following the pragmatist call for useful knowledge, constructivist grounded theory recognises the postmodern challenge that this complexity of life can never be fully captured by a generalised theory (Kearney 2007). Constructed theories are

partial and conditional, situated in time, space, positions, action, and interactions (Charmaz 2009). This is congruent with a culturally sensitive approach to theory that acknowledges culture as dynamic and views all interpretations as provisional and their analyses incomplete (Barnes 1996).

The ability and suitability of grounded theory to provide knowledge that is useful for healthcare practice has been demonstrated in Glaser and Strauss' landmark work on death and dying (Glaser & Strauss 1965), Charmaz's constructivist study of experiencing chronic illness (Charmaz 1991) and other grounded theory studies investigating people's healthcare experiences include whiplash patients' experiences of rehabilitation (Rydstad, Schult & Löfgren 2010), and patient and therapists' experiences of home-delivered rehabilitation (Stephenson & Wiles 2000).

The inductive nature of grounded theory is particularly relevant to gaining understanding in areas where there is little previous knowledge, or when what is known from a theoretical perspective does not satisfactorily explain what is going on (Wuest 2007). Growing migrant populations provide a contemporary challenge to the monocultural and monolingual lens of much healthcare knowledge. This is an opportunity for grounded theory to address issues of practice with an explicit focus on diversity to provide knowledge for healthcare that is relevant to culturally and linguistically diverse people (Green et al. 2007).

2.3 Chapter conclusion

In this chapter, I have reviewed both the literature relevant to the study's substantive topic of healthcare after stroke for older people with LEP and the literature which informed the study's theoretical and practical approaches. This has provided the grounding for the design and methods of my study and for a meaningful discussion of its findings. Conducting in-depth interview research with people from multiple language groups was a challenging endeavour in practice to achieve the rigorous, culturally sensitive and successful study which I aspired to. In the next chapter, I outline the specific methods that were used in the study to realise a constructivist grounded theory approach to understanding the healthcare experience after stroke for older people with LEP from CALD backgrounds.

3 Design and methods

The complexity of cross-language qualitative research heightens the demand for a thorough description of the decisions made during the research process (Temple 1997). This chapter describes the study design and methods that were used to realise a constructivist grounded theory approach to understanding the healthcare experience after stroke for older people with LEP. Reflexive and transparent accounts of the study's design, data collection, data analysis, ethics and rigour are provided.

3.1 Design

The study's design was informed by a combination of a constructivist grounded theory approach, literature recommendations for the conduct of cross-cultural research, and a systematic review of the methodological rigour of healthcare studies using in-depth interviews with older people from multiple language groups (see chapter 2, section 2.2). The philosophical premises of constructivist grounded theory enable incorporation of diversity, recognise co-construction of meanings, and support the construction of knowledge for practical application; making it an appropriate research approach to address the aim of my study. The constructivist approach to grounded theory also encourages innovation and the development of new understandings of studied life with an emphasis on the use of its methods as heuristic devices rather than rigid rules (Charmaz 2008d). The potential for flexibility in the research process was helpful to meeting the methodological challenges of interviewing people from multiple language groups about an under-researched topic.

Data were obtained directly from the people who were the focus of the study, that is, older people with LEP who had suffered a stroke. Semi-structured, in-depth interviews allowed an inductive exploratory approach to data collection and enabled rich data to be collected from participants who spoke different languages.

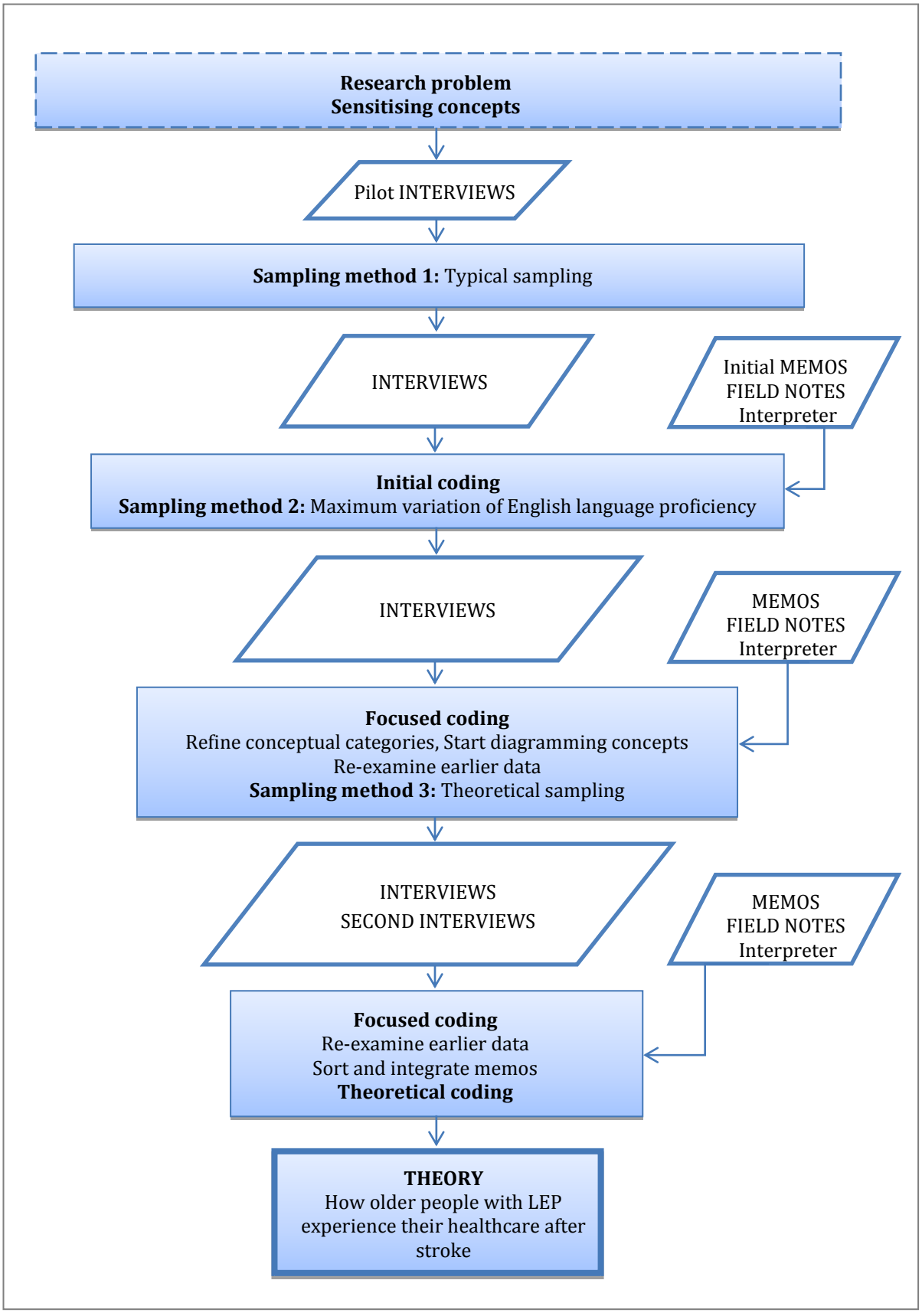


Figure 3.1 Flowchart of research design.

Professional interpreters played a key role in data collection and were recognised as assistants to the research process and co-constructors of interview data. All data were translated to English for analysis; a decision enforced by the financial limitations of the study but with recognised implications for the credibility of the analysis. The use of second interviews, theoretical sampling and interpreter debriefs maximised the rigour of the analysis, and participants' spoken languages were kept prominent in the study.

The research process, as shown in Figure 3.1, followed an inductive and iterative grounded theory design to ensure that the direction of the study and its analysis were determined by participant data rather than predetermined boundaries. As the study proceeded, theoretical sampling directed both the sampling strategy and interview guides, and second interviews provided the opportunity to clarify and extend participant data. The resultant theory was grounded in participants' data and offered an interpretive understanding of the healthcare experience after stroke for older people with LEP, with a view to informing healthcare practice.

3.2 Methods

3.2.1 Data collection

Sampling

Purposeful participant sampling was employed. This focused on gathering data that provided insights and in-depth understandings of the research topic (Patton 2002) to generate a robust grounded theory of how older people with LEP experience their health care after stroke (Charmaz 2006). To identify appropriate people to inform the study, a definition of the construct of 'limited English proficiency' was required.

Defining 'limited English proficiency'

The definition of 'limited English proficiency' needed to be relevant to the healthcare context after an acute stroke. Many definitions of LEP are generic tests of proficiency without consideration of the communication demands within a healthcare context. Examples of generic definitions include:, the interview needed to be conducted in language other than English (Shi, Lebrun & Tsai 2009, Gee, Ponce 2010), enrolment in 'English as second language' classes (Wolff & Ellis 2009), self-reported preferred language spoken other than English (Lopez-Quintero, Berry & Neumark 2010), or self-reported difficulty with speaking or understanding English (Wilson et al. 2005,

Ngo-Metzger, Sorkin & Phillips 2009, Thornton et al. 2009, Schenker et al. 2010). Yet older people with LEP perceive the communicative demand of talking with a doctor to be much harder than the demands of daily activities such as shopping (Klimidis et al. 2004). And communicative demands are likely to be even greater when an older person is affected by stroke and trying to communicate within an unfamiliar healthcare environment with unfamiliar healthcare staff.

The need for a measure of language proficiency with specific relevance to the healthcare context was recognised by Karliner et al. (2008). Based on a study with 320 adult patients who spoke Spanish and/or English, they found that using the census question of "How well do you speak English?" with a high-threshold response of less than "very well" as a screening question, combined with a language preference for healthcare question, provided inclusive and accurate identification of people who were likely to benefit from using a professional interpreter or bilingual health professional during their healthcare. So the definition for the construct of 'limited English proficiency' in this study was that the person preferred to speak a language other than English for their healthcare (irrespective of whether they had the opportunity, or not, to speak it during their healthcare experience after stroke) and replied to the question "How well do you speak English?" by nominating "well", "not well" or "not at all", rather than "very well" (see chapter 1, Figure 1.1).

Sampling methods

The sample was chosen using three purposive sampling methods: typical, maximum variation and theoretical. Initially, typical participant sampling of four older people with LEP who had received inpatient healthcare after an acute stroke was used to provide an overview of the healthcare experience and begin data analysis.

Subsequent sampling of nine older people was then guided by maximum variation of English language proficiency (Patton 2002). Sampling was directed to gain the participation of people who self-reported speaking English "well", those who self-reported "not well'' and those who self-reported ''not at all'. The diversity of the research sample was inevitably influenced by who was admitted to inpatient healthcare for stroke during the sampling period and who agreed to participate.

Theoretical sampling was used to collect pertinent data to refine emergent categories and make them more relevant and useful in advancing the theory (Charmaz 2006, Stern 2007). This included the purposeful inclusion of one participant who was an

older person with stroke from a CALD background, spoke English "well" and who preferred to speak English for his healthcare to help clarify conceptual ideas during data analysis (Charmaz 2006).

Theoretical sampling using second interviews with participants began prior to the completion of maximum variation sampling. Concurrent analysis of early interview data informed second interview questions to gain more directed information from participants for whom particular concepts relevant to the emerging theory appeared important in their experience (Morse 2007). For example, two participants who had refused the assistance of professional interpreters during their healthcare were asked about how they had determined the language proficiency needed to manage after stroke and why an interpreter had not been wanted. Emerging conceptual ideas from the analysis were also explored at later interviews, such as specifically asking participants about why they trusted, or did not trust, health professionals and how they decided on the value of their healthcare.

Theoretical sampling was also conducted using comparative examples in the research literature (Puddephatt 2006). As conceptual ideas became stronger in the analysis, I sought relevant literature from healthcare and communication fields to inform the developing theory. For example, the divergent and convergent uses of 'foreigner talk' in the conversation accommodation theory of Giles, Coupland and Coupland (1991) helped me to understand participants' experience of communication with health professionals.

Theoretical saturation

Theoretical sampling continued until the core conceptual processes that made up the developed theory were considered saturated by myself and my supervisors. In practice, this meant that recruitment was paused after first interviews were completed with fourteen participants. At this time, emerging ideas from the analysis were being strengthened by theoretical sampling in second interviews which continued for three months beyond recruitment of the fourteenth participant, and by theoretical sampling of the research literature. The possibility of further recruitment was considered throughout the timeline of second interviews and allowance was made with both recruitment sites and ethics committees for further data collection if required. However, theoretical saturation of the three core processes was determined

to be achieved with data from twenty-four interviews with fourteen participants, and theoretical sampling of the research literature.

It was difficult to make a confident decision on saturation and I hesitated at determining the right time to cease data collection. Grounded theory researcher, Janice Morse (2007, p. 243), suggests that, "once the researcher is convinced that they understand what they see, can identify it in many forms, and it appears culturally consistent, then the category may be considered saturate and sampling may cease". However, I was conscious during my study of the social constructionist premise that there is not one definitive explanation of a phenomenon. There were a number of processes in my study data that could have been developed to a conceptual level and so my decision needed to consider the relevance of each process and the subsequent depth of inquiry each required (Charmaz 2006).

As well as these considerations, I made my final decision of when theoretical saturation was reached by considering the size of the claims made by the study and its compatibility with established research (Charmaz 2006). My study was unavoidably influenced by the time and financial constraints of a doctoral research scholarship. It was modest in its scope as an exploratory study of the healthcare experience of a group of stroke survivors with whom in-depth research is a complex methodological process. It aimed to provide insights for clinical practice and highlight areas requiring further investigation. Consistent with Morse's definition, the cultural consistency of the study findings with contemporary research was confirmed in theoretical sampling and is demonstrated in the discussion of findings in chapter 5. This, combined with my thorough immersion in the conduct of my interviews, interview data and its analysis, satisfied me that I had understood the concepts and they were demonstrated across participants (Morse 2007). Therefore, I was satisfied that my study achieved theoretical saturation of the theory and its constituent processes as presented in the study findings (chapter 4).

Selection criteria

The inclusion and exclusion criteria for participants are given in Figure 3.2. Eligibility for the study was assessed by the recruiting physiotherapists at each of the four inpatient healthcare recruitment sites. I discussed the eligibility of potential participants with the recruiting physiotherapist via a phone call. The presence of cognitive or communication problems that excluded people from being study

participants were identified by the physiotherapists either from their own assessment or the report of the speech therapist in the person's case notes. On one occasion, I also spoke with a potential participant's speech therapist to determine the ability of a person with dysphasia to participate in an interview situation.

Inclusion criteria

- Aged 60 years or older
- Diagnosed as having an acute stroke
- Not born in Australia
- Prefer to speak a language other than English for their healthcare
- Self-reported English speaking ability 'well' or 'not well or 'not at all'
- Initial return to live in a community setting after inpatient stroke healthcare

Exclusion criteria

- Cognitive or stroke-related communication problem that prevents participation in research interview e.g. severe dysphasia.
- Live in residential care or nursing home accommodation.
- Live in rural area more than a half day drive from Adelaide.
- Previous stroke

Figure 3.2 Participant inclusion and exclusion criteria.

Two participants did not meet all criteria. During the first interview with the first participant she reported that she had previously experienced acute inpatient healthcare after a stroke. Her data were still included in the study primarily as I believed I had an ethical responsibility to use data which had been volunteered by a person in the belief that it would benefit my research and future healthcare. A second consideration was that she was a rich source of information about familiarity with healthcare which was valuable in later theoretical sampling. Subsequent to this decision, I made sure to carefully check each criterion with the recruiting physiotherapist prior to them inviting a person to participate. A second participant

who preferred to speak English was deliberately chosen for the analysis as explained in the earlier section on 'Sampling methods'.

Co–participants

During some interviews, the partner and/or child of the participant was present. Sometimes they sat in the background to listen or moved in and out of the room completing household tasks. Others were more involved in the interview. For six of the 14 study participants, family sat close by and intermittently participated in the interview. On most occasions this was to clarify or assist the interviewer to understand an aspect of the older person's story. For one couple, it was obviously an accustomed way for them to tell a story together as a 'duet' of voices (Falk 1980),

> *Interviewer (English): Is that the wife who's a nurse?*
>
> *Rosa (English): Yes, yes. She's English.*
>
> *Gino (English): Actually, that's end nurse, was a nurse but now a boss.*
>
> *Rosa: A big boss now.*
>
> *Interviewer: But now a boss?*
>
> *Rosa: In a nursing home.*
>
> *Interviewer: In a nursing home, ok.*
>
> *Gino: She do just three days a week something.*
>
> *Rosa: Not much now, before work more but now stopped.*[1]

For the frailest participant in the study who was only able to participate for a short part of his interview due to fatigue, his two sons talked about their father's healthcare experience while their father remained in the room listening to them talk.

This group of eight people, who I have called 'co-participants', were not purposively sampled and were not considered a primary source of data. The focus of the study and its data collection remained the older person with LEP. Including co-participants in the study was a considered response to a culturally sensitive situation which I encountered in the field. The older people with LEP appeared accustomed to, and comfortable with, the participation of their family during interviews. A constructivist grounded theory approach had been chosen for the study to allow such reflexive

[1] Please note that when participant data is directly presented in the text, the person's pseudonym and the language in which the words were spoken during the interview are also presented.

practice and flexibility in methods when required to be appropriate to the research situation (Charmaz 2006) and it is a quality integral to conducting responsible research with a vulnerable group of people, such as older people with LEP (Pyett 2001).

Although it was evident that most co-participants acted as carers for their family member with stroke, the term 'carer' was not used to describe this sample as they were not purposively selected to provide information on their carer role. Instead they were labelled as a 'co-participant' to indicate that their self-selected contribution was part of the participant's story and not a separate one.

Recruitment

Participant recruitment was conducted from August 2009 to May 2010. All participants were recruited from one of four sites located in northwestern metropolitan Adelaide, South Australia. The recruitment sites were two acute hospitals, The Queen Elizabeth Hospital (TQEH) and the Royal Adelaide Hospital (RAH); and two inpatient rehabilitation facilities, St. Margaret's Rehabilitation Hospital (SMRH) and Hampstead Rehabilitation Centre (HRC). The relative size of each site in 2011 was: RAH 650 beds, TQEH 327 beds, HRC 150 beds, SMRH 48 beds. The flowchart of a person's likely journey through healthcare facilities after stroke given in Figure 3.3 is based on information from the South Australian Stroke Service Plan 2009-2016. It shows that some patients with stroke are discharged back to the community straight from acute hospital care. Therefore, recruitment sites included both acute care and rehabilitation facilities to ensure there were opportunities to recruit people who did not go on to inpatient rehabilitation after acute healthcare for their stroke, and to recruit people who had received acute healthcare for their stroke in another region and were then transferred to an inpatient rehabilitation facility closer to home.

The four recruitment sites were purposefully chosen as typical of public (government-owned) health facilities providing specialised stroke care services to a multicultural community. Typical case sampling of recruitment sites was used to improve the potential generalisability and applicability of the developed theory to healthcare in regions with aging multicultural communities (Patton 2002, Schofield 2002).

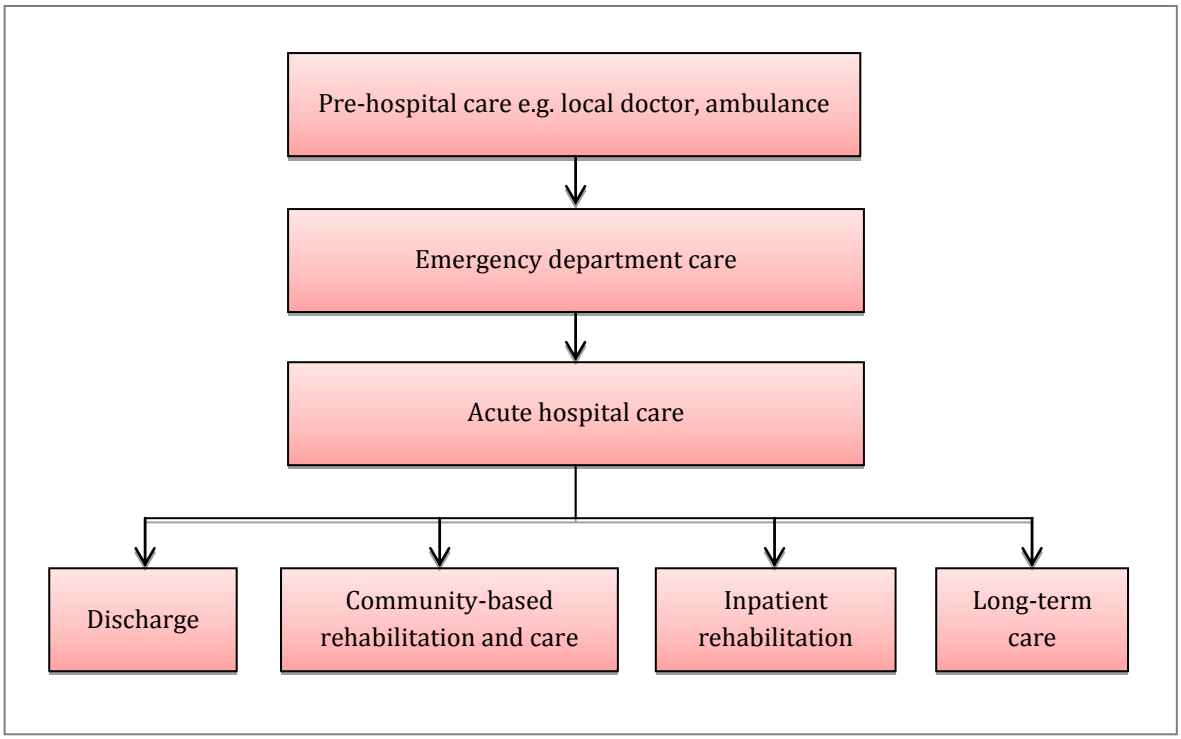


Figure 3.3 The patient journey after stroke.

Language profile of people admitted to healthcare after stroke

Determining which languages were likely to be spoken by potential participants prior to the study was difficult. In late 2008, neither the South Australian Department of Health nor the Central Northern Area Health Service (CNAHS) collected data on the language spoken by patients (personal communication, Angel Mihnev, Health Information Officer, CNAHS, 19/11/2008). St. Margaret's Rehabilitation Hospital reported that the four most common languages they required interpreters for were Italian, Greek, Polish and Vietnamese (personal communication, Rosalie Maher, Executive Officer, SMRH, 12/03/2009), but this data was not specific to patients with stroke and represented only a few of the diversity of languages known to be spoken in the CNAHS region.

Therefore, my study needed to accommodate not knowing the languages spoken by, or the cultural background of, participants prior to their recruitment. Although this approach differed from many cross-language healthcare studies (for examples see Webster, Thompson & Davidson 2003, Lam, Cheng & Chan 2004, Dohan, Levintova 2007, Fang et al. 2009), the strength of adopting such an approach was that the sample would reflect the diversity of the population who present for healthcare after stroke in this multicultural region.

To establish a language profile to inform my recruitment methods and assist the transferability of study findings to other community contexts, I collected data for the first six months of recruitment (August 2009 - February 2010) on the number of people admitted to each recruitment site after stroke according to the language they preferred to speak at home. Language was determined by recruiting physiotherapists using the 'language spoken' data on the front sheet of a person's casenotes recorded at admission to the facility, or the physiotherapist's own communication with the person.

The language distributions for people who preferred to speak a language other than English at home (LOTE), according to acute healthcare (TQEH and RAH) and inpatient rehabilitation healthcare (SMRH and HRC), are shown in Figure 3.4. Twenty different languages, other than English, were spoken at home by people who sought healthcare after stroke across the four recruitment centres. The most common languages spoken were Italian, Greek, Polish and Vietnamese, consistent with AIHW projections for South Australia's ageing migrant populations (Gibson et al. 2001) and the experience of interpreter usage at one of the recruitment centres (SMRH).

People who preferred to speak a LOTE at home represented 16 percent of 387 people with stroke admitted to acute healthcare during this period, and 18 percent of 141 people with stroke admitted to inpatient rehabilitation healthcare (Figure 3.5). The proportions for individual sites are given in Table 3.1. The highest proportion was 30 percent reported for SMRH. Although the specific languages that were spoken did vary between the acute and inpatient rehabilitation healthcare contexts (Figure 3.4), the number of different languages spoken was consistent within each healthcare context with the greatest diversity of languages in acute healthcare after stroke (Table 3.1).

These data indicated that the languages spoken by people who need healthcare after stroke are not isolated to the main language groups of the region. It also confirmed that for this study to be reflective of and relevant to contemporary stroke healthcare practice, it needed to be inclusive of people from different language groups.

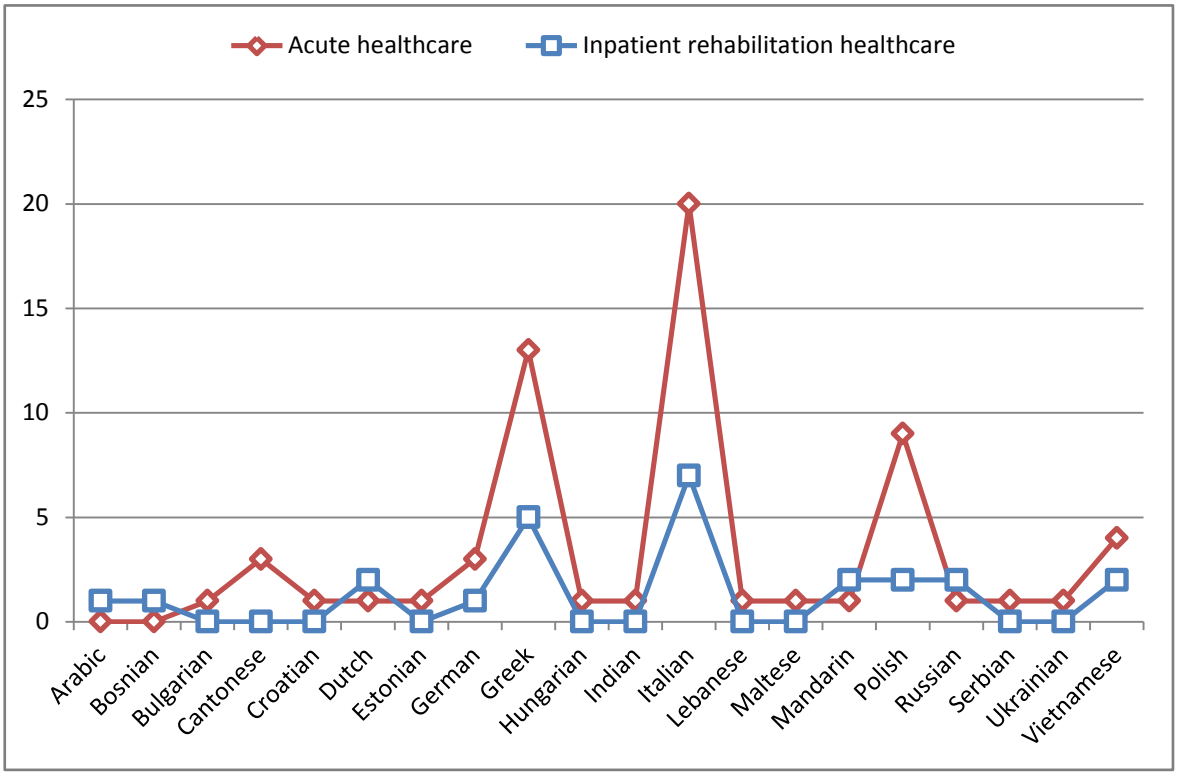


Figure 3.4 Number of stroke patients speaking a LOTE by language spoken (August 2009 – February 2010).

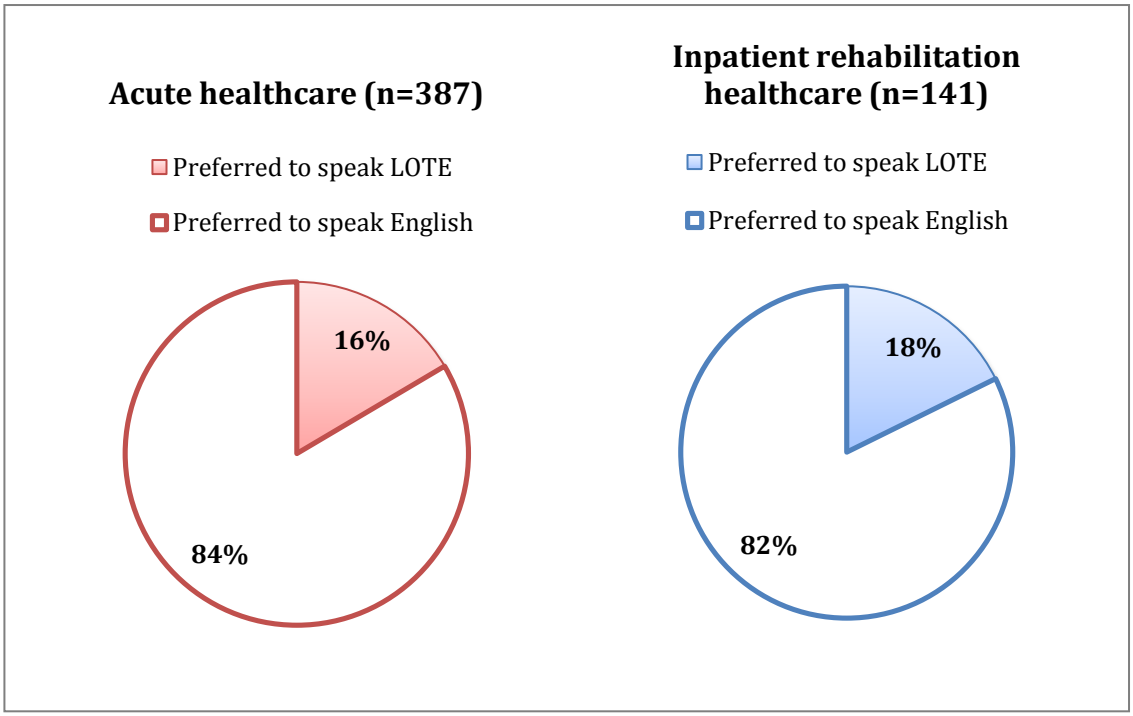


Figure 3.5 Percentage of patients who preferred to speak a LOTE (August 2009 – February 2010).

Table 3.1 Proportion of patients with stroke who preferred to speak a LOTE[a] and number of languages spoken, by recruitment centre (August 2009 – February 2010).

	No. of patients with stroke	**No. of patients who preferred to speak a LOTE at home**	**Number of languages spoken (LOTE only)**
Acute healthcare			
TQEH	159	31 (19.4%)	10
RAH	228	33 (14.5%)	12
Inpatient rehabilitation healthcare			
SMRH	50	15 (30%)	6
HRC	91	10 (11%)	6

[a] LOTE = Language Other Than English

Recruitment pathway

The recruitment pathway for the 14 participants who were recruited for the study is shown in Figure 3.6. Physiotherapists at each site agreed to assist with recruitment and provided feedback on development of the recruitment pathway. Physiotherapists were chosen as the primary recruitment contact because their role gave them access to potentially eligible patients and it was a method which had been successful in recruiting people after stroke, including people with LEP, within another study (Fryer et al. 2012a).

The recruitment pathway accommodated for not knowing the language of participants prior to recruitment by a strategic use of language assistants, including professional translators, professional interpreters and informal interpreters. The language used for recruitment was important to ensure that informed consent to participate was conducted appropriately (Liamputtong 2008) and to convey to potential participants that the study was serious about wanting to include them (Feldman et al. 2008).

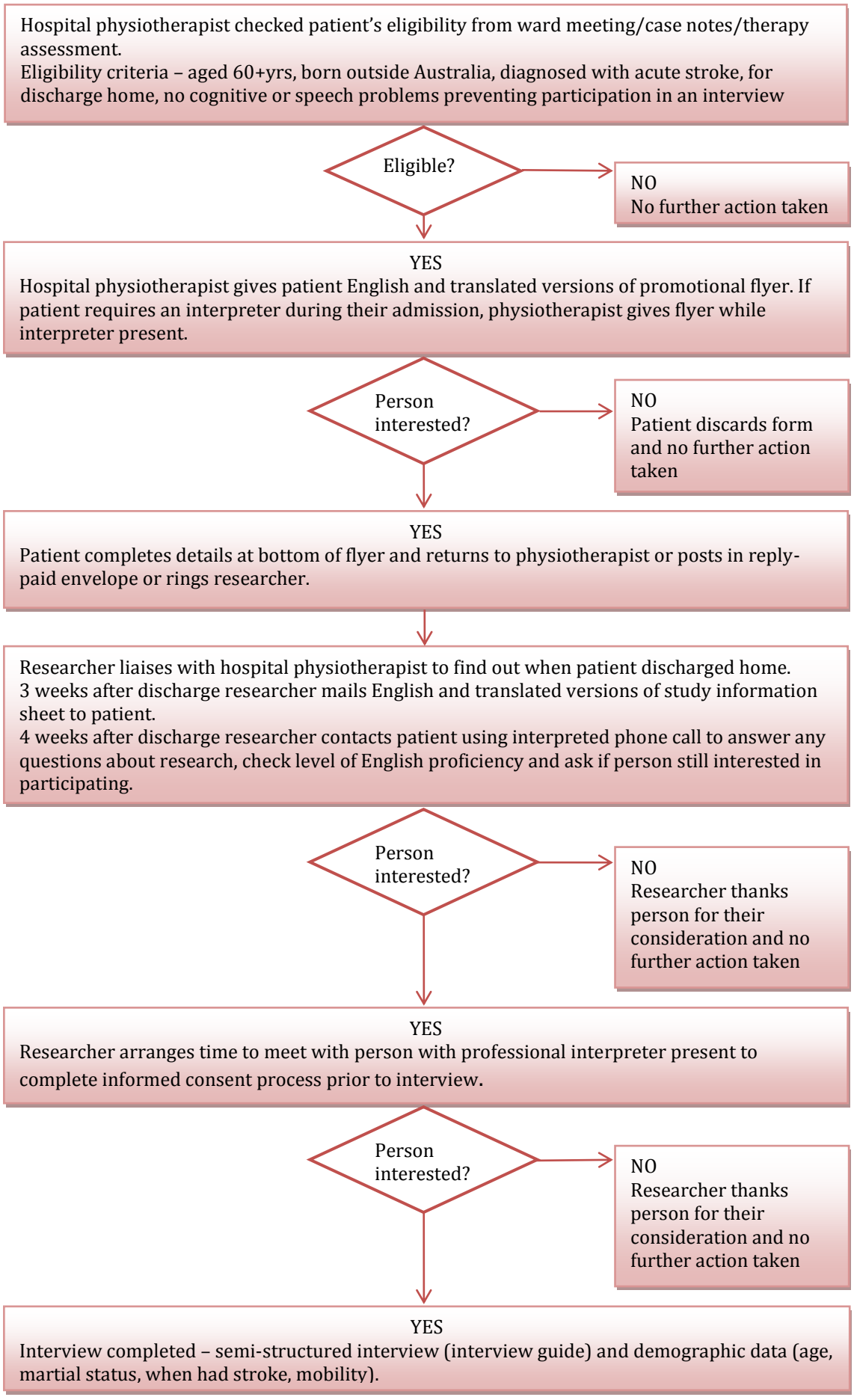


Figure 3.6 Flowchart of recruitment and consent process for participants.

Promotional flyers and consent forms were translated on an 'as needs' basis. When a potential participant was admitted to a recruitment site, the recruiting physiotherapist notified the researcher who then arranged for translation of the study's promotional flyer (Appendix I). Translation services were sought via email from accredited professional translators listed on the website of the Australian National Accreditation Authority for Translators and interpreters (NAATI) (http://www.naati.com.au/). The use of an accredited online source widened the pool of translators available to do the work in a timely fashion. An explanation of the purpose of the flyer and the study were given to translators in the email communication. Most translators were able to complete the work within five days, which was suitable for my study as a person after stroke stays in acute care for an average of six days (NSF 2009). Direct access to translators allowed the individual contractor to set their own fees. This was advantageous on several occasions as some translators offered discount fees when they were aware of the purpose of my study.

The recruiting physiotherapist gave the promotional flyer to potential participants when the language assistant used by that person during their healthcare was present; either a professional interpreter or an informal interpreter such as an adult child or friend. Both English and translated copies of the promotional flyer were provided so that the person's literacy was not assumed and the information could be read by interested family who may be able to speak but not read the older person's preferred language (Irvine, Roberts & Bradbury-Jones 2008). Eighteen of the thirty-four people who were eligible for the study and approached by recruiting physiotherapists declined to participate. Three potential participants were missed by the recruiting physiotherapists.

When the researcher received a flyer with a person's contact details and a confirmation of their preferred language, a translation of the consent form (see Appendix J) was arranged by working with the same translator as for the promotional flyer. Staggering translations in this way ensured limited research funds were not wasted if a person was not interested to participate after getting the flyer information, as was the case for two languages (Russian and German). The written translation of each consent form was checked prior to its first use by the professional interpreter who was assisting with interviews in that language. A problem with a translated consent form was noted on only one occasion and this was due to a printing error with the Unicode text of a Vietnamese document.

An interpreted phone call was used to contact the potential participant approximately four weeks after their discharge from inpatient healthcare. If the contact details of an English-speaking family member were nominated on the returned flyer then a phone call in English was made to them instead. During the phone call, the researcher established if the older person was still interested in participating, what their level of English proficiency was and answered any questions about the study. If the older person was interested in participating, a convenient time for an interview was then arranged and the researcher asked if they had any preferences regarding the professional interpreter to be present at interview, such as dialect or gender. Three people who had agreed to be contacted by the researcher then declined to participate at this time. The reasons they gave for declining participation at the time of the phone call were: the carer was too stressed about the number of health workers already visiting her husband to allow another person to visit; the older person was too scared to repeat his story for fear of legal repercussion; and a carer declined her grandmother's involvement because the older woman was very tired and unable to talk for long. One person who was contacted by the researcher was not limited English proficient, according to the definition of LEP (Figure 1.1), and so was determined to be ineligible for the study.

Informed consent

Detailed study information (Appendix K) was provided verbally in the person's preferred language at the time of interview or provided in English by the researcher if the person had declined the attendance of an interpreter. A verbal translation of the study information was used because the information sheet was lengthy (to meet the requirements of the Human Research Ethics committees) and was, therefore, an expensive document to translate in written form. Verbal translation was an economical and practical use of available language resources as the professional interpreter was already present to assist with the interview. If the person agreed to participate, they were given a consent form in their preferred language, or in English if they preferred (Appendix J), to read and then sign. At this point, the interpreter offered to read aloud the consent form and several participants accepted this offer.

All professional interpreters involved in my study were accredited with NAATI and sourced from one local agency. The use of a single interpreter agency ensured an interpreter was available at the time of the phone call or interview and reduced the workload requirements on the researcher to negotiate arrangements. Using a single

agency allowed me to develop a relationship with its manager and I was able to request the most experienced interpreters to assist me with the interviews.

Co–participant recruitment

The eight co-participants were not purposively recruited but voluntarily participated in data collection at the time of participant interviews as described in the previous section on 'Sampling'. As such, there was not a planned recruitment strategy for this group. So rather than disrupt the co-operative story-telling of the participant and co-participant during the interview, I waited until the interview had ended to ask if the information shared by the co-participant could be used in the study. If the co-participant had not been present for the verbal translation of study information prior to the start of the interview, the information was provided again and the co-participant was given a consent form to sign. Again, the interpreter offered to read the consent form aloud.

Interviews

Data from participants were collected using semi-structured, in-depth interviews an average of eight weeks after they were discharged from inpatient healthcare. Follow up interviews were then completed with 10 participants at an average of 21 weeks after their discharge. The protocol for the conduct of the first interviews is shown in Table 3.2. The protocol was informed by a constructivist grounded theory approach (see chapter 2, section 2.2.2), a systematic review of the methodology of published studies using interviews with older people from multiple language groups (see chapter 2, section 2.2.1), recommendations from the literature for cross-language research, and the practical experience of both myself and my supervisors in conducting research in this cross-language context. Integral to a culturally-appropriate and rigorous conduct of interviews in the multilingual context of the study was the interview structure and guide, the use of pilot, practice and second interviews, and thoughtful consideration of the language of the interviews, the involvement of professional interpreters and the transcription of interview data. These elements of my study's interview protocol are explained in the following section.

Table 3.2 Interview protocol.

When	Researcher actions	Researcher actions if professional interpreter declined by participant
Prior to interview	Read literature for awareness of language and cultural group. Meet with professional interpreter (first time) to discuss: • study topic and aim • purpose of interview and their role in interview • conceptual equivalency of interview guide • cultural background of language group • Interpreter's own experience and views of topic.	Read literature for awareness of language and cultural group.
During interview	Complete informed consent prior to start of interview (translated). Encourage participant to speak language as they wish. Use interview guide and address questions to participant. Use professional interpreter to seek clarification of uncertain terms or unclear talk. Digitally record interview.	Complete informed consent prior to start of interview (translated or English). Repeat information back to clarify uncertain terms or unclear talk. Digitally record interview.
Immediately after interview	Debrief with professional interpreter for possible clarification and evaluation of interview. Record field notes for interview and interpreter debrief.	Record interview field notes.
Prior to second interview	Transcribe first interview from recording. Analyse first interview.	Transcribe first interview from recording. Analyse first interview.
Second interview	Check interpretation of meaning from first interview. Clarify any uncertainty. Introduce concepts from analysis.	Check interpretation of meaning from first interview. Clarify any uncertainty. Introduce concepts from analysis.

Interview guide and structure

The aim of study interviews was to explore each participant's experience and allow the participant to identify what was important to them in their story. Exploratory interviews usually have an open format with some pre-planned questions, relying on the interviewer to follow up on participant's answers and to probe for more or new information to gain rich data for analysis (Kvale & Brinkmann 2009). Drafting of a semi-structured interview guide began by looking at published interview guides from instructional texts (Minichiello et al. 1995, Charmaz 2006, Kvale & Brinkmann 2009) and other grounded theory studies (Hutchinson 1993, Stanley 2006). The questions and structure then changed by trial and error during practice and pilot interviews, keeping an exploratory investigation of healthcare experience at the fore. The final interview guide for the first interviews with participants is included as Appendix L.

An example of the development of the interview guide was the changes made to the opening question. Initially, practice interviews opened with the question, "*Tell me what it was like for you during your hospital stay?"* This was quickly found to be unsuccessful in eliciting rich data as interviewees struggled to instantly evaluate and communicate how they felt about their experience, and it precluded their experience before they reached the hospital. In consultation with my supervisors, it was decided to use interview strategies that 'gave the person the floor' in telling their story. We realised from the practice interviews that it could not be assumed when or how participants' healthcare experience began after stroke so they needed the opportunity to nominate its beginning. It was also recognised that the idea of a set narrative structure may be variable and not, therefore, appropriate for all participants (Temple & Koterba 2009) and so the interview guide did not strictly follow the phases of a narrative structure. However, the idea of eliciting a narrative from participants prompted the inclusion of cues to what story I was interested to hear in the interview and where to locate its start. The following statement was made by the interviewer at the start of each first interview,

> *Now, I'm going to ask you to tell me about what happened after your stroke, right up to being here at home today. I want you to just keep talking in your own time and I will listen. I'd really like to hear your story. Later I may ask you a few questions, but for now I'll just listen to you. So, when did you have your stroke?*

Participants then chose how they related their experience after stroke and probes were used to extend their responses (Patton 2002, Wuest 2007) or to draw out and understand specific parts of their experience. For example, the following probe was used in one interview to gain more information about how the participant experienced not being directly addressed by the doctor in the hospital's Emergency Department,

> *Can you tell me what it is like for you when the doctor talks to your son and cannot talk to you?'* (Interviewer, English)

Once the storytelling was complete, relevant demographic information was then sought from participants to aid the analysis of their data and the transferability of study findings. Demographic information included participants' age, migration history, education level, circumstance of learning English (Temple & Koterba 2009), current living arrangements and their physical ability after stroke.

As the research proceeded, more focused information was desired and the guide was adapted for each participant's second interview to gain specific data for developing the theory (Charmaz 2004). The guide for the second interview was altered for each participant to accommodate for the different information requiring clarification and the interview's timing in respect to analysis and theoretical sampling. An example of an interview guide for a participant's second interview is given in Appendix M.

All interview guides for both first and second interviews finished with open invitations to participants to tell me anything that had not yet been mentioned about their care after stroke and to ask any questions. Several participants took the opportunity to ask for information or help relevant to their stroke and healthcare, including advice on how to relieve leg numbness, information about the duration of stroke recovery, *"Can you tell me how long a stroke holds a person in its grip?"* (Krystyna, Polish), assistance with helping their carer migrate to Australia, and help finding out who was installing their bathroom rail and why they hadn't shown up to do it. It was frustrating at these times that my role as researcher in the study did not allow me to provide expert advice and treatment to participants as the qualified physiotherapist that I am. But I had engaged in a relationship of trust with participants as a University researcher who was listening to their stories at a stressful and vulnerable time in their lives and so I did not believe that I was ethically or legally

entitled to act outside of that role. This did not mean that I could not help with participants' queries within the boundaries of the researcher role as an act of reciprocity (Liamputtong 2010); I provided two participants with stroke information from the National Stroke Foundation, I assisted another participants to find the names of local physiotherapists who could assess and treat his leg numbness, I asked the physiotherapist who had recruited one participant to find out who was installing his rail and communicate it back to him, and I also provided a participant with a letter that confirmed he had voluntarily contributed his time to participate in my study.

The length of interviews ranged from 29 minutes to one hour and 46 minutes, with an average duration of one hour and eight minutes. Interview time included both participant and their co-participant (if applicable) talking. Participants were given the choice of interview location and time. All but one participant chose to be visited at home and interviews were conducted in the living room or around the kitchen table, often over a cup of tea or coffee. One participant chose to be interviewed at the researcher's University, where we sat in comfortable chairs around a table in a meeting room with refreshments. All participants were given a small gift of cholesterol-free almond bread or summer fruit as a token of appreciation for their participation.

Practice and pilot interviews

Conducting in-depth interviews was a new research skill for me as I was more accustomed to the structured and focussed questioning of clinical assessments. The development of my interview technique was influenced by instructional texts which conceptualised research interviews as producing contextual, negotiated and constructed knowledge (Charmaz 2006, Kvale & Brinkmann 2009). Following Kvale and Brinkman's advice that "the craft of research interviewing is learned by practice interviewing" (Kvale & Brinkmann 2009, p. 89), I first consulted with two of my supervisors who were experienced in qualitative interviewing then practiced and practiced.

Practice interviews were conducted with five English-speaking women who had recent experiences of inpatient healthcare. The interviewees spoke English as their preferred language, were female and close in age to myself or my mother so it was a comfortable context for me to practice skills such as phrasing, intonation, sensitive listening, as well as trialling interview guide formats and the practical skill of digital

recording. I then practiced transcribing three of the interviews which allowed me to develop another skill required for my study and to reflect on my interview conduct.

Pilot interviews were an opportunity for me to trial the developed interview guide and interview skills with people who were close in age and experience to the intended study sample. The first two pilot interviews were conducted with English-speaking older people who had previously had a stroke. These interviews allowed me to trial the guide and practice techniques without the complexity of interpretation. I then conducted a pilot interview with a person with LEP who preferred to speak Mandarin and had previously experienced a stroke. I practiced my interview techniques with the assistance of a professional interpreter, trialling the interview question and probes in a cross-language context. It was not possible to pilot the interview guide and protocol with all languages due to the uncertainty of the sample's language profile and limited time and economic resources; instead, I used pre-brief sessions with professional interpreters to discuss conceptual equivalence of the interview guide, and an open style of questioning during interviews to allow participants to direct how they wished to tell their story.

Second interviews

Second interviews were conducted an average of 21 weeks after first interviews to ask more focused questions (Charmaz 2006) and to gain a thicker description of aspects of a participant's experience that were important to emerging concepts (Geertz 1973), as directed by theoretical sampling. An example from my study was a question I used in a second interview to explore the process of deciding the need for language assistance during healthcare,

> *I'm interested in how you decide when to get help with language during your healthcare. So, when you are going to be talking with someone about your stroke, say a doctor or a nurse or a physio, how do you decide if you will need help to understand?* (Interviewer, English)

Second interviews were also an important tool for the linguistic and cultural integrity of my analysis. I prepared for interviews by reading available texts about the migrant history and experience of people from the same language group and talking with the professional interpreter for that language about the community, but I recognised that a shared language did not mean that people shared all life experiences and

participants would bring different beliefs and meanings to events. Second interviews provided an opportunity to check with participants that I understood their meaning of an experience. This was not always a straightforward task due to the context of interpreter-mediated talk but was a successful strategy when used with sensitivity as demonstrated in the following example with one participant,

> *Interviewer (English): Last time you told me you liked to have help in Greek, in case you answered wrong and you might damage yourself.*
>
> *Andreas (Greek): I don't know if I have said that. That is the first time I have heard this because when I have an interpreter there, the interpreter tells me, I answer properly. I never said that I made a mistake, that I said this.*
>
> *Interviewer: I think you meant that you were concerned that if you did not have an interpreter you may answer something wrong. Is that right?*
>
> *Andreas: That's it, that's what I was thinking. Then they will think, "What is he talking about? He can't go home." Just keep me in.*

Second interviews were conducted with 10 of the study's 14 participants. Two participants did not have second interviews because of their poor health, one carer was too distressed by her husband's behaviour after stroke to agree to a second interview, and further data was not required for the analysis from one participant.

Language of interviews

Participants spoke seven different preferred languages (Table 3.3) and English was sometimes their third, even fourth, language. Self-reported English language proficiency during the interpreted phone call to arrange the interview time was not a reliable predictor of participant's language use during interviews except for the participant who spoke English "not at all". I conducted all interviews and always spoke English, my only proficient language. The following statement was made at the start of each interview to encourage participants and co-participants to use their preferred language or to speak in English as they wished,

> *(Interpreter name) is here today to help us by interpreting our talk. I am also happy for you to speak in English at any time if you wish to.*
> (Interviewer, English).

Table 3.3: Language and interpreter use by participants during interview.

Participant	English proficiency	Preferred language	Interpreter present
Katariina	Well	Estonian	×
Benigno	Well	Italian	×
Sadik	Well	Croatian	✓
Gino	Well	Italian	✓
Nam	Not at all	Vietnamese	✓
Waldemar	Not well	Polish	✓
Emilio	Not well	Italian	✓
Ming	Not well	Cantonese	✓
Vincenzo	Well	English	×
Christos	Well	Greek	✓
Krystyna	Not well	Polish	✓
Andreas	Not well	Greek	✓
Emanuele	Not well	Italian	✓
Thao	Not well	Vietnamese	✓

Participants often spoke a mix of their preferred language and English, with the extent of the mix differing between participants. Four participants who reported speaking English "well" chose to speak English for all or most of their interviews; even when an interpreter was present for one participant. Yet, the two other participants who reported speaking English "well" used their preferred language for all or most of their interviews. Even the participants who reported speaking English "not well" used occasional English words. The strategies of 'code-switching' between languages and 'lexical borrowing', using a word from the preferred language when an appropriate word in the second language is not known, are common during native/non-native speaker interactions and well-documented in sociolinguistics (Holmes 2001). It was not an aim of this study to determine the linguistic patterns of interview conversations; however, it did demand flexibility from interview and transcription methods.

When participants did speak in English, their speech was often heavily-accented and they *"talk in broke"* (Krystyna, Polish) with grammatical and pronunciation differences, *"Nothing am I go, I can't walking more than normal"* (Sadik, English). Professional interpreters helped when present by interpreting the accented English talk when it was difficult for me to understand. Respecting the participant's choice to speak in English, other strategies which I used were to ask the participant to repeat the sentence or repeating the information back to the participant for them to confirm my understanding, as used in the following example,

> *Gino (English): I said because, because it's (unclear).*
>
> *Interviewer (English): Sorry, because..?*
>
> *Gino: Because it's only little. The doctors say only little stroke.*
>
> *Interviewer: Because it's only little stroke?*
>
> *Gino: Yeah.*

If still unsuccessful, I apologised for my difficulty in understanding and asked for them to repeat the information in their preferred language.

For the two participants who declined an interpreter (Table 3.3), my challenge to understand their accented and limited English speech was greater and it required frequent requests for them to repeat or clarify talk. This was a sensitive but essential balancing act between interrupting the flow of the interview conversation and ensuring a good understanding of the participant's meaning (Marshall & While 1994). The interview was even more complex for two participants who chose to speak mostly in English as they also had a speech difficulty secondary to their stroke. The disabilities of dysphasia (Benigno) and dysarthria (Gino) required these participants to put a lot of effort into finding or pronouncing words, subsequently limiting the length of sentences they spoke. I used the same strategies outlined above, often using probes to draw out responses, and made extensive field notes of the conversation after each interview to refer to during transcription.

Professional interpreters

Professional interpreters assisted with 19 interviews with 11 participants. The interpreters were Ratka (Croatian), Piero (Italian), Minh-Hua (Vietnamese), Monika (Polish), Jean (Cantonese) and Erricos (Greek). They had all been working

professionally for over ten years and had extensive experience interpreting in healthcare situations. The assistance of a professional interpreter facilitated the shared understanding between me, the interviewer, and the participant at the time of the interview (Esposito 2001, Hennink 2008). Real-time professional interpretation allowed me to hear the interview dialogue as it occurred and to intervene to clarify responses or to rephrase questions at the time of the conversation that were later recorded in the interview's transcription. I was able to make decisions based on the data as it was being produced and to start my analysis by directing new questions while data was being collected (Larkin, Dierckx De Casterlé & Schotsmans 2007).

The use of professional interpreters is a method of bridging language discordance between the researcher and participant in cross-language qualitative research (Esposito 2001, Temple, Young 2004, Larkin, Dierckx De Casterlé & Schotsmans 2007, Hennink 2008). However, it is not a simple solution as there is often no exact translation of words or concepts between languages. In agreement with the views of Temple (2006), I understood all interpretation to be conditional, that is, it depended on the context in which it occurred. Interpretation of participants' data to English was situated within the context of the interpreter-mediated interview and the translation memories and histories of the interpreters (Temple & Koterba 2009). Therefore, the professional interpreters involved in my study were co-constructors of interview data (Wadensjö 1998), and their potential influence on the data was recognised.

Interpreters were prepared for their research role. As indicated by the interview protocol (Table 3.2), I met with each interpreter for an hour's 'pre-brief' approximately one week prior to their first interview. During the pre-brief, I explained the study purpose, the aim of the interview and the role I anticipated for the interpreter (outlined on the summary sheet for the meeting in Appendix N). A written copy of the study summary sheet, participant information sheet and interview guide were given to the interpreter at this meeting to help them prepare for the interview. The idea of conceptual equivalency was important to the interpretation (Twinn 1997, Birbili 2000) and so I encouraged each interpreter to actively select words or phrases to convey meanings which constructed the reality as presented by the participant to the researcher (Temple 1997, Hennink 2008),

As I do not speak a second language, it is important for this research that I understand the 'idea' of what the participant is telling me – what meaning they give to events that happened and how it made them feel.

The interview guide was reviewed by each professional interpreter for appropriateness of questions and any anticipated translation difficulty, but no one recommended changes.

To gain insight into the context of interpretation for each interview, I also used the 'pre-brief' to explore each interpreter's experience and perceptions of the research topic as suggested by Hennink (2008). Finally, I asked each interpreter about their perspectives on the study topic; their experience with healthcare interpreting work; if they were from the same community as the participant; and how they related to or perceived the participant's community (Hennink 2008). These discussions were recorded as field notes to aid transparency of my study, to assist with my awareness of the cultural group of the participant and interpreter and my understanding of the context of each interpreter-mediated interview. A few interpreters closely identified with the study through personal experiences with older relatives who had suffered a stroke and they shared these stories with me. Another interpreter had a strong belief that the Australian healthcare system was much better than the healthcare in his country of birth and we spent time at his pre-brief and in a couple of interview debriefs discussing its relevance to the healthcare experiences being reported by participants. It was interesting that it was not a perspective that emerged from participant data.

During the study, the interpreter and I met for a short debrief after the participant interview was completed. In the debrief I sought clarification of any terms or phrases that remained uncertain, and asked for the interpreter's perception of the conduct of the interview, that is, how they perceived the ease of the participant in answering questions or any difficulties noted. Sometimes the interpreter also volunteered historical information as background to the participant's reported migration or work history.

It was necessary to work with multiple interpreters because multiple languages were spoken in the study sample. One interpreter was used per language for consistency of interpretations. All interpreters were accredited with NAATI, requiring them to abide

by the Australian Institute of Interpreters and Translators Incorporated (AUSIT) Code of Ethics (http://www.ausit.org/eng/showpage.php3?id=650). I was comfortable and experienced working with interpreters in a research situation (Fryer et al. 2012a) and I attended a 'Working with interpreters' workshop offered by another metropolitan health service (separate to CNAHS), prior to data collection to consolidate my skills. To my dismay, the presenter at the half-day workshop focused on achieving the most economical service from interpreters rather than skilling attendees in effective working relationships with interpreters. I did gain useful practical advice from the handouts and realised that I had gained a valuable insight into how language services could be perceived by healthcare providers, that is, as an untrustworthy tool to be controlled rather than an opportunity for collaborative working.

Field notes

Field notes were written into a notebook after each interview to construct a context for making sense of the data later in analysis (Patton 2002). Details about the setting, the participant's reaction to questions, co-participant involvement and quality of the information were recorded. My notes began as novice description, gaining greater depth in writing as my study progressed. Consistent with a constructivist approach, I strived not to omit or gloss over the 'more messy' details of human experience that occurred in the interview context (Emerson, Fretz & Shaw 1995), as the following example of field notes about Emanuele's wife, Paola, depicts,

> *In the early part of the interview, Mrs. ___ continued washing dishes very loudly. She then made a phone call next to us at the table. It was short and I assume to family. Although I sensed Mrs. ___ was reluctant for us to be there, I also understood that she was unsure of us and our purpose despite the informed consent, and so involved her family. All the banging made me nervous about the (digital) recording though!*

(Paola's daughter arrived at the house a short time after the phone call. Reservations allayed, Paola then offered us some wonderfully strong coffee.) Brief notes were jotted down during interviews as a reminder of relevant probes or ideas to discuss with the interpreter in the following debrief.

Transcription of interview data

The first five interviews were transcribed by me in English using NVivo 8 software. All English talk, direct and interpreted, was transcribed as spoken; no grammatical corrections were made. This early work assisted my immersion in the data and enabled early analysis. However, the time demanded to transcribe lengthy interviews made it difficult to complete transcriptions concurrent to data collection as required by grounded theory's constant comparative method. Therefore, 17 of the remaining 19 interviews were professionally transcribed in English. One agency was used for all professional transcriptions to establish a relationship with the agency manager. She gave my work to the more experienced transcribers, matching familiarity with language if possible. I chose to transcribe both second interviews with participants with speech difficulties myself because of the difficulty in understanding their speech.

Each professionally transcribed interview was carefully checked and many corrections needed to be made due to the difficulty that the transcribers experienced with participants' and interpreters' accented English. My presence as the interviewer at all interviews and my detailed field notes assisted with corrections yet there were still occasional words in each interview that could not be understood or recalled at transcription. The temptation to guess at meaning was avoided; unclear phrases were followed up at the second interview or the uncertainty was acknowledged on the interview transcription.

Participants

Study participants were 13 older people with LEP after stroke, one older person from a CALD background who preferred to speak English, seven co-participants who were LEP and one co-participant who was English proficient. The demographic information for participants is given in Table 3.4, and for co-participants in Table 3.5. The sample was diverse in preferred language, self-reported level of English proficiency, years lived in Australia, healthcare facilities attended, and their level of functional independence. Functional independence was assessed based on the participant's reported need for assistance, or not, to dress and walk within their home. If they required assistance to mobilise, then the type of assistance such as walking aid used was noted.

The majority of participants had not learnt English before migration and had not completed secondary schooling, but two were tertiary educated and four had an earlier exposure to English. An important point in noting the diversity of the sample was that it allowed the study to explore common issues in their experiences of healthcare as people with LEP, regardless of their ethnic background, their social characteristics or the particular services they used; a strategy shared by Edwards, Temple and Alexander (2005) in their investigation of the use of interpreters. A brief synopsis for each participant and co-participant is given in Appendix O.

3.2.2 Data analysis

Data analysis was guided by constructivist grounded theory's "systematic yet flexible guidelines for collecting and analyzing qualitative data to construct theories 'grounded' in the data themselves" (Charmaz 2006, p. 2). The use of data coding and written memos, both progressing from initial ideas through to a conceptual level as the study proceeded (see Figure 3.1), were integral to the process of analysis.

Coding

My coding followed the process outlined by Charmaz (2006). Each English transcript of interpreted interview talk was initially coded line by line, staying close to the data and identifying active processes within it. The initial codes I used were quite descriptive, such as, 'comparing self with others' and 'dismissing need for help'. An example page of my initial coding is given in Appendix P. As the number of interviews increased, data were compared incident with incident, within and between participant data, comparing healthcare events such as 'admission to hospital' and 'transfer to rehabilitation'. Comparison of events in the patient pathway after stroke helped me to identify processes in participants' experiences of these events and generate new ideas about what was happening in the data. Three months into my analysis I had created over 130 individual initial codes, including the in vivo codes 'hospital was like a holiday', 'they didn't tell me much' and 'now it's alright', and 19 codes labeling demographic data or a healthcare event on the patient pathway. A list of the initial codes is provided in Appendix Q.

Table 3.4. Demographic information for participants (in order of when first interview conducted).

	Age (years)	Gender	English proficiency	Preferred language	Interview language[a]	Learnt English	Years in Australia	Education	Acute hospital	Rehab centre	Dressing ability	Mobility
Katariina	82	F	Well	Estonian	English	Estonia	61	Tertiary, Australia	B	n/a[b]	independent	independent
Benigno	76	M	Well	Italian	English	Australia	55	Primary, Italy	A	A	independent	independent
Sadik	65	M	Well	Croatian	Croatian English	Australia	26	Incomplete secondary, Macedonia	B	n/a	independent	frame
Gino	85	M	Well	Italian	English Italian	Australia	48	Primary, Italy	B	B	independent	independent
Nam	81	M	Not at all	Vietnamese	Vietnamese	N/A	21	No schooling	A	A	needs assist	wheelchair
Waldemar	86	M	Not well	Polish	Polish	Australia	20	Secondary, Poland	A	n/a	independent	independent
Emilio	81	M	Not well	Italian	Italian	Australia	55	Primary, Italy	A	A	independent	frame
Ming	86	M	Not well	Cantonese	Cantonese	Malaysia	20	Secondary, Malaysia	B	n/a	independent	independent
Vincenzo	83	M	Well	English	English	Italy	58	Primary, Italy	B	B	independent	independent
Christos	74	M	Well	Greek	Greek	Australia	48	Not known	A	A	independent	independent
Krystyna	83	F	Not well	Polish	Polish English	Australia	59	Primary, Poland	A	A	independent	frame
Andreas	88	M	Not well	Greek	Greek English	Australia	50	Primary, Greece	A	A	independent	independent
Emanuele	82	M	Not well	Italian	Italian English	Australia	47	Incomplete primary, Italy	B	n/a	needs assist	frame
Thao	66	F	Not well	Vietnamese	Vietnamese	Vietnam	5	Incomplete secondary, Vietnam	A	A	needs assist	walking stick

[a] Language that participant chose to speak the most during interview/s is listed first, [b] n/a = not applicable.

Table 3.5. Demographic information for co-participants (in order of when relevant participant's first interview was conducted).

	Related to	Relationship	Age (years)	Gender	English proficiency	Preferred language	Language of interview[a]	Learnt English	Years in Australia	Education
Helena	Sadik	wife	60	F	Well	Slovenian	Croatian English	Australia	26	Incomplete primary Slovenia
Rosa	Gino	wife	82	F	Not well	Italian	Italian English	Australia	48	Incomplete primary Italy
Hung	Nam	son	>60	M	Not at all	Vietnamese	Vietnamese	N/A	6	Primary Vietnam
Son	Nam	son	>50	M	Well	Vietnamese	English	Home country	30	Primary Vietnam
Donna	Emilio	wife	73	F	Well	Italian	English Italian	Australia	49	Primary Italy
Eva	Andreas	wife	63	F	Not well	Greek	Greek	Australia	11	Tertiary Russia
Paola	Emanuele	wife	79	F	Not at all	Italian	Italian	N/A	47	Incomplete primary Italy
Daniella	Emanuele	daughter	58	F	Very well	English	English	Australia	47	Incomplete secondary Australia

[a] Language that participant chose to speak the most during interview/s is listed first.

Focused coding then helped me to identify the initial codes and processes that were becoming more important in the analysis by appearing regularly in the data and/or being given prominence by participants in their stories. Actions remained the central focus of the analysis. Focused coding was an intensive task of moving back and forth between data with each coding development, using deductive reasoning to question what was happening, how it 'fitted' with what I already knew, and how I was interpreting it. Helpful to this stage of developing the focused codes was using critical questions of the coded process (Charmaz 2006, p. 51),

> What process is at issue here?
> How does the process develop?
> How does the participant act/think/feel while involved in the process?
> When, why and how does the process change?
> What are the consequences of the process?

Asking these questions sharpened the structure of the code, helped to identify its relationships with other codes in the analysis and to identify the gaps needing to be filled. It was also a method of checking if the code 'stood up' to being of importance in the developing theory with supporting data. The following excerpt from a memo written for the focused code, 'being told the rules' demonstrates the use of this questioning in focused coding. In this instance of analysis, a link is made to another code, a new code/property is suggested, and a gap is identified to be filled by second interview data.

> *25/10/2010 11:27 AM* ***Being told the rules***
> ***How does the participant think/feel/act while in this process?***
> *Doing what is expected. Overall it seems to be acceptance of care and trust to follow rules given by health professionals. A trust that health professionals know what needs to be done after stroke so need to do what they say. Katariina, Benigno and Gino take extra medication. Benigno did not walk outside until allowed to by nursing staff. I need to start a new code, 'accepting the rules' for this experience which I anticipate will link into ideas of trusting health professionals and care received. Is it 'accepting' or 'doing what I'm told'. Occasionally the participants will 'speak up' against the rule, question it, e.g. Andreas and being strapped in to ambulance trolley, Krystyna going home. But this is not always successful for the participant e.g. Andreas is still strapped in. Gino 'spoke up' with his actions of driving licence. Need to find out who told him that he could not drive and why he ignores (second interview analysis). Sadik resisted his family rules at the*

beginning. Emanuele resists rule to go to rehab - discusses with his family and family then agree.
For Ming, the rule was not to ask for information and Ming continued to follow this rule during his care until invited to ask info by me during interview. Perhaps more culturally related to what is expected of someone in his role. Check more in second interview analysis.

During focused coding, initial codes were often merged or altered as data interpretation became more nuanced. The initial code 'explaining stroke' started with the first participant explaining their stroke as, *"just a problem with the blood"* (Katariina, English). The code was changed to 'understanding stroke' several interviews later to emphasise the action of participants in understanding their condition, rather than emphasizing their action when explaining it at interview. In focused coding it became 'making sense of stroke' and the properties of the process were defined, including how participants made sense of stroke, when were they satisfied with their understanding of stroke, and what were the consequences when participants made their own sense of what a stroke was. This focussed coding later informed the theoretical process of '*hanging on to the familiar*'. Relations between codes were also developed, for example, the codes 'being told' and 'being fobbed off' formed conditions of the process '*being told and being a good patient*'. Focused coding gained an overall picture of the healthcare experience after stroke for older people with LEP but the analysis remained at a descriptive level.

The next step in analysis was to conduct theoretical coding as a method of integrating the focused codes into a coherent story (Charmaz 2006). Theoretical coding began during the iterative process of analysis and data collection when first interviews were completed, recruitment was paused and several second interviews remained to be conducted. I found that theoretical coding was the hardest part of the analysis as it required the confidence and ability to apply conceptual abstraction to the data. Gibbs (2007, p. 54) describes it as moving away from codes that are couched in participants' world views and using new, theoretical ways of explaining the data. Achieving a higher level of conceptualisation was not an entirely structured or linear progression, rather relying on an intangible "something" that occurred when discussing, memoing, reading and thinking about the data (Corbin & Strauss 2008, p. 9).

During theoretical coding, the analytical support of my supervisors was very helpful. Their diverse disciplines and experience in sociological theorising (sociolinguistics

and health sociology) provided different impressions of the data which challenged my interpretations and emerging ideas. I tried not to look too far from the data in developing theoretical codes (Charmaz 2006). Conceptually I thought of the data in terms of processes encompassed by conditions, responsive actions and emotions, and then consequences. I wanted an active story of the experience; a story that could be applied to clinical practice situations rather than confining its usefulness to static themes. An integral step was to check that all data from the focused coding analysis could be integrated within the developed theory. By hard intellectual work and being prepared to raise some ideas to abstraction and then watch them fall when they strayed too far from the data, three theoretical processes were developed. Each process was considered in theoretical sampling and saturation and I continued to use the critical questions to inform the structure of each theoretical process.

The resultant theory did not possess the overarching explanatory concept or core process that is often associated with grounded theories (Corbin & Strauss 2008). A single dominant process was not identified in the data and was not forced to appear. This approach was consistent with the constructivist view that assumes complexity in worlds, views and actions and constructs theory that reflects this complexity (Charmaz 2006). The substantive theory I developed consists of three conceptual processes which offer an interpretive understanding of the healthcare experience after stroke for older people with LEP. It was developed to promote the communication of that understanding to others; to tell a good analytical story.

Memos

Memos were integral to 'doing' grounded theory analysis, forcing me to think about the data and my coding process (Corbin & Strauss 2008). Initially I handwrote memos in a journal, detailing my planning decisions and study progression. However, my entries were spasmodic in timing, often forgotten when I was busy interviewing, and were more reflexive report rather than incisive analysis. Following the advice of Gibbs (2007, p. 40), I started a new memo with each new code and routinely added to the memo each time the code was used or changed. After attending a grounded theory workshop led by Kathy Charmaz in April 2010, I began to title each memo, included data in my ideas and used the memos to ask questions of my data. The following example dated a month after the workshop, is a typical memo from early in my

analysis. I had started to explore relationships in the analysis and highlighted ideas to pursue.

> *6/05/2010* ***being discouraged to talk***
> *In Gino's interview, Gino mentions that the doctors on ward round 'they get mad' at rehab centre B if patients ask questions. This is the first time I have heard a participant feel directly discouraged to talk by a health professional. Other times they have explained lack of talking to staff because of work or time pressures on staff. Will it occur again? It may be related to 'knowing the rules'? Was this just another way of letting Gino know what the rules are - not to ask questions on ward round? It is good to know then that Gino broke the rules to ask a question that he felt was important - the probability of stroke reoccurrence. I will explore this more in 'breaking the rules'. And he got a lot of benefit from asking the question as the answer gave him 'courage'.*

The memos became more advanced during focused coding. I often used Charmaz's critical questions to ask questions and make comparisons within the supporting data as well as other processes. In the following excerpt from a memo linked to the focused code, 'getting back to normal' (which later became the theoretical idea of 'wanting the familiar' in the process of *'weighing up the value of care'*), I made comparisons between participants and started to delineate the properties of the process.

> *17/11/2010 1:49 PM* ***getting back to normal: identifying the process***
> ***What process is at issue here?***
> *Getting back to normal. 'Normal' refers to what the person values in their 'before-stroke' life. This can include both intrinsic dimensions (physical and intellectual capabilities, independence in tasks) and extrinsic dimensions (home/familiar environment e.g. family, friends, language, food, garden; responsibilities e.g. being able to drive wife to appointments, do Christmas shopping).The ability to be autonomous in managing their life.*
> ***Under which conditions does this process develop?***
> *Both intrinsic and extrinsic dimensions of getting back to normal occur during recovery from stroke. Can be assisted by therapy (but then cannot be as well!). Strongly influenced by the active agency of participants e.g. speaking up, self-motivating, and the assistance of family/friends.*
> ***How does the participant think, feel, act while involved in this process?***
> *Participants desire and expect to get back to normal. And they expect their healthcare to help them to get back to normal i.e. expect that healthcare professionals will have this aim. Proud of their achievements when get back to normal, e.g. Benigno walking, Gino strength, Ming walking, Krystyna gardening and cooking.*
> *Success. Pride, especially if has been noted by health professionals, e.g. Benigno's physio (first interview) and nursing staff (second interview), Gino's physio votes.*

Compares self with others to reinforce own achievement of normality, e.g. Gino, Benigno, Katariina, Andreas.

Conceptual ideas relating to the analysis were also memoed but separately to the coding memos. Conceptual ideas were sparked during coding sessions, analysis discussions with my supervisors, or inspired by the research of others. These more advanced memos explored ideas with relevant literature and related the new understanding back to the analysis, suggesting where the ideas fitted and where they may lead. The following example explored the idea of patient participation in healthcare. I explored the idea of people needing an understanding of their healthcare to engage with it and how this may relate to the participants in my study who independently made sense of their healthcare.

6/09/2010 10:16 AM ***needing understanding to actively participate***
In their investigation of patient perceptions on goal setting in neurological rehabilitation (excluding people with LEP, see memo on 'constructions'), Holliday et al (2007) state, 'An understanding of the process of rehabilitation appeared to be necessary to enable the active participation of patients' (p391). They note that some patients expected an end result but with little idea of what was involved in order to achieve this. And for some patients, they did not expect to be actively involved in goal setting but viewed it as getting 'from A to B and get better really' (p392). The authors perceived the patient as expecting to get naturally better but I wonder if, like for some of my participants, he also expected it would happen as the rehabilitation team knows what they were doing and he did not think he needed to know.
So if people need understanding to participate, what if they do not seek understanding? Then if they are not given information or resources to understand, they will continue to not understand and surely that has consequences for them valuing care and therefore participating.
In their discussion on staff perspectives on goal-setting in neurological rehabilitation, Van der Weyer et al (2010) note the 'patients may be unfamiliar with the process of goal setting within their lives in general, and consequently not appreciate the process as a way of establishing direction for treatment ' (p1425). They warn against staff 'misinterpreting' behaviour as lack of motivation or being 'passive' as staff note that the 'very passive' patients are hard work to set goals with. But is it 'passivity' or not being familiar with the process? Van der Weyer et al (2010) has provided me with some more refs to follow up on goal setting and communication between therapists and patients that may provide more insight to my analysis of expectations and experiences of understanding during rehabilitation and hospital care - (Parry 2004, Liu 2004, Holliday 2007.

Advanced memos then integrated the main processes from focused coding into theoretical processes and an overall theory. Advanced memos used ideas from earlier coding memos and concept memos to develop conceptual abstractions of the analysis

and tie the processes together. Again I used Charmaz's questions to provide a basic structure to the memos but I focused on writing them as if I was presenting my analysis as a theoretical argument. Each memo added more to the argument. As the memos developed, they formed parts of the desired analytical story and eventually became my findings chapters.

Diagrams were used regularly during analysis for three purposes. First as a clustering tool during initial and focused coding to initiate ideas about the conditions and relationships of processes (Charmaz 2006). It was sometimes easier to try out potential links graphically before committing the idea to writing. Later in analysis, diagrams were useful to gain a quick graphic representation of the developing theory at different stages to see if the scope, directions and connections between processes were 'working' and to play with changes (Charmaz 2006). An example of this is provided in Appendix R. I also found diagramming to be an excellent method of communicating my analysis to my supervisors when seeking assistance or feedback.

Computer–assisted analysis

NVivo 8 computer software was used to assist my data management and analysis as the central storage and flexibility it offered was a practical solution to working between a shared office at University and a shared home study space. Computer programs have been recognised to support grounded theory analysis (Corbin & Strauss 2008), however, there are concerns that the software can become the focus of the research rather than the data and the intimacy of the analysis process disappears (Hesse-Biber 2007). To address these concerns, all initial coding of first interviews was done by hand. Not only did this allow me to practice and develop my qualitative coding skills, it was also an easy way to compare coding in group discussions. It satisfied a need to 'get my hands dirty' in analysis and gain an initial 'feel' for qualitative coding that I did not believe the computer interface could offer.

All second interview coding was completed using the computer software and a coding and memoing structure determined by the analysis. The software facilitated a more expeditious analysis as my confidence and skills in coding increased, and it allowed easy recording of emerging relationships between items. I attended NVivo 8 training before, and during, my analysis. All study data and analyses were regularly backed up to the University's server.

The design and methods of the study that have been presented so far in this chapter have little worth to the reader unless they can be trusted to be rigorous and ethically sound. In the final section of this chapter, I demonstrate how issues of rigour and ethics were considered and addressed within my study.

3.2.3 Rigour and ethics

In-depth qualitative research in a multilingual and cross-cultural context presented many methodological and ethical challenges for my study. Although the reporting of the rigour and ethics of the study has been positioned at the end of the methods chapter, they were not considerations which were left to the end of the study. Influenced by the unique challenge of conducting research with multiple language groups and exhortations in the literature to attend to rigour throughout the research process (Morse et al. 2002), the rigour and ethical considerations of the study were at the forefront of its planning as demonstrated in chapter 2 (section 2.2) and were also attended to throughout the research process.

Rigour

Methodological rigour was defined in Chapter 2 (section 2.2.1) as the means by which researchers show "integrity and competence" in their research (Tobin & Begley 2004) and so enhance the usability of the research findings for readers (Sandelowski 2004). The evaluation of my study's rigour is framed by Lincoln and Guba's (1985) four constructs of the trustworthiness of interpretive research: credibility, transferability, dependability and confirmability. In ensuring the rigour of the research process during its planning and conduct, I paid particular attention to issues of language and communication (Hennink 2008).

Credibility

Credibility is the degree to which the reader can be confident that the findings are an accurate representation of the phenomenon which the study sought to understand and theorise (Pyett 2003). The credibility of my study related to its representation of the healthcare experience after stroke for older people with LEP. Credibility was demonstrated by the coherence of the study's constructivist grounded theory research approach with its aim to understand the experience of a culturally and linguistically diverse group of people (Ballinger 2006), as explained in chapter 2,

section 2.2, and the consistency of study findings with established knowledge, as discussed in chapter 5, section 5.1. Credibility of my study was also demonstrated by strategies that were used during data collection and analysis.

The assistance of professional interpreters was integral to the credibility of the collected data. The interpreters were accredited professionals who were experienced in healthcare situations. Real-time professional interpretation allowed each participant to participate in the interview in a language they were proficient in so they could have familiar words available to them to express themselves accurately. It also allowed me, the researcher, to hear the interview dialogue as it occurred and to intervene to clarify participant responses at the time of the conversation so I could accurately interpret their meaning. Professional interpreters also assisted my cultural awareness of each participant's migrant background before the interview to aid my interpretation of participants' meaning. This was supplemented by reading relevant literature beforehand and discussing the conduct of the interview and its data with the professional interpreter afterwards.

The credibility of the data collection was strengthened by practice and pilot interviews which honed my interviewer skills and the interview guide. Data was sought from the people whose healthcare experience was being investigated and so the sampling strategy identified older people with LEP. The open format of the first interview encouraged participants to share their story with me in its entirety and I took time to establish a rapport with them and their family members who were present to encourage this information sharing (Shenton 2004).

The use of one person to conduct interviews and check transcriptions ensured consistency in the collection of data. I attended to reflexivity about the influence I brought to data collection and analysis (Finlay 2002) by examining my own background, perceptions and interests on the research process in memos, field notes and I was reflexive about the research process and decisions made in my reporting of the study. This included providing a personal account of myself as the researcher in Chapter 1, section 1.3.

A particular issue for credibility that arises in research conducted with people from diverse language backgrounds is how to analyse data from multiple languages

(Liamputtong 2010). The ideal solution would be to employ bilingual analysts for each language group but due to practical considerations involving cost and availability, a compromise was reached in my study for all analyses of interview data to be conducted from transcriptions of the professional English interpretation of the talk. This method of analysis has been demonstrated, in a qualitative healthcare study with women who spoke Cantonese, to produce the same major conceptual categories as when the data was analysed in the spoken language despite some minor differences in text (Twinn 1997). It is also an approach supported by grounded theorist, Phyllis Noerager-Stern, from her experience supervising research students in Thailand. She suggested that as grounded theory is generated from multiple sources and comparisons of data, it is the substance rather than the grammar of the interview data which needs to be accurate,

> *…so what difference does it make if Mary said, "I don't think I can go on", or "I just can't go on". The essence is there – Going on might be the substantive code* (Stern 2009, p. 58).

The credibility of the data analysis was then confirmed in several ways. The grounded theory method of the constant comparison of data within and between participants provided triangulation via data sources (Shenton 2004). In this way, an important process in the experience of one person was confirmed by its presence in the experiences of several other participants as well. I also took my analysis back to the field. Participants' second interviews provided the opportunity for a form of member-checking (Lincoln & Guba 1985) to clarify that I understood participant's meaning as they intended for it to be understood and emerging ideas were introduced and explored (Charmaz 2006). Following the constructivist approach, as little as possible was presumed about the data constructed in the interviews (Berbrier 2008).

Frequent debriefing about the study strengthened the credibility of the analysis (Lincoln & Guba 1985, Tinker & Armstrong 2008). I regularly met with my three supervisors, who were from different disciplinary backgrounds, for group analytic discussions. Modelled on a group process used by Van der Weyer and her colleagues (2010), the meetings provided an opportunity for my supervisors, as experienced analysts, to sensitise me, as the study analyst, to different nuances in the data and the possibilities for alternative interpretations. The findings of the study were also

exposed to peer scrutiny (Shenton 2004) by presenting to other researchers and clinicians in the fields of gerontology and physiotherapy at conferences and health service talks.

Transferability

Transferability of a study is demonstrated by providing sufficient information to enable the reader of the research to draw conclusions about the relevance and possible transfer of the findings to their own situation (Lincoln & Guba 1985). To this end, the contexts and methods of the study's sampling and recruitment are fully described in section 3.2.1 of this chapter. Extensive demographic information of participants and co-participants, including their level of education, years lived in Australia and mobility status, are provided in Tables 3.4 and 3.5. This information is supplemented for interested readers by the participant and co-participant synopses in Appendix O.

Dependability

The constructivist grounded theory approach of the study recognises that the empirical world may be constructed in multiple ways by the researcher and participants (Charmaz 2008a), and so contrasts with the positivist idea that the research and its findings will produce a single truth that can be tested by replication. The dependability of the study is, therefore, understood as the provision of sufficient information for future researchers to repeat the study's process, if not necessarily to gain the same results (Shenton 2004). It is an assessment which entails a degree of trust in the integrity of the researcher in reporting the research process; a trust which must be earned by a demonstration of honesty, reflexivity, discipline, and rigour in reporting (Pyett 2003). The dependability of my study is demonstrated by the detailed description of its methods given in this chapter which has aspired to demonstrate the trustworthy qualities which Pyett (above) has demanded of it.

Confirmability

The confirmability of a study is explained by Shenton (2004, p. 72) as the steps taken "to help ensure as far as possible that the findings are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher". The constructivist approach of this study, which recognises that the

researcher is actively involved in the construction and interpretation of data, then appears to contradict the idea of confirmability. However, the approach aspires to develop theory that is grounded in the experience and meanings of participants while recognising that the preconceptions of the researcher may "influence, but may not determine" the study findings (Charmaz 2006, p. 67). The key is for the researcher to be reflexive about their influence on the research and regularly examine their decisions and whose point of view they are reflecting in their analysis (Charmaz 2006).

To achieve confirmability in the present study, the influence of the researcher and professional interpreters to the data collection and its interpretation were acknowledged and examined through discussions with interpreters and other peers, and reflexive writing in field notes, memos and study reporting. Taking the researcher's interpretations back to participants during interviews ensured that if the interpretation did not fit to participants' understandings then it was discarded. For example, I had interpreted one participant as not wanting to do what the ambulance officers were asking of him. When I checked this at his second interview, I found my initial interpretation was wrong in that he was reluctant to leave his home but never intended to disobey the instructions of the ambulance officers. Peer scrutiny from supervisors and conference audiences also ensured that the researcher's interpretation was discussed and debated. An audit trail of coding decisions is retained within the computer file of the analysis. Finally, by providing a reflexive personal account of myself as researcher in chapter 1, the reader can make their own judgement of the confirmability of the study's findings.

Ethical considerations

The study was initiated and conducted with the intention of being a just and ethically sound experience for the participants and their communities. It was recognised that there are complicated historical, social, political and cultural agendas which affect people from CALD backgrounds and that researchers working with these people have the responsibility to ensure that the research benefits rather than further marginalises a group of people who are already vulnerable (Pyett 2001, Liamputtong 2008, Liamputtong 2010). The following section discusses the ethical considerations that were made in the practice of my study.

The premise of my study was that it would benefit the participants and their communities by bringing attention to a group of people who have previously been ignored in the research of healthcare after stroke and by providing practical recommendations to improve healthcare for older people with LEP. Rather than focusing on as a 'special' group, the study sought to highlight that people with LEP are a significant part of the diverse community of people who suffer a stroke in Australia each year. And by exploring their experience, the aim was to examine the similarities in their healthcare experience to the extensive reporting of English-speaking stroke patients, as well as identifying differences. In its research practice, the study addressed the ethical concerns of cultural sensitivity, informed consent, the status of languages and management of participant confidentiality.

Cultural sensitivity

A recognition of the different cultural backgrounds of participants, the researcher and the professional interpreters informed decisions and actions during the study. A person's 'culture' was understood to be a complex, contextual and fluid concept; not prescribed by an age, country of birth or language spoken but influenced by all these factors for the individual plus wider social, political and economic influences (Culley 2006, Mallinson & Popay 2007, Underwood, Satterthwait & Bartlett 2010). The principles of the cultural sensitivity of the research approach were discussed in chapter 2 (section 2.2), and were demonstrated in practice by:

- making recruitment and informed consent available in the preferred languages of potential participants,
- respecting each participant's preference for study participation, location of interview, spoken language, interpreter characteristics and co-participant involvement,
- attempting to gain an awareness of the participant's migrant background and cultural norms prior to their first interview by reading literature and talking with people from their language and cultural group,
- taking time to establish a rapport with participants and interpreters by spending time in conversation with them and sharing food and drink at interviews, as well as looking at several cherished photo albums,

- using a semi-structured interview guide which allowed participants to direct how they told their story,
- seeking to understand the meaning of an experience for a participant by asking the participant about it rather than assuming a stereotype,
- asking interpreters about their perspectives on the topic, and
- being reflexive of my own cultural beliefs concerning my research and the interactions between myself and participants in field notes, memos, peer discussions and study reporting.

Informed consent

Informed consent in cross-cultural research has been described as a "thorny subject" (Liamputtong 2008, p. 3) and it was a research process that was poorly conducted or reported in most of the papers which were included in the systemic review of cross-language qualitative studies (chapter 2, section 2.2). Research investigating the quality of informed consent with people with LEP in a healthcare setting found that when a person's preferred language is not used, it is not certain if they can be fully informed (Hunt & de Voogd 2007). The process of informed consent in the study took into account the language that each person preferred to speak (NHMRC, ARC & Universities Australia 2007) and information was provided verbally as well as in written form in case the participant was illiterate or had difficulty reading after their stroke. Participants were able to speak with another person about their study involvement.

The only time when a participant was obviously hesitant during the informed consent process was when the interpreter read the information sheet formally, word for word, rather than interpreting the researcher speaking the information to the person (see the synopsis for 'Christos' in Appendix O). The formality of consent procedures can be intimidating to people from CALD backgrounds (Liamputtong 2008, Liamputtong 2010) and it was obvious from this experience that providing information in a conversational format, with opportunity for discussion and questions, was a more sensitive and effective process and so was continued in that way. Two participants chose for their informed consent to be in English and so information was provided verbally in English, although a translated consent form was

also provided for one participant. Again, an opportunity for questions was provided in a conversational format.

Status of languages

The preferred languages of participants have been purposefully and clearly recognised within the methods and reporting of the study but it is acknowledged that participant data was analysed in English. The translation of all research data to a single language for analysis has been challenged as silencing alternative ways of constructing the social worlds through language (Temple 2006) and perpetuating a hierarchical power relationship when English is used (Temple & Young 2004). The translation of data to English for analysis was not a decision I took lightly but was inevitably required due to the practical and economic limitations of my study; external funding for the increased involvement of professional interpreters was sought on three occasions but the applications were unsuccessful. Ensuring the rigour of the analysis of English transcripts was discussed in the previous section on the 'credibility' of my study.

The importance of the preferred languages of participants to my study, the participants and to the healthcare experience being investigated was recognised with the following strategies:

- presenting the language profile of the community of patients with stroke in the methods section of my thesis (section 3.2.1),
- reporting participants' preferred language and language of interview in their demographic profile,
- enabling recruitment, informed consent and data collection to be in the preferred language of each participant,
- recognising the integral role and influence of interpreters in data collection, and
- exploring participants' decision making around their use of their preferred language and professionals interpreters in their healthcare experience.

Confidentiality

Confidentiality of participant data is an important part of responsible research conduct (NHMRC, ARC & Universities Australia 2007) but it is a practice which often causes dilemmas for qualitative researchers (Wiles et al. 2008). One strategy used to manage participant confidentiality in my study was to give all participants the opportunity to choose a pseudonym (Liamputtong 2010). The pseudonym was used when transcribing the interview conversation, in all subsequent data management, even in discussions with supervisors, and in all reporting of the study. But some participants elected not to choose a pseudonym either because they could not think of one at the time or they did not want one. This presented one of the dilemmas identified by Wiles et al. (2008). I wanted to respect the choice of the participant but I was concerned that in the unfamiliar research setting they could not fully realise how widely their information would be disseminated with the consequent risk of being identified and then not being able to control the outcome of that identification. The researcher has responsibility for minimising the risk of potential harm from research involvement (NHMRC, ARC & AVCC 2007) and so when a participant did not choose a pseudonym, I chose a culturally-appropriate name to use, in discussion with the professional interpreter.

Participant data was then further anonymised by 'de-identifying' data such as place of residence and healthcare facility they attended when the interview talk was transcribed. However, each participant's true language data and some relevant personal and social history were reported in Tables 3.3, 3.4 and 3.5 and in Appendix O. This latter data was kept in the reporting of my study as it was valuable for the reader to understand who the individuals were in relation to their experience and to establish the study's relevance and transferability to diverse aging multicultural communities. Hertz (1997) has recognised that the more researchers try to capture of the individual in the study and not to lose them to a category, the more they risk not being able to guarantee anonymity. So while the data was 'de-identified' to minimise risk of harm, enough was kept to tell a story of the individuals and their experience for integrity of research. It was a tricky ethical balance within the study.

One final strategy to protect participant confidentiality was to use professional interpreters who were accredited with the national authority and so had their own

code of ethics regarding client confidentiality. Professionalism was important because the interpreters came from the same small migrant communities as the participants; sometimes the interpreter and participant recognised each other from a previous job or a shared church community. All professional interpreters signed a confidentiality statement (Appendix S) and were defensive of their status as ethical professionals when they felt it was being questioned. In one interview, the participant expressed his concern that interpreters talked about client information in his community. The interpreter who was present was quick to reassure the participant that this should never happen and would not happen with her.

Ethics approvals

Ethics approval for the study was gained from the University of South Australia Human Research Ethics Committee, the Royal Adelaide Hospital Research Ethics Committee and the Central Northern Adelaide Health Service Ethics of Human Research Committee (Appendix T).

3.3 Chapter conclusion

In this chapter I have detailed how the complex methodological challenge of qualitative research using in-depth interviews with a sample of older people from multiple language groups was rigorously and ethically realised in my study. The findings of the study will be presented in the next chapter as a substantive grounded theory of three conceptual processes which provide a unique understanding of how older people with LEP experience their healthcare after stroke.

4 Findings: a constructivist grounded theory

The study findings present a substantive, middle range, constructivist grounded theory of the healthcare experience after stroke for older people with LEP from CALD backgrounds. The theory consists of three conceptual processes entitled, *'hanging on to the familiar'*, *'being told and being a good patient'* and *'weighing up the value of care*'. In the initial section of the chapter I have provided an overview to introduce the theory and to explain how it has been presented within the chapter. The three processes of the theory are then consecutively presented in each of the following three sections of the chapter.

4.1 Overview of the theory

The theory presented within this chapter is an interpretation of how older people with LEP experience their healthcare after stroke. It is a theory that has been derived from the interview data, as described in the previous chapter, and has been rendered to inform healthcare practice. The three (theoretical) processes which form the theory tell how study participants experienced their healthcare from the time their stroke occurred to when they participated in a study interview up to six months after going home from inpatient healthcare. Together, the processes tell a complex story that could not be isolated to one major concept or core category (Figure 4.1). Instead, each process reveals an important but distinct part of the story which interweaves and overlaps with the other processes to make up the whole healthcare experience (Figure 4.2).

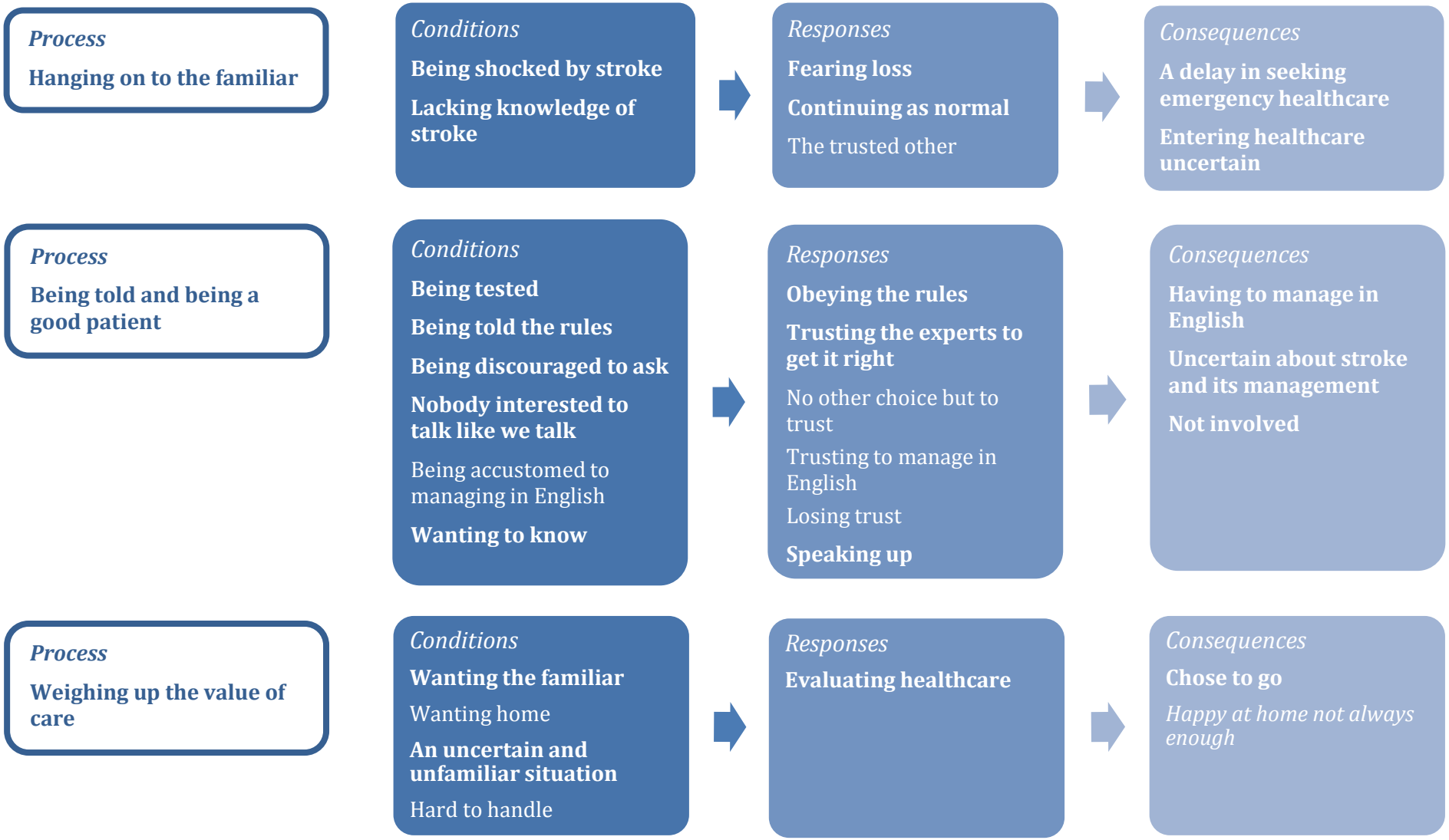


Figure 4.1 Overview of the theory (category listed in bold with subcategory/s {if applicable} listed underneath in normal text)

The three theoretical processes were brought forward in the study's analysis because they best reflected and explained the complexity of participants' experience. The importance of each process was determined by its prominence in the study data, but it was ultimately me, as the researcher, who decided which ideas were foregrounded and which sat in the background. Therefore, the theory is an interpretation of healthcare experience that is grounded in the stories of participants but inevitably developed, albeit in line with the requirements of a reflexive research process, through my own cultural lens.

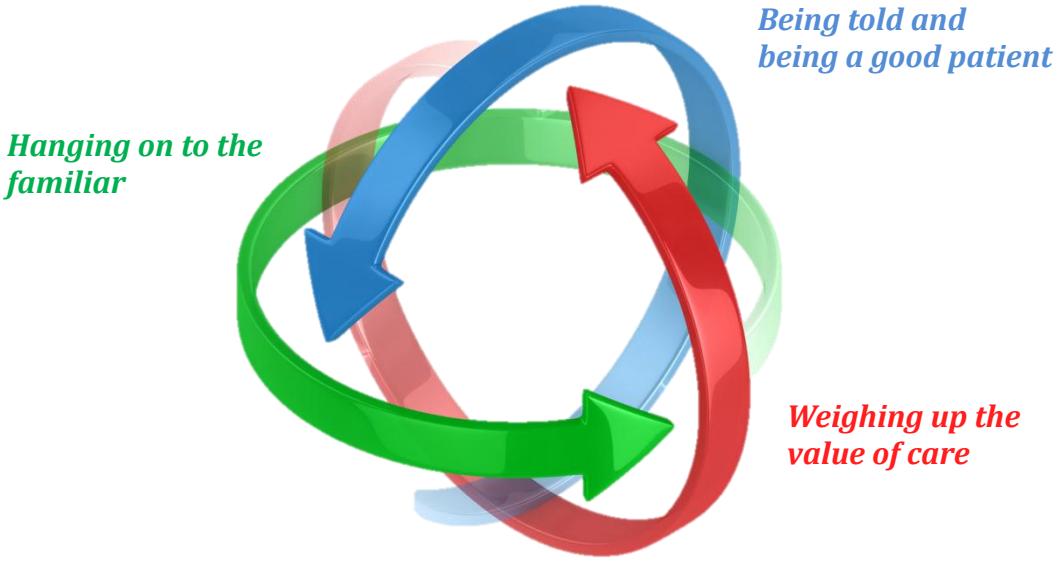


Figure 4.2 The dynamic nature and interweaving relationship of theory processes.

The theory of healthcare experience after stroke portrays what was an acute experience for participants which they neither expected nor were prepared for. The uncertainty and unfamiliarity of their situation is evident in the first process of *'hanging on to the familiar'* as they responded to being shocked by their stroke. The idea of a tension existing between the familiar and unfamiliar for participants begins here, to continue throughout the theory. When the stroke occurred, participants acted to continue as normal and hold on to the autonomous and familiar life that they valued. The process of *'hanging on to the familiar'* delayed participants seeking help and they eventually entered healthcare uncertain and fearful. The process also introduces the integral role of the 'trusted other' in the theory, as people who were constant sources of support and influence in the experience of participants.

'Being told and being a good patient' is the second process of the theory. While the chosen title suggests that two processes are represented, it is one complex theoretical process that reflects the interaction of the participant and the healthcare context. Participants are portrayed encountering healthcare while wanting to resolve the uncertainty of what had happened to them and its impact on their future. The model of healthcare they met was a system which positioned them as passive patients who were dependent on experts to decide their recovery. The idea of expert trust is a strong presence within this process with a scope of authority that extended to influence how participants used their preferred language during healthcare. While the topic of language was interwoven through the theory, just as it was interwoven through the experiences of participants, issues around the use of language had particular importance within *'being told and being a good patient'*. Participants responded to their healthcare in a way which they trusted to be best for their recovery and getting back to their familiar lives. But their actions of being good patients had consequences for their ability to engage with their healthcare and the decisions they subsequently made in the process of *'weighing up the value of care'*.

In this third and final process in the theory, participants evaluated the worth of the healthcare in helping them to achieve their own goals in recovery. It was not an evaluation which was always favourable to their healthcare. Participants took opportunities to make decisions which had consequences for their recovery from stroke and future health management. The three processes of the theory will be further elaborated in the subsequent sections of this chapter. First, I explain the structure of the theory and how I have chosen to present it in the chapter.

4.1.1 A matter of presentation

The rendering of the theory within these pages reflects my interpretation of participants' experiences. My presentation of the findings has been influenced by the study's aim to develop a theory that can be applied to the clinical setting. Thus, it has been written in a way to be accessible and to make intuitive sense to health professionals (Brown, Stewart & Ryan 2003). With this purpose in mind, data were analysed and the findings are presented as dynamic processes that could resonate with the activity of healthcare practice, rather than static descriptive themes.

The three circling and intersecting arrows in Figure 4.2 communicate the dynamic and interactive nature of the processes in participants' healthcare experience. Individually, the arrows, representing the three processes of the theory, are dynamic entities which overlap each other. Together they form a sphere of experience. The sphere of experience is shown with no clear boundary to separate it from the space around. This signifies that the healthcare experience for participants was influenced by concepts and contexts that sat outside the idea of a sterile and isolated healthcare setting. Such influences included the sociocultural beliefs that were brought to the experience by each participant and the health professionals whom they interacted with, and the demands of a regulated healthcare system.

Despite the important information given by Figure 4.2 and explained above, it was impossible in practice to include the detailed structure of the processes in the same format. Therefore, the detailed presentation of the theory's processes in the overview (Figure 4.1) and chapter sections is in a linear format to provide information in a way that is readily understandable. Each process is written and presented, both diagrammatically and in text, in the logical format of (problematic) conditions, responses and consequences. Each category from the analysis is listed in bold with the subcategory/s (as applicable) underneath in normal text, as shown in Figure 4.3.



Figure 4.3 Layout of each theoretical process within the findings.

In a similar way, the sequential presentation in the chapter of the three processes which make up the theory was chosen in part for ease of reading and interpretation, and not only as a representation of how they were configured within the experience. For the meaning of each process is not tied to its place in the sequence of presentation. Just as the human experience of illness does not always fit neatly into one linear and progressive process (Charmaz 2006), there was no rigid temporality to participants' healthcare experiences. Conceptual processes were interwoven and interacting throughout it, as has already been explained. However, the experience and

theory needed to start somewhere and so it began when the stroke occurred, with the process of *'hanging on to the familiar'*.

4.2 Hanging on to the familiar

'Hanging on to the familiar' is the first process presented in the theory of the healthcare experience after stroke for older people with LEP. It incorporates the conditions experienced by participants of being shocked and lacking knowledge at the occurrence of their stroke, their subsequent responses of fearing loss and attempting to continue as normal and then the consequences of delaying access to emergency healthcare and them entering healthcare still uncertain, as outlined in Figure 4.4.

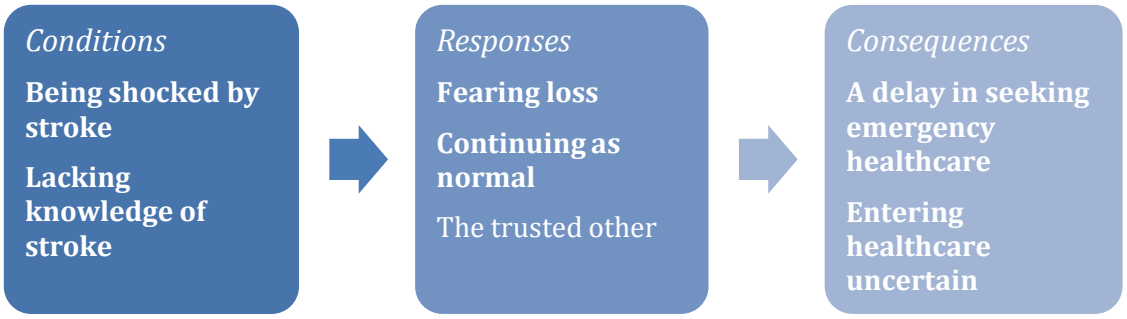


Figure 4.4 Structure of the process *'hanging on to the familiar'.*

'Hanging on to the familiar' was not where I had anticipated a theory of healthcare experience to begin when I was planning this study. I had thought that the theory would neatly start with the person with LEP already located in an acute healthcare environment such as a hospital Emergency Department. However, it was soon apparent during interviews with participants that my expectation was mistaken. The process of participants getting to healthcare from when their stroke occurred was an inherent part of their healthcare experience. Their initial response to their stroke, which included the people involved, emotions that were felt and actions which happened, foreshadowed many aspects of their later experience in the processes of *'being told and being a good patient'* and *'weighing up the value of care'.* The occurrence of stroke not only shocked people with its disabling effects but also forced them to leave a context of comfort and autonomy to enter healthcare.

Although the process of *'hanging on to the familiar'* predominantly captures participants' experience of their entry to healthcare, the ideas it introduces of a tension existing between the familiar and unfamiliar and the integral role of the 'trusted other' are concepts that are not confined to this point of the experience. *'Hanging on to the familiar'* is a key component in understanding the overall theory of the healthcare experience after stroke for older people with LEP.

4.2.1 Conditions of 'hanging on to the familiar'

Stroke happened suddenly to participants. It unexpectedly disabled them: affecting their body or mind, or both, without giving them time to prepare or plan their response (condition: being shocked by stroke). The experience of Andreas while playing a game with friends was typical of the sudden interruption to normal lives,

> *And as we were playing backgammon, the dice, when I was throwing them, one of them was thrown from my hand in one direction and the other one in another* (Andreas, Greek).

Of course, suffering a stroke was more than an interruption to normal routine as the effects of the stroke persisted with varying severity and disability. Within a short space of time, participants went from functioning in their normal life to being disabled and being uncertain about what was happening and what it meant for them and their future (condition: lacking knowledge of stroke).

Being shocked by stroke

All participants were shocked by the unexpected and sudden nature of their stroke, as Thao explained, "*It just happened out of the blue"* (Vietnamese). Participants repeatedly made the point during interviews that they were given no warning that the stroke was going to happen. Indeed, many reported that they had been feeling quite well immediately before their stroke. All had been living in the community and independent in their mobility and daily activities prior to their stroke. For three participants, the stroke occurred soon after they had received a clean bill of health from a doctor or ambulance officer. The disappointment that a trusted expert had been wrong was then added to the shock of the stroke event,

> *And doctor told me everything was right. Cause cholesterol was bad one. He said everything fine and I was happy to hear it. Then Saturday I went out to the shop and I come back Saturday afternoon and I feel weak. Couldn't do nothing then* (Benigno, English).

Sometimes the shock of the stroke's occurrence was emphasised by its immediate dramatic consequences. For example, Emilio went from holding a newspaper in one moment to falling onto a concrete footpath in the next. And Christos' sudden vision changes whilst driving caused him to veer his car off the road into a building crane,

> *(I) could not see properly whilst I was driving the car. And then from there right side I could not see where, from the other side was alright. And I had an accident then* (Christos, English).

These secondary effects added physical injuries and further distress to the stroke event. For other participants, the initial physical effects of stroke were not so pronounced, such as a mild slurring of their speech, and so their shock came when friends or family noticed something was wrong and they were suddenly being told to go to hospital. Katariina had not realised that stroke had affected her facial muscles and voice and so she was surprised by her neighbour knocking on her door saying that an ambulance was coming,

> *And I thought, my goodness gracious nothing wrong with me and now they just want to shift me out of the house to hospital, what's going on? So, and of course, she had the nerve to tell me yes, she had also rang ambulance and my daughter. And I thought, good grief really. I did not know, I think I was a numb person all this* (English).

Stroke was something which participants felt unprepared for. This was not just because of its sudden nature and a perceived absence of warning signs, but also because of a lack of knowledge about the condition.

Lacking knowledge of stroke

Participants' strokes occurred in the context of them having limited knowledge about the symptoms of stroke or its management. Several participants shared Christos' experience of knowing *"Nothing, never"* (Greek) about stroke. For the participants

who did have some knowledge about stroke from the media or from knowing someone with stroke, it proved to be of little help in knowing what to do when they were affected. As Emilio explained, his experience did not match his prior understanding that there would be warning signs he could act on,

> *I wasn't expecting anything like that because I was reading an article in the paper that said, you know, yeah you know, then normally you get some warning that something has happened or something about that. Well I was feeling very well and I'd been eating and I eat everything. I was feeling well so I wasn't expecting anything like that* (Italian).

Krystyna, whose husband had received healthcare in Australia after stroke, reflected that she and her husband had learnt little about the condition at that time. Krystyna suggested that having LEP had influenced their ability to gain useful health knowledge as they had not understood the English term 'stroke' without a Polish translation, *"He knew he was sick and he knew it's stroke, but he didn't really know what the word stroke means"* (Polish). The lack of recognition of the English word 'stroke' was reported by another participant, Sadik, who did not understand the significance of the condition when a doctor told him he needed to go to hospital because he had no knowledge of the word or the condition. Only Katariina possessed a good knowledge of the symptoms and management of stroke from her years of nursing work and having previously suffered a mild stroke. Yet, even her knowledge of the need for immediate medical attention after stroke was initially overridden by her shock at its occurrence.

When participants lacked knowledge of stroke, they lacked an accurate reference for understanding the nature and significance of the shocking event. They had experienced a sudden loss of their normal ability, such as difficulty talking or moving, yet were unsure of the cause. Waldemar explained the confusion he felt at the time of his stroke,

> *I knew that I couldn't move, but I didn't know it was a stroke or it was my brain or something else. I don't really know much about medication and treatment, so I don't know what it was, I didn't know what it was. I didn't know it was a stroke* (Polish).

The conditions of being shocked by stroke and lacking knowledge of stroke left participants uncertain and needing to respond to the stroke event.

4.2.2 Responses of participants in 'hanging on to the familiar'

Participants responded to the conditions of being shocked by stroke and lacking knowledge of stroke by fearing its effects on their abilities and independence (response: fearing loss) and acting to continue as normal in their routines and activities (response: continuing as normal). They were also influenced in their response by their past experiences of illness and healthcare which will be highlighted in the next section. As the process' title of *'hanging on to the familiar'* implies, participants were hanging on to what was familiar to them in their response to an uncertain situation. Their action of continuing as normal had to change at some point for them to access emergency healthcare and it was another part of the familiar in the role of the trusted other which was a catalyst for the change.

Fearing loss

The uncertainty for participants about what had happened and what it meant for their future caused many to feel scared, sad, anxious and even suspicious about what had happened. They often feared the worst about their sudden symptoms, such as Gino who had a friend who was terminally ill, *"So I was worried about the prospect of the cancer…"* (English) and Ming whose wife had died from stroke two years earlier, *"I was thinking, 'Die. I'm die'"* (Cantonese). From very early on in their experience after stroke, participants were feeling dismayed at the prospect of what was to come, "*You can imagine what a person feels when a person knows they'll be an invalid forever"* (Krystyna, Polish). Perhaps the best example comes from the words of Andreas which his wife, Eva, overheard him saying repeatedly to himself soon after his stroke, *"You are finished Andreas, you are finished Andreas"* (Eva, Greek).

But not all participants initially responded with such fear or anxiety. Those who did not initially perceive the stroke as a threat to their abilities or independence had a less dramatic response. Thao did not have the knowledge to recognise his leg weakness as different to any of the other times he had suddenly become ill from another chronic illness. Christos was checked and cleared of illness by the ambulance officers who attended him after the car accident caused by his stroke, and so he

initially accepted their diagnosis that everything was ok despite his shock at what had happened. And Sadik, who had been told by a doctor that he had a stroke, did not understand the English word and had a profound dislike of hospitals so he decided, *"It was late at night and I thought, 'Just one night, it won't matter'"* (Croatian). These participants still experienced the emotional response to stroke of dismay and fear for their future but it did not come until later in their healthcare experience when they became more aware of how the stroke would affect their abilities and independence, as Thao felt during his inpatient rehabilitation,

> *To be honest I felt very sad because I had been active with full of energy, but suddenly I was paralysed and suffer from this sort of condition* (Thao, Vietnamese).

In the context of sudden uncertainty after stroke, participants looked to what was familiar to them for certainty and comfort. The concept of the 'familiar' is defined within the theory by what held value and gave importance to participants as individuals in their lives before their stroke. The comfort and certainty which the familiar offered was in contrast to the uncertainty and unfamiliarity presented by the stroke. What constituted the familiar was individualised to each participant, however, it included their previous physical and cognitive abilities, normal routines and social roles, family and friends, the context of their home, and the autonomy of *"my usual life"* (Benigno, English). One way in which participants held on to the familiar and resisted the unfamiliar of stroke was by continuing with normal routines and delaying or refusing to attend emergency healthcare.

Continuing as normal

Participants attempted to continue their normal daily activities immediately after stroke. They persisted with familiar roles and routines despite being aware, or made aware by others, of their sudden disability. For those who feared the loss of the abilities and independence which they valued, continuing as normal was a form of resistance. Benigno continued to sit and watch television even though his arm was too weak to use the controls, fearful and unsure about what his symptoms meant, *"I was sitting here the television too loud. It bothered me but did not, didn't have the guts to push the remote control"* (English). Sometimes participants actively resisted the concern or help of others in their attempts to continue as normal. Two male

participants continued to drive their cars when they had marked arm weakness from stroke. Driving was an important signifier of independence for both men and an ability which they did not want to be taken away from them. Both were offered help by friends or family but initially refused it, as Andreas describes here,

> *I was not feeling my right hand well… I was driving my car and the man asked me, 'If you cannot drive, I'll drive you.' And I said, 'No, I will drive'* (Greek).

Two of the participants who lived alone in their own homes, Katariina and Krystyna, continued as normal by insisting that they should remain at home after the stroke. Katariina resisted her friends' attempts to get her to go to hospital as she feared the loss of her independent lifestyle, *"…a vendetta. Wanting to get rid of me from home"* (English). Krystyna was so disabled by her stroke that she laid on her living room floor for two days before her son found her, but even then she did not want to be taken away from her home,

> *(Polish) He saw me lying down, he said, 'What are you doing here?' I said, 'I'm lying down." And he went and got the phone and he ring ambulance. I told him, 'No, no, don't call them. (English) Only help me, I get up.'*

Continuing as normal was also a response which was grounded in participants not realising the seriousness of their condition or its need for an urgent response. Rather than actively resisting the threat of the unfamiliar, they responded in a familiar way to uncertainty about their health. Emanuele always consulted his family when he was unsure what to do. Despite realising that something was wrong, he went to bed as normal and waited until morning to speak with his wife and children about the stroke so he did not disturb them late at night, *"Because I wanted to talk to them (children) before the ambulance"* (Italian). Not only did Emanuele wish to consult with his children but he, and his wife, also relied on their children to call the ambulance because they were not confident that they would be able to manage the phone call with their LEP,

> *If I have to call myself with the telephone I have got some difficult because I haven't done any schooling here. So that one of the reasons to call the children*

was they could call the ambulance, they speak English better (Paola, Emanuele's wife, Italian).

Thao and Christos also responded in their own familiar ways to illness. They made appointments to talk with their local doctors, whom they had established relationships with, rather than seeking emergency healthcare; thus, missing the significance of their stroke symptoms rather than resisting the stroke.

Sadik's refusal to attend emergency healthcare and continue as normal at home was in part due to him misunderstanding the seriousness of his condition but was also influenced by his distrust of hospital care. Sadik was dissatisfied with the effectiveness of advice and healthcare that he had previously received in hospital and so he chose at the time of his stroke to continue as normal at home. His wife, Helena, recalled his response to her own concern that he should go to hospital,

We had an appointment on the Monday with the specialist (who noticed the stroke). On the Tuesday I wanted him, and I said, 'You have to go in to the hospital.' And he said, 'Yep. If I go into hospital they are going to say nothing is wrong with you, go back home' (Croatian).

Some participants were not able to physically continue as normal after stroke because they could not get up from where they had fallen. An example is given by Emilio, who fell outside his back door,

I called out to my wife… she couldn't manage on her own so she called the next door neighbour and you know, you know, she couldn't lift me on her own. And then said, ah they'd lift me up and then I fell again. I tried to move on my own I wasn't able to (Italian).

However, the physical constraints did not mean that these participants did not share the response shown by others to want to continue as normal for as long as possible. This is demonstrated by Emilio's several attempts to get up and Krystyna's pleas to her son that she should remain at home.

Eventually all participants did get to emergency healthcare. But none did so independently. For the participants who were able to initially continue with normal activities, they realised as their stroke disability worsened that the tasks they

attempted could not be finished, such as walking, using cutlery or the TV remote. But the realisation that they could not continue as normal still did not mean that they sought emergency healthcare. Instead, each participant needed a catalyst to get emergency healthcare and that catalyst was a person who filled the role of a 'trusted other'.

The trusted other

The bridge between participants having a stroke and them attending emergency healthcare was the involvement of a 'trusted other'. A trusted other was a person who gave the participant reassurance and certainty during their healthcare experience when things were not making sense or meeting their expectations. A trusted other was someone whom the participant knew and trusted, and who knew the participant as a person before their stroke. Often they were someone who was a regular visitor to the participant and so they were present when otherwise the participant was too disabled to leave their home. Although the role of the trusted other is introduced here within the process of *'hanging on to the familiar'*, they continue to be of importance later in the healthcare experience of older people with LEP and are present in other processes of the theory. Conceptually, they can be considered as the certainty and comfort of the familiar realised in a person.

To access healthcare after stroke, all participants relied on a trusted other noticing the seriousness of the stroke and acting on it. Andreas' wife, Eva, describes when she took action after her husband's stroke,

> *...and then he couldn't fasten the belt in the car because I was driving and he couldn't use this hand to put it on. And I could see he couldn't get out normally and then I realised and then I say, "Let's go to the hospital"' But it was after lunch, it was early... He did not tell me anything I just was watching him and I just realised. Otherwise would have gone to the hospital straight away on Friday* (Eva, Andreas' wife).

The trusted others who initiated emergency healthcare for participants after stroke were not simply bystanders. For most participants it was a family member; a partner, child or grandchild. However, the role could be filled by others. Christos, who was estranged from his family, sought and followed the advice of his local doctor whom he

had attended for twenty-two years. The role of the trusted other was not necessarily confined to the same cultural or language group. Christos' doctor was from a German background and Katariina's neighbours who rang an ambulance for her were from different migrant backgrounds. It was the sharing of a caring and trusting relationship that meant the trusted other knew when things were wrong and then was able to persuade the participant to access the unfamiliar, but needed, healthcare.

Sometimes the trusted other had a difficult time convincing the participant to stop 'continuing as normal' and to attend emergency healthcare. It took three days before Sadik conceded to his family's pleas for him to go to the hospital. He then made it contingent that he would go only if his daughter took him. Helena, Sadik's wife, recalls the emotion of the situation,

> *She cry and she say, 'Mum, we must bring him to hospital.' And we call the ambulance but Sadik say, 'No ambulance, you bring me'* (Croatian)

Getting participants to emergency healthcare also required trusted others to bridge a language gap for several participants. Emanuele and Nam both specifically relied on their children who were proficient in English to call for an ambulance. Trusted others were responsible on all occasions for either calling an ambulance or directly escorting the participant to hospital. Although all participants eventually got to emergency healthcare with the help of a trusted other, there were consequences of the process of *'hanging on to the familiar'* for the effectiveness of their stroke management and for their ensuing healthcare experience.

4.2.3 Consequences of 'hanging on to the familiar'

The response of participants to continue as normal when they were faced with stroke had consequences for their access to effective medical management of their stroke recovery (consequence: a delay in seeking healthcare). They also entered healthcare in a state of still being unsure about what had happened and what was going to happen (consequence: entering healthcare uncertain).

A delay in seeking emergency healthcare

The active response by participants to continue as normal delayed them getting emergency healthcare after their stroke. All participants, except perhaps Thao,

reached emergency healthcare well past the small window of opportunity for them to have thrombolysis therapy. It was unfortunate for Thao that, despite his children's actions in recognising the seriousness of his condition, *"But my children didn't take me to see a doctor they instead they took me to the hospital directly'"* (Vietnamese), he still suffered an extension in severity of his stroke the following day while being observed in hospital. Several participants reported that their symptoms worsened between the occurrence of stroke and the time they eventually accessed emergency healthcare. Over the three days in which Sadik delayed going to hospital his initial leg weakness had progressed to a facial droop, difficulty walking and a serious infection. The relationship between the delay and participants' individual recovery from stroke cannot be shown from the data collected in this study, however, the delay did mean that participants entered healthcare in a more disabled and often weakened state from their efforts in continuing as normal. They also entered healthcare in a state of uncertainty.

Entering healthcare uncertain

Participants began their experience of inpatient healthcare still uncertain and often fearful about what had happened to them and what it meant for their future. The conditions of being shocked by the stroke and lacking knowledge about it were not resolved during the process of them getting to hospital. Participants' uncertainty about their stroke and future was accompanied by a continued trust in what was familiar and certain to them and a reluctance to leave their normal lives behind. In this way, the process of *'hanging on to the familiar'* did not disappear when participants stepped through the hospital door, rather its conditions and responses continued to be a part of subsequent processes.

The next process presented in the theory is *'being told and being a good patient'*. It takes up the analytical story from when participants entered inpatient healthcare. It is a stage of many expectations, both met and unmet, with eventual consequences for how participants valued their healthcare after stroke.

4.3 Being told and being a good patient

Participants entered healthcare wanting to resolve the uncertainty of what had happened to them and its impact on their future. The model of healthcare they encountered was a system which positioned them as passive patients who were dependent on experts to decide their recovery. Participants responded to these conditions in the process of *'being told and being a good patient'* in a way they trusted to be best for their recovery and getting back to the familiar. But it had consequences for them engaging with their healthcare and the decisions they later made. The structure of the process is provided in Figure 4.5. Language was an important element within the process as the predominance of English in participants' healthcare experience formed part of the (problematic) conditions, as well as influencing the responses by participants and the consequences of the process.

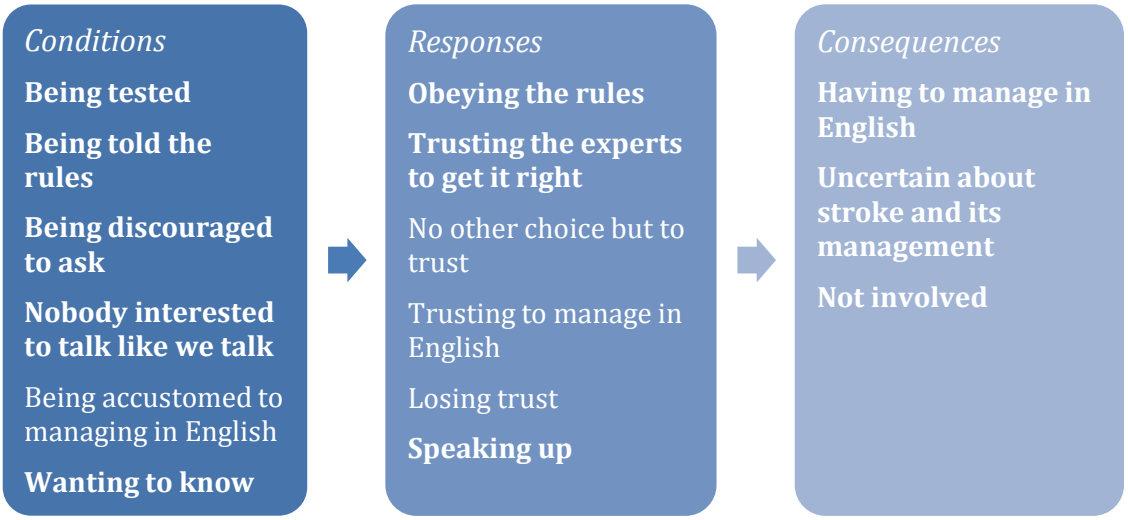


Figure 4.5 Structure of the process *'being told and being a good patient'*.

'Being told and being a good patient' is a substantial process within the developed theory in terms of the amount of information it presents and the dominance of the process within the overall experience of participants. It is a process which incorporates participants' uncertainty and their expectations of healthcare from *'hanging on to the familiar'*, and has consequences which influence the following process of *'weighing up the value of care'*. In presenting this part of the theory, I was cautious about using a title which emphasised the actions of participants when the process portrayed a healthcare context that did little to encourage them to

meaningfully participate. Yet the title needed to acknowledge that participants' responses in the process were not thoughtless acquiescence but a complex reaction to what they encountered during their healthcare. Therefore, the condition of 'being told' was included with the action of 'being a good patient' to reflect the influence that the positioning of participants by their healthcare had on their responses in this process of their healthcare experience after stroke.

4.3.1 Conditions of 'being told and being a good patient'

On admission to hospital after their stroke, each participant entered a new and unfamiliar social role as a disabled patient. While participants were differently affected by the sudden health event, no one entered healthcare the same as before their stroke. All participants experienced some weakness of their arms or legs such as Krystyna described, "*I was so weak I couldn't walk, I couldn't do anything"* (Polish). Stroke also affected different dimensions of cognition, hearing, speech and language, adding to communication difficulties. For a few, but not all, the ability to speak English deteriorated, *"The English I knew enough for myself, but now I have become sick with the stroke they have gone down"* (Christos, Greek). In many ways, participants entered healthcare physically and cognitively less able than before their stroke.

In this state of being disabled by stroke, participants had also become patients within a system of healthcare. They had suddenly lost the autonomy they had before the stroke and were dependent on healthcare to help them to recover it. As presented in the process of *'hanging on to the familiar'*, participants were fearful about potential loss; initially scared that they would not survive the stroke, "*I didn't expect I'd be alive"* (Krystyna, Polish), then fearful that they would continue to be kept away from their familiar home and life in hospital or institutional care.

The patient role which participants were given during healthcare positioned them as passive recipients of expert services. Healthcare in the large part was something done to them, not with them; and usually done in English. Participants experienced healthcare as an authoritative system which tested them (condition: being tested), told them how to behave (condition: being told the rules), and discouraged them from seeking information (condition: being discouraged to ask). The healthcare system

was perceived to give little importance to languages other than English (condition: no one interested to talk like we talk). Yet participants had an interest to know what was happening and what it meant for their recovery back to their familiar lives (condition: wanting to know). These problematic conditions underpinned participants' subsequent responses in the process of *'being told and being a good patient'*. Each condition is expanded upon in the following sections.

Being tested

The perception of being tested by health professionals dominated participants' experiences of healthcare after stroke. Initial testing was perceived as important and necessary for health professionals to make a diagnosis and to decide treatment as Benigno explained, "*They test me to see everything's alright"* (English). All participants expected to undergo diagnostic and monitoring tests after their stroke and they appreciated being tested as a demonstration of attentive healthcare practice. Ming provided a particularly detailed example of being impressed by the hospital *"service"*,

> *I remember they have all the, what sort of, x-ray my head, the neck, chest, my lungs, x-ray. Group of doctors every day come in to see me, and measure my, maybe blood pressure several times during the day. There is a needle or thermometer put into my mouth, put inside my mouth several times a day. Underneath my armpit they put something. Every day it's like that, every day like that. And then a lot of nurses, you know, busy around me. The service was very good, very good* (Ming, Cantonese).

Being tested did not require participants' involvement except to submit to the conditions of the test. While such investigations were expected, they were conducted on health professionals' terms and at their discretion. For Gino that meant waiting *"…til 4 o'clock in the morning"* (English) to access the correct machine.

But the perception of being tested and checked by health professionals did not cease when medical investigations were complete. Therapy sessions and daily inpatient routines were also perceived by participants as occasions of being tested by health professionals, this time to determine their level of functional recovery and ability to manage at home,

> *…they (therapist) told me to make a coffee and then second day the same to check if I remember how* (Krystyna, Polish)

> *Only once it took me (to physiotherapy), and they did not come again. Because what they asked me to do, I was doing them very quickly, so they said, 'That's alright'* (Andreas, Greek).

The perception of constant scrutiny during healthcare placed health professionals as the authority to determine if the patient had passed or failed the test. Conversely, it confined the patient's role to the competency of their test performance. When Krystyna disagreed with the assessment that she had failed her test to go home, she found that her opinion did not affect the test result,

> *Because I wanted to go home and they were saying no. So they took the interpreter so they could explain to me why they have to leave me in care because I would be in danger at home. And I understood this, but I was also thinking that if I was not falling over there, and I was able to go to the toilet and to walk to the dining room, I could do the same at home* (Krystyna, English).

In rehabilitation, the organised discharge and family meetings were interpreted as critical occasions when the participant was present to hear health professionals and family pass judgement if they could go home. Gino's interpretation of the meeting included being given a score on his recovery by the experts,

> *… everyone got to say if I'm able to stay home or not. That's a conclusion. Because every nurse say, he can do shower himself…Can dress himself, you know. Everyone got to say, or the physio, can I walk you know, how many points I have. Because they give you point, what you do (English).*

Participants were aware when they interacted with health professionals that their performance would inform the decisions made about their future healthcare and autonomy. Once home in the community, participants still experienced being tested by health professionals; having regular blood tests, checks of home and mobility safety and, ultimately, assessment of their readiness to be discharged from outpatient therapy. They attended to the tests according to the rules they were told.

Being told the rules

Most interactions between health professionals and participants were perceived as the participant being told the rules of the healthcare context; what they were required to do, *"They tell me if you don't take them (medication) I will come back again"* (Andreas, Greek) and what had been decided by others, after testing, as best for their treatment and recovery after stroke, *"They told me that they will send me there (rehabilitation) for me to become better, to recover"* (Christos, Greek). Rules were often referenced to participants' recovery and safety, but did not invite their involvement. Transfers between care facilities or discharge decisions were often communicated to the participant as a directive to be followed without question; the immediacy of the event from when participants were told reinforcing that the decision did not invite their involvement,

> *…and then one day they came and they said today you're going home* (Emanuele, Italian)

> *I was there for a few days and then one day they said, 'Oh, now you can go'* (Ming, Cantonese)

> *No, (they) don't ask me. They just saying they send me there* (Gino, English).

Being told the rules provided some certainty to participants by instructing them about how to behave in the healthcare context. Rules limited choice and communicated the behaviour that was expected of a patient,

> *Because if I can't walk outside, they said, 'No, he can't go outside, he gotta walk inside.' When ready to go outside, they let you know (Gino, English).*

Rules also communicated to participants that they only needed to understand simple, directive commands in English to fulfill their role as patient. Emanuele explained the common perception by participants that rules were simple to follow even with LEP, *"I had no problem understanding whatever she (physiotherapist) told me, I understood, very simple thing"* (Italian). Being told the rules did not make a requirement, or provide encouragement, for participants to participate in the communication initiated by the health professional; they simply needed to comply with the command to show understanding. Rules could be communicated with a few words, *"… nurse came and*

ask me, 'Walk, walk.' There's a long corridor, and the nurse go to me, 'Walk'" (Ming, Cantonese), possibly repeated or supplemented by actions if the participant had difficulty understanding,

> *For example, in the first instance if they tell me 'Up' I wasn't able to understand. But they repeat it a few times and then I was able to understand* (Thao, Vietnamese).

But rules were one-way communication; directed by health professionals and discouraging a reciprocal response from participants to engage in their healthcare. Being told the rules contrasted with the rare occasions across the study interviews when participants experienced health professionals taking the time to share information in a two-way discussion. The use of this alternative form of interaction enabled choice and informed decision-making by participants rather than an expectation that they would just follow directives. Sadik was very reluctant to stay at the hospital after his stroke, but the actions of an Emergency Department doctor to sit down and talk with Sadik and his wife about his infection risk enabled them to make the decision to stay,

> *Very, very, very nice doctor really. She sit down and she talked with me and she talked with him and she explained everything, what's going to happen* (Helena, Sadik's wife, English).

This type of interaction with health professionals was not a strong presence in participants' experiences as the overwhelming perception by participants was that they were told what they must do. It was a perception reinforced by the behaviour of some health professionals.

Being discouraged to ask

The positioning of participants to a passive role in healthcare was not isolated to being tested and being told the rules; their position was also framed by what was discouraged. During interviews, when I asked participants who spoke some English what they would do if they did not understand a conversation, they replied easily, '*If there's something I don't understand, I ask*' (Christos, Greek). However, this simple strategy was not always available to them in the healthcare context as some

behaviours of health professionals discouraged the participant to initiate communication. Christos provided a typical example of participants' experiences of doctor's ward rounds,

> *When you're in hospital, and the doctor just passes by, doesn't come to visit you, they just go and talk in-between them and they tell you nothing* (Christos, Greek).

Even when a participant did get the opportunity to talk to a health professional they could still feel discouraged to speak up, as Gino explained,

> *Gino (English): Because you can't ask too many things, they get mad [laugh].*
>
> *Interviewer (English): You can't ask too many things, they get mad?*
>
> *Rosa, Gino's wife (English): He (doctor) not like you ask so many questions.*

Sometimes the use of evasive responses or generic platitudes by health professionals stopped participants' questions. Mostly this occurred during interactions with nurses and the following experiences of Krystyna and Christos are two examples of several given in study interviews,

> *I tell my friends there, 'I'm waiting for doctor, specialist doctor, but he's not coming.' And I ask them, 'Doctor specialist coming to you?' 'No.' 'To you?' 'No.' And the nursing then, 'For sure for minute coming' (The specialist never came)* (Krystyna, Polish)

> *You were unwell and you wanted something, the nurses would say, 'Alright, I give you tomorrow'* (Christos, Greek).

The busyness of staff also discouraged participants from seeking information. Health professionals, particularly nurses, were perceived as overworked and too busy with their duties to provide explanations. The provision of information to patients was then perceived to be something extra to their busy workload and not always available. Katariina confirmed this perception from her own experience of previously working as a nurse,

> *But they were so, too busy I think to explain anything. They just, that was just their routine thing and that's it, no. I know myself we didn't have time as nurses to talk with the patients really, a little bit longer* (English).

Most participants experienced health professionals giving information about their condition and treatment to their children instead of to them. Katariina was an exception because her daughter instructed the doctor to speak directly to her mother, and two other participants did not have children present to take the role. Participants were not always given a reason why they were bypassed by health professionals but they assumed it was because their family would understand the information better than they would; either because of their limited education, *"I understood most of it but a few things I didn't because I didn't do my schooling you know"* (Emilio, Italian) or because their English proficiency was inadequate to understand,

> *(Polish) Because his English is better. He (Krystyna's son) signed all the papers and everything. Even now they ring him. (English) Pharmacist and doctor and everything, (unclear) package coordinator. Everybody talk with him because sometimes some words I don't understand* (Krystyna).

It was interesting that participants did not feel excluded by this scenario involving trusted others, unlike their perception of the discouragement for them to seek information that was communicated by other health professional behaviour. The exception was Katariina who prided herself on her medical knowledge and English language ability and so did not like to be excluded from conversations related to her health. Participants trusted their children and perceived them as reliable conduits of messages; telling their children was like telling them as Thao explained,

> *It doesn't matter to me whether they talk to me directly or whether they talk to my family member, that's okay by me* (Vietnamese).

Getting information via their children was a familiar scenario for participants as their children often interpreted for them in the community when the use of their own language was not available. The language context of healthcare was similar to this community scenario for participants as the low importance they perceived to be given to the use of languages other than English was another discouragement for them having a strong voice in their healthcare.

Nobody interested to talk like we talk

Participants perceived that the language they preferred to speak was not an important consideration during their healthcare after stroke. The healthcare context they entered patently operated in a language (English) which they had limited proficiency in. Few health professionals were observed to speak a language other than English, *"Nobody interested to talk like we talk"* (Gino, English), and were generally considered to lack the interest or initiative to use the participant's language as Gino and Krystyna simply acknowledged,

> *Because everybody talking English. Even if you answer in Italian they don't understand.* (Gino, English)

> *It's always been English to me and that's all* (Krystyna, Polish).

Emilio was even asked to use a shortened, anglicised version of his Italian name during his inpatient healthcare, rather than his real name, because the health professionals found it *"very hard"* to pronounce, "*Because (real name) quite you know, it's got all these vowels so it is hard for the Australian people"* (Emilio, Italian). Emilio accepted the change to his name as it was a name which his English-speaking neighbours in his street already called him for the same reason.

Translated written resources were rarely offered to participants during their healthcare experience, and the few occasions when there was a health professional who did speak the participant's language were seen to occur by coincidence rather than design. The availability of translated resources and bilingual health professionals differed between healthcare facilities as well as between language groups.

Participants did not presume that a professional interpreter would be available to them during their healthcare and it was not always offered. Thao did expect an interpreter service at the hospital as a professional interpreter had previously been organised for his outpatient appointments, but no interpreter was provided when he was admitted for stroke and his son spoke with the doctors. When professional interpreters were used, they were perceived to be organised at the discretion of the health professional, not the patient, and primarily used for the accurate completion of

tests, such as Emilio's vision assessment, *"They send an interpreter when they test me, my sight"* (Italian), or for formal meetings. At other times, the use of an interpreter was seen to be initiated as a reactive decision to the participant's obvious misunderstanding *"…then they realised that he doesn't understand English and after that every time they would bring an interpreter"* (Eva, Andreas' wife, Greek) rather than a planned strategy.

Outside of assessments and meetings, there were few occasions when the participant's language preference and needs were intentionally accommodated within their healthcare after stroke. Occasions that were reported included: the use of Italian words during Emilio's inpatient speech therapy, health professionals agreeing to contact Sadik's daughter by telephone so she could interpret for him, Thao being accorded a Vietnamese-speaking case manager to liaise with and coordinate his healthcare in the community, both Thao and Krystyna having some care workers in the community who shared their preferred language, and professional interpreters being provided for Nam's son to learn tasks to care for his father, *"…anything we needed to understand then the interpreter to help us to understand"* (Hung, Nam's son, Vietnamese). There was also a professional interpreter organised for Krystyna's discharge meetings. This deliberate accommodation to a participant's preferred language was not a consistent feature of healthcare and was an exception to the majority of each participant's healthcare that was conducted in English.

Being accustomed to managing in English

It could easily be assumed that language would dominate the unfamiliarity of the healthcare environment for participants. However, while participants' preferred languages were perceived to be a low priority in healthcare, the specific situation of receiving services in English was a scenario which participants were accustomed to prior to their stroke. They were familiar with the use of their communication being restricted by the language ability of others such as the earlier example of Emilio's neighbours calling him by an anglicised version of his Italian name. This was even the case in the context of participants' homes as many reported that their grandchildren did not share their language, so they talk in *"broke"* with English-speaking family or neighbours as Krystyna explained, *"If I forget one word, then I tell different one, explain, and then she understand and I understand her"* (English).

During the interviews, participants readily made comparisons of their healthcare situation after stroke with how they managed without professional interpretation in English-speaking work or social contexts. Some were proud of managing independently using English language skills they had learnt from short courses or work contexts, often supplemented by watching television shows or using dictionaries as Waldemar provided a typical example, "*And if I knew I was going to have a conversation with someone, I would prepare with my dictionary"* (Polish). Family or friends were regularly relied upon to interpret English conversations in the community that were more complex than familiar day-to-day interactions or to translate documents as Andreas and Emanuele provide just two examples of,

> *It's a family friend. He is helping a lot of filling in forms, things that I don't know* (Andreas, Greek)

> *Like now if I have to go to any specialist I always go with one of my children* (Emanuele, Italian).

Several participants who spoke English *"well"* or *"not well"* had already accepted an English-speaking healthcare context before their stroke by attending a general practitioner who did not speak their preferred language. For Krystyna, it was a matter of convenience despite her recognition "*There's a lot of words I don't use, I don't know them, I don't remember them"* (Polish). Others had prioritised choosing someone whom they trusted to be a good doctor with the belief that they could manage in English with this trust.

The positioning of participants as passive patients by the conditions that have been outlined so far cast health professionals as the expert authorities and confined participants to obeying the rules with little opportunity to have a voice or choice in the decisions that were made. But participants were not passive individuals; they were people who had an interest in what was happening to them and what it meant for their future. The final condition in the process of *'being told and being a good patient'* was 'wanting to know'.

Wanting to know

The passive role given to the participants as patients, which have been portrayed in the previous conditions of the process, did not recognise their desire for autonomy and their active interest in what was happening to them and why. Their prior lack of knowledge about stroke did not mean that participants were content with a lack of knowledge about their condition and healthcare. As Emilio insisted, *"Cause I like knowing things"* (Italian). During the study interviews, they were eager to demonstrate to me their interest and ability to manage their healthcare by explaining their medications, displaying hospital appointment letters, reporting their latest test results and demonstrating rehabilitation exercises.

Participants who did not have medical knowledge did not expect to understand the expert knowledge of health professionals, *"I can't know all these things, the doctors know that"* (Andreas, Greek), but they did want to know about their stroke and its management to enable them to make decisions about their healthcare and future. Christos expressed this sincerely, *"I feel better, it would have direct me better, I would have known better"* (Greek). Information which participants reported wanting to know from health professionals included their diagnosis, test results, medication changes, likely recovery and discharge plans. Knowledge about how to prevent a second stroke was of special concern as most shared Christos' fear of being disabled again, *"I don't want this ever to come back again"* (Greek).

At times during the healthcare experience, the cognitive effects of stroke made it difficult for several participants to understand and retain the information they were told by health professionals. This seemed to be especially the case during the earlier stages of healthcare. Krystyna and Waldemar provided some examples of how they had experienced difficulty in their thinking,

> *I didn't even have it in my head to try to remember names* (Krystyna, Polish)
>
> *I couldn't think, the thoughts were not coming to my head, so I didn't know - am I to cry, am I to whinge?* (Waldemar, Polish).

But this still did not mean that the participants did not want to be given information. Just as they physically and cognitively improved during their healthcare, participants'

ability to comprehend and retain information also improved. All participants returned to live in the community and, except for Nam, were involved in self-managing their health. They wanted information relevant to their condition and its management that would enable them to optimally self-manage their health and recovery following their discharge from healthcare. They wanted to return to being successfully autonomous.

The only participant who did not express a desire for information was Nam. His cognitive and severe physical disabilities were persistent after stroke and made him very frail and reliant on his children to manage his health and healthcare. For Nam, it was his children who wanted the information about their father's healthcare because it helped them to care for their father, *"…help us to know how to help him"* (Hung, Nam's eldest son, Vietnamese). Preventing stroke was also a concern to Nam's children both for Nam's and their own future health, but, as one son explained, they did not perceive that they had been given that information during Nam's healthcare,

> *About care and things like that I think they do (tell you). But about what happened to the stroke and why, the reasons and things like that and how you avoid things or how you (unclear) at that and things like that, no we don't have any information about that* (Son, Nam's son, English).

The conditions of the healthcare context which participants entered after their stroke positioned them as passive patients with little knowledge or voice in the care they received, contrasting with their own perception of themselves as motivated individuals with an interest in what was happening to them and their future. Participants' concern that their familiar lives were at stake during their healthcare heightened the importance of how they responded to this problematic combination of conditions in the process of *'being told and being a good patient'.*

4.3.2 Responses of participants in 'being told and being a good patient'

Participants responded to the conditions of the healthcare model presented to them by being good patients. They conformed to the expectations of the patient role (action: obeying the rules), and viewed this action as integral to their recovery from stroke. Participants trusted health professionals as experts in stroke recovery,

perceiving that there was no alternative available to them (action: trusting the experts). But it was a trust with boundaries that they could be crossed and the trust lost. Occasionally participants stepped out of their good patient role to speak up for more information (action: speaking up). Each of these responses is presented in detail in the following sections.

Obeying the rules

Participants accepted and adopted the role that they perceived to be expected of them in the healthcare context which they entered after their stroke. Participants behaved as good patients by obeying the rules, "*Whatever I was told, that's what I did"* (Andreas, Greek), not talking back *"I didn't feel I ask the doctor…they work on me, I let them do"* (Benigno, English), and striving to pass their tests, *"…they try to give me this stick and I try how long can I go"* (Sadik, English). The positioning of participants as passive recipients of healthcare was so effective that some participants reported obeying rules even when it made them uncomfortable such as Katariina, *"I had to have a nasty needle just here somewhere'* (English), or when they did not know the purpose of the rule as typified in Ming's experience,

> *Ming (Cantonese): There's a long corridor, and the nurse go to me, 'Walk.'*
>
> *Interviewer (English): Why did she ask you to do that?*
>
> *Ming: I don't know. Exercise (pause), but I just want to.*

Despite being from diverse cultural backgrounds, participants shared the belief that to be a good patient they must listen to the experts and do what they were told. Thao provided his interpretation of what a good patient should do,

> *I believe that a good patient in the hospital is the person who comply with all the regulation and rules set up by the hospital there, for example, you have to comply with the time when you go to sleep, when to eat, when you need to exercise and so on* (Thao, Vietnamese)

This expectation of good patient behaviour was reinforced not just by the conditions of the healthcare context, but also by some trusted others who encouraged the participant to obey the health professionals' orders. However, the response of being a good patient and obeying the rules was not simply a passive acquiescence by

participants. Just as indicated by Ming's explanation of why he obeyed a rule, *"I just want to"* (Cantonese), participants obeyed the rules with an active intent to aid their recovery from stroke and to get home. Despite the limitations of their stroke disability or their passive positioning in the patient role, participants credited their own efforts to push themselves and obey the rules as integral to their recovery. Christos and Gino provided just two examples of participants recognising their own active role in their recovery from stroke,

> *I pushed myself quite a bit and I became better* (Christos, Greek)

> *I do because I want to do well. I want to rehabilitate myself* (Gino, English).

Participants were also fearful about what would happen if they did not obey the rules. Participants' fear of loss at the occurrence of stroke translated to a fear during healthcare that they would be kept from going home. They worried that if they did not pass what they perceived to be a 'test', such as being unable to complete tasks during a therapy session or self-care without help, then they would not be discharged and even risk going to institutional care. Andreas explained why he did not ask for help when he had difficulty showering himself, "*Then they will think, 'What is he talking about? He can't go home.' Just keep me in"* (Andreas, Greek). Some participants also feared that if they complained about their healthcare it would be troubling their good patient role and risk their healthcare and recovery. Thao explained why he chose not to complain when he was left sitting in the dark in a bathroom for a long period of time,

> *I just keep it for myself because I thought that I was a patient, I went to the hospital and I'm afraid that if I spoke out then there would be some sort of problem and I didn't want that happen. So I just kept that for myself* (Thao, Vietnamese).

In responding to the conditions of *'being told and being a good patient'* by obeying the rules, participants trusted that the people who made and enforced the rules were acting in their best interests.

Trusting the experts to get it right

Just as their own actions of obeying the rules met participants' expectations of the patient role, the authoritative actions of health professionals were perceived as fulfilling an expert role. Participants trusted that health professionals had an expert knowledge of what was best for a person to recover after stroke. This trust was particularly strong for Ming whose family members held professional positions as doctors and dentists,

> *… now I'm in the hospital they are supposed to take care of me and my life is in their hands…what they can do should be the best for me* (Cantonese).

The behaviour of health professionals to give directives and perform tests fitted with participants' ideas of an expert making decisions and checking all was right. When a health professional told the participant that their test results had improved or they were recovering well then the participant believed them and took strength from that in their efforts to recover, as Waldemar experienced, *"…my mood improved, I was feeling better"* (Polish). Krystyna and Benigno provide two more examples of many from interviews which demonstrated just how encouraged participants were by the trusted words of health professionals,

> *(The nurses) Give you hug, kiss you, and tell, "You'll be alright, don't worry, you'll be alright." And this help, yeah, it help. I think maybe, maybe it's true, maybe these people know from this experience, yeah* (Krystyna, English)

> *Interviewer (English): And if your specialist is happy, how do you feel?*
>
> *Benigno (English): Oh, much happy [laughs]. He was talking about me, my heart.*

Participants' relinquished the responsibility for decisions relating to their healthcare with the trust they gave to health professionals. Sadik explained, *"I'm not the one that should be deciding whether I go home, they're the ones that should be"* (Croatian). Health professionals were expected to use their expertise to decide what was in the best interests for the participant during healthcare and for their future recovery. Trusted others were also expected to make decisions in the best interests of the participant, but while the role of the trusted other came from an established personal

relationship, the trust in health professionals was based on expertise and was perceived to be participants' only choice during their healthcare experience.

No other choice but to trust

Participants were in a situation after their stroke where they felt they had no other choice but to place their trust in health professionals, *"… you have to have your trust and respect otherwise you might as well not go to hospital and doctor"* (Katariina, English). The healthcare context after stroke was unfamiliar to most participants and their families, they had no expert knowledge of stroke to guide them or time to prepare their response, and something of great importance to them was at risk. Sadik, who was initially reluctant to be a good patient, was persuaded to trust healthcare and comply with treatment once he realised the risk that an infection presented to his recovery,

> *I wanted to go home. I really don't like hospitals. But in the blood test they found some kind of disease, infection of some sort. Very dangerous* (Sadik, Croatian).

The act of trusting was itself a risk for participants. In the unfamiliar context of healthcare after stroke, they did not know the majority of health professionals whom they were required to interact with. The trust was then accorded to the expert role rather than the individual, as both Emanuele and Nam's son explained,

> *I trust them because they are a doctor, what else can I do?* (Emanuele, Italian)

> *Because we don't know anything else and we have to rely on and trust the doctor* (Hung, Nam's son, Vietnamese).

This placement of trust did not appear to be a naive action taken by participants. Several participants recognised that their trust had associated risks if the health professional was wrong but they still felt that there was no better alternative available to them in their position. This view was clearly expressed in the words of Katariina and Benigno,

> *I know they also do mistakes, and I also know they are not gods* (Katariina, English)
>
> *They can make mistake but you hope for the best [laughs]* (Benigno, English).

The strength of participants' trust in health professionals carried them through the unfamiliar situation of healthcare after stroke and enabled them to accept a passive role in decisions related to their healthcare and recovery. The trust was extensive across the healthcare experience and incorporated participants trusting that health professionals would know and meet their language needs.

Trusting can manage in English

Trust in the expertise of health professionals underpinned participants' trust that they could manage with LEP in the English-speaking context of healthcare after stroke. They trusted that they only needed to understand enough of the communication with health professionals to be good patients. Thao explained how he interpreted his role in healthcare communication,

> *I didn't really ask for anything (for language interpretation), because like when I was in the hospital they are simple things like up, down and things like that and I just follow that* (Thao, Vietnamese).

Participants generally perceived that understanding *"…all the major things, you know like I should get antibiotics, the tooth has to come out…"* (Sadik, Croatian) was enough for them to manage during healthcare. Emanuele gave specific detail of what he felt he needed to understand when he spoke with a specialist doctor, *"If I can remember what is the seventy five (percent of what is said) then I understand everything"* (Emanuele, Italian).

Participants also trusted that the language context of their healthcare would be as controlled by the experts as all other aspects of their care. Just as participants had relinquished the responsibility for other healthcare decisions, they trusted that health professionals would accurately decide when language resources, such as an interpreter, were needed for communication. Andreas summed up what was a standard expectation by participants, *"It's their (health professionals') job"* (Greek). It

was a responsibility that was especially important for Christos who did not have a trusted other who was able to step in and help him to understand, yet Christos felt that his expectation for language assistance was not met during his healthcare after stroke, *"Because they (health professionals) should say to people who they need and they should have interpreter"* (Greek). If language resources were not provided, then it was assumed by participants that the experts did not want them be provided and it was not in their role, as a patient, to ask for it.

The trust in being able to manage in English during healthcare after stroke was so strong for some participants that they refused the help of a professional interpreter, even when it was offered. Despite differing educational, work and language backgrounds, Katariina, Gino, Benigno, Emanuele and Sadik were all proud of their ability to manage in English-speaking contexts and perceived their LEP to be adequate for the demands of the patient role. Benigno, Emanuele and Sadik also shared a distrust of professional interpreters. Sadik and Benigno were both concerned about the confidentiality of interpreters within their local community as Sadik explained,

> *I have heard that the interpreters, when they come and they are at an interpreting job then they go into the communities and they talk about this patient, that patient, this happened and that and this. I don't want. I want my private life to be private life. I don't want everybody to know* (Sadik, Croatian).

Emanuele's distrust was based on his previous experience in an outpatient specialist appointment when he perceived that an interpreter made an inaccurate translation, "*He (interpreter) was translating the wrong thing"* (Daniella, Emanuele's daughter, English). However, his stance proved to be negotiable as Emanuele agreed to the presence of a professional interpreter at his study interviews, *"I didn't think they were all the same"* (Emanuele, Italian).

Other participants welcomed the help of professional interpreters and translated resources during their healthcare, when they were provided. Thao, and Nam's son, Hung, both struggled to manage in their local English-speaking community and were reluctant to burden their busy families with the role of interpreter, *"…the*

(professional) interpreter is the best because my children are quite busy as well" (Thao, Vietnamese). But even these participants accepted that language resources were provided at the discretion of the experts and they trusted to manage in English during healthcare outside of the times when an interpreter was present.

A silent acquiescence to managing in English was not an assurance that the participant did not want to use their preferred language during healthcare. Rather, it was acquiescence to the role they perceived given to them and an acceptance of not understanding everything that was said in English. Participants did not perceive it to be within their patient role to ask to speak their preferred language, as Ming and Krystyna's words demonstrate,

> *I don't demand that, but of course it is better if I could have someone who speak my language* (Ming, Cantonese)
>
> *…there were situations (when I needed an interpreter) but they never asked me if I want one* (Krystyna, Polish).

Yet not being able to understand English conversations during healthcare was distressing at times for participants as described by Thao, "*I felt very sad in that situation"* (Vietnamese).

The strength of participants' trust in health professionals to take care of all their healthcare needs after stroke did not mean that the trust was invulnerable to being lost. When participants' expectations of expert behaviour were not met, the boundaries of trust could be crossed and lost.

Losing trust

Expert trust was lost when a health professional was perceived to not fulfill the expert role expected of them such as failing to demonstrate expert health knowledge or not acting in the participant's best interests. Benigno lost trust in his local doctor because he did not detect any problem in Benigno's blood tests only days prior to his stroke. Benigno also believed the doctor had paid little attention to his previous health complaints and so wasn't to be trusted to care for Benigno's best interests, *"…he wasn't caring about me anyway"* (Benigno, English). Christos lost trust in in the health professionals at rehabilitation when he perceived they were not giving him the

information and attention he expected. The persona of expertise was also important to participants' trust. Inconsistent information or a perceived lack of knowledge by health professionals did not fit with the expert role,

> *How can you trust when somebody say one thing and then somebody else say something else? How can you trust them?* (Krystyna, Polish).

When expert trust was lost, participants sought to distance themselves from the health professional and find reassurance from others whom they still trusted. Benigno changed his local doctor to one who was recommended by close friends. Christos requested to leave inpatient rehabilitation to be with *"my people"* (Greek), good friends whom he trusted would care for him. Krystyna distanced herself from her local doctor by no longer heeding his advice,

> *I went to see a doctor regarding my arteries, because I had an artery on that side which used to be a problem but they unblocked. And now the other one is blocked and I have headaches in that half of a head. And so I ask him, 'Why is it so?'…And he said, 'No, the pain you have here is not the result of the block artery, is the arthritis' and that threw me off totally so I'm not asking anymore* (Polish).

Obeying the rules of healthcare and trusting health professionals as experts were responses by participants which fulfilled the role of the good patient that they perceived to be expected of them. They were also responses which participants interpreted as being beneficial to their recovery from stroke. However, there were occasions during the healthcare experience when obeying the rules was not an adequate response for participants and they spoke up to gain more information than the process of '*being told and being a good patient*' had afforded them.

Speaking up

Speaking up was an action taken by participants to find out information despite the perceived discouragement for them to ask. Speaking up was an attempt to get information which the participant felt was important for them to know about their health but which had not been provided to them. Gino was a man who had worked with numbers all his life, and it was important to him to know his probability of

having a second stroke; so he spoke up during a ward round to find out his chances, *"I asked the doctors, 'I maybe come back again, you know. Could I have it (stroke) again?'"* (Gino, English). Ming spoke up in the Emergency department to find out his diagnosis, both Christos and Krystyna asked to find out what 'stroke' meant, Andreas spoke up when his independence was questioned, and Katariina spoke up to go home.

But not all participants acted to speak up for more information. A gap in knowledge which mattered to the participant needed to be recognised before they spoke up to fill it. Some participants did not identify information they wanted during their healthcare beyond what they and their family were told, *"I did some physio, do this, do that but no I didn't ask them anything"* (Emanuele, Italian). If an important gap in knowledge was identified by a participant, the action of speaking up was still not an easy or routine strategy for them. Participants first waited and trusted that the information would be shared by a health professional. It was only when the expectation was not met and the information remained important to the participant, or the situation was pressing, that they spoke up. For Christos, this was a long time in coming and he was eventually driven to speak up by his frustration at not knowing what his condition was,

> *To answer you sincerely, I was at (inpatient rehabilitation) thirty-five days and I didn't know what stroke means. I wasn't told. Until one day when there was a doctor there, was coming to (inpatient rehabilitation) two or three times a week, and one day I just stopped him and I asked him, I told him to tell me what it means* (Christos, Greek).

Andreas' decision to speak up when he was strapped onto a hospital trolley during his transfer between healthcare facilities was more hasty as he was upset that his independence had been confined,

> *And I ask the girl, 'Why are you tying me up? I'm well and I can sit just like that.' She said, 'No.' I have to be one hundred percent* (Andreas, Greek).

Speaking up required the participant to have opportunity; they needed to be able to communicate with the person who possessed the information which they sought and to perceive that it was appropriate for them in their patient role to speak to that person. Speaking up did not always require language interpretation as some requests could be made using English within the participant's level of proficiency, as Andreas

did in the example above. It appeared to be an action which was easiest for participants with greater proficiency and confidence in using English. Vincenzo, the participant who preferred to speak English, was able to ask many questions of health professionals on repeated occasions to get the information he wanted during his healthcare after stroke,

> *…you see there are things you ask why a few times and they tell you, they explain, that's good enough. I did ask many, many questions regarding the sickness of mine, but that was okay* (Vincenzo, English).

For participants who wanted information but had less proficiency and confidence, they needed to wait for an opportunity to speak up in their preferred language. This included using the interpreter provided during meetings to ask questions of the health professionals, *"And I ask, 'Where I would go?' and 'Where I would stay?'"* (Christos, Greek), or asking a health professional who shared their language. Sharing a preferred language with a health professional did not happen often, or at all, for some participants. Ming was able to speak to the international student nurses who visited his ward to ask questions about his healthcare, *"Among those student nurses or whatever, some are Chinese-speaking, and they explained to me, they talked to me…"* (Cantonese). Family members were also used by some participants to speak up as mentioned earlier in the response subcategory of 'trusting can manage in English'. It was a matter of the participant taking advantage of the language resources which they perceived to be available to them. No one stepped so far out of their patient role as to request the assistance of a professional interpreter to be able to speak up.

The success of speaking up was dependent on the response of the health professional. The doctor whom Gino asked about the chance of a second stroke replied that there was only a small chance of it happening. This was encouraging news for Gino, *"A bit of courage, you know. I got a bit of courage"* (English). But the receipt of a negative response to a request acted as further discouragement to the participant to speak up. Ming did not ask any more questions of health professionals during his healthcare experience after the Emergency doctor rebuffed his request for a diagnosis, *"I'd better speak and explain things to your daughter who will understand better"* (Cantonese). And after Andreas had been denied his request to sit up while he was transported to the rehabilitation facility, he then did not speak up at rehabilitation when he thought

they were asking him for money to be admitted to the facility. According to Andreas' wife, the staff were actually asking Andreas for his valuables to secure them but the request was in English which Andreas did not understand and he was reluctant to speak up to question what the experts were asking of him.

Speaking up opposed the perceived discouragement to participants to ask for information during healthcare. A step further in resisting the passivity of the patient role that was given to participants by the conditions of '*being told and being a good patient*', was when participants chose to resist the advice of health professionals and altered the direction of their healthcare path. This was a significant event within the healthcare experience of participants and is presented in the third and final process of the theory, *'weighing up the value of care'*. Before turning to that process, the consequences of *'being told and being a good patient'* are presented. Despite isolated instances of speaking up, participants were left uncertain and uninvolved in decisions about their healthcare and the future management of their stroke recovery.

4.3.3 Consequences of 'being told and being a good patient'

While the conditions of *'being told and being a good patient'* may have been effective in achieving an initial context of expert certainty and security for participants after their stroke, the process had eventual consequences for participants' ability to engage with their healthcare. Despite being good patients and trusting health professionals to decide what was best for them during their healthcare, participants spent most of their healthcare trying to understand what was happening in a language they were not proficient in (consequence: had to manage in English), they were given little of the explanatory and detailed information that they wanted (consequence: uncertain about stroke and its management) and were kept out of important decisions that were made about their healthcare (condition: not involved).

Having to manage in English

All participants managed in English by their own initiative for a large part of their healthcare experience. They had to manage in English to understand what was happening, what was required of them and what it meant for them for the majority of their healthcare when their preferred language was not available. The occasional presence of an interpreter, or a simplified English rule to follow, enabled only small

snapshots of information for participants in a large and significant life experience. As Gino explained, he had to work out how to get the information that was not given to him, *"No, the nurses, the doctors and the nurses telling me nothing. I find them out myself*" (Gino, English).

There was no standard way for participants to manage in English during their healthcare after stroke. They used strategies which were trusted and familiar to them and which they perceived to be available at the time. The strategies varied between participants and healthcare settings, including:

- asking trusted others from family and friends to help them understand,

  Because it was after hours and when would the interpreter come? And he, the friend, said, 'I will come and help' (Andreas, Greek)

  I thought I could manage by myself up til a certain point and then if there was something, my children were always there so I would use say one of my children and they would clarify things with me (Emanuele, Italian)

- asking questions of health professionals who shared their language,

  Actually there was a nurse who's in our religious community who also goes to this church and she is Vietnamese so I talk to her. I asked her about it and she explained to me (Thao, Vietnamese)

- asking health professionals to speak 'clearly' in English,

  I asked them to speak to me slower and clearer so I can understand (Andreas, Greek)

- teaching health professionals to use words from their preferred language,

  …another example when they say "good" and then I just repeat, but in Vietnamese I say 'tốt' and they learn my language. And next time when they want to say good they say 'tốt' in Vietnamese (Thao, Vietnamese)

- relying on their observational skills,

Because I look at that (the box of medicine), I know, it tells the same thing (as box at home), but this one is, this one is half (Ming, Cantonese)

- talking with other patients using *"broke"* English (Krystyna) or another shared language,

  And the guests (other patients) were telling me many times what I should be doing (Christos, Greek)

- or by tolerating not understanding,

  Andreas (Greek): Sometimes they were talking very quickly and so I couldn't understand.

  Interviewer (English): What did you do then, when they talked too quickly?

  Andreas: Nothing [laughs].

Having to manage in English was accepted by participants as part of being a good patient and trusting the expert health professionals to know what was best for them. But this language context compromised their ability to understand what was happening and to engage in their healthcare. The risk of miscommunication of information was increased when participants managed in English. The familiar strategies which participants used helped them to follow the rules but did not always enable them to understand the detailed information that they wanted to know or enable them to participate in a conversation. Waldemar explained how his strategy of asking health professionals to talk slowly in English was not enough for him to understand all that was said,

> *Because if they (health professionals) talk slowly, then for example if a sentence is seven words, I would catch maybe three or four, but if they talk fast…[shrugs]* (Waldemar, Polish)

Using a trusted other as an informal interpreter was a convenient and familiar strategy for participants to manage in English but was not always successful. Trusted others were not always available to help,

> *Well, in hospital when the children they are there, they are there, and if they are not there I just have to manage on my own* (Emanuele, Italian).

And trusted others sometimes withheld or delayed passing on information. One co-participant, who was a daughter of a participant, acknowledged that she had previously withheld medical information from an older relative when acting as an interpreter. In another example, Ming was aware that his daughter did not pass on information about his diagnosis and healthcare management until eight days after his stroke,

> *Not immediately (tell me). It was after I was discharged from the hospital, then my daughter did tell me something* (Ming, Cantonese).

Participants may not always have realised when information had not been passed on by a trusted other and so they would have simply missed out on it without knowing the information they had missed. Having to manage in English was not always perceived as a problematic issue by participants in their experience but it likely contributed to the general perception that they missed out on all they wanted to know during their healthcare.

Uncertain about stroke and its management

The process of *'being told and being a good patient'* left participants lacking knowledge about many aspects of their stroke and their healthcare. The uncertainty they had experienced at the sudden occurrence of their stroke in the process of *'hanging on to the familiar'*, remained with them in many ways throughout their healthcare experience. At the time of interview, participants' understanding of stroke and their symptoms was consistently inaccurate or absent. "*I even today don't really, don't fully understand what does it mean, stroke?*" (Krystyna, Polish). They often did not know why healthcare decisions had been made, such as which therapies they received or when they were going home, and were unsure what services were available to them in the community. Thao provided a typical response when asked about the arrangements for him to have rehabilitation healthcare in the community, *"I don't know about that because everything was arranged by the hospital"* (Vietnamese). Trusting and obeying the rules of experts had left participants with little means to make informed choices about the management of their health after stroke.

Participants' uncertainty about stroke and the management of their recovery was also shown by what they asked when there was an opportunity for questions at the end of their study interview. Ming asked what treatments were available for his persistent leg numbness, Benigno wanted help in finding out who had taken money to install a rail in his bathroom and when they would be coming back to do it (he had been waiting several weeks), both Krystyna and Thao requested information about stroke in their preferred languages, and Nam's family asked how stroke could be prevented. Participants were still seeking to fill important gaps in their knowledge about their stroke and its management even though the bulk of their healthcare experience after stroke had finished.

The uncertainty was upsetting for participants who entered healthcare wanting to know about their health and its management after their stroke. Being unsure about what was happening was felt keenest by those participants who perceived that their ability to return to their familiar lives was at risk. This was particularly the case for Katariina who not only feared for the loss of her independent lifestyle but also had a nurse's interest in knowing about her health. Katariina explained how upset she was at missing out on what she wanted to know,

> *…it's very sad really, because I think really I would like to be able to understand myself as much as I can, you know for what's happening with me and my body* (English).

Health professionals limiting the information they gave to participants also had the potential to limit what was an important source of motivation and reassurance for people in their recovery from stroke. Krystyna explained how powerful the words of health professionals could be in a person's recovery, *"All the good words together, they collect themselves and they help sick people"* (Polish)

There was a general perception by participants that health professionals *"…didn't tell me much'* (Benigno, English) which contributed to their uncertainty. Participants were told rules by health professionals but, as Krystyna complained, *"…they (health professionals) didn't explain anything"* (Polish). In the simplification of healthcare communication to rules-based talk, and mostly in English, it seemed that something was omitted from the full message. Being told the rules provided instruction but not

explanation, exemplified by Andreas' experience of being told to take medication, *"They (health professionals) told me to take the tablets, not to delay in taking them"* (Greek). Participants were then uncertain about the instruction's purpose or its importance. Andreas worried about possible side-effects of the tablets he had been told to take, *"But I don't know how far they will take me, I don't know if they will affect me in any way"* (Greek). The process of *'being told and being a good patient'* had met participants' expectations of the roles of patient and expert in healthcare but it missed out on engaging them in healthcare decisions and stroke education.

The action of speaking up provided a degree of certainty to the participants who chanced it, but it was a strategy which was only used on isolated occasions by a few participants for snapshots of knowledge and so had limited benefit. The participant needed to notice that information was missing before they could speak up to get it. In the unfamiliar situation of healthcare after stroke, participants were not always aware of what they would need to know or they felt unable in their patient role to speak up. And so the action of speaking up provided discrete occasions of certainty for participants within a larger experience of being uncertain.

Participants' uncertainty related to the process of *'being told and being a good patient'* was highlighted by the contrasting certainty of information that was gained when several participants experienced a different process of healthcare communication. They were satisfied with the extent of information they received when health professionals told them more than just the rules and they were able to communicate in a language they were proficient in with the opportunity to ask questions. Sharing English as a preferred language gave Vincenzo plentiful opportunities to engage with his healthcare, even to question expert decisions, which were not available to other participants. He chatted easily with health professionals, other patients and even the facility's security guards throughout his inpatient and outpatient healthcare experience and was able to read the daily planning board in rehabilitation to get all his questions answered to his satisfaction. Nam's son, Hung, was not able to share such chat with English-speaking health professionals but he did use the regular provision of a professional interpreter during training sessions with his father in rehabilitation to ask questions that arose for him over time. Both Sadik and Emanuele appreciated talking with a doctor who *"…explained everything"* (Helena, Sadiks' wife,

English). And Thao demonstrated a good knowledge of the mechanism of his stroke at his study interview because he "…*understood well what the interpreter told me"* (Vietnamese) when his diagnosis was given to him by the doctor.

Professional interpreters were an effective tool for communication between participants and health professionals, but the confinement of their use during healthcare to the occasions when health professionals determined that they were needed reduced their potential benefit for informing participants. As noted by one of the professional interpreters assisting with the study, who had worked in healthcare settings for many years, professional interpreters were often *"underused"* (Monika, English) by only being asked to translate assessment instructions or ready-made decisions. The subsequent requirement for participants to manage in English for the majority, if not all, their healthcare experience increased the risk of miscommunication of information as presented in the previous section. The continued uncertainty about their stroke and its management was both upsetting for participants and instrumental in them not being engaged in their healthcare after stroke. The process of *'being told and being a good patient'* did not just keep information in a silo of knowledge away from participants; it also kept decisions about their healthcare and recovery out of their hands.

Not involved

'Being told and being a good patient' was a process that did not encourage or enable participants to have a meaningful role in decision-making about their healthcare after stroke. Already in a shocked and disabled state when they entered healthcare, the process gave participants a role that was dependent on the authoritative decision-making of health professionals. The process conditions of being told and being discouraged to ask did not allow participants to be involved in collaborative discussion or goal-setting with health professionals. Therefore, healthcare after stroke was often shaped by the rules of experts rather than participants' needs and wants in their recovery.

There were many examples across the data where participants were not involved in key decisions about their healthcare. These included decisions about when they were being discharged from inpatient or outpatient healthcare, what language they could use, what therapies they received, and what the goals of their rehabilitation were. The

role they had been given did not lead them to expect it to be any different. In one example, Emanuele was told by the physiotherapist providing his outpatient therapy that she would not be coming back any more. Emanuele had not reached his own goals for physical recovery after stroke and did not know why the therapy had stopped but, being a good patient, he did not object to the expert's decision. This left Emanuele still physically disabled by stroke so that he could not walk outside of his home, but with no plan or idea for how he would be able to continue his recovery,

> *(Italian) I don't really know if I could have asked her (physiotherapist) to keep on coming, quite frankly. (English) I don't know* (Emanuele).

In Emanuel's example above, there was no professional or informal interpreter present at the time the physiotherapist told him that his treatment would cease. Although Emanuele understood her instruction, it is unlikely that he would have managed in English to meet the complex communication requirements for collaborative planning of his healthcare even if it had been offered to him. This was unlikely to be possible when they only understood the major things in the conversation (Sadik), seventy percent of it (Emanuele) or three out of seven words that were said (Waldemar), if not less.

The process of *'being told and being a good patient'* needed to change for participants to be involved in making decisions about their healthcare after stroke. The sharing of information in a two-way conversation and being able to use their preferred language opened up opportunities for participants which were otherwise not there for them to engage in their healthcare. Krystyna provided a vivid example of how being able to use her preferred language with a care worker enabled her to initiate an active role in arranging her healthcare. This contrasted with the lack of such opportunity when she managed in English,

> *Interviewer (English): Can you tell me, what it means to you, to have a care worker who speaks Polish?*
>
> *Krystyna (Polish): It's good, I can tell her everything and she can explain everything to me. So when there's something I don't like, I explain to the care worker and she explains to me it's not their fault, it's a second company she works for. And then I said, in this case, I'll talk to the boss.*

Interviewer: Okay. If your care worker did not speak Polish, how would you have organised the meeting?

Krystyna: I don't know. Maybe there would be some other way, but I don't know.

However, the experience for Krystyna to have both her preferred language and an opportunity to ask questions and make decisions available to her was not shared in the stories of other participants, excepting Vincenzo who could use English language to ask questions of different people.

Sometimes, the passive role given to participants was intensified by the psychological and physiological effects of stroke. Recovery after stroke was a dynamic process and a sense of shock and grief affected some participants' ability to interact with health professionals at times in their experience. This happened during the early part of Krystyna's healthcare experience, *"When a person is sick, they don't care about anything. I was just lying there quietly thinking, 'Hmm it's all gone'"* (Krystyna, Polish). Waldemar and Emilio had more enduring changes to cognitive processing and memory that affected their capacity to be involved to differing extents. Waldemar gave an insight to the effect these changes had on his ability to participate in his healthcare,

> *And I spent three weeks in the hospital. And I was mostly passive there, just lying down and just being alive. And I didn't know why the stroke happened and nothing really, and I didn't even thought why it happen to me* (Waldemar, Polish).

These participants presented extra, but not unique, challenges to involving them in making decisions about their healthcare after stroke.

The process of *'being told and being a good patient'* dominated participants' experience of healthcare after stroke. It met their expectations of patient and expert roles in healthcare but failed to provide the certainty of knowledge and involvement in decision-making for them to be engaged with their healthcare and its planning. The consequences of *'being told and being a good patient'* influenced how participants interpreted the meaning and value of their healthcare after stroke. This is further explored in the next, and final, process in the theory.

4.4 Weighing up the value of care

The process of *'weighing up the value of care'* was continuously occurring in participants' healthcare experience, from the time they first encountered healthcare after their stroke. It was a process driven by each participant wanting to recover familiar abilities and contexts after their stroke, yet finding themselves in unfamiliar situations where they were given little certainty about the benefits of their healthcare to what they valued. In *'weighing up the value of care'*, participants reclaimed a place of importance in their experience by making their own evaluations of the meaning of their healthcare for them. The evaluation informed participants' adherence, or not, to their healthcare after stroke. The structure of the process is given in Figure 4.6.

The process of *'weighing up the value of care'* started early in my analysis as an idea that participants were 'making sense of the unfamiliar' in their healthcare. However, as my analysis progressed, I realised that the idea of 'making sense' stopped short of capturing all of what was happening in the coded data. What I had initially thought of as 'making sense' was a combination of participants 'managing in English' to understand their healthcare, and them 'evaluating their healthcare' to give it a value and meaning that was relevant to them. So I developed these two ideas separately; the first was integrated into the process of *'being told and being a good patient'* and the other became a response by participants in the process *of 'weighing up the value of care'*, but they remained connected by 'managing in English' being an influence on the evaluation.



Figure 4.6 Structure of the process *'weighing up the value of care'*.

4.4.1 Conditions of 'weighing up the value of care'

Participants wanted their healthcare after stroke to help them to return to the meaningful activities and contexts which they enjoyed in their familiar life before the stroke occurred (condition: wanting the familiar). They missed the comforts which the context of home provided them. Yet their healthcare after stroke was often unfamiliar to them, lacking the purpose and comforts which they sought. The process of *'being told and being a good patient'* had left participants uncertain about what was happening in their healthcare and what it meant to them getting back to their familiar life (condition: an uncertain and unfamiliar situation). This combination of contrasting conditions was a problematic situation for participants, especially as their healthcare experience after stroke progressed.

Wanting the familiar

Participants sought to recover and return to their familiar lives throughout their healthcare experience. The condition of wanting the familiar after stroke was typified by Waldemar's wish during his inpatient healthcare, *"I want to be as I was before the, before my stroke"* (Polish). It was a strong desire from when participants initially attempted to continue as normal at the time of their stroke. The concept of the 'familiar' was defined within the theory by what held value and gave importance to participants as individuals in their lives before their stroke. What constituted the familiar was specific to each participant, including their previous physical and cognitive abilities, normal routines and social roles, family and friends, and the autonomy of *"my usual life"* (Benigno, English).

Returning to familiar activities and contexts promised participants a degree of autonomy and control in their daily activities that was in contrast to the dependence they experienced within the process of *'being told and being a good patient'*. The importance of the familiar to participants during their healthcare was signified by the distress they experienced when they perceived that they were positioned further away from it, either by physical distance or implication. It was the opposite of what they were expecting, and wanting, to happen. Krystyna and Andreas provided two of several examples of participants perceiving that the familiar was taken away from them within a process of *'being told and being a good patient'*,

> *They told me I am going to go to (Residential Care facility) where some people are mental. Well, that means I'm mental too or not normal. So I cried and I become depressed and sick* (Krystyna, Polish)

> *I was upset because they took me to do those (exercises) with some people who are completely disabled, people who couldn't move. And they put me in there with them!* (Andreas, Greek).

Andreas was so upset by the situation that his wife organised to take him out for regular day trips to his home and familiar community settings to avoid the situation and to comfort him. A key part of the familiar for participants, particularly during their inpatient healthcare experience, was their home. It was a context which offered them many elements of the familiar which they missed, including activities, roles and people.

Wanting home

Participants believed that they would feel better and recover better at home. Katariina missed the peaceful quiet of her home compared to the noisy hospital environment, *"You cannot sleep properly. There is traffic all night long"* (English). For some who lived alone, wanting to return to the familiar of home was heightened by their concern for its welfare such as the security of their possessions or the survival of their garden, *"…I was worried about my house that it got broken in, so I wanted to go home"* (Waldemar, Polish).

But the idea of home for participants was much more than bricks and mortar. As their time in hospital or rehabilitation progressed, they increasingly missed the comforts and meanings of home which were not readily available to them. These included the food they liked, their choice of language and familiar company, and the opportunity to be engaged in meaningful activities,

> *Because I'm used to being occupied, to be doing something all the time. Here in the house (at home) I work all the time and I was thinking that if I don't do anything perhaps my brain will become worse* (Andreas, Greek).

Home was a context where participants had control over their daily routines, as Gino's wife Rosa helped me to understand during an interview, *"At home do everything you want"* (English).

Only Thao reported that going home did not offer him what he wanted during his inpatient healthcare after stroke. Thao perceived that the context of his home would not provide him with the comfort and certainty he sought because a large part of his familiar was missing for him there. Thao still experienced difficulty walking and was unsure if his therapy would continue at his home. Also, his wife was chronically ill with Parkinson disease and his eldest daughter, who had previously cared for him when he was ill, had been unable to migrate to Australia from Vietnam, *'... that daughter had helped me a lot during my time when I was injured'* (Vietnamese). The company of Thao's daughter at his home was perceived to be so important to him that his family had hired a lawyer to seek permission from the government for her migration,

Trusted others were an important part of home for all participants. As Nam's son, Son, explained, people helped to make his father's home a familiar and comfortable place,

> *...he (Nam) want to come home and surround him with the children. Sometimes this person coming, another person coming just give him a little bit...happiness. That's why, and might be more comfortable when you can speak your language* (English).

Trusted others were introduced in the theory's initial process of *'hanging on to the familiar'* as people who knew participants before their stroke and shared a trusted personal relationship with them. They were a personification of the familiar that provided certainty and comfort as Benigno explained, *"A lot of people (after stroke) scared, get scared. They need to be assured they're going to be allright"* (English). The importance of trusted others to the idea of home for participants was exemplified in the experience of Christos. He was evicted from his house while he was in hospital and the house was then knocked down. Christos was distressed by the uncertain prospect of where he was to live, but sought to return to live in the community with

his friends where he felt he belonged, *"…I want to be always with my friends, to forget, forget the condition I'm suffering from"* (Greek).

Visits from trusted others during participants' inpatient healthcare provided someone for them to talk with and get advice from, as well as distraction from ward routine. Some even brought in home-cooked meals. Ming and Emanuele explained how they felt about the visits,

> *And, in fact, when I was in the hospital I had many visitors and I won't feel that lonely there. My daughter, my other son-in-law or whatever, they visited me, so I'm not that lonely there.* (Ming, Cantonese)

> *It wasn't that nice sitting there all the time. And then, the relatives would come and that was the best part.* (Emanuele, Italian).

But occasional visits were not enough to satisfy participants yearning for the familiar during their inpatient healthcare experience after stroke.

Despite the importance of familiar comforts, activities and contexts to participants during their healthcare, they were provided little chance to express it. Occasionally they spoke up about going home during rehabilitation meetings (see responses in *'being told and being a good patient'*), but the simple language of asking to go home could not capture in its message the full extent of what participants wanted from their healthcare. The absence of meaningful patient engagement in healthcare left participants without an opportunity to communicate their specific wants and needs to health professionals (see consequences of *'being told and being a good patient'*).

Wanting the familiar was desired by participants throughout their healthcare experience, with most wanting to go home during their inpatient healthcare and all participants wanting to regain familiar abilities and roles as they recovered. But rather than their healthcare bringing them closer to the familiar, participants perceived that their healthcare after stroke was often an unfamiliar and uncertain situation for them to be in.

An uncertain and unfamiliar situation

The processes of *'hanging on to the familiar'* and *'being told and being a good patient'* left participants in a situation which was unfamiliar to them and where they were often uncertain about what was happening in their healthcare. Unlike the meaningful activities and roles which they participated in within their familiar life before their stroke, they experienced little engagement in their healthcare planning or decisions after stroke (see consequences of *'being told and being a good patient'*). They lacked a good understanding of how their healthcare was relevant to what they wanted, especially once the focus moved from the diagnosis of their condition to rehabilitation. Being told the rules did not communicate the value of what health professionals were doing with them. The situation was uncomfortable for people who wanted to know and who wanted the familiar in their recovery. At times, they even perceived their healthcare to be taking them further from the familiar rather than closer to it. It was a situation which was experienced to varying extents in both inpatient and community healthcare contexts.

Hard to handle

The unfamiliarity and uncertainty which participants experienced was evident in the many complaints they made during study interviews about not knowing why decisions had been made during their healthcare and becoming bored during their stay in hospital or rehabilitation facilities. Participants had limited meaningful involvement in their inpatient healthcare not only as a consequence of the process of *'being told and being a good patient'*, but also because of the large periods during their days when they perceived themselves to be without any organised therapy or ways to keep busy. Christos provided a detailed picture of how hard it was to handle the uncertainty and boredom which he, and other participants, experienced,

> *There is nothing you can do there (at rehabilitation). Okay, they help me at the beginning, I became better. But there is nothing you can do. There is nothing there to occupy yourself so the day will come pass. I just had to walk, to watch things, to watch TV or you go and do exercise by yourself. It was boring. You couldn't, you could not handle it all the time* (Christos, Greek).

There was little to distract participants from boredom. Having LEP in a predominantly English-speaking inpatient context limited their ability not only to communicate with health professionals but also to socialise with others in healthcare. This was not only boring but also isolating for some. It was simply down to luck if there was another patient who shared their preferred language for the chance of a good conversation, or the availability of some translated literature to read. All the television programmes were in English. Emilio found that his Italian newspapers which his family brought in for him were thrown in the bin by cleaning staff. The boredom felt by participants was in stark contrast to the experience of Vincenzo, who filled his weeks of inpatient healthcare by talking in English with various other people to better understand what was happening, and for his own enjoyment,

> *The day is full of things happening there and we make it happen with our friendships…with other patients, yeah. Talking is very interesting people there* (Vincenzo, English).

The awkward juxtaposition of participants wanting their healthcare to be relevant to the familiar, but then being in a situation which was unfamiliar to them and where they were not sure what was happening, prompted them to make their own assessments of the meaning and worth of their healthcare for them. Within the limitations of their good patient role, it was up to each participant to determine what value their healthcare had for their recovery after stroke.

4.4.2 Responses of participants in 'weighing up the value of care'

Participants responded to the conditions of wanting the familiar and the uncertain and unfamiliar situation of their healthcare after stroke by independently evaluating what meaning their healthcare had for them and their recovery (response: evaluating healthcare). As they had been given little information by health professionals, their evaluations were mostly informed by the information they gained from others when managing in English and their own expectations of healthcare. It was an evaluation which was not always favourable to their healthcare after stroke.

Evaluating healthcare

Participants evaluated the perceived effectiveness and benefits of their healthcare after their stroke for its relevance to what they wanted in their recovery. Evaluating

healthcare was not an action invited by the model of healthcare which expected good patients to just follow the rules made by experts. Rather, it was a response which participants undertook independently to make a judgement about what was happening in their healthcare and to reclaim some agency in their experience.

Participants either valued their healthcare as being of benefit to their recovery, or they perceived it to be of low value in helping them get back to the familiar. The conclusion of their evaluation varied according to different situations and at different times during their healthcare experience. One part of their healthcare, such as speech therapy, could be valued highly and another part, such as their daily ward routine, valued negatively. The same healthcare conditions which a participant had valued early in their experience were not necessarily perceived as being of benefit to them later. Initially in their healthcare, all participants wanted to find out what had suddenly disabled them. They easily valued the healthcare process of being told and being tested during the first few days of healthcare for providing the certainty of an expert diagnosis. But as they recovered and no longer perceived their survival to be at risk, the same process did not engage them in how they were to get back to their familiar life and so they ascribed a lower value to it.

A specific example was provided by Andreas. When he was in hospital, Andreas understood that if he did not take his medications he would not get well, *"...if you don't take them (tablets) I will come back again"* (Greek). He was eager to recover from his stroke and go home and so he took the prescribed medication. But after he was home, Andreas perceived that the medication was stopping him returning to the activities he wanted to do, "…*because they bother my knees, my knees hurt, tummy ache, I don't want to take them"* (Greek). As Andreas now felt well recovered from his stroke, he valued returning to his previous roles and activities more than the medication's value in keeping him well. Despite his local doctor reiterating the medication's benefits in preventing stroke, Andreas stopped taking the tablets.

To perceive the therapeutic value of their healthcare, the benefits of it had to be readily apparent and relevant to the participant's own goals in recovery at that time. Thao and Emilio appreciated the dramatic improvements in their mobility and speech during their respective physical and speech therapies, and so valued them highly for helping their recovery,

At first there were two people support me to exercise and then eventually they reduced to one person to help me to exercise. And then I could start standing up and move around a bit and they provided me with a walking stick. And then, since when I was given a walking stick I can move around and they asked me not using the wheelchair because I was able to walk around with the stick (Thao, Vietnamese)

Because at the beginning I couldn't really speak that much, I could not really talk that much you know, so it (speech therapy) did help (Emilio, Italian).

For Krystyna, her move to a transitional care facility was valued for its geographic benefit to her returning to the familiar rather than for therapeutic reasons, "*I was thinking, 'Ah two weeks, nothing will happen. I'll go and it's closer to home*'" (Polish). But there were few incidences of such positive evaluations in participants' experiences, especially as the duration of healthcare progressed; instead, participants often perceived their healthcare after stroke to be of low value in helping them regain the familiar that they wanted.

The relevance and effectiveness of healthcare after stroke were not always tangible to participants. When the participant's own goals remained unrecognised and not addressed, the effectiveness of treatments was not observed by participants. This situation is well illustrated by an example from Waldemar's experience. He did not see the point of balance exercises which the community physiotherapist had given him and so dismissed its importance for his recovery, *"… maybe in my life I don't need to do this [walks heel-toe pattern]. It's not a skill I'm likely to use in my time"* (Waldemar, Polish). This was despite Waldemar planning to return to a demanding balance activity of riding his bike to the shops. In an experience that was similar for many participants, the connection between the therapy and Waldemar's own goal for returning to a familiar activity had not been made.

Participants' evaluation of their healthcare was influenced by information they gained from others. When they were unsure about a healthcare situation, they listened to the experience of others who they trusted to know about it and who they had the opportunity to talk with, such as trusted others or other patients with stroke. In one example, of several across the study data, the information Krystyna gained from

talking in *"broke"* (English) with other patients influenced how she perceived the value of the residential care facility she was supposed to move to,

> *Krystyna (Polish): But some women who already were there in this hospital (residential care facility), they told me it was a very bad hospital. And I tell my son I don't go there.*
> *Interviewer (English): The women who told you it isn't a good hospital, who were those women?*
> *Krystyna: Some English persons. There were two women who had a stroke and she was there and she was in (Rehabilitation Centre A) but they send her there to (residential care facility) and they decided to amputate her leg.*

In their uncertainty, participants also used comparisons with other patients, or with their own experiences of another serious illness, to evaluate their healthcare. If they considered themselves to be less disabled in these comparisons, then the therapeutic value of healthcare was considered to be of less importance for them. Benigno still had a speech disability (dysphasia) at his study interview but he compared his recovery favourably with other stroke patients he had observed during inpatient healthcare who were less physically independent,

> *Benigno (English): I been happy. At Rehabilitation Centre B, recover in hospital, these people who need... [struggles to find words, motions pushing something with both hands].*
> *Interviewer: Frames? The people who need the walkers?*
> *Benigno: To walk. To carry them. And I was on my own, doing everything on my own.*

Benigno's emphasis on "*doing everything on my own"* (English) highlighted the importance of regaining autonomy in participants evaluations of the effectiveness of their healthcare. Several participants suffered from other health conditions which were very painful and more disabling than their stroke. Healthcare after stroke was then perceived to be of less importance and value to them than healthcare attention which addressed their more debilitating health condition.

The cultural expectations of participants, as well as their expectation for relevance to the familiar, influenced their evaluations. The healthcare process of *'being told and being a good patient'* did not allow for cultural expectations of healthcare to be addressed between the patient and health professional. When the participant's expectations of their healthcare after stroke did not match with the healthcare they were provided, its value was not always appreciated. In one example, Emanuele was disappointed with the lack of hands-on treatment by the physiotherapist who visited him in the community. He evaluated the treatment as simple and not effective in treating his disabilities, "*She make me walk with a frame. Just walking, no physio as much, no massage, nothing. Just walking with the frame*" (Emmanuel, Italian). These evaluations of healthcare had consequences for decisions made by participants to adhere to their healthcare after stroke, or not.

4.4.3 Consequences of 'weighing up the value of care'

After evaluating their healthcare, many participants chose to leave their healthcare in favour of returning home (consequence: chose to go). While this was a happy occasion for those participants who perceived their healthcare to be of low value to their recovery, it had further consequences for their recovery from their stroke and the future management of their health condition (consequence: happy at home not always enough).

Chose to go

Many participants chose to go from their healthcare after stroke because they believed, after weighing up the value of their healthcare, that going was of more benefit to them than what was offered by their healthcare. The choice to go promised more comfort, more certainty and more occupation. Gino's brief statement summed up what many believed about the value of their post-acute healthcare experience after stroke, "*All these things I can do better at home. Why got to stay here?"* (English). From my own perspective as a physiotherapist with a background in rehabilitation, I was overwhelmed by how underwhelmed most participants were with their healthcare after stroke. Even though evaluating healthcare was not an action that participants were invited to make during their healthcare, the response had important consequences for their adherence to expert advice and the amount of healthcare they received after stroke.

Within the study, participants chose to discharge themselves from an inpatient context, refused to go to rehabilitation or prematurely stopped their healthcare in the community, even when a health professional offered for it to be continued, *"She ask, we said, 'No.' 'We need it?' 'No'"* (Sadik, English). Their decision to go could be interpreted as a loss of trust, not in the specific expertise of an individual health professional but in the capability of the healthcare they were experiencing to meet their expectations for recovery. It was not a decision that was necessarily related to the extent of the participant's recovery. Sometimes they chose to go because they felt that they had recovered so well that their healthcare would offer no further benefit, *"… I became so well that I did not want to stay there anymore"* (Andreas, Greek), but it was also driven by their evaluation of the healthcare as not living up to their expectations for getting them back to the familiar.

The choice to go was not a rash one. Participants did not act in a way they thought to be unsafe as they did not want their condition to deteriorate or to have another stroke. It was an action based on their evaluation of effectiveness and relevance. Emanuele was a man who sorely missed his family and home while he was an inpatient after his stroke. Despite being told by the doctor that rehabilitation would improve his walking, Emanuele had made his own evaluation of what healthcare offered him and he saw no good reason to stay any longer away from his home,

> *I wanted to go home because I was just staying in bed doing nothing with me so, you know. They were giving the medication which I could have taken at home anyway so, you know* (Italian).

The belief that healthcare could be done, or even done better, by the participant themself or their trusted others in a more familiar and comfortable context was a strong reason given by participants for choosing to go. The skill and complexity of therapies were missed when participants did not understand their purpose. Therapies were instead perceived as simple checks and exercises, as portrayed in the process of *'being told and being a good patient'*, without specific benefit to the participant or having any specific skill in application. In one example, Sadik's wife, Helena, explained why she thought that she was more than capable of continuing Sadik's therapy herself at home,

This one (health professional) maybe does come and one body make exercise with him and the massage you know. And I , I say, 'I make massage (unclear) all the time. And I help him to walking.' You know, when one body come in half an hour and walking with him. This is nothing. I must walking all day with him. I'm all day with him. All night with him. I think I can do that (English).

The company and support of trusted others was an important pull of the familiar for participants not just for their help with administering or accessing healthcare but also for the reassurance and comfort they provided.

A participant's familiarity with healthcare after stroke was not a complete panacea to the choice to go. Katariina had experienced healthcare after a stroke two years previously and had an understanding of its processes from nursing for many years at Hospital B. Yet her annoyance at not knowing why certain tests were endlessly repeated or why she needed to stay, and her concern for the welfare of her home, prompted her to repeatedly ask to go home. Katariina did not speak up outside of her good patient role to question health professionals about what she did not understand; she just chose to leave the situation.

The perception that healthcare was of little value to their recovery did not always result in participants choosing to go. Not because they didn't want to, but because they did not perceive an opportunity for them to exert their choice. Benigno and Gino were too firmly positioned within their good patient role to disobey the expert decision for them to attend rehabilitation despite them believing that it would not be of any benefit to them,

Interviewer (English): So tell me, if you wanted to come home, why did you go to rehabilitation?

Gino (English): Because they sent it to me there.

Their adherence to the rules did not mean that they valued the of prospect of rehabilitation or its eventual circumstance,

Interviewer (English): What at rehabilitation, what treatment did you get there?

Benigno (English): Not much because I didn't needed any [laughs].

Paradoxically, when some participants did value their healthcare after stroke for aiding their recovery they then experienced their access to beneficial treatments being reduced. Ming was discharged from the *"good service"* (Cantonese) he was experiencing in hospital without being offered the opportunity for rehabilitation, although perhaps it had been offered to his children who did not consult him. Thao and Christos both expressed disappointment at what they perceived to be a reduction in their rehabilitation healthcare,

> *I always look forward to the physio session where I can have the exercise, or people help me to recover, really help. And after two weeks they found that I started to move around and they reduced the time when we had the physio treatment* (Thao, Vietnamese)

> *For all those months I went twice to do exercise. Nothing else, nothing. When they say that you're a bit better health wise, they leave you and they look after the others* (Christos, Greek).

Fortunately for Thao, the arrival of physiotherapy students for a clinical placement meant that he again received regular physiotherapy treatment for which he was very thankful. However, he was further upset when he was told he was to be discharged as he was unsure if his physiotherapy would continue. The assurance that a community physiotherapist would visit him at home helped to ease his distress (the physiotherapist then did not show up until after Thao had been home for two weeks). But for Christos, his disappointment in his ensuing healthcare, prompted him to make the choice to go and he asked to leave the rehabilitation facility.

Being discharged when they positively valued their healthcare was rationalised by the few participants who experienced it as an expert judgement on their entitlement to a finite resource. Emilio explained how he made sense of being sent home when he valued his rehabilitation for helping his recovery,

> *… because they can't keep you there forever, you know, for a long period of time. There are people you know, without legs or you know, with amputee and*

> *everything which need, need more assistance. So they can't keep you there very, very long time* (Emilio, Italian).

Such rationalising was not needed by Vincenzo, the participant who preferred to speak English. When health professionals at Rehabilitation Centre B told him that his outpatient therapy was to finish, Vincenzo feared that the community healthcare option they advised would not meet his needs. So he successfully spoke up and negotiated in English to keep attending at the Rehabilitation Centre for longer,

> *… they give me a list, where I can go. There's one (gym) in (suburb close by), there's one here in (suburb lives in). You have to pay there too, they are private place, they gym. The only thing I said, 'How do they know what I should do?' She said, 'Definitely I don't think they know.' And then I was a bit worried. I said, 'But you have a choice, you can come here if you want, we don't charge you anything.' It wasn't for that I went there, I knew everyone, they knew me so we continued what they started. That's a good thing that, because I don't know what would have happened here* (Vincenzo, English).

For Vincenzo, the opportunity was not isolated to a stay or go decision but his confidence and proficiency in communicating in English enabled a negotiation. As presented in the process of *'being told and being a good patient'*, the action of speaking up was easiest when participants were able to use their preferred language. Negotiation around choosing to go or stay was attempted by a few other participants in different situations but without Vincenzo's successful result, such as Krystyna's attempts to negotiate going home from rehabilitation,

> *All the time I was telling them, 'Let me go home, let me go home.' I even asked them to let me go home for a week for a trial. They didn't let me to do this* (Krystyna, Polish).

Leaving healthcare was perceived by the participants who had not valued it highly as a very positive part of their healthcare experience. However, the choice to go had further consequence for participants who had not achieved what they wanted in their recovery after stroke before their rehabilitation was ceased.

Happy at home not always enough

Irrespective of the disability that participants might have, those who had perceived their healthcare to be of low value to their recovery and wanted the familiar were very happy when they went home. They interpreted their choice to go as a choice of freedom; leaving the passivity and uncertainty of healthcare for the comfort and autonomy of home. When I asked these participants how they felt when they went home, they told me of their joy with a smile on their face so broad that on a couple of occasions the interpreters who were present commented on it,

> *Free* (Gino, English)
>
> *I was flying* (Andreas, Greek)
>
> *Oh the relief…* (Benigno, English)
>
> *You can imagine how happy I was* (Emanuele, Italian)
>
> *He is most content to be at home* (Helena, Sadik's wife, Croatian).

Even Ming, who had highly valued his hospital care before he was discharged, felt better in his stroke recovery at home, "*I feel more comfortable coming home. I feel better"* (Ming, Cantonese). Participants felt similarly contented when they chose to stop a community healthcare service. They were happier getting help from trusted others than continuing the healthcare which they perceived to be of low value to them, as Sadik insisted on telling me, *"(English) Honestly, the best thing that helped me, (Croatian) the best therapist… [pointed to his wife].*" Only Thao was not effusive about going home. As has been explained earlier, he was concerned about the continuation of the physiotherapy he valued and was also upset that the familiar comfort and reassurance of his eldest daughter as his carer was not available at home.

Participants' happiness at getting back to familiar routines, surroundings and trusted others overshadowed any concerns they had about their long term recovery from the stroke. Participants just wanted to be back with what was familiar to them and they trusted that everything would be sorted out, would even be better, once they were home and returning to their familiar activities and routines. This faith in the restorative power of the familiar was explained simply by Waldemar, "*I was happy*

that when I got home I was able to move at all, and the rest will, I will learn gradually" (Polish). But this did not happen for all the participants who chose to go.

Participants had gained no more knowledge about their stroke and its management. By the time of the study interviews, some participants realised that they were not getting better as they had hoped and they were not sure what to do. They reported symptoms such as their arm weakness or limited mobility getting worse, or their memory not returning. On two occasions, participants asked me for healthcare advice at the end of their study interview. Even those participants who were satisfied with their recovery at the time of the interviews were unsure how to prevent a second stroke. In their uncertainty, participants then relied on their own judgement or that of trusted others, who were not always experts in healthcare.

This consequence of *'weighing up the value of care'* had the potential for significant impact on participants' health and function. In one example, Christos noticed his arm function getting weaker after he left rehabilitation and so he went to a physiotherapist who was recommended by a friend, *"A friend of mine said, told me that he had gone there*" (Greek). This arrangement was at cost to Christos compared to the public rehabilitation facility he had chosen to leave and the physiotherapist he attended was not necessarily skilled in treating the effects of stroke. Another participant who chose to go but had difficulties in their recovery was Sadik. He experienced a severe deterioration in his physical condition and mobility after choosing not to go to inpatient rehabilitation and refusing home rehabilitation. At his first interview Sadik complained of going "…f*rom bad to worse. Every time, every day, whole body so collapse. When I try to stand up I have no energy, you know"* (English). He was readmitted to hospital before his second interview could take place three months later.

4.5 Chapter conclusion

In this chapter, I have presented and explained a constructivist grounded theory of how older people with LEP experience their healthcare after stroke. The complexity of the healthcare experience was reflected in the theory's three dynamic and inter-related processes. *'Hanging on to the familiar*' told how participants responded to the shocking occurrence of their stroke by continuing as normal and delaying seeking

help. It was a process in which the pervasive uncertainty of the experience began and the important concepts of the 'familiar' and 'trusted others' were introduced. *'Being told and being a good patient'* portrayed how participants encountered a healthcare context which positioned them as passive patients and expected them to trust the experts to decide their recovery. Although participants responded by being good patients, the process had consequences for their ability to understand and engage with their healthcare. Language was an important influence on the conditions and actions within this process. 'W*eighing up the value of care'* then explained how participants evaluated their healthcare in relation to their own goals in recovering their familiar lives. Unfortunately, it was an evaluation that often left healthcare wanting and had consequences for how participants managed their stroke recovery. In the next chapter, I discuss the relevance and importance of the theory to current understandings within the literature about healthcare after stroke and, more generally, healthcare for people with LEP. Specific points of clinical relevance from the theory are discussed and recommendations made for both research and healthcare practice based on the study findings.

5 Discussion

This study aimed to understand how older people with LEP from CALD backgrounds experience their healthcare after stroke, to provide knowledge to inform improvements in healthcare practice for the benefit of this group of people. Having presented my theory of healthcare experience in the previous chapter, I now discuss its contributions to, and implications for healthcare practice and research. The discussion of the theory is presented in three sections. First, I locate the theory within contemporary knowledge in the fields of healthcare practice after stroke and healthcare for older people with LEP. Second, I specifically discuss the role of language in the theory. Third, I discuss the presence of similarities as well as differences in the issues that the theory raises for contemporary stroke healthcare. The limitations of my study are then acknowledged before I summarise the recommendations for healthcare practice and research from my discussion and conclude the thesis.

5.1. Locating the theory within the healthcare field

A discussion of where and how the developed theory fits within current understandings of healthcare research and theory is presented first to establish the theory's relevance to both the fields of healthcare after stroke and healthcare for people with LEP, and to highlight new knowledge from my study findings. The developed theory encompassed experiences across healthcare contexts and stages of personal recovery. Its complexity reflects both the complexity of all human experience and the complicated pathway of healthcare after stroke. To provide a structure to the discussion of the theory, each of the theory's processes (*'hanging on to the familiar'*, *'being told and being a good patient'* and *'weighing up the value of care'*) has been presented separately. However, it must be remembered that all

processes are interwoven and intersecting within the theory to form a dynamic and complex experience for the person with LEP.

5.1.1 Hanging on to the familiar

'Hanging on to the familiar' identified that participants delayed seeking emergency help after their stroke, a phenomenon consistent with what is known about the help-seeking behaviour of other groups of people after stroke (Kwan, Hand & Sandercock 2004, Sprigg et al. 2009, White, Magin & Pollack 2009, Teuschl & Brainin 2010). My finding, along with previous reports that people from minority ethnic groups have significantly longer prehospital time delays after stroke (Teuschl & Brainin 2010), suggests a potential disadvantage for older people with LEP in their recovery from stroke. Their delay in getting emergency treatment, especially longer than three hours, can detrimentally affect the potential of stroke thrombolysis treatment in reducing death or future dependency (Hacke et al. 2008, Wardlaw et al. 2009). Therefore, interventions to reduce prehospital delay for older people with LEP need to be informed by an understanding of how the delay occurs (Evenson et al. 2009), as provided by the process of *'hanging on to the familiar'*.

The process provides a preliminary insight into how older people with LEP initially respond to their stroke. The action of 'continuing as normal' clearly resonates with previously identified themes of people 'maintaining a sense of normality' (Moloczij et al. 2008) and 'acting as if nothing had happened' (Hjelmblink, Holmström & Kjeldmand 2010) after their stroke. They all conceptualise the action of people attempting to continue their daily life instead of seeking emergency help. A difference in my findings is the position of 'continuing as normal' as the predominant response to stroke compared to its position in the other studies as one of a number of factors influencing behaviour. It could be that the difference is a result of how *'hanging on to the familiar'* was structured as a dynamic process rather than static themes. It could also be that the finding indicates a difference in the response to stroke between older people with LEP and people who proficiently speak English. The response of participants in my study was grounded in the conditions of being shocked by stroke and a lack of knowledge about stroke. A heightened context of uncertainty could be related to the poor awareness of stroke and its management that has been associated

with LEP (DuBard, Garrett & Gizlice 2006, Fang et al. 2009) and may have influenced why 'continuing as normal' was the predominant response of participants.

The response of participants to their stroke shared other similarities with what is known about the behaviour of people after stroke. The 'fear of loss' which accompanied participants' responses in *'hanging on to the familiar'* is similar to the 'threatened control of bodily functions, autonomy and integrity' identified by Hjelmblink, Holmström and Kjeldmand (2010) in a small group of Swedish people after stroke. Other themes that have been identified in help-seeking behaviour after stroke were present as moderators to the process in my study. A 'perception of medical services' (Moloczij et al. 2008) was present in *'hanging on to the familiar'* as the influences of past healthcare experiences on participants' response, such as Sadik's unhappiness with a previous hospital admission leading him to avoid hospitals and further delay. The 'presence or influence of another person' (Moloczij et al. 2008) is found in the catalyst role of the trusted other in changing participants' response to their stroke (discussed in next section).

Collectively, these findings suggest that older people with LEP's response to their stroke is grounded in uncertainty and shock but, like people who are not LEP, they are also influenced by past and present social interactions which need to be addressed along with improving their stroke awareness in any intervention to improve their access to emergency healthcare after stroke (Moloczij et al. 2008, Teuschl & Brainin 2010). Targetting the family and friends of older people with LEP in stroke awareness campaigns and using languages relevant to the community would target the people who are most influential in the situation. Further investigation is required to explore if these approaches are effective to reduce the time between the stroke event and seeking healthcare for older people with LEP.

The trusted other

Trusted others played an important role facilitating older people with LEP to seek emergency healthcare after their stroke. The role resonates with previous studies' identification of "bystanders" (Zerwic, Young Hwang & Tucco 2007, Moloczij et al. 2008, Teuschl & Brainin 2010) or "another person" (Moloczij et al. 2008) who assisted people to access emergency help after stroke. The concept of a trusted other in the developed theory involved an active contribution by these people to change a

person's help-seeking behaviour at a critical juncture after stroke, indicating a greater role than the tag of 'bystander' suggests.

A trusted other was someone whom the older person with LEP had a close relationship with pre-existing their stroke, and who knew the older person as more than a stroke patient. The term 'trusted other' was used in the theory for two reasons. First, it was to discourage an interpretation by readers that the role could only be filled by a family member or friends. Some trusted others were local doctors or neighbours with whom the person had shared a longstanding relationship with. Second, the term provided an immediate cue to the key construct of the role. Trusted others were defined in the theory by the personal trust they shared with the older person with stroke. They were the people who the older person relied on for reassurance and advice throughout the theory's processes. They were influential in the older person's information–seeking and decision-making in the processes of *'hanging on to the familiar'* and *'weighing up the value of care'*, and were an integral, and expected, support when the older person with LEP went home.

A shared language was not essential, but was often part of, the longstanding relationship between the older person and their trusted other. Indeed, the role of the trusted other shared qualities of loyalty and trust that people with LEP have reported to value in the informal interpreters they use (Edwards, Temple & Alexander 2005) and the two roles often overlapped. But all trust was not equal in the developed theory. The personal trust which participants shared with a trusted other differed to their trust, and sometime distrust, in the competency and confidentiality of professional interpreters. It also differed to the expert trust they had in health professionals; a trust which was based on expectations of expertise and soon lost if the health professional did not meet their expectations. Hupcey and Miller (2006) have described a similar discrimination between the "deep-seated" trust of family and friends and the "fragile" trust of health professionals.

Although it cannot be expected that health professionals will become trusted others to older people with LEP in the short time frame of healthcare after stroke, their relationship can be strengthened and the quality of healthcare subsequently improved by them demonstrating more of the traits of trusted others. Traits associated with interpersonal trust and valued in trusted others include treating the

person as an individual, and being compassionate and respectful (Hupcey et al. 2004, Hupcey & Miller 2006, MacLeod & McPherson 2007). It is not only older people with LEP who may benefit from this practice as patients with stroke have already expressed the desire to be "treated with humanity" (Mangset et al. 2008) and to be "personally valued and treated with respect" (Peoples, Satink & Steultjens 2011) by their health professionals. These qualities are supported by models of patient-centred and culturally competent healthcare (MacLeod & McPherson 2007, Garrett et al. 2008a). Alternative models of healthcare, and the idea of expert trust, are returned to later in my discussion of the process of *'being told and being a good patient'*.

It was by exploring the healthcare experience after stroke for older people with LEP as a whole, rather than focussing on a specific period, that the significance of the trusted other in the experience was recognised. The trusted other is present in the findings of previous studies of stroke healthcare but their recognition of its importance has been limited to the specific areas of healthcare studied. Elements of the trusted other are found in the family and friends who people with stroke want to remain connected to during their healthcare (Morris, Payne & Lambert 2007, Peoples, Satink & Steultjens 2011), who provide the majority of support and relationships for people during their stroke recovery (Alguren, Lundgren-Nilsson & Sunnerhagen 2009), the allies in planning meetings when patients are making decisions about their future (Hedberg, Johanson & Cederborg 2008) and the family, friends and neighbours who provide social support for a successful discharge from inpatient healthcare after stroke (Ellis-Hill et al. 2009). The prominence of the role of the trusted other in my findings may have been because they had greater importance for the healthcare experience of people with LEP for whom unfamiliarity and uncertainty, and consequently the need for reassurance and support, may be heightened (Luhmann 2000).

The role of trusted others in supporting older people with LEP after stroke needs to be acknowledged and accepted in healthcare practice. They have already been recognised to be important in healthcare for older people (Gitlin & Wolff 2011) and for people with LEP (Brach, Fraser 2000, Garrett et al. 2008a). In the USA, the largest hospital accreditation authority recommends that patients from CALD backgrounds are given the opportunity to nominate the individuals who provide "emotional

support, give comfort, and alleviate fear during the course of the patient's hospital stay" (The Joint Commission 2010, p. 16). To add to these recommendations, patients from CALD backgrounds should then be able to access their nominated individuals, or trusted others, whenever they need to and have opportunity for them to be involved during ward rounds, patient education, and other "crucial decision-making and care processes" (p.16). For healthcare after stroke, trusted others could be encouraged to be involved during therapy sessions to facilitate a comfortable and supportive environment for the older person with LEP. They could also be supported to conduct rehabilitative exercises or activities with the older person outside of formal therapy sessions.

In encouraging recognition of the role of trusted others in healthcare after stroke, I must caution that their inclusion should not be to the exclusion of the older person with LEP. The process of *'being told and being a good patient'* highlighted the situation of health professionals giving information to trusted others instead of to the older person with LEP can leave the older person feeling uncertain about, and not engaged in, their healthcare; even if the older person accepts the practice. This can be addressed by a professional interpreter being present during critical healthcare conversations with patients with LEP, such as discussions of diagnosis, treatment, goal setting and discharge planning, even when a bilingual trusted other is present. The use of interpreters is discussed more in section 5.2. The nature and extent of the trusted other's involvement can be negotiated between the health professional and older person in a private conversation (Garrett et al. 2008a). The potential burden on trusted others also needs to be considered when involving them in healthcare. The provision of adequate language resources and opportunities in healthcare for the older person with LEP to openly communicate with health professionals can relieve trusted others of needing to be present for long periods to facilitate such interactions (Garrett et al. 2008a).

The emergence in the theory of the importance of the trusted other, and support for their role from other healthcare research, suggests that further investigation of how to effectively involve trusted others in healthcare after stroke for older people with LEP, is warranted. But trusted others were not an isolated source of support and

comfort in healthcare after stroke for older people with LEP. Conceptually, the trusted other could be considered as the concept of the familiar realised in a person.

The concept of the familiar

The concept of the familiar was key in all three processes within the emergent theory. In *'hanging on to the familiar'*, the concept encompassed what participants were reluctant to leave at the time of their stroke. In *'being told and being a good patient'* it was the familiar of participants' preferred language and trusted others which gave them comfort and certainty. And regaining their familiar lives was a condition of the participants' evaluation of their healthcare in the process of *'weighing up the value of care'*. The concept of the familiar was developed in the theory to encompass the social and physical entities which gave participants comfort, certainty and control in their lives, such as familiar surrounds, their favourite foods, preferred language, personal relationships, social roles and activities.

The meaning of the familiar resonates with the meaning of home for older people that has been identified in the literature (Molony 2010). Indeed, wanting home was an important subcategory of the condition of wanting the familiar in the process of *'weighing up the value of care'*. Both concepts of home and the familiar offer the older person empowerment and freedom, comfort and belonging, meaningful relationships, and recognition of them as individuals. And just as older people fear losing their home (Gillsjö, Schwartz-Barcott & von Post 2011), participants in my study also feared being unable to recover and regain their familiar lives. The idea of the familiar within the developed theory extends the idea of home beyond the ideological confines of place to also incorporate the social roles and activities in the community which were meaningful to individuals, such as driving a car or membership of their social club. This confirms the importance of regaining life roles that has been identified for people from CALD backgrounds during their recovery from traumatic brain injury (Saltapidas & Ponsford 2007).

Despite its importance, the familiar was interpreted to be absent from participants' healthcare after their stroke. Not just in terms of the tangible environment such as an absence of their preferred language and foods, but also the lack of autonomy, comfort and meaning gained from familiar roles and activities. The interpretation of a disconnect between healthcare and the familiar was influenced by the healthcare

context which participants entered, as portrayed in *'being told and being a good patient*', and led to them largely perceiving healthcare to be of low value to them in the process of *'weighing up the value of care'*. Previous studies of stroke rehabilitation have also found that healthcare fails to recognise what holds meaning for people in their recovery and what gives them meaning as an individual (von Koch, Wottrich & Holmqvist 1998, Bendz 2000, Cott 2004, Olofsson, Andersson & Carlberg 2005, Morris, Payne & Lambert 2007, Ellis-Hill et al. 2009). Von Koch, Wottrich and Holmqvist (1998, p. 371) observed that the stroke patients in their case study "did not have any familiar role or meaningful context, environment to relate to", and it is likely that the absence of familiar contexts and meanings was heightened for participants in my study with LEP.

Strengthening the connection between healthcare after stroke and what older people with LEP value in their familiar lives has the potential to increase their healthcare's relevance and effectiveness. My study is not the first to call for a stronger connection between healthcare and what holds meaning in the lives of individual stroke patients (Bendz 2000, Holmqvist & von Koch 2001, Bendz 2003, Olofsson, Andersson & Carlberg 2005, Cott, Wiles & Devitt 2007, Ellis-Hill et al. 2009), however, by demonstrating that its importance extends to healthcare for older people with LEP, the call is made louder and more urgent. One strategy for strengthening the connection is the greater involvement of trusted others, as suggested in the previous section of my discussion. The importance of the familiar to participants' healthcare experience, and further recommendations for strengthening the connection to it in practice, continue to be addressed in the remaining discussion of my theory.

5.1.2 Being told and being a good patient

A traditional medical model (Engel 1977) dominated participants' experience of the healthcare context after stroke, as portrayed in the process of *'being told and being a good patient'*. Participants expected and appreciated as 'good service' the authoritative stance of health professionals which is frequently taken in the critical acute phase of stroke healthcare (Pound et al. 1995, Bendz 2000). However, my study found that the traditional medical model of healthcare delivery was a poor fit to engaging participants in their rehabilitation healthcare; a finding also reported by others (Bendz 2000, Cott, Wiles & Devitt 2007). Although, 'being told the rules'

instructed participants about how to play the healthcare 'game' (Hyndman 1985), they acted as a divergent communication strategy (Giles, Coupland & Coupland 1991) and reinforced the patient's position as less powerful to the rule-making health professionals. The institutional context of 'being tested', 'being told the rules', and 'being discouraged to ask' separated participants' healthcare from their familiar lives, even when the rehabilitation was provided in their home.

The power asymmetry between participants and their healthcare was widened by the language discord; a situation that has previously been identified for people with LEP (Liamputtong & Watson 2006, Garrett et al. 2008a). The process condition of 'no one interested to talk like we talk' implicitly and practically positioned participants as passive recipients of care. Implicitly, it communicated that healthcare was provided on the terms of the English-speaking authority without a need for the patient with LEP to understand or contribute to these terms. Practically, health professionals' reliance on simple English phrases for communication, with scarce use of professional interpreters or translated resources, restricted the opportunity for participants to understand information and to participate in planning their healthcare. Unfortunately, this is supported by how health professionals have reported they communicate with patients with LEP (Wardin 1996, Sze-Mun Lee, Sullivan & Lansbury 2006). However, the process could be improved. Participants in my study were empowered to speak up about their needs when they were able to use their preferred language and were given the opportunity for an open dialogue with health professionals; that is, a change was made to both the language context and their patient role. This suggests that not only does language assistance for people with LEP need to be improved in stroke healthcare (discussed further in section 5.2) but that an alternative model of healthcare which strengthens the meaningful involvement and autonomy of the patient with LEP is required. As Bendz (2000) proposed over ten years ago, and my findings highlight, patients need to be facilitated by their healthcare to express their own aims and needs during their rehabilitation and to actively participate in its planning for it to be successful; even across a language divide.

A model of healthcare which recognises patients' own beliefs and needs about their healthcare, and encourages a more autonomous role for them in its planning, is

patient-centred care (Mead & Bower 2000). The need for patient-centred care during rehabilitation after stroke has been established (Bendz 2003, Cott 2004, Olofsson, Andersson & Carlberg 2005, Ellis-Hill et al. 2009) and incorporated into clinical guidelines for stroke healthcare (NSF 2010). However, as evident from the findings of my study and reported by others (Candlin 2000, Redfern, McKevitt & Wolfe 2006, Luker & Grimmer-Somers 2009a), the translation of a patient-centred care model into practice can get lost in the guidelines.

A model of patient-centred, culturally competent healthcare would be particularly well-suited to addressing the difficulties experienced by participants in the process of *'being told and being a good patient'* and recognising the importance of the familiar in healthcare for older people with LEP. It is a healthcare approach which shares the principles of collaborative and individualised attention to a person's needs and beliefs, as well as incorporating specific recognition of the importance of language and family involvement in providing quality healthcare for people from CALD backgrounds (Garrett et al. 2008a, The Joint Commission 2010). Patient-centred, culturally competent models of healthcare have already been recommended to improve the quality of inpatient healthcare and its outcomes for people with LEP in both the USA (The Joint Commission 2010) and Australia (Garrett et al. 2008a). The findings from my study support extending their relevance to healthcare after stroke.

The principles of patient-centred, culturally competent healthcare should commence from the acute stage of healthcare after stroke. While recommendations for patient-centred healthcare after stroke are usually associated with rehabilitation settings, it is now accepted that rehabilitation after stroke needs to begin as early as possible once medical stabilisation is reached (Canadian Stroke Network, Heart and Stroke Foundation of Canada 2006, NSF 2010). It was evident in my findings that participants already wanted healthcare to be relevant to their familiar lives early in their hospital admission. The patient-centred principle of empowering patients in healthcare decision-making are also valid for acute hospital care (Garrett et al. 2008a). This was evidenced by the experience of one participant, Ming, who was denied information about his condition in the emergency department and thus denied the opportunity to participate in decisions about his hospital admission and treatment.

In advocating for changes to the current model of healthcare, I acknowledge that such changes are not easily made (Candlin 2000, Anderson & Funnell 2005). Introducing a new model of healthcare practice cannot be confined to the interaction between the patient and health professional but requires a whole of system approach recognising the need for supported systemic, organisational and professional support as well as individual change (NHMRC 2005, Redfern, McKevitt & Wolfe 2006). For example, increasing the use of professional interpreters for the benefit of older people with LEP during stroke healthcare will require education and training for health professionals as well as the funding and organisation of comprehensive language services to meet increased demand. Positioning such service improvements within a wider discourse of patient safety has been suggested to increase the opportunity for their support in an environment of funding constraints (Garrett 2009). Another consideration is that some older people with LEP may be unable or unwilling to have a greater role in decision-making about their healthcare (Arora, McHorney 2000, Deber et al. 2007). The preference of the patient should be respected in this situation once the health professional has ensured, through effective communication in the person's preferred language, that it is what they want and the older person has been given the opportunity to speak up if the healthcare does not fully meet their needs (Anderson 1995).

Before finishing my discussion of the process of *'being told and being a good patient'*, I return to the idea of expert trust in the theory. Expert trust gave power to health professionals' words. Luhmann (2000, p. 97) suggests that trust necessarily "presupposes a situation of risk", and it was the risk that participants may not recover from the disabling effects of stroke which helped to strengthen their expectations of the role of health professionals and trust that they would know and do what was best for their recovery. Despite participants' expert trust in health professionals encouraging them to take a passive role in their healthcare, a phenomenon that is not isolated to older people with LEP (Kraetschmer et al. 2004), it was also capable of providing participants with reassurance and hope during a difficult experience. Hope is important in recovery after stroke (Tutton et al. 2011), exemplified by a participant in my study, Gino's, statement, *"I got a bit of courage"* (English). But it can be challenging for health professionals to ensure that they are communicating realistic expectations for recovery rather than giving false hope (Wiles, Cott & Gibson 2008).

To provide realistic hope, the health professional needs expertise and knowledge about stroke recovery, a good understanding of the individual and their concerns, and be able to communicate effectively with them (Tutton et al. 2011). Health professional's talk can only communicate hope if the older person with LEP understands it, reinforcing the importance of effective communication for this group of people during their healthcare after stroke.

The process of *'being told and being a good patient'* has highlighted that older people with LEP need better opportunities to be engaged in their rehabilitation, to express their individual needs in their recovery and to receive the communication of hope from health professionals. I have suggested that these qualities can be facilitated by a model of healthcare that is patient-centred and culturally competent. Importantly, it is a model which encourages meaningful discourse between the patient and health professional. The importance of communication within the theory continues to be discussed in the next process of *'weighing up the value of care'*, and the role of language in the theory is discussed in section 5.2.

5.1.3 Weighing up the value of care

The process of *'weighing up the value of care'* provides a fresh understanding of how the experience of uncertainty in healthcare after stroke can influence the decisions and actions of older people with LEP regarding the management of their stroke recovery. It is well established that the healthcare experience after stroke is often characterised by little information from health professionals (Hanger et al. 1998, Perry et al. 1999, Röding et al. 2003, Morris, Payne & Lambert 2007, Eames et al. 2010) and the person with stroke feeling uncertain or "in the dark" (Ellis-Hill et al. 2009) about managing their recovery (Chenoweth et al. 2003, White, Magin & Pollack 2009). To be meaningfully involved in planning about their healthcare, patients needed to be helped to understand the potential risks, benefits and the alternatives of different healthcare options so that they can select an option that best accommodates their personal preferences (Anderson 1995, Woolf et al. 2005). The uncertainty about stroke and healthcare that was experienced by participants in my study was conceptualised in the process of *'weighing up the value of care'* as an uncomfortable and problematic situation for people who wanted their healthcare to help them recover their familiar lives. The response by participants was to make their own

evaluation of the worth of their healthcare and this had consequences for their adherence to it and the effectiveness of their stroke management. This interpretation extends what is known about the lack of information during stroke healthcare to a dynamic understanding of how uncertainty can influence the effectiveness of the older person with LEP's healthcare for their recovery from stroke; an understanding that may also be relevant to the experience of other groups of patients after stroke.

Participants' perception of their stroke healthcare having a low value for them was firmly grounded in poor communication practices. 'Being told the rules' by health professionals failed to communicate to participants the relevance and meaning of stroke healthcare to their own goals in recovery; and so the value of their healthcare for getting them back to the familiar life they sought was not always tangible or clear to them. White, Magin and Pollack (2009) identified a similar process occurring for a group of English-speaking Australian stroke patients, for whom "the inadequacy of communication could be seen as compromising participants' confidence in their therapeutic process" (p. 86). Poor communicative practices have also been implicated in why people choose to discharge themselves from hospital against medical advice (Onukwugha et al. 2010), a scenario similar to the process consequence that participants 'chose to go' from their healthcare.

Health professionals cannot assume that older people with LEP will understand the benefit of their healthcare to their recovery after stroke without explaining it to them or enabling them to participate in its planning. Lequerica and Kortte (2010) have suggested that patients need to have the means to understand and be involved in the planning and goals of their rehabilitative healthcare for them to be able to meaningfully engage with it. What an older person values in their recovery cannot be assumed to be known by health professionals without asking the older person. The process of *'weighing up the value of care'* shows that what is needed is an approach to stroke healthcare which encourages the older person with LEP to share their goals, concerns and plans for the future, and then establishes the relevance of healthcare to their individual and familiar context. Such an open dialogue also allows the older person's cultural and health beliefs concerning their healthcare after stroke to be recognised and addressed between the health professional and patient. This change in communicative practice will require both training for health professionals to

improve their communication skills for shared goal-setting and decision-making, both with and without interpreters, and a shift in the model of rehabilitation healthcare to support the meaningful participation of the patient in healthcare decision-making (Candlin, Candlin 2003, Gordon, Ellis-Hill & Ashburn 2009), such as the model of patient-centred, culturally competent healthcare recommended in the previous discussion on *'being told and being a good patient'.*

Collaborative and patient-centred goal-setting can make stroke healthcare more meaningful and effective for the patient and their situation as it facilitates their individual needs and beliefs to be incorporated in healthcare planning (Bendz 2003, Cott 2004, Brock et al. 2008, Young, Manmathan & Ward 2008, Ellis-Hill et al. 2009, Leach et al. 2010), however, it was not present in the experience of participants. Perhaps goal-setting was conducted but, if so, participants did not recognise this and so its effectiveness must be questioned. Goal-setting is already acknowledged to be a challenging practice for both patients and health professionals after stroke even if they share the same main language (Bendz 2000, Parry 2004, Wohlin Wottrich et al. 2004, Leach et al. 2010, Weyer, Ballinger & Playford 2010, Laver et al. 2011, Rosewilliam, Roskell & Pandyan 2011), and so it is likely to be even more challenging across a language discord. Therefore, it is essential that goal-setting is conducted in the patient's preferred language and that it is part of a systems approach which encourages patients to have an active voice in their healthcare (Redfern, McKevitt & Wolfe 2006).

Making healthcare after stroke relevant to what older people with LEP value in their recovery is not just about dialogue but can also be influenced by the setting of healthcare. A surprising finding in the process of *'weighing up the value of care'* was that participants did not perceive their transition from hospital to home to be problematic. This finding was unexpected because studies with English-speaking participants have often reported the discharge period as being a time of many practical problems for the person with stroke who feels unprepared and unsupported by their healthcare (Chenoweth et al. 2003, Cott 2004, NSF 2007b, Ellis-Hill et al. 2009). Participants shared some of the difficulties reported in the other studies such as uncertainty about healthcare arrangements and unmet healthcare need; but rather than focussing on what was missing in their stroke recovery and healthcare at the

time of discharge, their interpretation focussed on what they gained by returning to a context where they were comfortable, secure and had meaningful roles and activities to return to. It was an experience shared by participants in a Swedish study whose joy and relief at going home to "repersonalisation and autonomy" overshadowed their anxieties about the transition period (Olofsson, Andersson & Carlberg 2005).

The difference in discharge experience between the participants in my study and that previously reported for English-speaking stroke patients may be attributable to the support which participants received from their community of trusted others. Ellis-Hill et al. (2009) proposed that established networks of social support help older people who are living alone to have successful discharge experiences from hospital after stroke. Participants in my study had an established support base already in place prior to their experience of stroke healthcare because of the language assistance they needed from trusted others, as well as the close cultural ties of migrant families and communities. The discharge experience may have also been influenced by the stoic nature of the participants in my sample. Discharge home after stroke has been observed to be less distressing for the person with stroke when they have a level of resilience and a capacity to independently manage the problematic situation (Luker & Grimmer-Somers 2009b). Stoicism is a trait which appears to fit participants in my study who proudly gave examples of times when they had used their own initiative and resources to manage a situation that had been challenging to them after their migration, such as how they learnt to speak English for their workplace. Stroke may have been a new experience for participants but it was one of many challenges which they had faced and independently overcome in their lives.

The happiness and relief expressed by participants in my study when they went home indicates the importance of this familiar context for them. It was as if the momentum of their recovery after stroke (Ellis-Hill et al. 2009) only picked up speed once they had reconnected with the familiar. The positive perception of discharge was only diminished when the familiar of home was perceived to be incomplete and not offer the comfort and certainty that was sought, such as Thao's concern about managing his wife's disability as well as his own without his daughter caring for him. It is a reminder that the theory provides an understanding of how older people with LEP experience their healthcare in the form of processes that are grounded in social

conditions, and so the individual context and needs of the person must always be recognised in its application to healthcare practice. However, the joy that was experienced by participants at their return to a familiar context suggests that this same context could be used to improve not just the comfort and happiness of the older person with LEP, but also bring the familiar they wanted to their rehabilitation after stroke.

The potential of home rehabilitation

Home rehabilitation offers the potential to strengthen the connection between what older people value in their familiar lives and their rehabilitation healthcare after stroke. Home rehabilitation describes rehabilitation provided in the home of the person with stroke, rather than in an inpatient or outpatient facility (Hillier & Inglis-Jassiem 2010). Getting healthcare at home is not an option for the early, acute phase after stroke when people are more likely to survive and regain their health if they receive their healthcare in the setting of an organised inpatient stroke unit (Stroke Unit Trialists' Collaboration 2007). But after the acute period is over and rehabilitation is the primary focus of healthcare, the option for healthcare in the home context is possible and increasingly being encouraged (Hillier & Inglis-Jassiem 2010).

The accessibility and effectiveness of home rehabilitation after stroke for people with LEP is promising. Home rehabilitation has already been shown to be the preference of many stroke patients (Weiss et al. 2004, Gregory et al. 2010). It has also been shown to provide better functional outcomes than rehabilitation provided in an inpatient or day-centre context (Hillier & Inglis-Jassiem 2010). The mechanism for improved effectiveness of rehabilitation delivered in the home is likely to be a combination of several factors identified in the literature which also address issues for older people with LEP that have been raised by the findings of my study. These factors may include: facilitating of the person with stroke to step out of a passive patient role and adopt more autonomous roles that are familiar to them in their home context (von Koch, Wottrich & Holmqvist 1998), potentially assisting the transition of a person's sense of self after stroke (Cott, Wiles & Devitt 2007); assisting the person to have insight and understanding of their stroke and its consequences (Olofsson, Andersson & Carlberg 2005); and providing an environment that is more comfortable and

supportive to an individual's needs than inpatient healthcare after stroke offers, with easier access to familiar people and resources. Arguably, these benefits would be of greater importance for people with LEP from CALD backgrounds for whom language may widen the difference between home and the inpatient healthcare context.

This is not to say that home rehabilitation is an easy or quick fix to the difficulties experienced by participants during their healthcare after stroke. Healthcare at home still needs to be made meaningful to the older person with LEP. As the process of *'weighing up the value of care'* demonstrated, if the primary concerns of the person with stroke are not perceived to be addressed then the person will not be engaged with their healthcare whether it is on a hospital ward or in their own living room. Previous research has shown that the context of a patient's home can facilitate patient-centredness in healthcare after stroke. It shifts the dynamics of the patient-health professional relationship as the health professionals are now guests in the patient's home and take a "friend" rather than "expert" role during interactions in the person with stroke's home (von Koch, Wottrich & Holmqvist 1998, Doig et al. 2011). Therapy is also made more relevant to the person's familiar life situation. The success of the healthcare, however, still requires effective communication between the person with LEP and the health professional. Moving to a home context does not guarantee that a familiar informal interpreter from family or friends will be present or appropriate. A decision about the need for an interpreter, and then who will act as interpreter, will still need to be made and it is likely that the health professional will need to organise a professional interpreter to be present rather than using someone who is more familiar. The interpreter decision during healthcare is further discussed in section 5.2 of this chapter.

Moreover, a person's home is not neutral territory (Gillsjö, Schwartz-Barcott & von Post 2011), and so health professionals must take care that their presence in a person's home does not remove the context of familiarity and freedom that is so strongly sought by older people with LEP after stroke. More broadly, the positive potential of home rehabilitation for older people with LEP after stroke is cautioned by the recognition that it can introduce problems to the healthcare scenario for health professionals, carers and patients. Personal safety, travel time and poor ergonomics can be problematic for health professionals (Hillier & Inglis-Jassiem 2010). The

burden on carers can be increased as they miss out on the opportunity for respite that comes with inpatient or day-centre rehabilitation (Dow 2004, Low, Roderick & Payne 2004); although this may be outweighed by the benefits they perceive from the context (Low, Roderick & Payne 2004). Highlighting, once again, that the individual needs and context of the person must be understood and considered in healthcare decisions. Further research is also needed to specifically investigate the effectiveness and appropriateness of home rehabilitation for older people with LEP.

So far, the discussion of my findings has focussed on concepts and issues relevant to healthcare for older people with LEP that have been raised by the processes of the developed theory. These issues include the pervasive uncertainty of healthcare after stroke for this group of people, the importance of their familiar lives and trusted others in their healthcare experience, and the need for a patient-centred and culturally competent model of healthcare to facilitate improved healthcare communication and engagement with older people with LEP in their recovery after stroke. Many times in this discussion, the need for effective communication between the older person with LEP and their healthcare has been highlighted. Although I recognise that communication is much more than spoken words, the language that is used when communicating with people with LEP is integral to its effectiveness and so the important role of language within the theory is now addressed in my discussion.

5.2 Bringing language to the fore

Language was not given explicit prominence by participants in their healthcare experience but language is interwoven through the processes of the developed theory. For example, it contributed to participants continuing as normal in *'hanging on to the familiar'* when some were reluctant to independently contact emergency services because of their LEP. A shared language was often part of participants' relationship with trusted others and a part of the familiar contexts which they wanted. And the condition of 'nobody interested to talk like we talk', in *'being told and being a good patient'*, contributed to participants' being passively positioned and their perception that they received little information from health professionals. It was participants' uncertainty, grounded in their communication with health professionals and having to manage in English, which influenced them to perceive their healthcare after stroke to be of low value in the process of *'weighing up the value of care'*.

In bringing the influence of language within the developed theory to the attention of readers and users of this research, my intention was not to ignore or disagree with participants' interpretation of its place in their healthcare experience. Highlighting a major concern which participants see as routine is accepted within a constructivist research approach (Charmaz 2006) and does not imply that the researcher's interpretation is more valid than the participant's; rather that they are two different, and possibly both valid, perspectives and understandings of the situation (Pyett 2003). My intention in bringing language to the fore in this discussion was to recognise that understanding the role of language within the healthcare experience of people with LEP is knowledge that is lacking in the field of healthcare practice after stroke and can inform improvements in the quality of healthcare for this group of people.

The lack of importance directly attributed by participants to language within their healthcare experience was an interesting finding in itself. Brugge et al. (2009) also found in their investigation of the healthcare experiences of adults with LEP that participants seldom volunteered examples of difficulty understanding what a health professional told them. With striking similarity to the process of *'being told and being a good patient'* in my study, their participants were more likely to complain about not being told anything at all. They did not, or could not, isolate the role of language from other elements within their experience. In other words, they took it for granted (Garfinkel 1967). Perhaps the finding from both studies is because language is enmeshed with participants' concerns about a lack of information, the relevance of treatments, and health professionals' behaviour. People with LEP who have lived in an English-speaking community for some time can be accustomed to the scenario of 'managing in English' and its associated difficulties within their daily lives, so they may no longer recognise its impact. It may also be that in telling their story to an audience of a researcher and professional interpreter, participants minimised the influence of their LEP within their stories to impart a more capable representation of self (Riessman 2003).

The lack of importance attributed to language by participants in their healthcare experience suggests that the use of their preferred language in this context cannot only be thought of in terms of access. People with LEP may not independently give

significance to their language needs during healthcare after stroke and, therefore, will be unlikely to independently identify their language needs or initiate these needs being addressed. This finding increases the onus on health professionals to be aware of the importance of language in providing quality healthcare for people with LEP and to actively address the issue in practice. To this end, my discussion will now focus on issues within the findings that specifically relate to language and that have important relevance to healthcare practice. They are the complexity of the use of interpreters during healthcare after stroke for older people with LEP, and the missing translated resources.

5.2.1 The interpreter decision

Professional interpreters were not a strong presence in the healthcare experience after stroke for participants. To a large degree this was because they were not physically present, a scenario also found in the routine underuse of professional interpreters in healthcare reported by many studies (for example Gray, Hilder & Donaldson 2011, Phillips & Travaglia 2011, Schenker et al. 2011). The absence of professional interpreters was either because they were not offered by health professionals, not requested by the participant, or had been declined by the participant. On the few occasions when a professional interpreter was present within a participant's healthcare experience, the interpreter's presence was limited to a role determined by the health professional rather than the patient. Yet the effective use of professional interpreters is known to be an essential component of delivering quality and effective healthcare for people with LEP (Brach & Fraser 2000, Karliner et al. 2007, Priebe et al. 2011).

One notable consequence of participants managing in English without professional interpretation was that they perceived the majority of their communication with health professionals as 'being told the rules'. It was transactional communication without collaborative discussion and negotiation of meaning; missing the 'chat' which can communicate much information between patients and health professionals during interactions (Gordon, Ellis-Hill & Ashburn 2009) as well as develop rapport and trust (Hupcey et al. 2004). It cannot be known from the nature of the data in my study whether the perception of one-way simplicity of communication was in the participant's reception of the message or how the message was spoken by the health

professional. Irrespective of where it occurred, the simplification of talk often lost the meaning and value of its message and this contributed to the low evaluation of healthcare after stroke by participants.

While previous studies have noted that people with LEP often "get by" without professional interpreters during healthcare (Bonacruz Kazzi & Cooper 2003, Schenker et al. 2011), the mechanism behind this has not been understood from the patient perspective outside of exploring their preference for the use of professional or informal interpreters (Edwards, Temple & Alexander 2005, Garrett et al. 2008b, Hadziabdic et al. 2009). Although Edwards, Temple and Alexander (2005) suggest that participants in their study made up their own minds about whether they needed an interpreter in healthcare, findings from my study propose that this is only one part of the interpreter decision for older people with LEP after stroke. The developed theory in my study of healthcare experience after stroke extends the knowledge of the patient's role in the interpreter decision by constructing the involvement of professional interpreters as a complex decision for older people with LEP, influenced by their perception of the language and healthcare expertise of themselves and others, their perceived position and authority to make the interpreter decision, and who they trusted.

Expectations of expertise

When participants were asked if they needed a professional interpreter, or if it was left for them to initiate an interpreter's presence, they were placed in an expert role to decide their language needs in an unfamiliar context and disabled state; and so it was not always an informed decision. Deciding whether they needed a professional interpreter was a decision made intuitively by participants based on how they had managed in previous interactions which they considered to be comparable, such as office settings or outpatient appointments. Participants then extrapolated from those experiences to the unfamiliar healthcare setting they had entered, an intuitive judgement which has previously been identified to occur in the communication between nurses and people with LEP (Isaacs et al. 2011). Some participants perceived the language requirements of healthcare were within their capability and so they refused an interpreter. But their assessment of need was not contextual to the unfamiliar healthcare setting they were in and may have been complicated further by

them lacking health literacy in English (Zun, Sadoun & Downey 2006). Participants who had not had a previous stroke or worked in the healthcare environment were unable to know what the demands of communication during healthcare after stroke would be, how the stroke could affect their normal communication ability or the potential disadvantage to their recovery if they were unable to communicate effectively. Their refusal to use an interpreter likely, but unwittingly, disadvantaged their own healthcare by contributing to their uncertainty and lack of involvement in healthcare planning.

Participants' decision to use an interpreter, either professional or informal, was also influenced by their perception that health professionals would be responsible for all their healthcare decisions in the process of *'being told and being a good patient'*, and encompassed a trust that the health professionals would make the right interpreter decision for them. While it is not unusual for patients to delegate the responsibility for healthcare decisions to health professionals (Arora & McHorney 2000, Deber et al. 2007), as discussed in section 5.1, expert trust in health professionals has not previously, to my knowledge, been proposed to extend to the organisation and use of professional interpreters. Participants did not perceive that organising an interpreter was the patient's responsibility during healthcare. Participants trusted that health professionals would know when a professional interpreter was needed and would organise for one to be there. If a professional interpreter was not organised, then it was viewed as the expert's judgement and was not openly questioned even if the participant would have liked to use one. Conversely, two of the participants who had refused professional interpreters accepted them at interviews for this study when I, presenting as an expert researcher, suggested that an interpreter would aid my understanding.

Health professionals have an opportunity and a mandate to demonstrate the leadership in the interpreter decision that participants expected of them. Such leadership requires health professionals to give people with LEP the knowledge, opportunity and encouragement to use a professional interpreter at any point during their healthcare. This can be facilitated by asking people with LEP, "In what language would you prefer to discuss your healthcare?" (The Joint Commission 2010), not just once but as part of an ongoing attention to potential language needs during the

different stages of healthcare and the person's recovery from stroke. All people with LEP in healthcare need to be aware of their right to use a professional interpreter, the interpreter's role and ethical responsibility for confidentiality, potential benefits of interpreter usage to their healthcare and its outcomes, and how they can access a professional interpreter. This information can be communicated using a translated written resource, a professional or informal interpreter in-person or via telephone.

Sometimes health professionals may have to prescribe a professional interpreter to be present for situations which have more complex language demands, where communication difficulties are likely but may not be anticipated by the older person with LEP. For example, when the health professional is explaining the stroke diagnosis or medication changes, gaining consent for a procedure, or conducting rehabilitation goal-setting or discharge planning. Achieving effective communication between the older person with LEP and their health professional will also require the health professional's own need to use an interpreter to be evaluated independent of the person with LEP's needs. Health professionals can expect the professional interpreter's role to be confined to helping the patient to understand their instructions (Wardin 1996). Yet, the role of the professional interpreter is to facilitate communication for both parties and they can help the health professional to understand the patient's desires. As I experienced during interviews in my study, it only takes a slight shift in accent to make even a conversation in simple English difficult to understand. Health professionals can evaluate their own need for an interpreter when communicating with a patient with LEP by asking themself, "Am I always sure that I have understood what the patient is saying to me in our conversation?" If they have any difficulty in understanding the patient, then a professional interpreter needs to be organised for the interaction. Working with professional interpreters during healthcare after stroke is not just about the person with LEP understanding but also about the health professional understanding their patient.

Although the evidence which supports health professionals working with interpreters to improve the quality of healthcare for people with LEP is based on the use of professional or trained medical interpreters (Flores 2005, Karliner et al. 2007), it was informal interpreters who often filled the language gap between health professional

and participants in my study. This finding is supported by many previous reports of informal interpreters being used in healthcare settings (for example Garrett et al. 2008b, Diamond et al. 2009, Schenker et al. 2011). The findings from my study contribute to understanding how this may occur during healthcare after stroke.

Trusted to interpret

Most participants relied on informal interpreters who were trusted others to fill language gaps when they were managing in English during their healthcare after stroke. Using an informal interpreter, that is, a person who was not specifically trained or accredited to be an interpreter, was a familiar and accepted strategy for participants from their community life where they had managed in English many times before. It was also a strategy which they could use without stepping out of their patient role to ask health professionals to provide one. Sometimes an informal interpreter was nominated by the participant to be used during a conversation or meeting, and sometimes they were used by the health professional without the participant being consulted. Their use was often not formally arranged, excepting the experience of Sadik whose daughter agreed to interpret over the telephone whenever needed. Rather, it was a matter of chance if the informal interpreter was present at the right time to interpret for an interaction between the older person and health professional. On several occasions participants reported this chance was missed and so the trusted other later clarified for the participant the information which had been given to them earlier without interpretation. Because this informal interpretation by trusted others happened outside of the direct patient-health professional interaction, it may not be obvious to health professionals that they are providing this service and so the person with LEP's independent ability to manage in English may be overestimated. The extent of language assistance needed to understand may even be underestimated by the older person themself as the process of assistance is so familiar.

Informal interpreters were people who the participant trusted, most often because of their relationship as a trusted other but sometimes because of their expertise as a bilingual health professional. This trust contrasted with the distrust some participants expressed for professional interpreters. It has previously been reported that many patients with LEP prefer people they know to interpret because they trust

the person to be an advocate for them and they appreciate the convenience (Edwards, Temple & Alexander 2005, Garrett et al. 2008b, Hadziabdic et al. 2009) and there have been recent calls in the literature for informal interpreters to be given a recognised place in healthcare for people with LEP (Edwards, Temple & Alexander 2005, Gray, Hilder & Donaldson 2011). This is not a straightforward suggestion as there are documented concerns about the safety and quality of interpretation by informal interpreters in a healthcare setting (Flores 2005, Karliner et al. 2007). In my study, information was sometimes withheld from participants by their trusted others which contributed to participants' uncertainty about their stroke and healthcare, and potential consequences for the person's ability to self-manage their condition. Therefore, health professionals need to be prepared for the situation when a person with LEP refuses to use a professional interpreter or when an informal interpreter is used. Gray, Hilder and Donaldson (2011) have found the successful involvement of informal interpreters is dependent on them being used in very closely proscribed circumstances, such as situations where clinical complexity is low and when there are no ethical issues with the particular person interpreting, such as a young child is not an interpreter and the person with LEP is happy with the choice. During healthcare after stroke, for example, informal interpreters could be involved during the regular therapy sessions which occur between the critical goal-setting and discharge-planning discussions for which a professional interpreter would need to be present. Menu completions and personal care such as showering may be other times when an informal interpreter is preferred by the person with LEP and so health professionals could negotiate with bilingual trusted others for them to be present at these times.

In some healthcare situations that are specific to the individual, the person's own English proficiency may be sufficient for the context and so an interpreter is not needed. But this cannot be assumed and it is not indicative that interpretation is not needed at other times during the person's healthcare. A person with LEP's ability to obey commands given to them by a health professional does not necessarily equate to them understanding the value or relevance of the treatment as shown by the consequence of 'choosing to go' in *'weighing up the value of care'*. Health professionals can check that a person with LEP has understood the information given to them by using strategies such as the 'teach-back' method when the person with LEP is asked to explain in their own (English) words the information that was provided to them

until it is clear that they understand (Zanchetta & Poureslami 2006, Andrulis & Brach 2007, The Joint Commission 2010). Simple, jargon-free language is easiest for people with LEP to understand (Andrulis & Brach 2007) but this does not mean that the detail of the information should be omitted on the assumption that the person with LEP, or their informal interpreter, will not understand. Such a scenario is discriminatory to the patient and their right to equitable access to quality healthcare (Australian Commission on Safety and Quality in Health Care 2008, Johnstone & Kanitsaki 2008), and, as discussed earlier, may miss out the information which communicates the value of the message. If the health professional cannot communicate adequately with the person with LEP to achieve a shared understanding and informed decision-making in simple English, or with an informal interpreter, at any time during the person's healthcare then a professional interpreter is needed for the interaction.

5.2.2 The missing resource

The scarce presence of translated printed information in the healthcare experiences of participants contributed to their perception of not being told much information about their stroke and healthcare. All interventions included in a meta-analysis by Smith, Forster and Young (2009) which demonstrated a statistically significant improvement in patient knowledge after stroke incorporated some form of printed information. None of these studies included people with LEP in their samples, but it is to be expected that stroke survivors with LEP would also benefit from being able to read and retain information about their new health condition as study participants were people who 'wanted to know' more in the developed theory of their healthcare experience.

The inadequate availability of translated information about stroke was made obvious during my study when I was unable to provide Krystyna with printed stroke information in Polish from internet sources internationally or the local recruiting healthcare facilities. This was despite more than 17,000 older people from Poland estimated to live in Australia in 2011 (Gibson et al. 2001). Currently, the Australian National Stroke Foundation provides free translated information sheets to download from their website (www.stroke foundation.com.au) which explain "all about stroke" in seven languages other than English. However, seven languages are not enough to

meet the demands of ageing Australian multicultural communities. As noted in the introductory chapter to this study, more than 33 different languages are spoken in the western area of Adelaide alone (ABS 2006), and at least ten languages other than English were spoken by people with stroke admitted to the study's two recruiting hospitals over a six month period (see section 3.2.1 in chapter 2). It is a pattern of multilingual aging communities which is also found in other countries with diverse groups of migrant people such as England and Wales (Lievesley 2010), Canada (Durst 2005), suggesting that translated stroke resources could be shared internationally.

To improve the feasibility of providing written stroke information for people with LEP from CALD backgrounds, it needs to be made freely available in many more languages. The specific languages which are required can be guided by predictions of ageing migrant populations based on census data, for example Gibson et al. (2001) in Australia, with the regular addition of languages as different migrant groups age. Ideally, translated stroke information would be available from a central point such as a government or stroke association website to promote its accessibility by health professionals, stroke survivors and their carers. This extent of language translation will necessarily be at a financial cost. However, access to information about stroke treatment and prevention is a right of all stroke patients, not just those who speak English (Chen, Youdelman & Brooks 2007, Australian Commission on Safety and Quality in Health Care 2008, Department of Heatlh 2010, Health and Disability Commissioner n.d.).

The functional health literacy of the older person with LEP must also be accounted for in all information strategies during healthcare after stroke, including the design and use of translated written resources (Zanchetta & Poureslami 2006, Sudore et al. 2009, Sorlie & Lopez 2011). Functional health literacy refers to a person's capacity to be able to read, calculate and act on oral and written information in healthcare settings. People with low functional health literacy are more likely to experience a poor health outcome, including a higher risk of cardiovascular death (DeWalt et al. 2004, Baker et al. 2007). Poor functional health literacy and LEP often co-exist; being of older age, from a CALD background and having a low level of formal education are all associated with having poor functional health literacy (Adams et al. 2009, Levasseur & Carrier 2010). These are demographics which fit the majority of participants in my study and

many in multicultural communities. Written translated resources with good use of graphics and plain, jargon-free language with culturally appropriate content aid comprehension by people with LEP (Dreger & Tremback 2002, Andrulis & Brach 2007, The Joint Commission 2010). In practice, the translated resource should always be given with an English version in case the person with LEP does not have the literacy to read or understand the information and so relies on another person to interpret who may have the skills to speak but not read their language. It also allows trusted others and carers who read only English to be able to access the information (Dreger & Tremback 2002).

Importantly, translated printed resources need to be distributed to patients with LEP as part of an active information process which includes a planned follow-up by health professionals for clarification and reinforcement (Smith, Forster & Young 2009); ideally with an interpreter present. The older person with LEP is not always going to speak up in a healthcare setting if they do not understand what they are being told, as highlighted in the process of *'being told and being a good patient'*, so health professionals need to check the person's understanding using strategies such as the "teach-back" method discussed in the previous section on the interpreter decision.

The timing of information is another consideration. Due to the shocking circumstances of stroke and its cognitive effects, not all people will be able to receive and recall information from the acute period of their healthcare and a person's information needs can change during their process of recovery (NSF 2007b, Ellis-Hill et al. 2009). Assessing the person's current understanding before sharing information can help to ensure the timing of the information is right for it to be meaningful to the individual (Ellis-Hill et al. 2009). People with LEP need to be supported to access information resources in their preferred language throughout their recovery including when they have returned to live in the community; this could be their local doctor, a stroke liaison person or translated resources.

This section of my discussion which has focused on the importance of issues associated with language in participants' healthcare experience ends with a word of caution about focusing only on language in the practice and research of healthcare communication between people with LEP and health professionals. Language, literacy and interpersonal communication are known to be interconnected in quality patient

healthcare (Sorlie & Lopez 2011). Neither a professional interpreter nor translated resources will fix poor interpersonal communicative practices between health professional and patient such as one-way communication. And just as I caution for research not to assume that communication with older people with LEP is all about language proficiency, I continue my discussion of the theory in the next section by emphasising that there is more to conclude from my findings than an idea of difference.

5.3 Similarities as well as differences

The emphasis so far in my discussion has been on study findings which are important and innovative to the fields of healthcare for people with LEP and healthcare after stroke. By doing this, I have not meant to present the idea of 'novelty' or 'difference' as definitive of the experience of people with LEP. My study aimed to privilege older people with LEP in an exploration of healthcare after stroke without further marginalising a group who has previously been silenced in the research literature (Pyett 2001, Liamputtong 2010). Therefore, I must emphasise that much of how participants experienced their healthcare shared issues and concerns that have been previously identified in the research literature for people who speak the same main language as spoken during their healthcare. Examples of this are given in the initial section of this chapter, such as participants' delay in seeking help after stroke, their passive positioning in healthcare, the disconnect between rehabilitation healthcare and what held meaning for participants, and the complaint of a lack of information. The strength of such similarities can be surprising given the 'other' status that is frequently given to patients who are from CALD backgrounds, but the surprise should be lessened when the possible explanations for such similarity are considered.

Similarities may exist between the healthcare experience of people with LEP and those who speak English proficiently because of the essential role of communication within stroke healthcare. Yolanda Partida (2007) from the Hablamos Juntos (We speak together) program in the USA suggests that the experiences of people with LEP can indicate challenges in healthcare that go beyond language differences and which have relevance for how health professionals communicate with all their patients. From my study, participants' experience of 'being told the rules' may be relevant to why people who speak the same language as their health professionals commonly

perceive that they are given little information about stroke. It suggests that the format of simply telling instructions to stroke patients is not an effective way to inform and engage with them about their condition and its management. This idea is supported by calls for more research on how health professional communication influences outcomes after stroke (Anderson & Marlett 2004) and the need to identify what makes active approaches to information-giving after stroke the most effective method (Smith, Forster & Young 2009). A research focus on how health professionals communicate information to people with LEP may enhance the understanding of this shared phenomenon and have the benefit of providing information for healthcare practice that is relevant to contemporary multilingual communities.

Similarities between healthcare experiences may also exist because a person's interpretation of a phenomenon is not wholly defined by a single feature of who they are as a person, such as the language they speak. A constructivist philosophy supposes that all people's interpretations of reality are influenced by their past experiences as well as current circumstances (Charmaz 2009). There are many social, cultural and economic factors which may influence both an older person with LEP and an older person who speaks English proficiently in how they construct their healthcare experience. These factors can include gender, age, education level, the patient role or the person's unfamiliarity with the healthcare system and its environment (Partida 2007). In this complex interplay of influencing factors we cannot be clear at any point which is the predominant influence on how a person interprets a given phenomenon. And so health professionals and healthcare organisations cannot assume to know the needs of an older person with LEP without asking them to find out.

Recognising similarities is not to ignore the evidence from my findings and previous research (see chapter 2) that having LEP can disadvantage a person's healthcare experience and outcomes. The role of language within the developed theory was shown to heighten the effect of shared issues such as participants' uncertainty and passive positioning, as well as introduce new issues to the already complex experience, including the role of the interpreter. However, I propose that such disadvantage can be recognised and addressed within an inclusive framework of culturally competent and patient-centred healthcare in which health professionals

are sensitive to how they evaluate and respond to the language needs of others. In writing about the practice of social work in multicultural communities in the USA, Charles Guzzetta advised that, "All practice should be sensitive to all clients, and practice that is sensitive to all clients is the most effective and ethical for each client" (Lum & Guzzetta 1997, p. 67). For a person's culture encompasses not just language but also gender, age, income, education, sexual orientation, ability and faith (Kumas-Tan et al. 2007) which may all influence their healthcare experience. And so I conclude the discussion of the findings from my study by restating my earlier call for healthcare after stroke to be both culturally competent and patient-centred to improve healthcare for older people with LEP and to benefit the recovery of all people after stroke. In the next section I address the limitations of my study before summarising the recommendations for healthcare practice and research from my discussion, and then concluding the thesis.

5.4 Limitations of the study

All studies have limitations which need to be acknowledged. This study presents an analysis of the experiences of a sample of older Australians with LEP from CALD backgrounds who had recently attended healthcare after suffering a stroke. The conclusions which I have drawn from the analysis are specific to this sample. In my study methods (chapter 3), I attempted to provide sufficient descriptive information for the reader to determine the transferability of the developed theory to other settings and populations (Lincoln & Guba 1985). However, further testing of the theory is needed in other diverse and larger populations to establish its wider relevance.

There were limitations to my study's sample due to the nature of their stroke and the use of interviews. Participants were required to take part in in-depth interviews and so people who were unable to communicate because of severe cognitive or communication disabilities were not able to participate (people with mild dysphasia or dyspraxia were included). Unfortunately, this excluded a small number of people from my study whose healthcare experiences are equally valid and important to understand. However, it is likely that their severe difficulty communicating in any language would have been more influential on their healthcare experience after stroke than their LEP and so perhaps their inclusion would not have been consistent

with the focus of the study anyway. My study is a start to understanding the complex healthcare experience for people with LEP and future research agendas in this area will need to consider the influence of other factors on the experience, such as severe communication difficulties. Now, a summary of the recommendations from my discussion is provided before the thesis is concluded.

5.5 Recommendations for healthcare practice

This study aimed to provide findings which could direct and inform improvements in healthcare practice after stroke. Recommendations for healthcare practice, including recommendations that have been presented in the preceding sections of this chapter, are summarised in figures 5.1, 5.2 and 5.3, 5.4 and 5.5. Recommendations have been grouped in each figure according to the topic that is their focus: trusted others, patient-centred and culturally competent healthcare, interpreters and translated resources.

Recommendations for practice: Trusted others

The family and friends of older people with LEP who are at risk of stroke are targeted in stroke awareness campaigns, using languages relevant to the community.

Older people with LEP be invited to nominate people who are their trusted others during their healthcare after stroke and helped to access them whenever they need to.

Opportunities are given for trusted others to be with older people with LEP during any decision-making and care processes.

Trusted others are supported to conduct rehabilitative exercises or activities with the older person outside of formal therapy sessions.

Figure 5.1 Recommendations for healthcare practice which focus on trusted others.

Recommendations for practice: Patient-centred and culturally competent healthcare

Healthcare after stroke for older people with LEP is guided by principles of patient-centred and culturally competent healthcare. In practice, this means that:

- Older people with LEP are treated compassionately and respectfully as individuals with their own beliefs and needs about their health and healthcare.
- The individual beliefs and needs of older people with LEP are not assumed without asking them, including their language needs. Regular opportunities are provided for older people with LEP to have an open dialogue with health professionals in their preferred language.
- Healthcare after stroke is relevant to what the older person with LEP values in their recovery and its relevance is understood by the older person. This can only be achieved by the older person having an active role in planning their healthcare. Goal-setting is a tool that can be used to facilitate this process.
- The option of home rehabilitation after stroke is offered to older people with LEP.

The successful introduction and conduct of a patient-centred and culturally competent model of healthcare after stroke will require it to be adopted at systemic, organisational and professional levels as well as changes in practice at the level of individual health professionals.

The individual context and needs of the person with LEP must always be recognised in the application of any theory of healthcare practice.

Figure 5.2 Recommendations for healthcare practice which focus on providing patient-centred and culturally competent healthcare

Recommendations for practice: Interpreters

It is recommended that health professionals demonstrate leadership in the use of interpreters with older people with LEP. This will involve:

- Asking older people with LEP "In what language would you prefer to discuss your healthcare?" not just once but as part of ongoing attention to, and dialogue about, their language needs during their healthcare and recovery after stroke.
- Ensuring older people with LEP are aware of their right to use a professional interpreter, the interpreter's role and ethical responsibility for confidentiality, potential benefits of interpreter usage to their healthcare and its outcomes, and how they can access a professional interpreter. This information can be communicated using a translated written resource, a professional or informal interpreter in-person or via telephone.
- Evaluating their own need for an interpreter when communicating with a patient with LEP by asking themselves, "Am I always sure that I have understood what the patient is saying to me in our conversation?" If they have any difficulty in understanding the patient, then a professional interpreter needs to be organised for the interaction.
- Using interpreters regularly and often to ensure people with LEP can participate in their healthcare. During rehabilitation, this could be a weekly session with a professional interpreter to ensure any changes in treatment are understood and their relevance is established to the collaborative goals.
- Being prepared for the situation when a person with LEP refuses to use a professional interpreter or when an informal interpreter is used. Health professionals can check that a person with LEP has understood the information given to them by using strategies such as the "teach-back" method when the person with LEP is asked to explain in their own words the information that was provided to them until it is clear that they understand.

Recommendations for practice: Interpreters (continued)

- Prescribing the use of professional interpretation for situations which have more complex language demands, where communication difficulties are likely but may not be anticipated by the older person with LEP such as collaborative goal setting.
- Accommodating an older person with LEP's preference for using an informal interpreter when the clinical complexity of the interaction is low and when there are no ethical issues with the particular person interpreting. For example, an informal interpreter could be used for regular therapy sessions that occur between the critical goal-setting and discharge-planning discussions.
- Attending training in working with interpreters. Respecting and involving professional interpreters as members of the healthcare team.
- Being prepared to be flexible in the mode of interpretation to maximise the availability of professional interpretation assistance, for example using interpreters via telephone or video calls.

Figure 5.3 Recommendations for healthcare practice which focus on the use of interpreters.

Recommendations for practice: Translated resources

Written stroke information for older people with LEP needs to be made freely available in the many languages that are spoken by this group of people in the community. The specific languages which are required can be guided by predictions of ageing migrant populations based on census data.

Translated resources must be distributed to older people with LEP as part of an active information process which includes a planned follow-up by health professionals for clarification and reinforcement using the person's preferred language.

Translated stroke information should be available from a central point such as a government or stroke association website to promote its accessibility by health professionals, people with stroke and their carers.

Translated written information is always given with an English version.

Written translated resources must be designed with plain, jargon-free language, a good use of graphics and culturally appropriate content.

Figure 5.4 Recommendations for healthcare practice which focus on the use of translated resources.

5.5.1 Recommendations for clinical guidelines

The recent Australian clinical guidelines for healthcare after stroke have very little to say about addressing healthcare to the needs of people with LEP, as highlighted in the introduction chapter to this study. However, they do suggest that the experiences of people with stroke and their families and carers can help to inform the improvement of stroke services and the guidelines themselves (NSF 2010, p. 30). Taking this opportunity to directly inform healthcare practice, I have made three specific recommendations for the Australian clinical guidelines from the findings of my study.

Recommended clinical guideline 1

All stroke patients are asked what language they prefer to speak during their healthcare. A person's preferred language must NOT be assumed. This question to be asked at admission and checked regularly by health professionals as the complexity

of information, importance of information, and effects of stroke on a person's cognition may change during a person's healthcare after stroke.

Recommended clinical guideline 2

For people who prefer to speak a language other than English during their healthcare after stroke, a professional interpreter is organised regularly (at least weekly) for discussions with the patient about their healthcare, including diagnosis, healthcare preferences, rehabilitation goal-setting, stroke management, and secondary stroke prevention. Printed stroke information which has been translated to their preferred language is also made available to them along with a copy in English. A professional interpreter is provided at any time when requested by the patient or when there is difficulty achieving a two-way conversation between patient and health professional.

Recommended clinical guideline 3

The existing statement on p.30 of the guidelines, "Rehabilitation is a proactive, person-centred, goal-oriented process that should begin the first day after stroke" (NSF 2010, p. 30), is endorsed with the addition, "…for rehabilitation to be person-centred, the individual needs of the patient must be known and the goal-oriented process must be conducted using the patient's preferred language."

5.6 Recommendations for research

The findings from this exploratory study provide a basis for future research directions in the under-researched area of healthcare after stroke for people with LEP from CALD backgrounds. Recommendations which specifically relate to the conduct of research with people from multiple language groups were presented in section 2.2.1 of chapter 2. Recommendations for directions in research, including recommendation which have been presented in the preceding sections of this chapter, are shown in figures 5.5, 5.6 and 5.7. Recommendations have been grouped in the figures according to their research focus: the population of people with LEP, the developed theory or communication in healthcare after stroke.

Recommendations for research: Population

The inclusion of people with LEP in stroke healthcare research is vital to increasing its relevance to growing multicultural communities and supporting equitable access to the benefits of research.

More research is needed to understand what relationship exists between having LEP and a person's health outcomes after stroke. Conduct of such research would be benefitted by the reliable and routine collection of patient language data by healthcare services and/or a stroke patient database.

However, healthcare research with people with LEP that focuses only on the influence of language can risk missing its relationship to other important factors and the wider social influences on the effectiveness of healthcare and its outcomes.

Figure 5.5 Research recommendations which focus on the population of older people with LEP.

Recommendations for research: Theory

Research is needed to understand how trusted others can be involved in healthcare after stroke to improve its quality and effectiveness for older people with LEP, and other people.

The usefulness of the process of *'hanging on to the familiar'* to healthcare practice requires further research with a specific focus on understanding the help-seeking behaviour of older people with LEP at the time of their stroke.

The process of *'weighing up the value of care'* warrants consideration in future research investigating patient adherence with stroke treatment and secondary stroke prevention.

The effectiveness and appropriateness of home rehabilitation for older people with LEP needs to be investigated.

Figure 5.6 Research recommendations which focus on investigating the theory.

Recommendations for research: Healthcare communication

The decision-making by people with LEP about the language they speak during their healthcare, especially in unfamiliar and acute healthcare situations, needs further investigation to inform healthcare practice and interpreter policy.

Research to understand how health professionals can effectively communicate stroke information to people with LEP is needed and may enhance the understanding of effective information-giving for all patients.

Figure 5.7 Research recommendations which focus on investigating healthcare communication.

5.7 Conclusion

My study aimed to provide knowledge that was useful to healthcare practice. If I could take myself back to being the research physiotherapist in 2007 who was looking for information about providing healthcare after stroke for older people with LEP, what knowledge would I gain from reading this study to apply to my practice? I would know that older people with LEP are likely to be uncertain about their stroke and healthcare, even several weeks after they have gone home, and that I need to provide regular opportunities for them to ask me questions and for me to give them information in their preferred language. I would know to take responsibility for the organisation of professional interpreters and to use them regularly and often during healthcare planning and therapy. I would know not to assume the expectations or needs of the older person with LEP, but to talk and collaborate with them on a treatment plan that is relevant to them. And I would know to find out who the older person's trusted others were and welcome their presence during therapy sessions and decision-making. Importantly, I would be sensitive to my own grounds for making decisions about the needs of an older person with LEP after stroke and look to a model of patient-centred and culturally competent healthcare to guide my practice as a health professional.

My study provides a preliminary theoretical understanding of how healthcare after stroke for older people with LEP can be improved in practice for the benefit of their

recovery. It is an understanding which has revealed the complexity of the processes involved in providing quality healthcare for this group of people. I hope that this is the first step in the future of an inclusive and comprehensive research agenda to inform quality and effective healthcare after stroke for multicultural aging communities.

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Appendix A: Published article, "The effect of limited English proficiency on falls risk and falls prevention after stroke"

Age and Ageing 2012; **41:** 104–131

Research Letters

The effect of limited English proficiency on falls risk and falls prevention after stroke

SIR—Language barriers disadvantage the health care of people with limited English proficiency (LEP) [1]. For people with stroke, having LEP has been associated with increased length of hospital stay [2] and underutilisation of anticoagulants [3]. There remain many gaps in the evidence regarding health care for stroke patients with LEP as researchers frequently exclude this group from studies. Falling is an adverse event for many stroke survivors. Up to 73% of people with stroke fall during the first 6 months after discharge home [4, 5]. Despite recent interest in falls prevention for people with stroke, [6] falls risk and falls prevention after stroke for people with LEP has not been specifically explored. The objective of this sub-study analysis of a randomised controlled trial was to determine if having LEP affected overall falls risk, falls risk factors, falls prevention strategies or planned health and support service use for community-dwelling people at risk of recurrent falls after stroke.

Methods

Data were extracted from the baseline assessment of a randomised controlled trial that evaluated the effectiveness of a multi-factorial falls prevention programme for stroke survivors who were at high risk of falling on return home after rehabilitation [7].

Participants

Adults who returned home after stroke rehabilitation were eligible for the study if they were at risk of recurrent falls (decreased balance or had fallen at any time during their hospital admission). Decreased balance was defined as a step test worst leg score of less than 7 or a Berg Balance Scale score of less than 49 [5]. Potential participants were excluded if they were being discharged to residential care or living ≥100 km from study sites. Participants were recruited from nine rehabilitation units in two Australian cities with established migrant communities, Melbourne and Adelaide. Participants were categorised as LEP if they required an interpreter during their assessment.

Treating physiotherapists assessed eligibility and provided study information prior to the patient's discharge from inpatient care. Potential participants were contacted 2 weeks after discharge to arrange assessment. Participants who had used an interpreter during inpatient care were offered a professional interpreter or they could choose to use an informal interpreter. All assessments were conducted in participants' homes prior to randomisation.

Assessment

Falls risk was measured using the Falls Risk for Older People in the Community (FROP-com) tool which has been demonstrated to have good reliability and moderate capacity to predict falls for community-dwelling older people [8]. Gait speed over 5 m [9] and the Timed Up and Go test (TUG) [10] were measured. Activity was assessed with the Human Activity Profile Adjusted Activity Score (HAPAAS), [11] and FIM™ [12] was used as a measure of functional independence. Checklists were completed for falls prevention strategies in place and planned use of health and support services.

Statistical analysis

Comparisons were made between groups using *t*-tests for continuous data and χ^2 for categorical data with PASW 18.0 software (alpha = 0.05, two-tailed for significance).

Ethics approval

Relevant human research ethics committees approved the study. Information and consent forms were interpreted in each participant's preferred language and participants or next of kin provided written consent.

Results

Participant characteristics

Twenty stroke survivors who had LEP (LEP group) and 136 stroke survivors who were proficient in English (EP group) were assessed a mean of 15 days (SD 11) following discharge from rehabilitation. In the LEP group, nine languages were spoken: Croatian (1), Greek (1), Hakka (1), Italian (7), Macedonian (2), Mandarin (2), Russian (1), Spanish (1), and Vietnamese (4). Six participants with LEP used a professional interpreter during assessment and 14 used an informal interpreter; either a partner (4) or adult relative (10). There were no significant differences on any demographic characteristics except for living arrangements (Table 1). The larger than expected number in the category 'living with family' for the LEP group contributed greatest to this difference (standardised residual 3.9). No more than one of the LEP group (5%) and five of the EP group (9%) had missing data.

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Falls risk and falls risk factors

The mean total FROP-com score was significantly higher for the LEP group (Table 2) indicating higher falls risk [8].

Table 1. Participant characteristics

	LEP group ($n = 20$)	EP group ($n = 136$)	*P*-value
Age, mean years (SD)	70.35 (10.49)	71.71 (10.64)	0.593
Gender, female (%)	9 (45.0)	48 (35.3)	0.400
Type of stroke[a] (%)			
Haemorrhage/subarachnoid	2 (10)	26 (19.1)	
Infarct	17 (85)	107 (78.7)	
Unknown	1 (5)	3 (2.2)	
Marital status (%)			
Married/defacto	15 (75)	84 (62.2)	
Single/widowed/divorced (%)	5 (25)	51 (37.8)	0.267
Living arrangement (%)			
Alone or with partner	8 (40)	116 (85.3)	
With family	12 (60)	20 (14.7)	<0.001
Length of stay			
Acute, mean days (SD)	20.15 (15.29)	18.35 (19.80)	0.698
Rehabilitation, mean days (SD)	46.00 (29.27)	54.59 (35.35)	0.303
FIM™ total score (SD)	101.6 (18.6)	108.1 (16.3)	0.103

[a]χ^2 not reported as more than 20% of cells contain frequency <5.

However, inspection of individual components of the FROP-com revealed that the LEP group had lower scores on the Abbreviated Mental Test Score (AMTS) component. Concerned that the AMTS may have been subject to cultural bias, [13] FROP-com scores were re-analysed with the AMTS removed and the resultant difference between groups was no longer statistically significant (Table 2). Diabetes (LEP 10/50%, EP 36/26.7%, χ^2, $P = 0.033$) and dizziness (LEP 9/45%, EP 30/22.1%, χ^2, $P = 0.027$) were more prevalent in the LEP group. A significantly greater percentage of participants with LEP reported needing assistance with activities of daily living (Table 2). The LEP group's activity levels (HAPAAS) were significantly lower and they were slower on gait speed and TUG (Table 2).

Falls prevention strategies

Both groups averaged between seven and eight falls prevention strategies in place by the time of assessment (LEP 7.4, EP 8.0). Significantly less of the LEP group reported exercising at home or in the community (LEP 11/55.0%, EP 106/77.9%, χ^2, $P = 0.027$). There was no significant difference between groups for other strategies. Please see figure in

Table 2. Differences in falls risk, falls risk factors, falls prevention strategies and planned health and support service use between groups

	LEP group ($n = 20$)	EP group ($n = 136$)	*P*-value
FROP-com			
Total score (SD)	23.8 (3.8)	21.4 (6.0)	0.021
Total score without AMTS component (SD)	22.6 (3.7)	20.9 (5.8)	0.105
Components of FROP-com			
Falls history			
Fell in 12 months prior to stroke (%)	5 (25)	42 (30.9)	0.592
Fell during inpatient stroke care (%)	10 (50)	60 (44.4)	0.641
AMTS (SD)	6.9 (2.1)	8.6 (1.9)	<0.001
Number of prescription medications (SD)	7.1 (3.5)	7.0 (3.1)	0.893
Number of chronic conditions associated with falls (SD)	3.4 (1.4)	3.4 (1.5)	0.894
Function (%)			
Uncorrected visual deficit limits functional ability	9 (45)	53 (39.3)	0.625
Uncorrected somatosensory deficit limits functional ability	7 (35)	48 (36.1)	0.925
Requires assist with activities of daily living	14 (70)	56 (41.8)	0.018
Requires assist with instrumental activities of daily living[a]	20 (100)	124 (92.5)	
Home environment has hazards	8 (40)	68 (50.7)	0.511
Feet and footwear (%)			
Foot problems, e.g. bunions	8 (40)	49 (36.3)	0.749
Inappropriate footwear	7 (35)	38 (28.3)	0.542
Nutritional status (%)			
Weight loss ≥3kg	12 (60)	47 (34.8)	0.03
Incontinent	5 (25)	36 (26.7)	0.875
Gait and physical activity			
5-m walk, mean speed m/min (SD)	22.5 (14.6)	33.4 (18.5)	0.013
TUG, seconds (SD)	38.0 (21.3)	26.1 (16.9)	0.006
Step test (worst performance), no. steps (SD)	2.9 (3.0)	3.8 (3.8)	0.277
HAPAAS (SD)	17.3 (9.3)	27.4 (13.4)	<0.001
Total number of falls prevention strategies in place	7.4 (2.7)	8.0 (1.9)	0.389
Total number of services provided in community	3.7 (2.0)	3.8 (1.6)	0.621
Total number of services provided in home	2.0 (1.1)	2.7 (1.8)	0.013

[a]χ^2 not reported as more than 20% of cells contain frequency <5.

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Supplementary data available in *Age and Ageing* online, Appendix 1.

Planned health care and support service use

Participants with LEP planned to access, or had accessed, significantly fewer services in the home (Table 2). The use of home help was the only individual service significantly different between groups (LEP 2/10%, EP 60/44%, χ^2, $P = 0.004$). An occupational therapist visit was the most reported service provided in the home (LEP 14/70%, EP 110/80.9%) and a visit to the local doctor was the most reported community service in both groups (LEP 17/85%, EP 112/82.45%). A physiotherapist visit was planned by at least half the participants of both groups (LEP 10/50%, 93/68.4%). Day centres were accessed least in both groups (LEP 0, EP 2/1.5%). Please see table in Supplementary data available in *Age and Ageing* online, Appendix 2.

Discussion

This is the first study to explore the relationship between English language proficiency, falls risk and falls prevention. The number of languages spoken in this sample is reflective of the linguistic diversity in many ageing multicultural communities. Worse gait and balance ability, lower reported activity levels, and a greater need for assistance with activities of daily living suggest that stroke survivors with LEP at risk of falling may be going home frailer than EP stroke survivors. The acceptance of fewer services in the home by the LEP group and a higher proportion living with extended family imply that informal carers are 'filling the gap' in services for this group. The primacy of family in the home care of older ethnic people has been reported, [14] but assumptions of cultural expectation may mask language and practical difficulties. Health professionals can support informal carers of people with LEP by ensuring they have adequate training and access to support services.

The local doctor was the main health care contact for most participants. This concurs with research exploring the falls risk information needs of Chinese–Australians [15]. The moderately high level of physiotherapy reported by both groups supports the uptake of allied health professionals for the community management of falls risk after stroke. The significantly lower proportion of participants with LEP exercising is a concern for both overall stroke recovery and falls risk management in this group. People with LEP are reported to be less likely to follow recommendations for treatment [1] and engage in less healthy exercise behaviours [16]. Increasing exercise participation by stroke survivors with LEP warrants further clinical and research attention.

The study is limited by small numbers in the LEP group and *post hoc* analysis. Despite interpreting all assessment tools, the use of informal interpreters by some may have affected the accuracy of translation and some self-report measures may not always have been culturally appropriate [13]. Conceptual and functional equivalence of self-report measures needs to be considered when selecting falls risk tools for research with multicultural communities, a significant challenge when many languages are represented [17].

In conclusion, this study was the first step in investigating falls risk and falls prevention for people with LEP. Findings suggest that LEP may have an effect on falls risk and health service use after stroke for people at risk of recurrent falls. Further research is needed to demonstrate the effect in a larger sample and to understand why these differences may exist.

Key points

- LEP may affect the pattern of falls risk and service use for people with high falls risk after stroke.
- Extended families are important for the falls risk management of stroke survivors with LEP.
- Falls risk evaluations in multicultural communities must consider the cultural appropriateness of included measures.

Conflicts of interest

None declared.

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Supplementary data

Supplementary data mentioned in the text is available to subscribers in *Age and Ageing* online.

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Factors that differentiate level of ambulation in hospitalised older adults

SIR—The adverse effects of low mobility in older hospitalised persons are well documented [1, 2]. The amount of time patients are limited to a bed or chair is an independent predictor of functional decline even after controlling for illness severity [3]. Ambulation is a potentially simple intervention to reduce low mobility in-hospital. A number of factors, however, can interact to influence how much a patient actually walks. Identifying factors associated with varied levels of ambulation would help clinicians identify older patients at risk for low levels of mobility. Although, previous studies have investigated perceived barriers to ambulation during hospitalisation from the perspectives of older patients and their primary nurses and physicians [4], no study has examined relevant factors using direct measures of ambulatory activity such as step counts.

We recently demonstrated that accelerometer technology can be used to collect continuous information on patient mobility in hospitalised older persons [5]. For this study, our objective was to identify subgroups of patients with shared clinical profiles who differed with respect to mean daily ambulation.

Methods

A cohort of patients 65 years and older admitted to an Acute Care for Elders (ACE) unit at a university teaching hospital was studied. A Step Activity Monitor (SAM) was worn by all patients from admission to discharge. Data were collected over a 5-month period in 2009; eligible patients included those 65 years or older of either gender. Patients were excluded for active bilateral lower leg infection, severe lower leg oedema, bilateral lower extremity amputations, terminal illness (i.e. admitted on a hospital contract) or severe agitation. Only patients with at least two complete 24-h days in-hospital were included in the analysis. The final sample included 198 patients. The study received approval from the University Institutional Review Board.

Assessment of ambulation

The SAM is a pager sized accelerometer worn around the ankle using a Velcro strap [6–9]. It provides no feedback to the wearer and is impervious to tampering. Total daily steps were determined for each patient and defined as the number of stride counts recorded by the monitor per 24-h (midnight-to-midnight) day multiplied by two.

Outcome

A mean daily steps metric was calculated for each patient based on the number of complete 24-h days the SAM was worn.

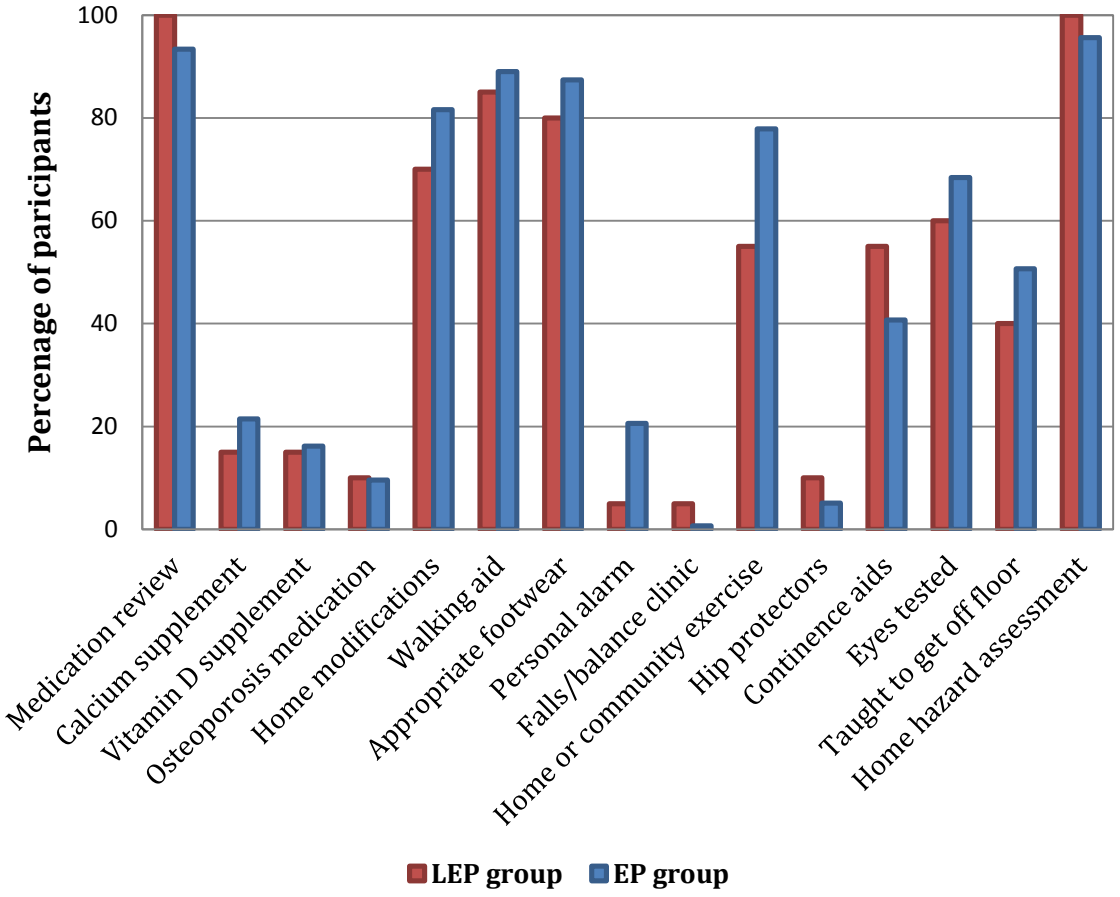
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Appendix B: Participant characteristics from randomised controlled trial

	LEP group[a] (*n*=20)	**EP group[b] (*n*=136)**	**Statistical test**	***P* value**
Age, years, mean (SD[c])	70.35 (10.49)	71.71 (10.64)	t-test	0.593
Gender, female, number of participants	9 (45.0%)	48 (35.3%)	X^2	0.400
Marital status, number of participants				
Married/defacto	15 (75%)	84 (62.2%)		
Single/widowed/divorced	5 (25%)	51 (37.8%)	X^2	0.267
Living arrangement, number of participants				
Alone or with partner	8 (40%)	116 (85.3%)		
With family	12 (60%)	20 (14.7%)	X^2	<0.001
Length of stay in healthcare, days, mean (SD)				
Acute	20.15 (15.29)	18.35 (19.80)	t-test	0.698
Rehabilitation	46.00 (29.27)	54.59 (35.35)	t-test	0.303
Functional Independence Measure, mean (SD)	101.6 (18.6)	108.1 (16.3)	t-test	0.103

[a]LEP group = limited English proficient group, [b]EP group = English proficient group, [c]SD = standard deviation

Appendix C: Percentage of participants from randomised controlled trial who had falls and injury prevention strategies in place



Appendix D: Differences in use of services between participant groups in randomised controlled trial

Service	LEP group	EP group	X^2 *P*-value
Provided in the home			
Community aged care package	4 (20%)	33 (24.3%)	0.675
District nursing services	4 (20%)	25 (18.4%)	0.862
Doctor home visit	3 (15%)	26 (19.1%)	0.659
Home help	2 (10%)	60 (44.1%)	0.004
Home rehabilitation	2 (10%)	30 (22.1%)	0.212
Meals on wheels	1 (5%)	22 (16.2%)	0.188
Occupational therapist home visit	14 (70%)	110 (80.9%)	0.260
Personal care	3 (15%)	34 (25%)	0.326
Post acute care services	4 (20%)	12 (8.8%)	0.124
Respite care	2 (10%)	13 (9.6%)	0.950
Provided in the community			
Community rehabilitation	12 (60%)	54 (39.7%)	0.086
Day centre	0	2 (1.5%)	0.584
Dietitian appointment	4 (20%)	29 (21.5%)	0.880
Doctor appointment	17 (85%)	112 (82.4%)	0.770
Falls and balance clinic	1 (5%)	4 (2.9%)	0.625
Group exercise	2 (10%)	12 (8.9%)	0.871
Outpatient appointment	9 (45%)	83 (61%)	0.174
Pharmacist	12 (60%)	66 (48.5%)	0.338
Physiotherapist appointment	10 (50%)	93 (68.4%)	0.105
Podiatrist appointment	6 (30%)	65 (47.8%)	0.136

Appendix E: Published article, "Qualitative studies using in-depth interviews with older people from multiple language groups: methodological systematic review"

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REVIEW PAPER

Qualitative studies using in-depth interviews with older people from multiple language groups: methodological systematic review

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FRYER C., MACKINTOSH S., STANLEY M. & CRICHTON J. (2012) Qualitative studies using in-depth interviews with older people from multiple language groups: methodological systematic review. *Journal of Advanced Nursing* 68(1), 22–35.
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Abstract

Aim. This paper is a report of a methodological review of language appropriate practice in qualitative research, when language groups were not determined prior to participant recruitment.

Background. When older people from multiple language groups participate in research using in-depth interviews, additional challenges are posed for the trustworthiness of findings. This raises the question of how such challenges are addressed.

Data sources. The Cumulative Index to Nursing and Allied Health Literature, Scopus, Embase, Web of Science, Ageline, PsycINFO, Sociological abstracts, Google Scholar and Allied and Complementary Medicine databases were systematically searched for the period 1840 to September 2009. The combined search terms of 'ethnic', 'cultural', 'aged', 'health' and 'qualitative' were used.

Review methods. In this methodological review, studies were independently appraised by two authors using a quality appraisal tool developed for the review, based on a protocol from the McMaster University Occupational Therapy Evidence-Based Practice Research Group.

Results. Nine studies were included. Consideration of language diversity within research process was poor for all studies. The role of language assistants was largely absent from study methods. Only one study reported using participants' preferred languages for informed consent.

Conclusion. More examples are needed of how to conduct rigorous in-depth interviews with older people from multiple language groups, when languages are not determined before recruitment. This will require both researchers and funding bodies to recognize the importance to contemporary healthcare of including linguistically diverse people in participant samples.

Keywords: cultural diversity, interviews, language barriers, older people, qualitative research, systematic review

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Introduction

International migration and the ageing of populations have created a growing need for healthcare research to address issues relevant to contemporary older multicultural communities. The proportion of older people from minority ethnic groups has been projected to increase significantly over the next few decades in Australia (Gibson *et al.* 2001), England and Wales (Lievesley 2010), Canada (Durst 2005) and the United States of America (USA) (Vincent & Velkoff 2010). Ethnic health inequalities have been well described for numerous health conditions (Green *et al.* 2003, Sheikh & Griffiths 2005, Minor *et al.* 2008, Danielson *et al.* 2010) and treatments (Shavers & Brown 2002, Hall-Lipsy & Chisholm-Burns 2010). The challenge for health researchers is to recognize this growing need and include older people who do not share the same preferred language(s) as the researcher or research team in participant samples.

The decision to include people from multiple language groups in a qualitative study sample is influenced by ethical considerations of fair access to participation in research and the benefits of research (National Health and Medical Research Council, Australian Research Council & Australian Vice-Chancellors' Committee 2007), policies of funding institutions (Corbie-Smith *et al.* 2006), research interests relevant to people from multiple language groups e.g. limited English proficiency, and consideration of the multicultural diversity of the aged community where research findings are to be applied.

Despite these strong incentives, published qualitative health research includes few examples of participant samples of older people from multiple language groups. This may be attributed to the research challenge being too great (Adamson & Donovan 2002, Mabel 2006), poor access to linguistic expertise, or a lack of financial resources. The lack of linguistically diverse participant samples acutely limits the relevancy and application of new health knowledge to contemporary multicultural communities. If researchers were more aware of how to overcome the challenges of conducting in-depth research with participants who do not share the same language, it may prevent these older people from being routinely excluded from research participation.

Including people from multiple language groups in a qualitative study, when the languages spoken are not determined before starting the research, is a unique situation in qualitative cross-language studies and clearly different from the traditional anthropological ethnography of one cultural group with established discrete languages. It restricts a researcher's ability to immerse in a single culture and its language(s) or to have sole reliance on the language skills of research team members. Engaging people from multiple language groups in qualitative research has been successfully demonstrated in healthcare using focus group methodology (Garrett *et al.* 2008). Yet there are few published examples of how researchers can conduct, and ensure the rigour of information produced by, in-depth interview research with participants who speak several different languages when the languages are not determined prior to the start of research.

Qualitative researchers endeavour to 'make sense of, or interpret, phenomena in terms of the meanings people bring to them' (Denzin & Lincoln 2005, p. 3) to understand how they make sense of their world from their point of view. The capability of qualitative research to access complex worlds has been identified as a promising approach to understanding the lives of minority ethnic older people (Matsuoka 1993). In-depth interviews are a tool of qualitative inquiry that use open-ended questions and probes to gain in-depth responses about peoples' experiences, perceptions, opinions, feelings and knowledge (Patton 2002). Through interviews, the researcher attempts to understand what the participant means by what they say. Yet, 'it is only through knowing what they say that we (researchers) can begin to address the question of what they mean' (Mishler 1986, p. 51).

Language is a fundamental tool for in-depth interviews; representing both the data and the communication process by which data is generated between the researcher and participant (Hennink 2008). Language carries particular meanings that incorporate a person's values and beliefs (Temple & Edwards 2002) and is a means for bridging the interpretive gap between participant and researcher to gain a better understanding of the phenomenon under study (Sarangi 2007). When the researcher and participant do not share a preferred language there is extra complexity and challenge in the research process to ensure the quality and trustworthiness of interview data and its interpretation. As Patton (2002, p. 392) has stated, 'It is tricky enough to be sure what a person means when using a common language, but words can take on a very different meaning in other cultures'. This does not mean it should not be, or cannot be, undertaken. However, it does mean a 'critical awareness' of related methodological issues needs to be achieved (Mabel 2006).

Methodological rigour is the means by which researchers show 'integrity and competence' in their research (Tobin & Begley 2004) and so enhance the usability of the research findings for readers (Sandelowski 2004). It incorporates Lincoln and Guba's (1985) idea of 'trustworthiness' and the constructs of credibility, transferability, dependability and confirmability; where methodological rigour is not simply a judge at the end of the research but is attended to throughout the research process (Morse *et al.* 2002). Hennink (2008,

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p. 22) has suggested that to improve methodological rigour in cross-cultural (and cross-language) qualitative research, 'greater attention is needed towards embracing language and communication issues throughout the entire research process'. This encompasses acknowledgement of the role and influence of language assistants within the process (Temple 1997, 2002, Edwards 1998, Larkin *et al.* 2007, Hennink 2008) and greater transparency of the strategies used and decisions made by researchers (Larkin *et al.* 2007, Hennink 2008). To date, it appears that the strategies used by researchers when the languages spoken by participants are not determined prior to the start of recruitment have not been properly explored.

The review

Aim

The aim was to undertake a methodological review of language appropriate practice in qualitative healthcare studies with older people from multiple language groups that used in-depth interviews and did not determine languages prior to recruitment. The objectives of the review were: (1) to appraise the quality of study methods and (2) determine the strategies used to ensure methodological rigour.

Design

A systematic review of study methods, similar to the meta-method study explicated by Paterson *et al.* (2001), was employed. Each study was individually appraised for quality and then an overall comparison and contrast of methods was completed. Paterson *et al.* (2001, p. 72) recommend the meta-method design to 'reflect critically on how qualitative research methods have been applied during a specific period of time and in relation to a specific question or issue'. This review applied the same procedures of study appraisal and comparison to reflect critically on how in-depth interviews have been applied in qualitative research with a specific population, i.e. linguistically diverse older people.

In the absence of published guidance on the reporting of systematic reviews of qualitative research, the reporting of this review was guided by the PRISMA statement (Moher *et al.* 2009) specifically following its recommendations for review introduction (rationale and objectives), methods (eligibility criteria, information sources, search, study selection, data collection process, data items, risk of bias in individual studies), results (study selection, study characteristics, risk of bias within studies), and discussion (summary of evidence, limitations, conclusions). The concept of 'risk of bias' as used in the PRISMA statement was interpreted for the purpose of this qualitative review as the appraisal of trustworthiness for individual studies (see supporting information Figure S1 in the online version of the article in Wiley Online Library).

Search methods

Nine electronic databases were searched for references for the period 1840 to September 2009: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus (including all Medline titles), Embase, Web of Science, Ageline, PsycINFO, Sociological abstracts, Google Scholar and Allied and Complementary Medicine (AMED). A limit was not placed on the years searched for each database to enable the broadest capture of papers for comparison; however no records published prior to 1991 were identified for consideration of eligibility. The search used keywords 'ethnic*'or 'cultural*' and 'aged' or 'old*' or 'elder*', combined with the keywords 'qualitative' and 'health'. The exact search terms and search limiters differed between databases due to the availability of search options (see supporting information Table S1 in the online version of the article in Wiley Online Library). Broad search terms were used to ensure that all studies meeting the inclusion criteria were captured in initial searches.

Inclusion/exclusion criteria

Studies were included in the review if they met the following criteria:

- Participants included at least one person aged 60 years or older.
- Participants included at least two people who preferred to speak a language that was different to each other and was not the native language of the country in which the research was conducted.
- Languages spoken by participants were not determined prior to the start of the research.
- In-depth individual interviews were used for data collection.
- Investigated topic was relevant to healthcare.
- Published in the English language in a peer-reviewed journal.

If the specific languages spoken by participants were not stated, the study was still eligible for inclusion provided it was clear that more than one non-native language had been spoken by participants e.g. if the country or region of the languages was given.

Papers which reported using close-ended questionnaires or surveys for data collection were excluded from this qualita-

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tive review. If the age of participants or number of non-native languages spoken by participants could not be determined from a reading of the full paper then it was excluded. Papers which reported other data collection processes and in-depth interviews were included and only methodology associated with the in-depth interviews was abstracted and appraised.

One reviewer (CF) conducted the database searches, screened titles and abstracts, and removed irrelevant papers. Full texts of potentially relevant articles were independently appraised by two reviewers (CF and SM, or CF and MS) using the 'Critical Review Form for Qualitative Interview Studies with a Multilingual Sample' (see supporting information Figure S1 in the online version of the article in Wiley Online Library). Any disagreements about study inclusion or appraisal were discussed and resolved through consensus of the reviewers.

Search outcome

Searches yielded 7539 potentially relevant records, from which 211 full text articles were retrieved and considered for inclusion in this review (Figure 1). From the 211 retrieved articles, nine satisfied the inclusion criteria and were critically appraised. The flow diagram for the review process and reasons for exclusion of 202 articles are given in Figure 1. Twenty-seven potentially relevant studies did not give enough detail to establish if at least two non-native languages had been spoken by participants.

Quality appraisal and data abstraction

Data abstraction and quality appraisal of studies were undertaken in parallel and guided by the McMaster University Occupational Therapy Evidence-Based Practice Research Group's protocol for the critical review of qualitative research (Letts *et al.* 2007a, 2007b). The protocol's Critical Review Form (Letts *et al.* 2007a) was adapted for the objectives of this review by incorporating recommendations from the literature for conducting cross-language qualitative research using in-depth interviews (see supporting information Figure S1 in the online version of the article in Wiley Online Library). Recommendations consisted of expert opinions based on their own experiences conducting cross-language research with single or multiple language groups

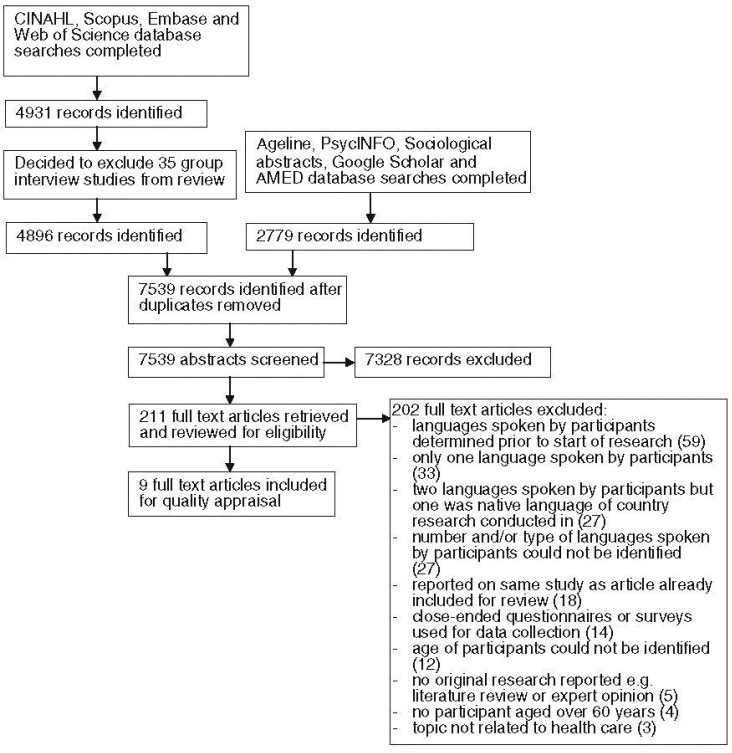


Figure 1 Flowchart of literature search strategy and results.

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and one relevant literature review (Wallin & Ahlström 2006). All sources of literature recommendations are identified and referenced on the Critical Review Form (see supporting information Figure S1 in the online version of the article in Wiley Online Library).

Data on study purpose, literature, design, sampling, data collection, data analyses and overall rigour were sought for the review (see supporting information Figure S1 in the online version of the article in Wiley Online Library).

Full texts of all nine studies included in the review were independently appraised by two reviewers (CF and SM, or CF and MS). Only published information was appraised. The quality appraisal of each paper was discussed between reviewers and any disagreements in appraisal were resolved through consensus of the reviewers.

The quality appraisal of each study was summarized in a table and grouped according to methodological process. One reviewer (CF) compared and contrasted the individual quality appraisals to identify themes and patterns in research process and rigour. The overall appraisal was then discussed among the three reviewers (CF, SM and MS) on several occasions to ensure credibility of the findings and to summarize the appraisal in a narrative manner. A summary of the quality appraisal of the nine included studies specifically relevant to cross-language research methodology is given in Table 2.

Data abstraction was undertaken independently by two reviewers (CF and SM, or CF and MS) and checked between reviewers. Any disagreements were discussed and resolved through consensus of the reviewers.

Results

Characteristics of included studies

The nine included studies were conducted in four countries with established and growing immigrant populations (Table 1). At least 12 different languages are represented across the sample groups. A strong focus on a single minority language group, Spanish, in cross-language healthcare research from the USA meant that no studies from this country met the review's inclusion criteria of at least two languages spoken that were not native to the country in which the research was conducted.

The areas of health care investigated by the included studies represent areas of relevance and concern to older people: cancer (Papadopoulos & Lees 2004, Manderson *et al.* 2005); chronic heart failure (Pattenden *et al.* 2007); home and respite care (Mackinnon *et al.* 1996, Netto 1998, Brotman 2003); mental health (Franks *et al.* 2007); pain (Löfvander *et al.* 2007) and quality of life (Moriarty & Butt 2004).

Table 1 Profile of included studies

Study	Mackinnon *et al.* (1996)	Netto (1998)	Brotman (2003)	Moriarty & Butt (2004)	Papadopoulos & Lees (2004)	Manderson *et al.* (2005)	Franks *et al.* (2007)	Löfvander *et al.* (2007)	Pattenden *et al.* (2007)
Country	Canada	UK	Canada	UK	UK	Australia	UK	Sweden	UK
Languages spoken by participants	Chinese dialects	From Afro-Caribbean, Bangladeshi, Chinese, Indian, Pakistani and other Asian ethnic groups	From Black, Chinese, Greek, Italian, and South Asian origins	Chinese, English, Gujarati, Hindi, Punjabi, Urdu	English, Greek, Sylheti	From Asia, Europe, Middle East, North America and the Pacific	From Africa, Britain, Eastern Europe, Portugal and South America	Arabic, Swedish, Sorani, Turkish, Urdu	English, Gujerati, Punjabi
Purpose	Describe experiences of Chinese elders cared for by their families	Investigate the need for, and use of, respite by carers of ethnic older people	Examine the work processes of an organization which provides elder care	Look at inequalities in quality of life among people from different ethnic groups	Explore meanings and experiences of cancer for men from different ethnic groups	Explore how immigrant and Australian women explain the onset of gynaecological cancer	Determine barriers to access mental health services by refugees, asylum seekers and migrant workers	Explore the main features and concepts of pain among immigrant and Swedish patients	Understand experiences and needs of a diverse group with chronic heart failure

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Table 2 Quality appraisal of included studies

Study	Mackinnon *et al.* (1996)	Netto (1998)	Brotman (2003)	Moriarty & Butt (2004)	Papadopoulos & Lees (2004)	Manderson *et al.* (2005)	Franks *et al.* (2007)	Löfvander *et al.* (2007)	Pattenden *et al.* (2007)
Study design stated	✔	x	✔	x	✔	x	✔	x	x
Theoretical perspective identified	x	✔	✔	✔	✔	✔	✔	x	✔
Cultural appropriateness of theoretical perspective considered	NS	NS	✔	✔	NS	NS	✔	NS	NS
Sampling									
Purposive sampling strategy described	✔	✔	✔	✔	✔	✔	✔	✔	✔
Strategy appropriate to language profile of community	NS	NS	NS	NS	✔	NS	NS	✔	✔
Recruitment in preferred language	x	NS	✔	NS	NS	NS	NS	NS	x
Informed consent in preferred language	NS	NS	✔	NS	NS	NS	NS	NS	NS
Data collection									
Clear and complete description of:									
site	✔	x	✔	x	x	x	✔	✔	✔
participants	x	x	x	x	✔	x	x	✔	Patients ✔ carers x
language assistants	x	x	✔	x	x	x	x	x	x
role of researcher	x	x	x	x	x	x	x	x	x
role of language assistants	x	x	✔	x	x	x	x	x	x
data collection procedures	x	x	x	x	x	x	x	x	x
Cultural sensitivity demonstrated	✔	x	x	✔	x	x	✔	x	x
Language assistants									
Bilingual researcher/s (professional)	x ✔	x ✔	x x	x x	✔ x	x x	x x	x ✔	✔ ✔
Interpreter/s									
Trained bilingual non-professional/s	x	x	✔	✔	x	x	x	x	x
Family member/s	x	x	x	x	✔	x	x	x	x
Not stated	x	x	x	x	x	✔	✔	x	x
No. of assistants/language	NS	NS	NS	NS	2	NS	NS	NS	2
Training provided	✔	NS	NS	NS	NS	NS	NS	NS	NS
Debriefs conducted	x	NS	x	NS	NS	NS	NS	NS	NS
Interviews in preferred language	Some	Some	✔	✔	✔	✔	Some	✔	✔
Performance of bilingual interviewers monitored	N/a	N/a	NS	NS	NS	NS	NS	N/a	NS
Language group involved in developing interview guide	NS	NS	NS	NS	NS	NS	NS	NS	NS
Agreed translation of interview guide	✔	NS	NS	✔	NS	NS	NS	NS	NS
Interview guide pilot tested	x	x	✔	✔	x	x	x	x	x
Standardized translation of interviews	NS	NS	NS	NS	NS	NS	NS	NS	✔

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Table 2 (*Continued*)

Study	Mackinnon *et al.* (1996)	Netto (1998)	Brotman (2003)	Moriarty & Butt (2004)	Papadopoulos & Lees (2004)	Manderson *et al.* (2005)	Franks *et al.* (2007)	Löfvander *et al.* (2007)	Pattenden *et al.* (2007)
Interview translations monitored for quality	x	x	x	x	x	x	x	x	x
Researcher reflexivity	x	x	x	x	x	x	x	x	x
Language assistant reflexivity	x	x	x	x	x	x	x	x	x
Data analysis									
Clear and complete description	✔	x	✔	x	✔	✔	✔	x	✔
Language group involved	x	x	x	x	x	x	x	x	x
Decision trail reported	x	x	x	x	x	x	✔	x	x
Findings consistent with data	x	x	✔	x	x	✔	✔	✔	✔
Meaningful picture provided	x	x	✔	✔	x	✔	x	x	✔
Evidence of:									
credibility	x	x	✔	x	x	x	x	x	✔
transferability	x	x	x	x	x	x	x	✔	✔
dependability	x	x	x	x	x	x	✔	x	x
confirmability	✔	x	x	x	x	x	✔	x	x

✔, appraisal item completed in the study; 'x', study's authors have explicitly stated reasons for not doing it; NS, item was 'not stated'.

Study design

Four of the nine studies described their study design: qualitative exploratory (Mackinnon *et al.* 1996); case study (Papadopoulos & Lees 2004); institutional ethnography (Brotman 2003); and grounded theory (Franks *et al.* 2007). The remaining five studies appeared to be a qualitative descriptive design, however, this was not made explicit in the text. A theoretical research perspective was provided by most studies (7/9). The cultural appropriateness of the perspective relevant to the research question and study sample was only addressed by three of these papers: Moriarty and Butt (2004) introduced 'racism' to the quality of life model they used; the standpoint of older ethnic women was privileged by Brotman (2003) in her institutional ethnography; and Franks *et al.* (2007) considered the context of an immigrant study population in their community psychology perspective.

All studies used purposive sampling strategies including maximum variation, convenience, snowball and theoretical. Only Brotman (2003) stated that participants' preferred languages were used during recruitment. Two studies reported that recruitment was conducted in the native language of the country in which the research was conducted in (Mackinnon *et al.* 1996, Pattenden *et al.* 2007). The remaining six studies did not clarify the language spoken when recruiting participants. Three studies explicitly stated informed consent was obtained from participants (Brotman 2003, Manderson *et al.* 2005, Pattenden *et al.* 2007), however, only one study confirmed that it was obtained in the preferred language of participants (Brotman 2003).

Data collection

Descriptions of data collection contexts and processes were limited in most studies. Clear descriptions of the study site were given in five studies; of the participants in three studies; and of the language assistants in one study (Table 2). Four studies lacked a clear language profile of participants, instead listing the geographical region associated with the participant's country of birth or language (Brotman 2003, Manderson *et al.* 2005, Netto 2006, Franks *et al.* 2007). The role of research team members, their previous experience with the research topic and their relationship to participants were not clarified in any study. The role of language assistants was only given by Brotman (2003) in Canada who trained members of participants' indigenous communities to assist with recruitment, data collection and data translation. However, the relationship between the language assistants and participants within their indigenous community was not described.

Three studies demonstrated cultural sensitivity in their data collection using processes such as acknowledging how each Chinese elder participant chose to culturally identify themselves (Mackinnon *et al.* 1996), asking participants their own definition of ethnicity and what ethnicity meant to them (Moriarty & Butt 2004) and forming a research advisory

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group with members of the local participant communities to guide their research decision-making (Franks *et al.* 2007).

Language assistants were involved in each of the included studies. Professional interpreters were most commonly used (four studies), then bilingual researchers (two studies) and trained bilingual non-professionals e.g. community members (two studies). Two studies did not identify who the language assistants were. A family member gave language assistance for an interview in the study by Papadopoulos and Lees (2004). In their discussion, the authors noted concerns about family members being used as language assistants in medical situations, however, the same authors gave no reflection on their own use of a family member as a language assistant in the research. The number of language assistants involved in the research was stated in only two studies, both using two assistants. Research training was given to language assistants in three studies. Debriefs between language assistants and researchers were either not conducted (two studies) or not stated (seven studies). Performance monitoring was not mentioned in the two studies which used trained bilingual interviewers.

By the nature of the inclusion criteria for this review, all the studies used multiple languages during the research, however, three studies did not clarify if participants' preferred languages were always used during interviews, e.g. Netto (1998) used interpreters 'where necessary'. Both Mackinnon *et al.* (1996) and Moriarty and Butt (2004) obtained an agreed translation of their interview guide across different language groups. It was interesting that despite this, Mackinnon *et al.* (1996) noted that the interpreters experienced difficulty in translating the word 'happy' in the context of one question and postulated this may have influenced the participants' lack of response to the question. Only two studies pilot tested their interview guide and only one of these confirmed the guide was pilot-tested with older people who spoke different languages (Table 2).

No evidence of reflexivity on the part of researchers or language assistants in the research was given by any of the included studies yet probable influences on the research findings were occasionally disclosed. Mackinnon *et al.* (1996) noted that findings from their study of older Chinese people did not agree with the beliefs of the young interpreters involved in the study but the authors did not reflect on how this disagreement may have affected the translation of participants' statements by the young interpreters. In another example, Papadopoulos and Lees (2004) used a participant's daughter as a language assistant for his interview about the meanings and experiences of his cancer without the authors' acknowledging how this may have affected the information provided by either party. And Netto (1998) introduced her study by locating it in 'the cultural insensitivity of the current service provision' without providing reference for her negative judgement of the health system or explanation of how this belief may have influenced her research.

Data analyses

As regards analytical procedures, six studies gave a clear and complete description of how they analysed interview data (Table 2). Involvement of people from participant language groups in the analysis of data was not mentioned by any authors. Findings were consistent with the presented data for six studies with the remaining three studies lacking explanatory data to support their conclusions. A meaningful picture of the phenomenon under study, i.e. a description of the theoretical concepts, relationships between concepts and integration of relationships among meanings that emerged from the data (Letts *et al.* 2007b), were provided by four of the nine studies (Table 2). The remaining five studies lacked clear integration of their key concepts which limited the reader's ability to gain a meaningful overall picture of study findings.

Overall rigour

No study met all four constructs of trustworthiness (Lincoln & Guba 1985). Two studies enabled transferability of their findings by providing clear descriptions of the research site and participants. Three of the remaining studies (Mackinnon *et al.* 1996, Brotman 2003, Manderson *et al.* 2005) lacked transferability because of inadequate description of the languages spoken by participants despite inclusion of other demographic information. Both Brotman (2003) and Pattenden *et al.* (2007) demonstrated the credibility of their research using a combination of several strategies including the collection of data in participants' preferred language, using prolonged observation, standardizing transcription and coding procedures, including negative cases, undertaking peer review and triangulating data sources and the research team. Confirmability of research findings was demonstrated by Mackinnon *et al.* (1996) who kept a personal log of observations and key points of their interviews and analytic memos. The research by Franks *et al.* (2007) was the only study to demonstrate both confirmability and dependability, documenting their complete research process as both a reflective tool and audit trail.

Discussion

Review strengths and limitations

It is recognized that including older people who do not speak the same preferred language as the researcher in participant samples is not a simple task (Matsuoka 1993, Adamson &

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Donovan 2002). The strength of this review is its attempt to systematically capture and appraise all reported examples of studies that have used in-depth interviews with older people who speak multiple languages, when languages were not determined prior to recruitment. By drawing on this information, suggestions have been made for achieving optimal practice in this complex research context that is of growing relevance to health researchers.

While this review characterizes the included studies as reflecting deficiencies in the management of language in research process, it needs to be qualified in a number of respects. The review has only appraised what was reported in the published article. Researchers often omit study details due to journal word limits and there is yet to be consensus on the reporting requirements for qualitative research. However, it needs to be recognized that this lack of detail also hinders the reader's ability to independently appraise the rigour and usefulness of the research for application to their own healthcare settings.

The research included in this review was limited to articles published in the English language and studies including older participants. Limiting searches to the English language was determined by time and resource constraints. Excluding articles in other languages could mean that other important insights may not have been obtained. The authors decided to focus on a single generational age group for this study, however, the Critical Review Form and method of review could be similarly applied to a sample of younger adult participants.

Methodological rigour of studies

For the qualitative in-depth interview studies considered in this review, where languages were not determined prior to the start of recruitment, the language diversity of participants in the research process and the methodological rigour of the studies were poorly addressed. This compromises the utility of the research findings for contemporary healthcare (Sandelowski 2004) and gives little contribution to the advancement of research knowledge on how to conduct rigorous in-depth interview studies in this unique multilingual context.

A major threat to rigour in each of the included studies was the absence of any critical reflection on the role of researchers and language assistants. In-depth interviews are recognized in qualitative research as a joint production of knowledge (Mishler 1986), where the generation and interpretation of data is influenced by the participants, the researcher and their relationship (Finlay 2002). Reflexivity is an integral tool for analysing how such 'subjective and intersubjective elements' influence the data and its interpretation (Finlay 2002). This may especially be the case when researcher and participant do not share the same cultural and linguistic background (Adamson & Donovan 2002) and the interpretive gap is widened. Strategies for reflexivity can include maintaining a reflexive journal of the researcher's own perspectives and influence during the study and methodological decisions made (Lincoln & Guba 1985), or writing reflexively when reporting findings (Finlay 2002).

Extending reflexivity to include the role and influence of language assistants in cross-language interviews recognizes that a third person is present in the conversation, bringing their own background and perspectives to the co-creative process (Temple & Edwards 2002, Larkin *et al.* 2007). By limiting the presence of language assistants to brief generic references in the methods or discussion notes, all but one of the included studies appeared to take a more positivist approach of viewing the language assistants as 'neutral conveyors of messages' (Temple 2002, p. 845). This disregards the active role of language assistants in the construction of qualitative interview data and so weakens each study's rigour (Hennink 2008). Cross-language research reflexivity can incorporate 'intellectual autobiographies' of language assistants in methodological discussions (Temple 2002), using a framework as given by Hennink (2008).

Another major threat to study rigour was the lack of recognition of multilingual issues in the analysis of interview data. When researchers are not fluent in the participants' language, 'the use of translated data may compromise the depth of analysis and the credibility of findings' (Irvine *et al.* 2008, p. 41) as subtle but important differences in meaning can be lost (Hennink 2008). Two studies addressed conceptual differences in the formation of interview guides, but no study discussed the potential loss of meaning from translating interview data to a common language (Smith *et al.* 2008) or involved members of the same language group in data analysis (Tsai *et al.* 2004). For studies with participants who are from multiple language groups, it is probable that analysis will occur with data that have been translated to the researcher's preferred language. This has consequences for the credibility of the analysis and the status of the language and its user in the study (Temple & Young 2004). Clarity is needed from researchers as to when the translation occurred, why it occurred and how it was considered in analysis. It is recommended that the role of language assistants is extended to analysis wherever possible (Tsai *et al.* 2004, Hennink 2008). If available resources do not allow a linguistically diverse team to assist with analysis, an extensive debrief with language assistants after data

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Table 3 Framework for best practice when conducting in-depth interviews with participants from multiple language groups

	Recommended practice	Suggested strategies
Study design	Theoretical perspective of the research is culturally appropriate to participants	Consider if research approach can be carried out with multiple languages and cultural groups Consult members of language groups in population of interest when planning research concept and approach
Recruitment	Recruitment materials available in preferred language and bilingual format	Print recruitment material in languages spoken in the population of interest and the main native language Translate materials as needed during recruitment to help manage project costs
	Recruitment methods are appropriate for the population of interest	Consult members of language groups in population of interest when planning recruitment strategies Be flexible in recruitment strategies for different language groups Use verbal recruitment strategies and established networks e.g. community groups, key persons Consider the literacy of participants in recruitment methods
Informed consent	Give study information and consent in participant's preferred language and bilingual format	To help manage project costs, consider interpreting study information orally to reduce the number of written translations required and translate consent form as needed
Data collection	Conduct research interviews in participant's preferred language	Different types of language assistants can be used for different language groups depending on resources available e.g. bilingual researcher or trained research assistant conduct interview, or monolingual researcher conduct interview with real-time interpretation by professional interpreter
	Interview methods are culturally appropriate to participants	Consult members of participant's language group and relevant literature when planning interview Check participant's preferences about language assistant e.g. gender, cultural group Pilot test interview guide with different language groups from population of interest
	Standardize interview guides across language groups	Consult language assistants in development of interview guides; discuss aims of research, purpose and structure of interview and concepts to be used Pilot test interview guides with different language groups from population of interest
	Recognize influence of language assistant on data collection	Use the same language assistant per language group Prepare language assistant for interview; discuss aims of research, purpose and structure of interview and concepts to be used Interview language assistant about their language competency and their experiences and perceptions of study topic and study population Conduct debrief with language assistant after each interview to discuss their impressions of the interview, important concepts that arose and any communication difficulties For bilingual research assistants, provide training in interview technique and conduct performance monitoring
Data analysis	Analyse data in language it was spoken	Prepare translator for the translation of the interview transcript; discuss relevant participant information, aim of research and interview and concepts used
	If not feasible, standardize and monitor the quality of translations of interview transcripts	Use one translator per language group Use of back-translation or second independent translation is unlikely to be economically feasible with multiple translations in multiple languages
	Recognize influence of the language spoken by participant when analysing interview data	Involve language assistants in data analysis; discuss terms and concepts used Use debriefs with the language assistants after interviews to inform the analysis Take findings from interview data analysis back to participants and discuss with them

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Table 3 (*Cotinued*)

	Recommended practice	Suggested strategies
Overall rigour	Transparent reporting of study methods	Give clear, detailed information about participants, researchers, language assistants and research process Report language spoken by participants in demographic information Report the role of researchers and language assistants in all stages of the research process, their language competence, and any relationship they have to participants e.g. community role. For language assistants, report how they were selected
	Practice reflexive research	Maintain a reflexive journal of research practice including how language appropriate practice was approached and conducted Give reflexive accounts of research methods and findings acknowledging the influence of language spoken by participants
Budget considerations	Include estimate of costs of translations and language assistance in research proposals and funding applications	Estimate required resources using the language profile of the population of interest

collection can assist cultural and linguistic interpretation, or study findings can be taken back to participants for feedback (Adamson & Donovan 2002).

Research in a multilingual context poses ethical, and methodological challenges (Edwards 1998, Liamputtong 2008). That eight of the nine studies included in this review did not report the use of participants' preferred languages during recruitment or informed consent raises questions about the ethical conduct of the research. Whereas informed consent gives prospective participants adequate information to make an educated decision about whether or not to participate in the study (Kripalani *et al.* 2008), for people from culturally and linguistically diverse backgrounds, it must take into account how language is understood (National Health and Medical Research Council, Australian Research Council & Australian Vice-Chancellors' Committee 2007) whether presented verbally or in written form (Liamputtong 2008). The potential for misunderstanding during recruitment and consent in cross-language studies also has implications for the credibility of collected data as the words participants use and the stories they tell in interviews are influenced by their relationship with the interviewer (Mishler 1986).

An innovative strategy for data collection when multiple languages are spoken was used by Pattenden *et al.* (2007) who engaged different types of language assistants to capitalize on language resources available i.e. a combination of bilingual researcher and professional interpreter. Rigorous in-depth interview research with older people from multiple language groups when all the languages are not determined prior to recruitment will require such smart uses of language resources to manage the additional expense to the research budget. Larkin *et al.* (2007, p. 473) described it as a careful balancing act of 'maintaining the tension of the weave' between consideration of language issues and research process. To be financially capable of optimal practice in studies with linguistically diverse participant samples, researchers must give an estimate of costs for language resources in funding proposals (Bustillos 2009) and funding bodies need to recognize that the costs are legitimate and necessary to enable research participation for a previously excluded population (Sin 2004, Bustillos 2009). When the languages spoken by participants are not determined prior to recruitment, estimates of required resources can be made using the language profile of the population of interest.

Based on information from the review, recommendations from the literature (see supporting information Figure S1 in the online version of the article in Wiley Online Library) and practical experience of the authors in conducting research in this cross-language context, a suggested framework for best practice when conducting in-depth interviews with participants from multiple language groups has been developed (Table 3).

Conclusion

This review found that health researchers are yet to meet the methodological challenges of including linguistically diverse older people in rigorous qualitative research using in-depth interviews. A framework for optimal practice has been developed. However, it is recognized that such complexity in this research context requires a number of considerations to be made in practice including the language and financial resources available. More examples

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What is already known about this topic

- International migration has created a need for healthcare research relevant to older multicultural communities.
- The quality and trustworthiness of interview data are challenged when researcher and participant do not share a preferred language.
- Strategies for rigorous in-depth interview research when multiple languages are spoken have not been explored.

What this paper adds

- The methodological rigour of studies using in-depth interviews with older people from multiple language groups is not strong.
- Language assistants require greater visibility and critical reflection in the conduct and reporting of cross-language research with multiple language groups.
- A framework is presented for optimal practice when conducting in-depth interview research with people from multiple language groups.

Implications for practice and/or policy

- In-depth interview research with people from multiple language groups needs to be taken out of the 'too hard' basket.
- Demonstrated examples are required of how to conduct rigorous and cost-effective qualitative research when languages are not determined prior to recruitment.
- To promote the inclusion of people from multiple language groups in health research, funding bodies must recognize the necessary costs of language assistance.

of rigorous qualitative studies with multiple language groups, when languages are not determined prior to recruitment, are needed to further the knowledge of successful research strategies. Transparent reporting of cross-language research methods will not only inform practice knowledge; it also has the potential to encourage researchers and funding bodies to give previously excluded people the opportunity to participate in healthcare research and to benefit from its findings.

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Conflict of interest

No conflict of interest has been declared by the authors.

Author contributions

CF, SM, MS and JC were responsible for the study conception and design. CF performed the data collection. CF, SM and MS performed the data analysis. CF, SM, MS and JC were responsible for the drafting of the manuscript. CF, SM, MS and JC made critical revisions to the paper for important intellectual content. SM, MS and JC supervised the study.

Supporting Information Online

Additional Supporting Information may be found in the online version of this article:

Figure S1. Critical Review Form for Qualitative Interview Studies with a Multilingual Sample.

Table S1. Individual database search strategies.

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Appendix F: Critical review form for qualitative interview studies with a multilingual sample

(Adapted from Letts, L., Wilkins S., Law M., Stewart D., Bosch J. & Westmorland M. (2007) *Critical review form - qualitative studies (version 2.0)*, viewed 26th August 2009, <http://www.srs-mcmaster.ca/Default.aspx?tabid=630>).

Citation:	
	Comments
STUDY PURPOSE: Was the purpose and/or research question stated clearly? O yes O no	Outline the purpose of the study and/or research question.
LITERATURE: Was relevant background literature reviewed? O yes O no	Describe the justification of the need for this study. Was it clear and compelling?
STUDY DESIGN: What was the design? O phenomenology O ethnography O grounded theory O participatory action research O other _____	Was the design appropriate for the study question and rationale? Explain. NB: researchers are advised to be cautious with the use of phenomenology and capturing the essence of a phenomenon if language is not shared, [1,2] or using analytic approaches that rely heavily on exact word usage or structure of the discourse e.g. discourse analysis[2]
Was a theoretical perspective identified? O yes O no Was the theoretical perspective culturally appropriate for participants?[1] O yes O no O not addressed	Describe the theoretical or philosophical perspective for this study e.g. researcher's perspective, framework for interview guide.[1]
Method/s used: ✓ interviews O participant observation O document review O focus groups O other _____	Describe the interview method and any other method/s used to answer the research question. Are the methods congruent with the philosophical underpinnings and purpose?

SAMPLING: Was the process of purposeful selection described? ○ yes ○ no	Describe sampling methods. Was the sampling method appropriate to the study purpose or research question?
Was sampling done until redundancy in data was reached? ○ yes ○ no ○ not addressed	Are the participants described in adequate detail? What is the preferred language/s of participants?
Was informed consent obtained? ○ yes ○ no ○ not addressed NB: can be written or verbal[4] Was it obtained in participants' preferred language?[4] ○ yes ○ no ○ not addressed	Was the recruitment method appropriate to the community of interest?[3] Were recruitment materials available in relevant languages and a bilingual format? i.e. main native language and second language.[3]
DATA COLLECTION: **Descriptive Clarity** Clear & complete description of: Site? ○ yes ○ no Participants? ○ yes ○ no Language assistants? ○ yes ○ no (how selected, level of language competence)[5,6,7] Role of researcher & relationship with participants? ○ yes ○ no Role of language assistants in all stages of research & relationship with: participants ○ yes ○ no researchers? [5,6,7]○ yes ○ no	Describe the context of the study. Was it sufficient for understanding of the 'whole' picture? How was cultural sensitivity demonstrated? i.e. understanding and knowledge of cultures of community/s of interest.[3,4,12] What was missing and how does that influence your understanding of the research?
Procedural rigour Was procedural rigour used in data collection strategies? ○ yes ○ no ○ not addressed	Do the researchers provide adequate information about data collection procedures? e.g. gaining access to site, field notes, training data gatherers.
Who were the language assistants? [4,13,14] ○ bilingual researchers ○ professional interpreters ○ trained non-professionals ○ other _____	How were language assistants trained or prepared for their research role? [6,9,10,11] Was word-for-word interpretation or conceptual equivalence desired? NB: Conceptual equivalence is recommended in cross-language qualitative research.[1,5]

How many language assistants per language? _____ NB: one or few recommended[1,9] Were debriefs conducted with language assistants after each interview?[4,9,14] O yes O no O not addressed	If bilingual interviewers were used, how was interviewer performance and comparability monitored?[10,15]
Were interviews conducted in participants' preferred language?[12,13] O yes O no Did members of language group/s participate in development of interview guide? [13,14] O yes O no O not addressed Was translation of the interview guide agreed across languages?[13] O yes O no O not addressed	Was the interview guide pilot tested?[13,14] Who was it tested with? Was any hybridity in the language of the interview acknowledged? e.g. some words spoken in main native language or hybrid/colloquial terms.[1,15]
Was the translation process for interview transcripts standardised?[3] O yes O no O not addressed	Describe the translation process.[3] What method was used to monitor translation quality? e.g. back-translation, two independent translators, consensus review.[6,12,16]
Identification of assumptions & biases of researcher? O yes O no Identification of assumptions & biases of language assistants? O yes O no	How were the potential assumptions of the language assistants identified and managed? e.g. intellectual biography, interviewing them about experiences and perceptions of research topic and study population.
DATA ANALYSES: **Analytical rigour:** Were data analyses inductive? O yes O no Were members of the relevant language groups included in the analysis process?[2] O yes O no Were findings consistent with & reflective of data? O yes O no	Describe the method/s of data analysis. Was the method/s appropriate to the research design and data? What were the findings?

Auditability: Was a decision trail developed?[12] ○ yes ○ no ○ not addressed Was the process of analysing the data described adequately? ○ yes ○ no ○ not addressed	Describe the decisions of the researcher re: transformation of data to codes/themes. Outline the rationale given for development of themes.
Theoretical connections: Did a meaningful picture of the phenomenon under study emerge? ○ yes ○ no	How were concepts under study clarified and refined and relationships made clear? Describe any conceptual frameworks that emerged.
OVERALL RIGOUR: Was there evidence of the four components of trustworthiness? Credibility? ○ yes ○ no Transferability? ○ yes ○ no Dependability? ○ yes ○ no Confirmability? ○ yes ○ no	Identify what the researcher used to ensure: **Credibility** (confidence in the truth of the data) Language awareness of researchers?[3] ○ yes ○ no Data collection takes into account preferred language of participants?[3] ○ yes ○ no Transcription of data in source language?[3] ○ yes ○ no Analysis of data in source language?[3] ○ yes ○ no Standardised translation procedures?[3] ○ yes ○ no Peer review of transcripts and tapes?[3] ○ yes ○ no Triangulation of participants, methods and investigators?[3] ○ yes ○ no Research team with different methodological perspectives and disciplinary interests?[12] ○ yes ○ no Other: **Transferability** (extent to which findings can be transferred to other settings) Clear detail of the community/research setting/language profile of participants?[3] ○ yes ○ no Other: **Dependability** (stability of data over time and conditions) Independent analysis of language specific data sets and comparison across data sets?[3] ○ yes ○ no Reflexive accounts of research process and methodological decisions? [3,9,10,13] ○ yes ○ no Other:

	Confirmability (objectivity or neutrality of data) Audit trail of data sets by bilingual reviewers?[3] ○ yes ○ no Member checking/taking findings back to participants?[3,9] ○ yes ○ no Acknowledgement of contribution of researcher and language assistants to data collection and interpretation? [6,11,17,18,19] ○ yes ○ no Acknowledgement of the influence of translation on the research? [6,7,13] ○ yes ○ no Other:
CONCLUSIONS AND IMPLICATIONS: Were conclusions appropriate given the study findings? ○ yes ○ no	What did the study conclude? What were the main limitations of the study? What were the implications of the findings for your area of study?

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Appendix G: Individual database search strategies used in systematic review

Electronic Database	Interface	Years searched	Keywords	Limiters
CINAHL	EBSCOhost	1982 – June 2009	(ethnic*or cultural*)	English language; Qualitative – best balance or high sensitivity; Aged, 65* years
Scopus (including Medline titles)	Scopus	1960 – June 2009	(ethnic*or cultural*) and qualitative and aged	Exclude subject areas: biochemistry, economics, agriculture, environment, engineering, comp, veterinary sciences, earth sciences, chemical sciences, arts.
Embase	OVID	1980 – June 2009	(ethnic*or cultural*)	English language; Human; Qualitative – 1 term high sensitivity; Aged, 65+ years
Web of Science	Web of Knowledge	1968 – July 2009	(ethnic*or cultural*) and qualitative and (aged or old* or elder*)	English language; Article
Ageline	OVID	1978 – August 2009	(ethnic*or cultural*) and health and qualitative	-
PsycINFO	EBSCOhost	1840 – August 2009	(ethnic*or cultural*) and health	English language; Human; Peer-reviewed journal; Journal article; Qualitative study; Aged, 65+ years
Sociological abstracts	CSA Illumina	1963 – September 2009	(ethnic*or cultural*) and health and qualitative and elderly	English language; Peer-reviewed journal; Subject area – Social Sciences
Google Scholar	Google	- September 2009	(ethnic or cultural) and qualitative and health and interviews and (aged, elderly, old)	Subject area – Medicine, Pharmacology and Veterinary Science, Social Sciences, Arts and Humanities; without the words: children, adolescent, statistical, focus group, quantitative
AMED	OVID	1985 – September 2009	(ethnic*or cultural*) and health	English language; Human; Qualitative – 1 term high sensitivity

Appendix H: Framework for best practice when conducting in-depth interviews with participants from multiple language groups

	Recommended practice	Suggested strategies
Study design	Theoretical perspective of the research is culturally appropriate to participants.	Consider if research approach can be carried out with multiple languages and cultural groups. Consult members of language groups in population of interest when planning research concept and approach.
Recruitment	Recruitment materials available in preferred language and bilingual format.	Print recruitment material in languages spoken in the population of interest and the main native language. Translate materials as needed during recruitment to help manage project costs.
	Recruitment methods are appropriate for the population of interest.	Consult members of language groups in population of interest when planning recruitment strategies. Be flexible in recruitment strategies for different language groups. Use verbal recruitment strategies and established networks e.g. community groups, key persons. Consider the literacy of participants in recruitment methods.
Informed consent	Provide study information and consent in participant's preferred language and bilingual format.	To help manage project costs, consider interpreting study information orally to reduce the number of written translations required and translate consent form as needed.
Data collection	Conduct research interviews in participant's preferred language.	Different types of language assistants can be used for different language groups depending on resources available e.g. bilingual researcher or trained research assistant conduct interview, or monolingual researcher conduct interview with real-time interpretation by professional interpreter.
	Interview methods are culturally appropriate to participants.	Consult members of participant's language group and relevant literature when planning interview. Check participant's preferences regarding language assistant e.g. gender, cultural group. Pilot test interview guide with different language groups from population of interest.

	Recommended practice	Suggested strategies
	Standardise interview guides across language groups.	Consult language assistants in development of interview guides; discuss aims of research, purpose and structure of interview and concepts to be used. Pilot test interview guides with different language groups from population of interest.
	Recognise influence of language assistant on data collection	Use the same language assistant per language group. Prepare language assistant for interview; discuss aims of research, purpose and structure of interview and concepts to be used. Interview language assistant about their language competency and their experiences and perceptions of study topic and study population. Conduct debrief with language assistant after each interview to discuss their impressions of the interview, important concepts that arose and any communication difficulties. For bilingual research assistants, provide training in interview technique and conduct performance monitoring.
Data analysis	Analyse data in language it was spoken. If not feasible, standardise and monitor the quality of translations of interview transcripts.	Prepare translator for the translation of the interview transcript; discuss relevant participant information, aim of research and interview and concepts used. Use one translator per language group. Use of back-translation or second independent translation is unlikely to be economically feasible with multiple translations in multiple languages.
	Recognise influence of the language spoken by participant when analysing interview data.	Involve language assistants in data analysis; discuss terms and concepts used. Use debriefs with the language assistants after interviews to inform the analysis. Take findings from interview data analysis back to participants and discuss with them.

	Recommended practice	Suggested strategies
Overall rigour	Transparent reporting of study methods	Provide clear, detailed information about participants, researchers, language assistants and research process. Report language spoken by participants in demographic information. Report the role of researchers and language assistants in all stages of the research process, their language competence, and any relationship they have to participants e.g. community role. For language assistants, report how they were selected.
	Practice reflexive research.	Maintain a reflexive journal of research practice including how language appropriate practice was approached and conducted. Provide reflexive accounts of research methods and findings acknowledging the influence of language spoken by participants.
Budget considerations	Include estimate of costs of translations and language assistance in research proposals and funding applications.	Estimate required resources using the language profile of the population of interest.

Appendix I: Promotional flyer for study (English version)

To improve health care after stroke, the University of South Australia is doing a study to answer this question:

How do people who have trouble speaking English experience the move from hospital to home after a stroke?

If you…

- have been in hospital after a stroke AND
- have any difficulty speaking or understanding English AND
- are 60 years or older

We would like for you to take part in this study.

The study will involve you speaking with a researcher for about one hour on two occasions with a professional interpreter present. All responses will be confidential. Taking part is voluntary.

If you are interested in taking part in this study and would like more information, please sign the form below with your contact details and give it to your hospital physiotherapist or post it to us in the attached envelope (no stamp needed) or ring the researcher Caroline Fryer on 8302 2283.

This study has been approved by the Human Research and Ethics Committees of the University of South Australia, The Queen Elizabeth Hospital, the Royal Adelaide Hospital, Hampstead Rehabilitation Centre and St. Margaret's Rehabilitation Hospital.

I ..... (insert name) am interested in taking part in this study. I agree to the researcher mailing me more information and ringing me when I return home so they can discuss the study with me.

Signed.....

Date.....

Contact phone number.....

Contact mail address.....

I prefer to speak.....language

Thank you very much for your help

Appendix J: Consent form (English version)

UniSA **Consent form** ***(translated language)***

Title: **How do people who have trouble speaking English experience the move from hospital to home after a stroke?**
Researcher: Caroline Fryer, PhD student Ph. 8302 2283
Supervisor: Dr. Shylie Mackintosh, Senior Lecturer Ph. 8302 2075

- The nature and purpose of this study has been explained to me in my preferred language. I understand and agree to take part.
- I understand the purpose of the study and my involvement in it.
- I understand that I may withdraw from the study at any stage and that this will not affect my status now or in the future.
- I understand that my identity will be kept confidential, and nothing will be published which could possibly reveal my identity.
- I understand that I will be audiotaped during the interview.
- I understand that the tape and my information will be stored securely in a locked office at the University and only the researcher and her University supervisors will have access to it.
- I understand that if I have any questions or concerns about the study I can contact the researcher or her supervisor or the University of South Australia Ethics Officer on 8302 3118.

PARTICIPANT:..... **DATE** ...../...../.....

INTERPRETER:..... **DATE** ...../...../.....

RESEARCHER..... **DATE** ...../...../.....

Consent Form version 1, 21 May 2009

Appendix K: Information sheet

Participant Information Sheet

Title: **How do people who have trouble speaking English experience the move from hospital to home after a stroke?**
Researcher: Caroline Fryer, PhD student Ph. 8302 2283
Supervisor: Dr. Shylie Mackintosh, Senior Lecturer Ph. 8302 2075

You are invited to take part in an important research study about your experiences of going home from hospital after your stroke. However, before you decide whether or not you wish to take part, you need to understand why we are doing the study, and what taking part would involve if you agreed.

Please listen to the following information carefully. The researcher will be happy to discuss it with you and answer any questions that you may have. You are also free to discuss it with others if you wish such as family, friends or your local Doctor. You do not have to make an immediate decision.

Participation in this study is voluntary. If you do not wish to take part, you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the study at any time without providing a reason. Your decision to take part, not to take part or to withdraw will not affect your routine health care, your relationship with those treating you or with the hospital you were treated in.

The research is being done to give health care providers information about how best to care for people after a stroke. The research is part of Caroline Fryer's PhD study at the University of South Australia and is supported by a South Australian Department of Health Research Award.

You have been invited to participate in this study because you have recently been in hospital after having a stroke and have returned to live at home.

Taking part in this study means the researcher will meet with you on two occasions at a place where you feel comfortable to meet, such as your home or at a university campus. When the researcher meets with you, you will be asked to tell her about returning to live at home and receiving health care in the community after your stroke. The interviews will be audiotaped. The interviews will last about one hour and an interpreter will be present to ask questions in your preferred language and interpret your responses for the English-speaking researcher. The researcher will arrange to interview you again in the same way about three months later to talk with

you about the research findings and ask you a few more questions about life after your stroke.

It is unlikely that you will have any discomfort from taking part in an interview. If you do become uncomfortable or upset during the interview, please tell the researcher and the interview can be stopped.

The tape and information from your interviews will be stored at the University of South Australia in a locked filing cabinet in a locked office. It will be kept for five years then destroyed. Only the researcher and her supervisors will look at your information. You will not be identified when your information is used. You can choose a name for the researcher to use when words from your interview are reported.

You will not be paid for taking part in this study.

It is unlikely that the research will be of benefit to you personally however it may help to improve the health care for future patients who have trouble speaking English. You will be sent a copy of the research findings in your preferred language when the study is completed in 2011.

If you have any questions about the project, please contact:
Caroline Fryer (researcher) on 8302 2283
or **Dr. Shylie Mackintosh (research supervisor) on 8302 2075.**

This project has been approved by the University of South Australia's Human Research Ethics Committee. If you have any ethical concerns about the project or questions about your rights as a participant please contact the Executive Officer or this Committee, on 8302 3118 or email: vicki.allen@unisa.edu.au.

The information as written above has been verbally given to

…… in their preferred language on

.....(date).

INTERPRETER:..... **DATE** ……./……./…….

RESEARCHER..... **DATE** ……./……./……

Appendix L: Interview guide

Interview guide

Introduction

Hello. My name is Caroline Fryer and I am a research student from the University of South Australia. And this is _____ (interpreter).

I have come to talk with you today about your experiences of health care since your stroke. First I need to explain the study to you and, if you are happy to talk with me today, I will ask you to sign a form. Then I will ask you some questions and we can talk together. _____ (interpreter) is here today to help us by interpreting our talk. I am also happy for you to speak in English at any time if you wish to.

Informed Consent

(Verbally provide translation of information form, leave English version, sign translated consent form)

Main study questions (30-40mins)

Now, I'm going to ask you to tell me about what happened after your stroke, right up to being here at home today. I want you to just keep talking in your own time and I will listen. I'd really like to hear your story. Later I may ask you a few questions, but for now I'll just listen to you.

So, when did you have your stroke?

Encouragement/prompts: Mmm, yes/yeah,
What happened (next/then)?
Where was that? When was that? Who else was there?
How did that make you feel?
Did you understand what was happening/they were saying? Could they understand you?

Probes after main story (10-15mins)

You mentioned _____, can you tell me more about that? e.g. meetings, discharge planning, contact with services, transport.

Who was important to you for coming home from hospital and getting care services now that you are home?

In your story that you have shared with me today, what is the most important part for you?

After having these experiences, what advice would you give to another person who has difficulty with the English language and is going home after a stroke?

Is there anything else you think I should know about your care after your stroke?

Demographic questions (10-15mins)

Before we finish the interview, I just need to find out a few things about you.

How old are you?

How many years have you lived in Australia?

When did you learn to speak English? (Have you learned to speak English?) Who helped you to learn? (Why did you want to learn English?)

How many years of schooling have you done?

Is anybody else living in the house with you at the moment?

And, at the moment, do you need any help doing your shopping?

In the morning, do you need any help to get dressed?

At the moment, are you using a walking aide when you are walking?

Conclusion

Finally, is there anything more you would like to tell me about your care after stroke?

Is there anything else you would like to ask me?

Is there a name, other than your real name, that you would prefer me to use when I report the information you have given me today?

I would like to talk with you again in 1 to 2 months time about your care since your stroke. Can I telephone you closer to then to make a time?

Thank you for talking with me today.

Appendix M: Example of second interview guide

Gino

Second interview

Thursday 3rd June 2010

Thank you for talking with me again. I really appreciate you sharing your story with me. I have a few questions to ask you to make sure that I understood your story as you want me to, and to find out a bit more about parts of your story.

Thinking back to when you had your stroke and you first went to the hospital, I understand the doctors were mostly talking to your son and daughter-in-law. Is that right?

- Why do you think the doctors were talking to your son and not to you?
- How did that make you feel at the time?
- When your son told you what the doctors had said, did he tell you in English or Italian?
- Has your son or daughters spoken to people on your or your wife's behalf before? What happened when Rosa was in hospital and rehabilitation (for her knee?)?

I remember you were doing gardening when your arm got weak and you managed to finish trimming the bushes. Then in the evening you went to your grandson's birthday party. Can you tell me more about why you decided to drive to the birthday party?

- After your stroke, who told you that your licence was being taken away? How did that make you feel at the time? Why do you think they told you that you could not drive?
- What does it mean to you to be able to drive?
- Can you tell me why you drive your car before you have your licence back?

I understand that the language you prefer to speak is Italian. Can you tell me when a person working at the hospital or at rehabilitation asked what language you prefer to speak?

- Was there a time during your care that you were asked about your Italian background?
- When were you offered an interpreter during your care?
- If a doctor at the hospital had suggested using an interpreter during your care, what would you have said?
- When would you use an interpreter?
- What do you do when you do not understand what someone has said to you?
- How do you feel if another person does not understand what you have said? Did that happen in hospital? When?
- Last time when I asked you about if any of the hospital or rehabilitation staff had asked what language you spoke, you said 'nobody interested to talk like we talk'. What did you mean by that?
- You mentioned speaking to another patient who spoke Italian, from Renmark I think. What did you talk about with this man? What did it mean to you to be able to talk in Italian with someone while you were in hospital?
- Did you get offered any written information in Italian? Did you get information in English? Are you able to read it?

I am interested to know if you had a choice about where you went for rehabilitation? (trust)

- Did you want to go to rehabilitation? Where did you want to go?
- What did you know about rehabilitation before you went?
- Why do you think that you went to rehabilitation? Is that what happened there?

Once you were at rehabilitation, I understand that you had a big meeting before you came home. Who asked for your son and daughter-in-law to be at the meeting? How did you feel about them being involved?

At the meeting, your d-in-law helped you understand what was talked about; it was about getting votes or a score wasn't it? What would have happened if you had only got a few 'votes'?

How do you think you would have understood that information from the meeting if your d-in-law had not been there?

I understand that one of your daughters was here at the house when the people from rehabilitation came to check it before you came home. Who suggested that your daughter was at your house when the therapist visited it? Were you here when the house was checked?

How did it make you feel to have someone from rehabilitation checking your house before you came home?

Then what was it like to come home after your stroke?

Now I understand that you have had a nurse for your swallowing, a physiotherapist and a cleaner come to see you at your home. When was the decision made for a physiotherapist and nurse to visit you at home?

How did you feel about having these people visit?

What choice did you have about who would visit you?

What is it like to have someone come in to your home to do exercises/check swallowing/clean, who you don't know?

What could happen if you were not so careful with the liquids you drank?

Last time I was here, the physiotherapist and nurse had left it up to you to decide if they needed to come back again. How do you feel about making that decision? Have you rung them? What would be something that you would ring the nurse or physiotherapist about?

There seemed to be a lot of rules during your care about where you could walk, using your walking stick, having somebody watch you shower, being careful what you drank. How did you feel about having these rules? Were there times that you didn't follow the rules?

At the hospital there was that time that you fell out of bed and nobody was there to help. Can you tell me why you didn't report your fall to someone at the hospital?

Since coming home, you went to your doctor and chemist to arrange for longer prescriptions. Why was that? Could you have got a regular ride to the pharmacist with your daughter?

You told me last time that you got a bit of courage from the doctors when they told you there was only a small chance of stroke happening again. What did you mean by 'courage'?

In hospital and rehabilitation, who were the people that you trusted to help you? Why did you trust them? Who do you trust to help you now that you are home?

Finally, is there anything more you would like to tell me about your care after stroke?

Is there anything else you would like to ask me?

Thank you for talking with me again and helping me to understand your experience of stroke care. I appreciate it very much.

Appendix N: Summary sheet for interpreter pre-brief

RESEARCH SUMMARY for Professional Interpreters **For interview on _____**

UniSA PhD student

Caroline Fryer ph 8302 2283 mob 0402 332 729

Title

How older people with limited English proficiency experience the transition from hospital to community care after stroke.

Overview of project

The aim of the research is to understand how the transition of care from hospital to community after stroke is experienced by older people with limited English proficiency from CALD backgrounds. Information from this research will inform health care professionals about how to assist stroke care for people with limited English proficiency.

Participants for this project will be people over the age of 60, who were not born in Australia, have been in hospital after having a stroke and have returned to live in the community, and have limited English proficiency.

All participants will be involved in two in-depth research interviews with a professional interpreter present. Each interview will last between 1 and 1 ½ hours. The first interview will be in the first two months after leaving hospital, and the second interview approximately two months later.

Interview

The aim of each interview is to allow the participants' own experiences and feelings about their transition between the hospital and coming home after stroke to emerge without being influenced by preconceived ideas. To understand how each participant experienced their care after stroke I want to hear their story as they wish to tell it to me – what was important to them, who was involved, how it made them feel, etc.

The interviews will follow a format of:

Introduction

Informed Consent*

Short explanation of how interview will run

Main interview question and storytelling**

Asking question to clarify parts of their story

Short questions about age, living arrangements etc.

Conclusion and thank you

Researcher and interpreter debrief***

***Informed consent:** Information about the study needs to be verbally translated for the participant, and both of us sign the form to verify this. If the participant agrees to continue with the interview they then need to sign a translated consent form.

****Storytelling:** The main part of the interview is to encourage the participant to tell their story of what happened after their stroke right up to the day of interview. I want to encourage them to talk in their own words and in their own time with minimal interruptions. I will encourage with: nods of my head, saying "Mmm" or "What happened next?" Please stop the participant to interpret when you need to but then ask them to continue their story from when they stopped and I will keep listening.

*****Debrief:** After the interview, it would be very helpful to me if we could meet so I can clarify any terms or parts of the conversation that I am unsure of, and discuss the interview with you e.g. if the participant appeared hesitant, used formal or informal language etc. I would also like to know if you have any previous experience of health care after stroke and /or interpreting for older people in health care situations. This should take between 15 and 30 minutes. We can sit in one of our cars to talk if that is ok with you.

Each interview will be digitally recorded and I will transcribe the interpreted conversation to analyse for my research.

Your involvement in the interview

I recognise and appreciate how important your interpreting skills are in helping me to gain useful and accurate information from the interview. As I do not speak a second language, it is important for this research that I understand the 'idea' of what the participant is telling me – what meaning they give to events that happened and how it made them feel. I realise this may sometimes be challenging to achieve but I hope we can work together to gain a good understanding.

Today I will read through the planned interview questions with you and discuss their translation to the preferred language of the participant. I would also appreciate any advice you have for successful interviews with people from this cultural background.

During the interview the participant can choose how much or little they wish to speak their preferred language. If I am unsure of a term or phrase, I will ask for your help to clarify it.

Confidentiality agreement

I have gained ethics approval from UniSA, The Queen Elizabeth Hospital and the Royal Adelaide Hospital for this research. A requirement of this ethics approval is that each interpreter involved in the study signs a confidentiality agreement.

Thank you. I look forward to working with you during this research study. Please do not hesitate to ask me any questions.

Caroline

Appendix O: Participant and co-participant synopses

Katariina

Katariina was an eighty-two year old lady from Estonia who lived by herself in an independent living unit. Katariina had experienced two strokes in eight years. The stroke prior to her research interview had slurred her speech, caused the muscles of her face to droop and made her feel very tired.

Katariina migrated to Australia with her husband over sixty years ago following the Soviet occupation of her country. Katariina was very patriotic to Estonia and missed the European languages and culture. In Australia, Katariina trained then worked as a nurse for nearly twenty years at Hospital B.

Katariina reported that she spoke English *"well".* Katariina was multilingual, speaking five languages: Estonian, German, English, Italian and Russian. Estonian was her preferred language, however, Katariina would speak whichever language in her repertoire was spoken by her conversation partner. Katariina spoke Estonian with her only child, a daughter, but was disappointed that her grandchild and son-in-law spoke only English. She chose to speak English without an interpreter present for both interviews. Katariina's English was heavily accented and spoken quickly. Owing to Katariina's nursing background, she was comfortable using medical terminology such as 'abdomen' and 'INR' during interviews, and only experienced difficulty when trying to use complex words such as 'strategical' and 'gastroenterology', *"I cannot pronounce the word properly at the moment. I always struggle. I wish English was bit different as it is but there"* (English) At both interviews Katariina and I enjoyed a hot drink together and shared German Stollen cake while looking through her photograph albums of Estonia and Europe.

Benigno

Benigno was a seventy-six year old man from Italy who lived independently in his own home. Benigno's stroke resulted in right arm weakness and the speech disability of expressive dysphasia which caused him some difficulty saying words and sentences to convey his thoughts.

Benigno completed primary school in Italy and worked on his family's share farm from the age of six to help support his widowed mother and siblings. Benigno migrated to Australia in the 1950s with his five brothers and a sister for better work prospects. In Adelaide, he worked in factories.

Benigno reported he spoke English *"well"* however, he preferred to speak Italian, *"the language of my birth country of course"*(English). He watched mainly Italian television shows and spoke Italian with his brothers and friends but spoke English with his son who had not learnt much Italian. Benigno regretted not learning more English when he first migrated, *"Sorry now but too late to be sorry"* (English). He chose to speak English without an interpreter present for both interviews. Benigno's expressive dysphasia made his speech difficult to understand at times and he used brief sentences during interviews. Benigno also used hand actions at times to help him communicate a word or message, such as pointing to his chest when explaining heart problems. For both interviews we sat in Benigno's lounge room and shared a conversation about local football.

Sadik

Sadik was a sixty-five year old gentleman who lived at home with his wife, Helena. Sadik's stroke had caused leg weakness that made Sadik unsteady when he walked and he reported having several falls since returning home.

Sadik and Helena had lived in Australia for twenty-six years. Sadik was from Macedonia and attended ten years of school in his home country before going to work in the Army, on farms and in mines to support his family, *"I have not money to buy clothes or something"* (English). Sadik had three adult children; one living close by and two living interstate. Sadik was *"shamed"* by the divided Yugoslavia and proudly considered himself an *"Aussie'* (English).

Sadik reported he spoke English *"well"*. Sadik learned to speak English on the factory floor, working the night shift many years with other European migrants, *"From everybody a little bit"* (Croatian). He also learnt English by watching television and being taught by his children as they learnt it at school. Sadik still required help with written English, *"Reading yes, writing very bad. Very bad."* (English). Sadik spoke Croatian with his family. Although initially reluctant to have a professional

interpreter present at the interview, Sadik agreed when I explained that it would help me, the interviewer, to understand. He spoke a mix of Croatian and English during the interview and rested on a couch in his lounge room as we talked. Helena fed us heaped plates of a Slovenian dessert. Sadik was only able to complete one interview as his health deteriorated, requiring hospitalisation.

Helena, Sadik's wife

Helena was a sixty year old woman from Slovenia. She married Sadik and had two children before the couple migrated to Australia. Helena had not completed primary school in Slovenia as her family insisted that she stayed home and take care of her brothers. Helena was now a proud *"Aussie"* (English).

Helena reported she spoke English *"well".* Like Sadik, Helena learnt English on the factory floor, from television shows and from her children. Helena's daughter continued to encourage her to learn English. Helena chose to speak a mix of Croatian and English when participating in Sadik's interview.

Gino

Gino was an eighty-five year old man from Italy who lived in the family home with his wife, Rosa. After his stroke, Gino experienced arm weakness and dysarthria and dysphagia which caused him difficulty when speaking and swallowing. Gino's strength had recovered enough by his interview for him to return to driving his car.

Gino migrated to Australia at the age of thirty-seven. He worked as a builder and was very proud of his achievements in the industry. Gino reported that he spoke English *"well".* He learnt English from a short correspondence course when he first arrived *"after six months I got to leave cause no more time"* (English), newspapers, television shows, on building worksites and from his children as they learnt it at school. He still spoke Italian with his children and with his friends but not his grandchildren who only spoke English. Gino was proud of his English language ability and at his second interview he insisted that he only continued to speak Italian because his wife could not speak English. Gino agreed to an interpreter being present for his interviews but chose to speak Italian only a few times when I was having obvious difficulty understanding his talk in English. Gino's speech was quite hard to understand at times due to the combination of his dysarthria and a heavy accent and it was very

helpful to have the interpreter present as Gino quickly became frustrated when he was not understood. For both interviews we sat around the kitchen table with Rosa busying herself around the stove behind us or sometimes sitting with us.

Rosa, Gino's wife

Rosa was an eighty-two year old woman how had migrated to Australia with their eldest child six months after Gino. They then had two more children who all lived locally. Rosa had not completed primary school in Italy as she needed to help her ill mother at home. She had not worked in Australia and had not attended any English language instruction. Rosa spoke English *"not well"* and joked about the difficulty her grandchildren had in understanding her Italian talk, *"No understand my grandchildren me Italiano"* (English).

Nam

Nam was an eighty-one year old gentleman who migrated from Vietnam in 1990 to join several of his nine children in Australia. He shared a home with his eldest son, Hung, before and after his stroke. Nam was very frail after his stroke and unable to stand or walk. His rehabilitation had focussed on training his family to be able to care for him at home.

Nam had not learnt English. Hung explained, *"…he is old, too old to learn"* (Vietnamese). Nam was able to speak Vietnamese and a Chinese dialect. At his interview, a professional interpreter was present but Nam was only able to talk in short sentences for a brief period before he became fatigued. Nam then stayed in a recliner chair while his sons talked. At Nam's second interview, more of his children were present and they were concerned that Nam was too confused to participate. So I did not interview Nam a second time but still spoke with his sons, Hung and Son, while Nam listened.

Hung and Son, Nam's sons

Hung was a man in his sixties from Vietnam who had migrated to Australia with his wife, Lan, seven years earlier. Hung and Lan did not speak English at all. They had attended English lessons for a few months when they first migrated but found it to be too hard and so had stopped. Hung used the professional interpreter for all of the interviews. Hung and Lan took care of Nam with the help of community care workers

for showering. It was a role which Hung accepted, *"I just think that us children we have to try our best to take care of our father"* (Vietnamese). Hung stood beside his father throughout the interviews.

Son was one of Nam's younger sons, aged in his fifties, who was the first of his siblings to migrate to Australia in 1980. Son spoke English *"well".* He had been provided with English classes by his employer, a large mining company. Son was the family member whom health and support services contacted regarding Nam's care because of his better English skills. Son was present for both of Nam's interviews, sitting at the back of the living room. He spoke English during the interviews.

Emilio

Emilio was an eighty-one year old man from Italy who lived at home with his wife. He migrated to Australia fifty-five years earlier. Emilio had a bachelor son who lived next door and regularly shared the evening meal with them, and a daughter who lived further away. Emilio's stroke had caused weakness in his left arm and leg so he was only able to walk short distances with a frame. This had left him very frustrated, *"I can do nothing you know"*(English). The stroke had also left him very emotionally labile and so Emilio would often get upset and start loudly sobbing during the interview conversation without being able to stop himself doing it.

Emilio spoke English *"not well".* He had learnt some English while working in the building industry but had not attended any lessons. At his interview, Emilio used the professional interpreter for all but a few sentences. We sat around the kitchen table sharing a hot drink while we talked.

Donna, Emilio's wife

Donna was a seventy-three year old woman from Italy. She migrated to Australia six years after Emilio. Donna spoke English *"well"* and spoke a mix of English and Italian during the interview. She had not worked outside of the home in Australia but had learnt English from the television and her children. Donna's daughter still encouraged her to continue to improve her English skills. Donna was distressed by Emilio's emotional lability which also upset his grand-daughters who Donna cared for during school holidays. When Emilio's second interview was due, Donna was herself sick and stressed about caring for Emilio and her grand-daughters. She and her son were

concerned that talking about the stroke would upset Emilio and so a second interview was not conducted.

Waldemar

Waldemar was an eighty-six year old man from Poland who lived alone in his own home. He was supported by his older brother and his nephew. Waldemar had migrated to Australia twenty-two years earlier but had not worked in Australia. Waldemar's stroke had initially left him very weak but at the time of his first interview he had returned to riding his bike to the local shops. Waldemar remained greatly troubled by the difficulties he still experienced with his memory since his stroke.

Waldemar spoke English *"not well".* He had learnt some English with the help of his brother and nephew but they had reassured him, *"If you learn English we'll speak English, if you don't learn we won't"* (Polish). Waldemar prepared for English conversations using a bilingual dictionary. During his interviews, Waldemar's speech was often long and rambling which was challenging for the experienced interpreter to translate and for me to keep him on topic. We spoke together while sitting in armchairs around a coffee table in his lounge room. Waldemar always met us in his front garden and kissed our hands when we departed.

Ming

Ming was an eighty-six year old man from China and Malaysia. He migrated to Australia with his wife in the 1990s. His wife had died from a stroke eighteen months earlier and he now lived with his son-in-law's mother and two grandchildren. Ming's stroke had caused mainly facial weakness and speech difficulty but he was still experiencing some leg numbness and weakness at interview. He was able to walk to the local shops with his son-in-law and attend church.

Ming spoke English *"not well"* but was more skilled at being able to understand English spoken by others. Ming had learnt English during high school in Malaysia, *"That time was still under British rule…"* (Cantonese), and then used it while working as a banker in that country. Ming's preferred language was Cantonese but he was also able to speak two other Chinese dialects and had known Malay at one time. He mostly

spoke Mandarin with family members and had little conversation with his grandchildren who spoke English. During interviews, Ming used the interpreter for all but a few sentences.

Ming was now a proud Australian citizen with a photograph of his citizenship ceremony on display next to a photograph of his late wife. He was also very proud of his children and grandchildren who had trained in medicine and dentistry. As we talked, we sat around the kitchen table sharing Chinese tea while smelling the delicious aromas of a meal being cooked in the outdoor kitchen. Ming said that he enjoyed the interviews because he did not get the chance to speak to many people.

Vincenzo

Vincenzo was an eighty-three year old man from Italy who had migrated to Australia in 1952. He had spent many years travelling around Australia working as a photographer. Vincenzo lived at home with his wife and he had three children who he had varying levels of contact with. Vincenzo had initially been unable to walk after his stroke but he had recovered with rehabilitation to be able to walk without any aids and to drive a car.

Vincenzo was a confident English speaker who reported that he spoke English *"well".* Vincenzo had learnt English from American soldiers who were stationed near him in Italy during the war and he had attended *"Night school for migrants"'* (English) in Australia as well as choosing to associate with people who spoke English, *"I was mainly frequenting Australians"* (English). At one time Vincenzo had acted as an Italian interpreter for a Catholic priest who was visiting men in gaol. English was the main language that Vincenzo and his wife, from the Philippines, spoke together. Vincenzo had also previously learnt to speak Greek and Filipino. He chose to speak English for his entire interview. We sat in armchairs in his lounge room to talk. Vincenzo's wife came home from work during the interview and offered us coffee.

Christos

Christos was a seventy-four year old man from Greece who lived with his good friend, Nick. Christos had been evicted from his rental accommodation while in hospital after his stroke and had been estranged from his family for some years, so his old friend

stepped in to help. Christos experienced arm and leg weakness after his stroke which still affected his ability to do some daily activities. Christos could walk slowly but independently.

Christos had migrated to Australia in 1962 and had worked in the building industry. Christos reported that he spoke English *"well"* but believed that his proficiency had deteriorated since his stroke. He used a professional interpreter for all but a few sentences during his interview.

Christos' interview was conducted at the researcher's University as it was easier for Nick to drop Christos off in town when he was out and about on building jobs. Christos was initially hesitant at the interview as he was unsure of its purpose; my telephone conversations had, at Christos' request, mostly been with Nick and the interpreter had presented the study information very formally during the consent process. Christos relaxed once I explained the questions that I would be asking him and he then consented and shared his story openly. We sat around a table in a meeting room with refreshments.

When we parted after the first interview, Christos agreed to speak with me again *"…whenever, as long as I am in good health"* (Greek). Unfortunately, that was not to be. Christos suffered a second stroke several weeks later which made him very weak and unable to speak. He remained in hospital for the rest of the study.

Krystyna

Krystyna was an eighty-three year old woman from Poland who lived alone with support from care workers and from her son who lived close by. Krystyna's stroke had weakened her legs and she now walked short distances with a frame. Krystyna relished being independent and had returned to baking but was disappointed that she could not get down to her vegetable garden any more.

Krystyna reported that she spoke English *"not well".* She had migrated after the war at the age of twenty-four with her husband and toddler son. They had no knowledge of Australia except what they had read, *"…book was writing all black people only living very close to sea"* (English). Krystyna taught herself English by talking with others. She worked in a factory but learnt little English there as it was not the language which the

employees shared, *"we talk German this time because we all come from German and we have only German language understand one to the other."* (Polish). Krystyna spoke *'in broke'* (English) with her neighbours from different migrant backgrounds and she also spoke Ukrainian with her son. During her interviews, Krystyna spoke mostly Polish with occasional sentences in English. We sat comfortably in armchairs in her lounge room to talk.

Andreas

Andreas was an eighty-eight year old man from Greece who lived at home with his wife, Eva. Andreas had migrated to Australia fifty years before. His stroke had left him with arm and leg weakness and he was still experiencing hip and knee pain when walking but the morning of his second interview he had been out helping his friend stake grape vines.

Andreas reported that he spoke English *"not well".* He'd had little opportunity to learn English while working in the building industry because, *"I work with Greek people many times, no work with Australian people to learn the language"* (Greek). Andreas spoke Greek with his wife and his friends. Andreas used the professional interpreter for most of the interviews when we sat around the kitchen table and were plied with home-baked sweet Russian pastries and strong coffee by Eva.

Eva, Andreas' wife

Eva was a sixty-three year old woman from Russia who had met Andreas while working as a nurse in Greece. She migrated to Australia eleven years earlier after marrying Andreas. Eva told us a funny story that when she met Andreas he had lied about his age and she only found out that he was ten years older after they were married by looking at his passport!

Eva reported that she spoke English *"not well".* She had attended English classes after migrating to Australia but had found it hard*, "maybe I come here young I just might quickly learn"* (English), and her ability had reduced with time as she spoke mostly Greek with her husband and friends. Eva spoke a little English with their neighbours. Eva had been volunteering at a local nursing home with Greek residents but had stopped a few years ago after being injured in a car accident.

Emanuele

Emanuele was an eighty-two year old man from Italy who lived at home with his wife, Paola. The stroke had caused his legs to weaken and Emanuele walked short distances in his house using a frame. He also suffered back pain which affected his mobility, although the week before his second interview Emanuele had used an electric scooter to visit his daughter a couple of streets away.

Emanuele reported that he spoke English *"well".* Emanuele had migrated to Australia with Paola forty-seven years earlier with their four children. He had only attended three years of school in Italy. Emanuele had learnt English in Australia by speaking it with others at the factory where he worked and learning from his children as they learnt it at school. His youngest son, who had done all of his schooling in Australia, still spoke in English with him but his other children spoke to their parents in Italian. During the interviews, Emanuele spoke mostly in Italian using the interpreter but he did speak some sentences directly to me in English. We sat around the kitchen table while we talked. Paola busied herself around the kitchen and sat down with us when her daughter, Daniella, was present. Paola served us some very strong coffee.

Emanuele's wife, Paola

Paola was a seventy-nine year old woman from Italy. Paola spoke English *"not at all"*. As her daughter explained, *"She does say a few words, but she's too embarrassed to say them, so she keeps them to herself"* (English). Paola had not worked outside of the home in Australia. Paola was initially unsure about our presence at Emanuel's first interview and so she rang her daughter for help. Once her daughter was present, Paola visibly relaxed and was happy to answer a few questions in Italian at the end of the interviews.

Emanuele's daughter, Daniella

Daniella was the fifty-eight year old daughter of Emanuele and Paola. Daniella was a proficient English and Italian speaker. Daniella had attended five years of schooling in Australia and then left at fifteen to earn money for the family. She married a boy from Italy when she was eighteen. Daniella lived nearby and was very close to her parents and siblings. She took seriously her responsibility to care for her parents and helped them on a daily basis.

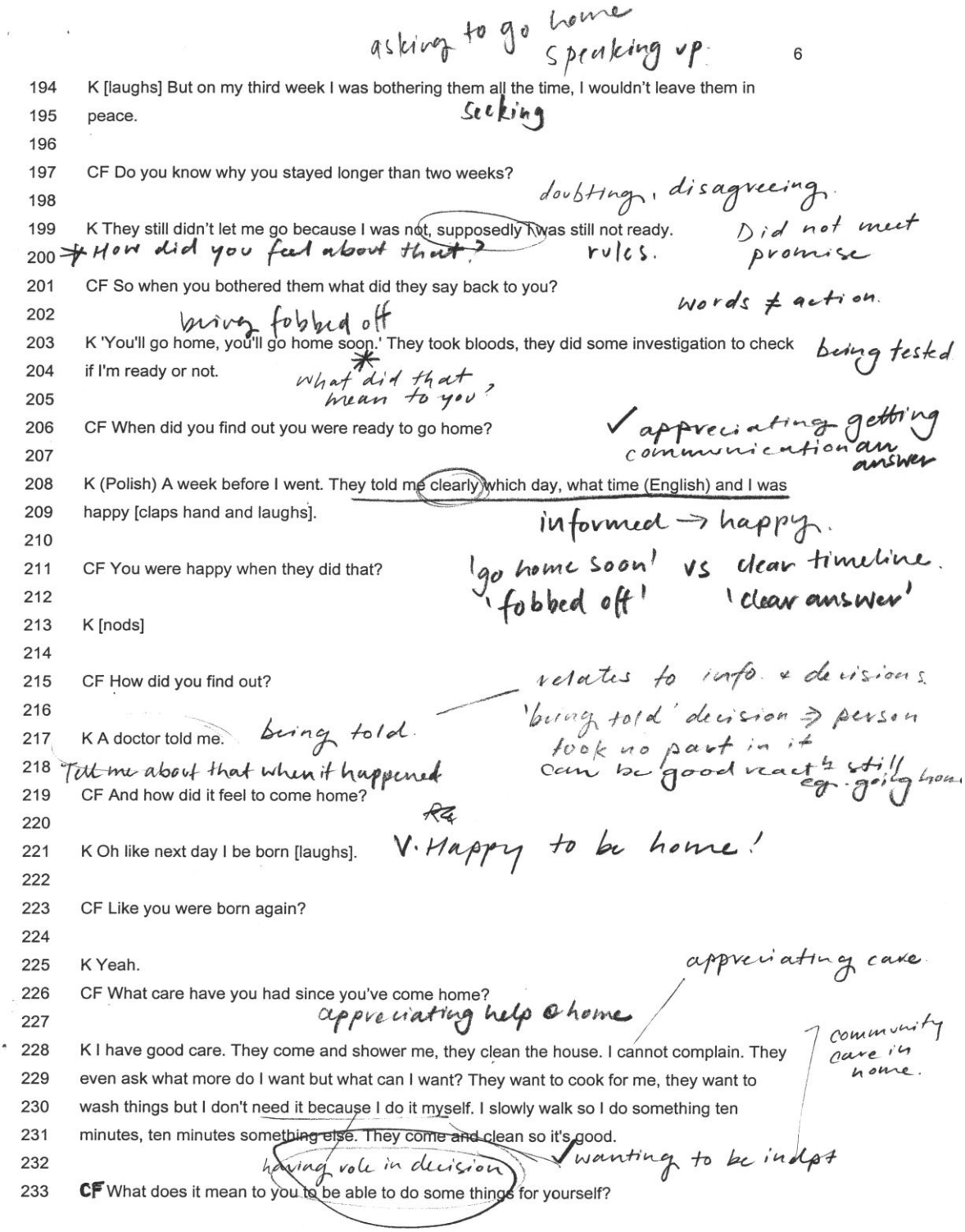
Thao

Thao was a sixty-six year old man from Vietnam who migrated five years previously with his wife. Thao had been in the military during the war in Vietnam and fought alongside Australian and American soldiers. Thao's stroke had left him very limited in his physical ability and he could only walk short distances inside his house with a splint on one ankle and using a quad stick for support. He could no longer use his right arm due to weakness and Thao was frustrated that he could not work in his garden as he did previously.

Thao reported that he spoke English *"not well".* He could speak some short phrases such as his address but when he spoke it during the interview I did not understand his heavily accented talk. Thao used the interpreter except for those few words. We sat in Thao's large living area to talk. Different people moved in and out of the house as we talked including a care worker, his son, his wife and a friend dropped round to offer him a lift out for lunch but none spoke to the interpreter or I while we were there.

Thao expressed his wish at both interviews to gain permission for his eldest daughter to migrate to Australia from Vietnam to help care for him. He was paying for a lawyer to help gain the permission. Thao was hopeful that we could help in some way and I provided him with a letter that confirmed his voluntary help in the study.

Appendix P: Example page of initial coding



194 K [laughs] But on my third week I was bothering them all the time, I wouldn't leave them in
195 peace.
196
197 CF Do you know why you stayed longer than two weeks?
198
199 K They still didn't let me go because I was not, supposedly I was still not ready.
200 How did you feel about that?
201 CF So when you bothered them what did they say back to you?
202
203 K 'You'll go home, you'll go home soon.' They took bloods, they did some investigation to check
204 if I'm ready or not.
205
206 CF When did you find out you were ready to go home?
207
208 K (Polish) A week before I went. They told me clearly which day, what time (English) and I was
209 happy [claps hand and laughs].
210
211 CF You were happy when they did that?
212
213 K [nods]
214
215 CF How did you find out?
216
217 K A doctor told me.
218 Tell me about that when it happened
219 CF And how did it feel to come home?
220
221 K Oh like next day I be born [laughs].
222
223 CF Like you were born again?
224
225 K Yeah.
226 CF What care have you had since you've come home?
227
228 K I have good care. They come and shower me, they clean the house. I cannot complain. They
229 even ask what more do I want but what can I want? They want to cook for me, they want to
230 wash things but I don't need it because I do it myself. I slowly walk so I do something ten
231 minutes, ten minutes something else. They come and clean so it's good.
232
233 **CF** What does it mean to you to be able to do some things for yourself?

Appendix Q: List of initial codes

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a particular day
accepting care organised by hospital
accepting explanation given by health professional
accepting fate
accepting what I have
acknowledging physical limitations to communication
adapting to new ways
appreciating being talked with
appreciating care
asserting independence
avoiding the disappointment of others
being asked about preferred language
being checked
being disappointed by lack of bilingualism
being discouraged to talk
being familiar with hospital
being given responsibility for care decision
being inconvenienced by care
being limited by language
being limited by other health condition
being limited by stroke
being protected by family
being proud of achievements
being proud of family
being proud of recovery
being shocked by stroke
being suspicious of actions of others
being tested
being told
being unable to remember care experience
being unaware of staff identities
being unsure of care arrangement
being visited by friends
being worried about person with stroke
believing family care is best
blaming others for misunderstanding

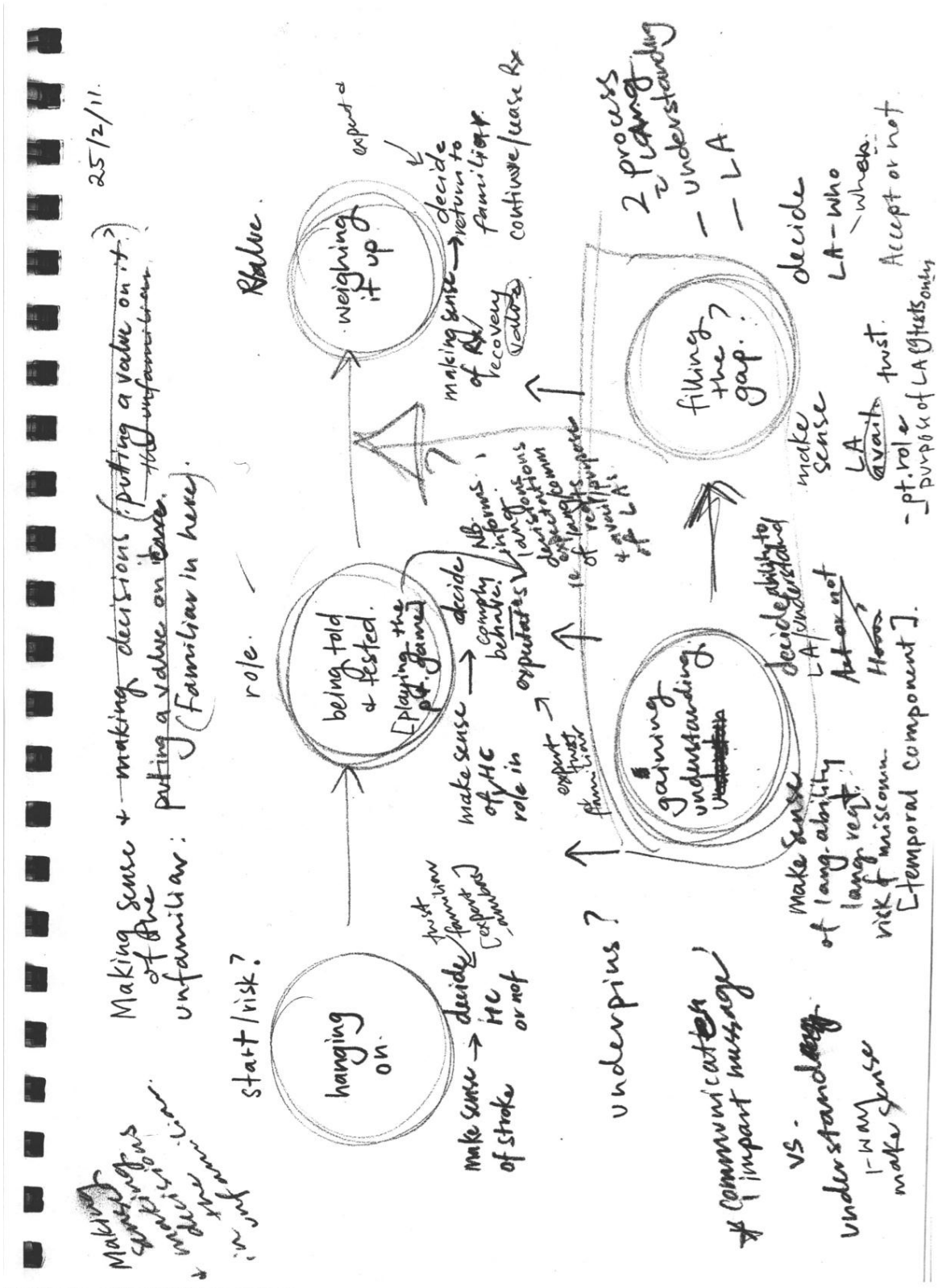
breaking the rules
choosing not to report incident
claiming to know how the person with stroke feels
comparing Australia to country of birth
comparing self with others
comparing stroke with other health condition
comparing with previous health care experience
comparing with previous stroke experience
complying because scared
delaying getting help
denying anything wrong
differentiating between written and spoken preferred language
disliking hospitals
disliking treatment
dismissing need for help
dismissing need for language assistance
distrusting interpreters
doing it on your own
downplaying changes due to stroke
establishing status
explaining culturally-related knowledge
fearing cognitive decline
feeling at a loss as to what to do
feeling encouraged
feeling relieved to be home
feeling sorry for family
feeling tired
feeling treatment didn't help
feeling understood
following decision made by family
following hospital advice
forcing self to get better
getting annoyed
getting help from family
getting help from friends
getting help from staff to understand
getting information via family
getting little treatment
going from bad to worse
guessing at diagnosis

having previous bad health care experience
hospital was like a holiday
identifying as an Australian
identifying important people
ignoring the signs of stroke
involving family
knowing own health
knowing the rules
lacking knowledge of rehabilitation
lacking knowledge of stroke
learning English
locating the stroke in normal life
losing trust in health professional
managing care independently
meeting family expectations
minimising the significance of the stroke event
missing the signs of stroke
Now it's alright.
others noticing stroke signs
perceiving only basic communication required for rehab
perceiving rehabilitation as exercise
perceiving work pressures on staff
persevering to finish task
preparing for old age
protecting the person with stroke
qualifying language ability
recalling previous bad health experience
recalling with humour
recognising a shared cultural background
recognising importance of communication in care
reflecting on past using stroke experience
refusing to accept stroke occurrence
relying on family for help
representing self as doing the right thing
respecting academic training
returning to normal tasks
sharing a preferred language
socialising with other patients
speaking up
taking initiative to understand

taking preventive measures
taking pride in intellectual ability
taking pride in language ability
taking time to recover
thanking god
they didn't tell me much
trusting health professionals
understanding stroke
using an interpreter
using family as language assistants
using humour to cope
using medical knowledge
using medical language
using preferred language in hospital
valuing test results in recovery
wanting to go home
wanting to regain independence
worrying about home

Identifying events for comparison:
comparison of care transitions
comparison of care transitions\being admitted to hospital
comparison of care transitions\getting community care
comparison of care transitions\going home
comparison of care transitions\going to rehabilitation
comparison of care transitions\receiving care at home
comparison of important events during care
comparison of important events during care\having a stroke
comparison of important events during care\receiving stroke diagnosis
difficulties with English during interview
tracking attributes
tracking attributes\age
tracking attributes\dressing ability
tracking attributes\education
tracking attributes\mobility level
tracking attributes\years in Australia
tracking information resources
tracking information resources\bilingual resources
tracking information resources\written resources

Appendix R: Example of diagramming developing theory



Appendix S: Confidentiality statement for professional interpreters

Interpreter Confidentiality Agreement

Title: **How do people who have trouble speaking English experience the move from hospital to home after a stroke?**
Researcher: Caroline Fryer, PhD student Ph. 8302 2283
Supervisor: Dr. Shylie Mackintosh, Senior Lecturer Ph. 8302 2075

I, …… (printed name of interpreter),

agree that the information interpreted for participants of this research study

will only be discussed with the researcher, and I agree to respect the right of

each participant to privacy and confidentiality.

Signed ……

Date ……

Appendix T: Letters of approval from Human Research Ethics Committees

Fryer, Caroline Elizabeth - fryce001

From:	Alice Granger
Sent:	Monday, 13 July 2009 2:09 PM
To:	Fryer, Caroline Elizabeth - fryce001
Cc:	Shylie Mackintosh
Subject:	Ethics Protocol P185/09 "How do older people with limited English proficiency experience the transition from hospital to community care after stroke"
Attachments:	Conditions September 2008.doc

Dear Caroline,

Re: **Ethics Protocol P185/09 "How do older people with limited English proficiency experience the transition from hospital to community care after stroke"**

Thank you for submitting your ethics protocol for consideration. Your protocol has been considered by the Deputy Chairperson of the University's Human Research Ethics Committee on behalf of the Committee.

I am pleased to advise that your protocol has been approved subject to you:

- Obtaining written approval from the organisations where the research will be undertaken before commencing the research
- Providing a confidentiality form/agreement for the interpreters to sign prior to their involvement in the study.
- Clarifying whether permission to use the NAATI-accredited professional interpreters from the SA Govt Interpreting and Translating Centre has been given; and clarifying whether there is a cost for using this service.
- Confirming that the researcher is acting as a researcher and not a treating physiotherapist for the purpose of this research and thus any advice offered to participants for referral to a support services will be as a researcher and not a treating physiotherapist.
- Amending section 4.2 by providing more details of where data will be stored.
- Amending the participant information sheets by including the following statement:
    - "This project has been approved by the University of South Australia's Human Research Ethics Committee. If you have any ethical concerns about the project or questions about your rights as a participant please contact the Executive Officer or this Committee, tel: +61 8 8302 3118; email: vicki.allen@unisa.edu.au"

Please note that the Deputy Chairperson's decision will be reported to the next meeting of the Human Research Ethics Committee for endorsement.

Please regard this email as formal notification of assessment.

Under the national guidelines, you must not begin your research before receiving final approval. Once you have submitted the necessary amendments, and they have been accepted, your approval will be finalised and you may commence your research.

Ethics approval is always made on the basis of a number of conditions detailed in the attachment; it is important that you are familiar with, and abide by, these conditions. It is also essential that you conduct all research according to UniSA guidelines, which can be found at http://www.unisa.edu.au/res/ethics/human.asp. These guidelines should assist you with the formulation of necessary papers such as the information sheet and the consent form.

1

Please note, if your project is a clinical trial you are required to register it in a publicly accessible trials registry prior to enrolment of the first participant (eg Australian New Zealand Clinical Trials Registry http://www.anzctr.org.au/Survey/UserQuestion.aspx) as a condition of ethics approval.

We look forward to receiving your amendments in the near future. In the meantime, please contact me if you have any questions

Kind regards

Alice

Alice Granger
Compliance Officer
Research and Innovation Services
University of South Australia
Mawson Lakes Campus
Tel: 08 8302 3523
email: alice.granger@unisa.edu.au

21 June 2009.

Ms Caroline Fryer
PhD Student
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Government of South Australia
SA Health

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www.health.sa.gov.au

Research Ethics Committee
Level 3, Hanson Institute
Tel (08) 8222 4139
Fax (08) 8222 3035
Email:
Heather.O'Dea@health.sa.gov.au

Dear Ms Fryer,

Re: "How do older people with limited English proficiency experience the transition from hospital to community care after stroke?"

RAH PROTOCOL NO: 090610.

Supervisor: Dr Shylie Mackintosh, Senior Lecturer

I am pleased to advise that Research Ethics Committee EXPEDITED APPROVAL has been given to the above project. Please quote the RAH Protocol Number allocated to your study on all future correspondence.

The following documents have been reviewed and approved:

- **Research Application**
- **Participant Information Sheet (Sample 1) Version 2 (11 June 2009)**
- **Participant Information Sheet (Sample 2) Version 2 (11 June 2009)**
- **Consent Form, Version 1 (21 May 2009)**
- **Interview guide**
- **Promotional Flyer for Sample 1 participants**
- **Introductory letter for Sample 2 participants**
- **Accept or Decline involvement letter, (Sample 2), Version 1 (11 June 2009)**

Research Ethics Committee deliberations are guided by the NHMRC National Statement on Ethical Conduct inHuman Research 2007.

The general conditions of approval follow:

- Adequate record-keeping is important. If the project involves signed consent, you should retain the completed consent forms which relate to this project and a list of all those participating in the project, to enable contact with them in the future if necessary. The duration of record retention for all clinical research data is 15 years.
- You must notify the Research Ethics Committee of any events which might warrant review of the approval or which warrant new information being presented to research participants, including:
  (a) serious or unexpected adverse events which warrant protocol change or notification to research participants,
  (b) changes to the protocol,
  (c) premature termination of the study,
  (d) a study completion report within 3 months of the project completion.
- The Committee must be notified within 72 hours of any serious adverse event occurring at this site.
- Approval is **ongoing**, subject to satisfactory annual review. Investigators are responsible for providing an annual review to the RAH REC Executive Officer each year using the Annual Review Form available at: http://www.rah.sa.gov.au/rec/index.php

Yours sincerely,

Dr A Thornton
CHAIRMAN
RESEARCH ETHICS COMMITTEE

Government of South Australia
SA Health

Ethics of Human Research Committee

03 June 2009

Ms C Fryer
School of Health Sciences
Division of Health Sciences
University of South Australia
GPO BOX 2471
ADELAIDE SA 5001

The Queen Elizabeth Hospital
28 Woodville Road
WOODVILLE SOUTH SA 5011
Lyell McEwin Hospital
Haydown Road
ELIZABETH VALE SA 5112

Dear Ms Fryer Application Number 2009094

The Ethics of Human Research Committee Chairman has expedited the approval of your protocol under Section 5.1.19 of the National Statement on Ethical Conduct in Human Research entitled:

"How do older people with limited English proficiency experience the transition from hospital to home after stroke?"

The following documents have been reviewed and approved:

- Human Research Ethics Application Form (UNISA)
- Interview Guide
- Recruitment Advertisement
- Introductory Letter for Participants
- Participant Information Sheet and Consent Form – Sample I Version 1 dated 21 May 2009
- Participant Information Sheet and Consent Form – Sample II Version 1 dated 21 May 2009

Approval Status: **FINAL**

Period of Approval: **03 June 2009 – 03 June 2010**

***Please note the terms under which Ethical approval is granted:**

1. Researchers are required to immediately report to the Ethics of Human Research Committee anything which might warrant review of ethical approval of the protocol, including:

a) serious or unexpected adverse effects on participants;
b) proposed changes in the protocol; and
c) unforseen events that might affect continued ethical acceptability of the project

2. Protocols are approved for up to twelve months only and a report is required at the end of the study or 12 month period. Extensions will not be granted without a report to the Committee.
3. Confidentiality of the research subjects shall be maintained at all times as required by law
4. All research subjects shall be provided with a Patient Information Sheet and Consent Form, unless otherwise approved by the Committee
5. The Patient Information Sheet and Consent Form shall be printed on the relevant site letterhead stating the contact details for the researchers
6. The Patient Information Sheet must state that the Executive Officer can be contacted for information regarding conduct of the study, policies and procedures, or if the participant wishes to make a confidential complaint
7. A report and a copy of any published material should be forwarded to the Committee at the completion of the project.

Yours sincerely

A/Professor Timothy Mathew
Chairman
Central Northern Adelaide Health Service
Ethics of Human Research Committee (TQEH & LMH)